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Departamento de Personalidad, Evaluación y Tratamiento Psicológico I
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TESIS DOCTORAL

Risk and protective factors in the mental health of adolescents living with HIV in Namibia

Factores de riesgo y protectores en la salud mental de adolascentes con VIH en Namibia

MEMORIA PARA OPTAR AL GRADO DE DOCTOR

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FACULTAD DE PSICOLOGÍA
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COMPLUTENSE
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Thesis Presented for the Degree of
DOCTORATE IN CLINICAL PSYCHOLOGY, FORENSICS AND HEALTH.

Shelene Gentz

Supervised by:
Isabel Calonge Romano
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- Gentz, S. Emotional and behavioural symptoms of distress in adolescents living with HIV in Namibia: a case-control design. Paper presented at XVI World Congress of Psychiatry, 2014; Madrid, Spain.
- Gentz, S. and Ruiz-Casares, M. Exploring the Strengths and Difficulties Questionnaire as a tool to assess mental distress in Namibia: a mixed method approach. Paper presented at the 5th conference of the International Society of Child Indicators, September, 2015, Cape Town, South Africa.
- Gentz, S. The mental health of adolescents living with HIV in Namibia: a case-control design. Paper presented at 1st conference of the National Commission on Research, Science and Technology, September, 2015, Windhoek, Namibia

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RESUMEN

Introducción: A pesar de que el 90% de los adolescentes con VIH en el mundo viven en África subsahariana, pocos estudios han examinado el impacto que tiene el hecho de estar infectados por VIH sobre su salud mental en este región. Además, los adolescentes con VIH en contextos de escasos recursos se enfrentan con factores de riesgo adicionales, como la pobreza, la falta de apoyo social y el estigma relacionado con el VIH. Este estudio examina la salud mental de los adolescentes que viven con el VIH en Namibia, un país con una de las prevalencias de VIH más altas del mundo. El estudio examina si estos adolescentes muestran mayores problemas de salud mental respecto a un grupo de comparación de la comunidad. Asimismo, el estudio evalúa los factores que predicen problemas de salud mental con el fin de identificar las potenciales áreas de intervención que permitan mejorar dichos problemas.

Métodos: En una fase piloto, se organizan grupos de discusión con 34 adolescentes y entrevistas con ocho informantes clave para explorar las percepciones locales sobre los problemas de salud mental, así como sus factores de riesgo y factores de proteccion. Dado que las propiedades psicométricas del instrumento seleccionado para medir salud mental, el cuestionario *Strengths and Difficulties Questionnaire*/ Cuestionario de Capacidades y Dificultades (SDQ), nunca habían sido exploradas antes en Namibia, se decidió administrarlo a 236 participantes con edades comprendidas entre 12 y 18 años en una fase piloto cuantitativa.

Para el estudio principal, se entrevistó a 99 adolescentes con VIH, quienes se encontraban informados de su estatus de VIH, en un Hospital Estatal en Windhoek entre julio 2013 y marzo 2014 en comparación con una muestra de adolescentes de la comunidad seleccionados al azar (n = 159). Los adolescentes estudiados tenían edades comprendidas entre los 12 y 18 años de edad. Las entrevistas evaluaron síntomas de trastornos emocionales y de comportamiento, utilizando el SDQ, y factores de riesgo, que incluyen, la pobreza, el apoyo social, la situación de orfandad y el estigma relacionado con el VIH. Se analizaron los datos con pruebas de t-test, chi-cuadrado, análisis de varianza (ANOVA) y análisis de regresión.

*Resultados:*Los adolescentes con VIH obtuvieron puntuaciones significativamente más altas en la escala total de Dificultades (p = 0,027) y en la escala de Problemas de conducta (p = 0,025) en comparación con el grupo de control. Estas diferencias se mantienen incluso después de controlar los factores socio demográficos. El nivel de malestar clínicamente significativo fue relativamente bajo en el grupo de VIH, el 12,2% obtuvo puntuaciones en el rango clínico en la escala de dificultades total, usando los puntos de corte ya establecidos en contextos occidentales. Sin embargo, un alto número de participantes en este grupo tuvo puntuaciones en el rango clínico en la escala de Síntomas emocionales (22,0%), aunque menos obtuvieron puntuaciones en el rango clínico para la escala de Problemas de conducta (12,2%), la escala de los Problemas con los compañeros (10,9 %) y la escala de Hiperactividad (4,0%).

El grupo de participantes con VIH que se quedaron huérfanos es significativamente más alto que el grupo de control, (62,6% vs. 20,8%, p < 0,001), y sólo el 36% en el grupo de VIH sigue teniendo ambos padres vivos. Hay menos participantes en el grupo con VIH que viven con los padres biológicos (75,5% vs. 57,6%, $p = 0{,}003$) en comparación con el grupo de control. El grupo con VIH anotó puntuaciones más bajas en su percepción del apoyo social (p <0,05), en particular en el apoyo del cuidador ($p < 0{,}05$) que en el grupo de comparación, pero no se registraron diferencias en su percepción del apoyo de los amigos y el apoyo de una persona auto-seleccionada. Los grupos no mostraron diferencias en los factores de pobreza. Tras controlar el factor orfandad y el apoyo social, las diferencias de salud mental entre los dos grupos ya no resultaron significativas, lo que sugiere que la orfandad y el apoyo social pueden desempeñar un papel como factor mediador.

Los factores que predijeron las puntuaciones en el rango anormal para los grupos combinados en la escala de dificultades total fueron, ser huérfano (OR = 7,09), la inseguridad alimentaria (OR = 14,44), menos bienes del niño (OR = 0,21) y menos apoyo social percibido (OR = 0,68). Menos bienes del niño fue también un predictor significativo para los síntomas emocionales (OR = 0,43), y problemas de conducta (OR = 0,14), mientras que el apoyo social bajo (OR = 0,85), junto con una mayor edad (OR = 1,54), fueron predictores adicionales para los problemas de conducta.

Para el grupo con VIH, el estigma relacionado con el VIH, la revelación del estado de VIH a otras personas y la falta de adherencia al tratamiento fueron asociadas con mayores niveles de síntomas de problemas emocionales y de conducta. El análisis de regresión mostró que los predictores más fuertes para los síntomas emocionales y de comportamiento para el grupo VIH eran el apoyo social, la pobreza y el estigma. Los bienes del niño ($\beta = -.231$, $p = 0{,}023$) y el estigma ($\beta = 0{,}268$, $p = 0{,}009$) fueron los mejores predictores de las puntuaciones más altas en la escala de dificultades total, mientras que el estigma ($\beta = 0{,}314$, $p = 0{,}002$) fue el mejor predictor para los síntomas emocionales. El apoyo social tuvo un efecto protector sobre los problemas con los compañeros ($p = 0{,}001$, $\beta = -.349$) y los bienes del niño ($p = 0{,}004$, $\beta = -.309$) un predictor de problemas de conducta.

Conclusión: Las conclusiones de la tesis sugieren que los adolescentes con VIH experimentan mayores problemas de salud mental que sus compañeros. Sin embargo, ciertos factores de riesgo y de protección, en particular, la orfandad y el bajo apoyo social, pueden ser factores mediadores, lo que sugiere que centrarse en estas áreas puede disminuir los problemas de salud mental en este grupo. En particular, para los adolescentes con VIH, las intervenciones deben centrarse en mejorar el apoyo que proporciona el cuidador. Por otra parte, las intervenciones dirigidas a los factores de pobreza, especialmente la inseguridad alimentaria y el alivio de los efectos de la orfandad son áreas importantes tantas para los participantes con VIH como para los adolescentes en general. Por tanto, se recomienda la identificación temprana de los adolescentes que viven con el VIH con problemas emocionales graves, sobre todo en los adolescentes con VIH con más problemas de salud mental, se evidencia el aumento de los problemas de adherencia al tratamiento. Además, se recomienda la asistencia a las decisiones relativas a la revelación del estatus de VIH y un esfuerzo centrado en la reducción del estigma relacionado con el VIH.

Palabras clave: adolescentes con VIH, salud mental, factores de riesgo y protectores, Namibia

ABSTRACT

Background: Despite the fact that 90% of the world's HIV-positive adolescents live in sub-Saharan Africa, little research in this region has examined the impact of HIV status on their mental health. Furthermore, HIV-positive adolescents in resource poor contexts face additional risk factors, such as poverty, poor social support and HIV-related stigma. This study examines the mental health of adolescents living with HIV in Namibia, a country with one of the highest HIV prevalence in the world. The study examines whether these adolescents show increased mental health problems when compared to a community comparison group and assesses which factors predict negative mental health outcomes in order to identify potential areas of intervention for improving mental health.

Methods: Group discussions with 34 adolescents and interviews with eight key informants explored local perceptions of mental health problems as well as risk and protective factors for mental health problems in a pilot phase. As the psychometric properties of the mental health instrument, the Strengths and Difficulties Questionnaire (SDQ), had never been explored in Namibia, it was administered to 236 participants between the ages of 12 and 18 prior to administration to the study sample.

For the main study, 99 fully disclosed HIV-positive adolescents between the ages of 12 and 18 were interviewed at a State Hospital in Windhoek between July 2013 and March 2014, using a standardised questionnaire and compared to a randomly selected matched community comparison group (n=159). Interviews assessed emotional and behavioural symptoms of distress, using the SDQ, and risk factors including poverty, social support, orphan status and HIV-related stigma. Data were analysed with t-tests, chi-squares, ANOVAs and regression analysis.

Results: HIV-positive adolescents reported significantly higher mean scores for total difficulties (p = .027) and conduct problems (p = .025) than the comparison group, even after controlling for socio-demographic factors. Using Western established cut-offs, 12.2% of the HIV group had scores in the clinical range on the total difficulties scale. However, a high number of participants in this group had scores in the clinical range for the emotional symptoms scale (22.0%), although fewer evidenced scores in the clinical range for conduct problems (12.2%), peer problems (10.9%) and hyperactivity/inattention (4.0%).

Significantly more participants in the HIV group were orphaned (62.6% vs. 20.8%, p < .001), with only 36% still having both parents living, and fewer lived with biological parents (75.5% vs. 57.6%, p = .003) when compared to the comparison group. The HIV group scored lower on total perceived social support (p < .05) and caregiver support (p < .05) than the comparison group, but no differences in perceived friend support and support from a self-selected person were present. The groups showed no differences in poverty factors. After controlling for the effects of orphanhood and social support, group differences in mental health were no longer significant, suggesting that orphanhood and social support may play a mediating role.

Factors which predicted scores in the abnormal range for the combined HIV and comparison groups for the total difficulties scale were, being orphaned (OR = 7.09), food insecurity (OR = 14.44), fewer child centred assets (OR = 0.21) and lower perceived social support (OR = 0.68). Child centred assets was also a significant predictor for emotional symptoms (OR = .43), and conduct problems (OR = 0.14), whereas lower social support (OR = 0.85), along with higher age (OR = 1.54), were additional predictors for conduct problems.

For the HIV group, HIV-related variables, particularly HIV-related stigma, HIV status disclosure to others and self-reported non-adherence were associated with higher levels of emotional and behavioural distress. Regression analysis showed that the strongest predictors for symptoms of distress for the HIV group were social support, poverty and stigma. Child centred assets ($\beta = -.231$, $p = .023$) and stigma ($\beta = .268$, $p = .009$) were the best predictors for higher scores on total difficulties scale, whereas stigma ($\beta = .314$, $p = .002$) was the best predictor for emotional symptoms. Social support had a protective effect on peer problems ($p = .001$, $\beta = -.349$) and child centred assets ($p = .004$, $\beta = -.309$) significantly predicted conduct problems.

Conclusion: The findings of this study suggest that HIV-positive adolescents experience more mental health problems than their peers. However, certain factors, in particular orphanhood and low social support, may mediate these differences, suggesting that focussing on these areas may decrease mental health problems in this group. In particular, for HIV-positive adolescents, interventions should focus on improving caregiver support. Furthermore, interventions targeting poverty factors, especially food insecurity, and alleviating the effects of orphanhood are important areas both for HIV-positive participants and for adolescents in general. Early identification of adolescents living with HIV with severe emotional problems is recommended, particularly as HIV-positive adolescents with more mental health problems evidenced increased adherence problems, highlighting the importance from a public health perspective. Furthermore, assistance with decisions regarding HIV status disclosure and a focussed effort on reducing HIV-related stigma is recommended.

Keywords: HIV-positive adolescents, mental health, risk and protective factors, Namibia

List of Abbreviations

AIDS- Acquired immunodeficiency syndromes

ALHIV- Adolescents living with HIV

ANC - Anti-natal care

ARV- Antiretroviral

ART - Antiretroviral treatment/ therapy

CDC - Centres for Disease Control and Prevention

EMIS - Education Management Information system

EPP - Estimates and Projections Package

HAART - Highly Active Antiretroviral Therapy

HDI - Human Development Index

HIV- Acquired immunodeficiency virus

MTCT- Mother to child transmission

MoHSS - Ministry of Health and Social Services

NDHS- Namibia Demographic and Health Survey

NGO - Non-governmental Organisation

PLHIV - People living with HIV

RNA - Ribo-nucleic Acid

UNAIDS - Joint United Nations Programme on HIV/AIDS

UNESCO – United Nations Educational, Scientific and Cultural Organisation

UNICEF - United Nations International Children´s Emergency Fund

UNDP - United Nations Development Programme

WHO - World Health Organisation

YPLHIV – Young People Living with HIV

Definitions

Orphans: This study follows the definition of the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2004) which defines an orphan as a child 18 and under who has lost at least one parent as defined by the. The terminology of single orphan, to indicate those who have lost one parent, and double orphan, to indicate those who have lost both parents was also developed.

AIDS-orphan: A child who has lost at least one parent to AIDS. This term is used interchangeably with “child orphaned by AIDS”.

Adolescents: Participants in this study includes adolescents between the ages of 12 and 18. However, the World Health Organisation (WHO) defines adolescents as aged between 10 and 19 (WHO, 2003a). As such statistics on adolescents, particularly HIV statistics, are often presented using the WHO definition. Furthermore, statistics are sometimes also presented separately for younger (10-14) and older (15-19) adolescents.

Adolescents/youth/children living with HIV: This term refers to HIV-positive adolescents/youth/children and is also used interchangeably with HIV-infected adolescents/youth/children. The Joint United Nations Programme on HIV/AIDS (UNAIDS) uses the age range of 0 - 14 to report statistics on children whereas youth encompasses those between the ages of 15 and 24. Young people living with HIV is also used and includes both youth (15-24) and adolescents (10-19) living with HIV.

HIV and AIDS affected children and adolescents: This term encompasses those children and adolescents affected by the HIV-positive status of a person living with HIV (UNAIDS, 2011). This includes children orphaned by AIDS and children living with an HIV- positive family member.

INTRODUCTION

Globally, there are an estimated 2.1 million adolescents (aged 10-19) living with the human immunodeficiency virus (HIV) (UNICEF, 2013). HIV is now the second leading cause of death in adolescents worldwide and the leading cause of death for adolescents in Africa (WHO, 2014). Adolescents living with HIV not only face medical and treatment challenges (Agwu & Fairlie, 2013; Lowenthal et al., 2014; Sohn & Hazra, 2013), but may also be confronted with parental ill health and death, poverty, stigma and poor social support, all of which can have important implications for their wellbeing (Benjet, 2010; Lowenthal et al., 2014; Richter, Stein, Cluver, & de Kadt, 2009; Richter, 2004; Walakira, Ddumba-Nyanzi, & Kaawa-Mafigiri, 2014). This study examines the effects of HIV and associated risk factors on one aspect of children´s wellbeing, mental health. The study is conducted in Namibia, which has one of the highest adult HIV prevalence in the world (14.0% in the general population) (MoHSS and ICF International, 2014). In fact, only five countries have a higher HIV prevalence in adults aged 15-49, and all are situated in southern Africa.

Identifying and treating mental health problems in people living with HIV (PLHIV) may have an impact on reducing the spread of HIV and on reducing AIDS related mortality. Research has shown that untreated mental health problems can cause a delay in the initiation of treatment (Tegger et al., 2008) as well as decreased levels of adherence once treatment starts (Nakimuli-Mpungu et al., 2012; Springer, Dushaj, & Azar, 2012; Williams et al., 2006). Adherence problems, as well as not starting or continuing treatment, could result in those already living with HIV becoming more infectious by increasing viral loads (Gardner et al., 2008; Sherr et al., 2010), potentially accelerating the spread of the virus in the general population. Furthermore, higher viral loads increase mortality (Lima et al., 2009; Nachega et al., 2006) in those already living with HIV. Understanding how HIV affects mental health is therefore a vital public health issue.

Although 90% of children with HIV live in sub-Saharan Africa, only seven empirical studies have examined the mental health of children and adolescents living with HIV in this region. Five studies examined emotional and behavioural difficulties in Zambia (Menon, Glazebrook, & Campain, 2007), Ethiopia (Tadesse, Tsehay, Belaineh, & Alemu, 2012), Botswana

(Lowenthal et al., 2012), South Africa (Small et al., 2014) and Rwanda (Betancourt, Scorza, Kanyangazi, & Smith Fawzi, 2014), and two studies examined prevalence of psychiatric disorders, one in Uganda (Musisi & Kinyanda, 2009) and one in Kenya (Kamau, Kuria, Mathai, Atwoli, & Kangethe, 2012). No similar comparative studies have been conducted in Namibia.

Understanding specific risk and protective factors, and the role of HIV in mental health, will help target interventions, a key issue for low resource settings. Although more studies have been conducted in high income and Western countries (Mellins & Malee, 2013), important contextual differences limit the generalization of findings from these contexts to low resource settings. This includes differences in the nature of the HIV epidemic as well as in the availability of resources to target service delivery (Breuer, Myer, Struthers, & Joska, 2011; Havens & Mellins, 2008; V. Patel, Flisher, Hetrick, & McGorry, 2007). Furthermore, there are important cultural factors to consider, such as the appropriateness of constructs, including diagnostic systems for mental health developed in the West, to contexts other than where they were developed (Summerfield, 2008). There may be important variations in the expression of mental distress and the meaning attached to symptoms (Kirmayer, 1989; 2001). More context specific research regarding mental health problems is needed in African settings. This study examines mental health in adolescents living with HIV, including risk and protective factors, in Namibia, a low resource setting. It also considers the appropriateness of the signs and symptoms included in a mental health tool, for the local context.

This chapter provides a brief introduction to the research context, outlining the specific social and economic circumstances within which children and adolescents live and grow in Namibia. It considers the main facts about the HIV epidemic, its prevalence and trends over time and the country response and progress in combating HIV. We then outline the conceptual underpinning of the study: ecological theory. Bronfenbrenner´s ecological theory proposes that children’s wellbeing is affected by the interaction of individual and contextual risk factors situated at different levels of the child´s environment (Bronfenbrenner, 1979; Bronfenbrenner, 1994). We conclude the chapter with the general objectives of the study.

1. Background to the study: The Namibian context

Namibia is situated in southern Africa and shares borders with Angola and Zambia in the north, Botswana in the east and South Africa in the south (Figure 1). The Atlantic Ocean stretches along the West coast. Covering 825 616 km^2, it is 1.6 times the size of Spain. According to the latest census, the country has a population of 2.1 million, with 37% of the country's population under the age of 15 years (Namibia Statistics Agency, 2013a). It is one of the most sparsely populated countries in the world. The large distances between places, for such a sparse population, brings challenges for the delivery of health and other services, particularly in the rural areas.

Figure 1 Map of Namibia showing major towns and location in Africa. Source CIA, 2014 World Factbook: Namibia (https://www.cia.gov/library/publications/the-world-factbook/geos/wa.html)

The country's official language is English, although there are more than 11 indigenous languages, the most widely spoken language group being the Oshiwambo language groups, spoken by just under 50% of the population (Namibia Statistics Agency, 2013a).

1.1 Social and economic situation

Namibia became an independent democratic republic in 1990 after a period of colonialism and Apartheid. As a consequence, the country inherited large inequalities, specifically along racial lines, as well as low economic growth, high unemployment and a high rate of poverty (National Planning Commission, 2012). A report by the National Planning Commission (2013) shows that, in the 25 years since Independence, Namibia has achieved improvements in the social and economic situation, but many challenges remain.

The country's economy is primarily based on mining, manufacturing, tourism, agriculture and fishing. The country has an estimated U$9185 Gross National Income (GNI) per capita (UNDP, 2014). A human development index (HDI) of 0.624 places Namibia as 127th out of 187 countries. The HDI is a summary measure for assessing long-term progress in three basic dimensions of human development: a long and healthy life, access to knowledge and a decent standard of living). Namibia has been classified as an upper middle income country since 2009. However, this classification, and the improvements shown in its HDI, obscures the large inequalities and widespread poverty which remain in the country.

A Gini coefficient of 63.9 shows that it is one of the most unequal societies of the world (Namibia Statistics Agency, 2012b). The Gini coefficient measures the deviation of the distribution of income among individuals or households within a country and can range from 0 (absolute equality) to 100 (absolute inequality). About one third (31.9%) of the population live below the international poverty line (< 1.25 US$ per day), with 15.7% of the population in severe poverty, using the multidimensional poverty index (UNDP, 2014). Using a cost of basic needs approach, which considers poverty as the number of households unable to command sufficient resources to satisfy their basic needs, close to 19.5% of households are classified as poor, of which 9.6% are severely poor (Namibia Statistics Agency, 2012b). The country also has a high unemployment rate (30% of the eligible workforce are unemployed) and of those in employment, a further 21% are considered as being in vulnerable employment, mostly working as unpaid workers on subsistence farms (Namibia Statistics Agency, 2013b). An analysis of the 2009/10 Namibia Household and Income Expenditure Survey showed that children are proportionately more affected by poverty than adults, with about 1 in 3 children (34%vs 28.7% of all ages), growing up in poverty, of which 18.3% (vs. 15.3% of all ages) are living in severe poverty, in this case defined as consumption poverty (Namibia Statistics Agency, 2012a; Namibia Statistics Agency, 2012b).

Occurring within these social and economic challenges, the consequences of HIV are exacerbated, for adults and especially for children. Economic difficulties, for example, may mean a lack of adequate nutrition required for optimum health and a lack of resources to attend clinic appointments and to access treatment. We now outline the HIV prevalence and trends in prevalence, as well as the country response to HIV.

1.2 HIV in Namibia

HIV in Namibia is predominantly spread through heterosexual contact and vertical transmission, also known as mother to child transmission (MTCT). As such, HIV affects the general population, rather than, as in other contexts, primarily specific subgroups, such as people who inject drugs or men who have sex with men (Prejean et al., 2011). This is not to say that certain subgroups in Namibia are not proportionately more affected by HIV. In fact, research suggests that men who have sex with men may be at a higher risk for HIV, but, are often neglected and excluded from HIV prevalence research (Baral et al., 2009; Lorway, 2006).

The first nationally representative HIV prevalence survey was conducted during the 2013 NDHS. The survey reported a National prevalence of 14.0% in adults between the ages of 15 and 49 (MoHSS and ICF International, 2014) (Table 1). Figure 2 shows that HIV prevalence varies in the 13 regions, ranging from 7.3% in the Omaheke region in the east to a high 23.7% in the Zambezi region (previously Caprivi) in the north east. Khomas region, where the current study took place recorded a prevalence of 11.9%. Apart from regional variations, the 2013 NDHS also showed variations within different age groups, with women between 35 and 39 having a prevalence of 30.9% (compared to 22.6% in men).

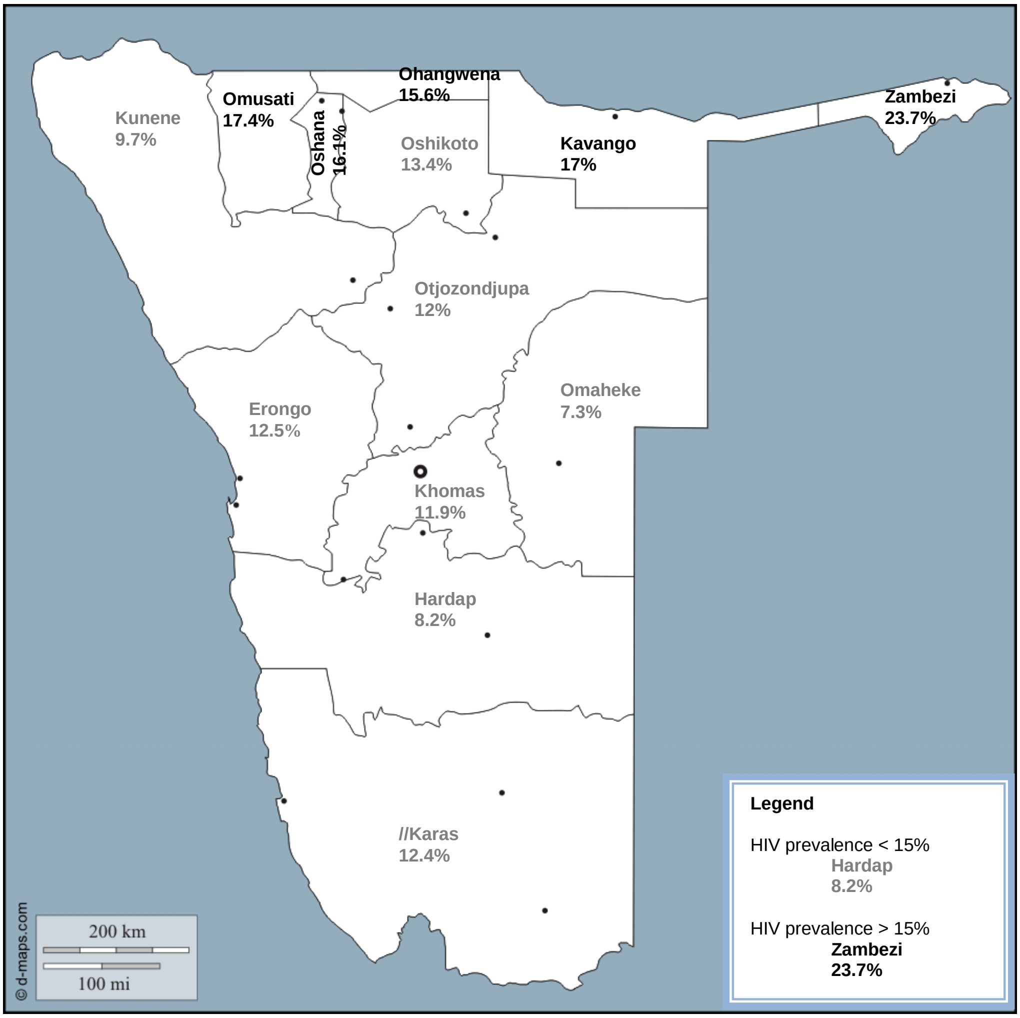

Figure 2 Regional HIV prevalence among women and men aged 15-49, Namibia (Source: 2013 Namibian DHS).

Before the NDHS 2013 was conducted, HIV prevalence was monitored with a bi-annual HIV Sentinel Survey amongst pregnant women receiving anti-natal care between the ages of 15 and 49. The survey started in 1992 with only eight sites. As of 2008, the National Sentinel Survey includes 35 district sites, covering all 13 regions of Namibia. These surveys allow us to observe important trends in the HIV epidemic over time. Figure 3, for example, shows that the prevalence in pregnant women has increased steadily over time, peaking at a level of 22% in 2002. Since then, there has been a steady decline, the most recent overall national HIV prevalence among pregnant women (15-49) being 16.9% (MoHSS, 2014b). While the slow downward trend shown by the Sentinel Survey shows that overall HIV prevalence is stabilising, future surveys in the general population will be necessary to confirm this. Furthermore, certain regions and demographic groups continue to need special attention as the epidemic may still be increasing (MoHSS, 2014b).

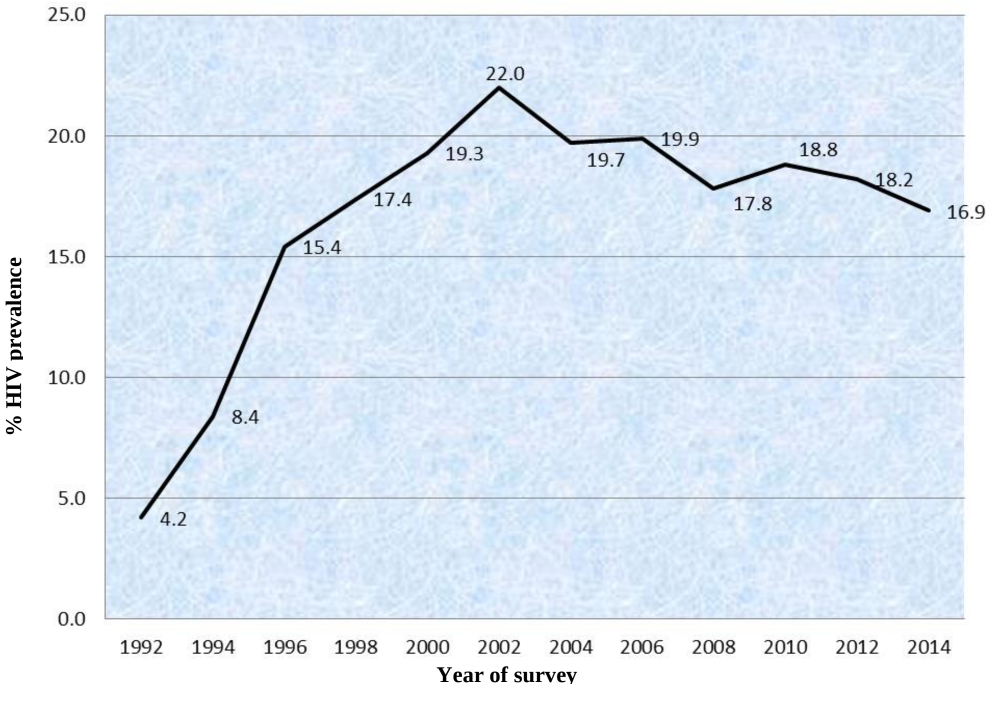

Figure 3 National HIV prevalence (%) among pregnant women, aged 15-49, attending antenatal care (ANC) in Namibia: 1992-2014. *(Source: MoHSS, 2014b)*

1.2.3 HIV prevalence in adolescents and children

Neither the 2013 NDHS nor the HIV Sentinel Survey report prevalence data for children (0-14) or adolescents (10-19). Data on prevalence in adolescents (10-19) is particularly hard to determine as HIV prevalence data has always split the adolescent age range with children (0-14) and young people (15-24).The NDHS 2013 does however report the prevalence in older adolescents (15-19) as 2.3% (MoHSS and ICF International, 2014).

In the face of the above limitation, child and adolescent prevalence has been estimated using the Estimates and Projections Package (EPP) developed by UNAIDS, WHO and partners. This should not be interpreted as formal prevalence as the accuracy depends on the quality of information gathered in the survey (Morgan, Walker, Gouws, Stanecki, & and Stover, 2007). Using the EPP, with data from the Sentinel Surveys[1], prevalence in children (0-14) is estimated to be about 2.6% (MoHSS, 2013). Overall, it is estimated that 10% of the total number of PLHIV are children aged 0-14 (MoHSS, 2012a). These children, if not already in adolescence, will be reaching adolescence in the near future. This is in addition to new infections occurring through, for example, early sexual debut or sexual abuse. Table 1 summarises the most current HIV prevalence data in Namibia by source.

Table 1 Summary of HIV prevalence statistics in Namibia

Indicator	**Prevalence**	**Year**	**Source**
National HIV prevalence in pregnant women using anti-natal care (15-49)	16.9%	2014	MOHSS (Sentinel Survey)
National HIV prevalence in the general population (15-49)	14.0%	2013	NDHS
National HIV prevalence in older adolescents (15-19)	2.3 %	2013	NDHS
Estimated National HIV prevalence in children (0-14)	2.6%	2013	MoHSS

1.2.4 HIV response and progress

The country has had a framework for responding to the HIV epidemic since 1987, starting with the AIDS Advisory Committee. Currently, the National Strategic Framework for HIV and AIDS (NSF) 2010/11 – 2015/16 outlines the plan for responding to the HIV epidemic

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[1] The estimations were conducted prior to the availability of the Namibian DHS 2013.

until 2016. Funding for the HIV response comes predominantly from Government funding. In the 2010/2011 fiscal year, a National AIDS spending assessment showed that about N$1,996.4 million (approximately 140 million Euros) was allocated for HIV and AIDS related activities, representing about 2.2% of the GDP, with more than half (59.7%) of the funding coming from public funds (MoHSS, 2012b). For the remaining funds, the country receives assistance from development partners, including the U.S President's Emergency Plan for AIDS Relief, UN agencies, the Gesellschaft für Technische Zusammenarbeit, other international agencies and the private sector (MoHSS, 2013). The following is some of the progress made, relevant to our study:

- There has been a steady decline in HIV incidence (MoHSS, 2009a). Namibia is one of 26 countries where adult HIV incidence has declined by more than 50% between 2001 and 2012 (UNAIDS, 2013).
- There has been a decline in vertical/ mother to child transmissions (MTCT). The percentage of MTCT rate has declined from 28% in 2006/7 to 5% in 2010/2011 (MoHSS, 2012a).
- Namibia is one of four priority countries (along with Botswana, Ghana and Zambia) that has met the goal of providing antiretroviral medicines to 90% of pregnant women living with HIV (UNAIDS, 2013). This has contributed to a major reduction in vertical transmission.
- The country has also made improvements in ART coverage for PLHIV. Namibia is one of few high epidemic countries to obtain ART coverage of over 80% in 2012 for PLHIV (UNAIDS, 2013). Using the then threshold for starting ART at a CD4+ lymphocyte (CD4) cell count of 350 cells/mm^3. ART coverage for adults improved from 67% in 2009/10 reporting period to 82% in 2012/13 reporting period. However, coverage is still lagging behind for children (67% in the 2012/13 reporting period) (MoHSS, 2013).

The above data illustrates that the reduction in the number of new child infections has been achieved by a concerted effort in the scale up of programmes for the prevention of mother to child transmission and access to ART. In addition, the ART programme, has contributed to prolonging the lives of children born in the previous two decades, when there were still high rates of vertical transmission. These children now reaching adolescents have become a priority worldwide and specifically in sub-Saharan Africa (Idele et al., 2014). It is with the care and treatment of this group that this study is concerned.

2. Significance of the study

The Namibian government has recently launched national strategic guidelines for the care of adolescents living with HIV (MoHSS, 2012c). The guidelines outline three primary objectives:

> (1) Diagnose adolescents living with HIV through HIV counselling and testing (HCT) and link them to care.
>
> (2) Deliver comprehensive, adolescent-focused, clinical HIV services to all adolescents living with HIV.
>
> (3) Strengthen the multi-sectoral support, services and linkages of adolescents living with HIV.

While the guidelines recognise and establish the needs of this group, a 2012 review conducted by Quinlan and Koster (2012) for UNICEF Namibia stated that:

> “There is no evidence on the socio-economic background of adolescents living with HIV, which could indicate a most vulnerable subgroup of adolescents... there are no studies that address the lived experiences of adolescents living with HIV, including their use of services, their sexual behaviour, prevention behaviour and encountered stigma etc.” (p. 74)

The current study contributes to this gap by examining the socio-economic and poverty indicators, as well as information on encountered stigma, for adolescents living with HIV in Windhoek, the national capital and the geographical centre of Namibia. In the light of the national guidelines (MoHSS, 2012c), empirical data on the existence of these and other major psychosocial problems (e.g. orphanhood), and their role in mental distress will be helpful to inform evidence-based planning (MoHSS, 2003). The data can also inform those support services that may serve a protective function for adolescents (objective 3 of the national guidelines) not only in the family, but also within the school and community systems.

Knowledge about protective factors for Namibian adolescents living with HIV are particularly important and can provide leverage points where existing processes can be strengthened. It is hoped that this study can later be expanded to include adolescents from other regions, particularly from more rural settings.

3. The research setting

The study sites for the current research, which include schools and a hospital, were selected from an urban township situated in the capital, Windhoek (See appendix 1 for a map of the study area). Windhoek currently has a population of 325, 858 and is situated in the centre of Namibia in the Khomas Region (Namibia Statistics Agency, 2013a). The township is known as the Katutura area[2]. The particular site was selected due to access to a paediatric ART clinic attached to the Katutura Intermediate Hospital. The high HIV prevalence in pregnant women at this site, as suggested by prior HIV Sentinel Surveys (MoHSS, 2012d) and confirmed by the most recent Survey (MoHSS, 2014b), was another consideration. The Katutura hospital is also one of four sites in Namibia conducting the highest number of early infant diagnosis (MoHSS, 2009b).

While HIV prevalence in the general population in Khomas region is slightly lower than the overall country prevalence (11.9% vs. 14.0%) (MoHSS and ICF International, 2014), a closer examination of site statistics within the region shows that the epidemic is more concentrated in the lower income north-western suburbs of Windhoek, where the current study is based (Aulagnier et al., 2011; MoHSS, 2014b). The most recent Sentinel Survey reported a prevalence of 19.6%, one of the higher prevalence sites, and higher than the national prevalence in pregnant women (16.9%) (MoHSS, 2014b). A lower prevalence was recorded at the Windhoek Central hospital (4.0%), also in Windhoek, but situated in a more southern part of the city. Smaller scale surveys in the general population in Khomas replicate these findings (Aulagnier et al., 2011).

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[2] We include as the Katutura area the municipal areas of: Greenwell Matongo, Goreangab, Hakahanna, Havanna, Katutura, Okuryangava, Soweto, Wanaheda. These areas include informal settings and low income formal settlements (See appendix 1).

Finally, the Katutura area is a low income area characterised by low social and economic development, making it of particular interest. Part of the social difficulties facing the area is a consequence of historical developments, in particular Apartheid policies. In the late 1950s, the north-western part of the city of Windhoek was built to accommodate all residents from the former “Old Location” as well as Owambo contract workers to the city. The “Old Location” had been established since 1912 to house black residents with each ethnic group having its own area. The people named the place Katutura, which literally means “we do not have a permanent habitat” in the Otjiherero language. By 1968, the Windhoek urban area was composed of three separate townships: Katutura for blacks, Khomasdal for coloureds and Windhoek for whites (Pendelton, 1994). The Katutura area was generally poorly serviced and poorly developed. Since independence, the laws have been abolished, yet the area is still low income compared to the high income areas in the south of the city and remains characterised by poverty and a poor level of public sector facilities (Aulagnier et al., 2011; City of Windhoek, UNAIDS, UNDP, PharmAccess, & Sacema, 2012).

Contributing to its social and economic situation is the large number of people who migrate from rural areas to the City, who use Katutura as their first point of entry. Along with Erongo region in the west, Khomas region has had the highest inflow of internal migrants in the country (Namibia Statistics Agency, 2015). Windhoek, in particular, has grown by 38% since 2011 (City of Windhoek et al., 2012; Namibia Statistics Agency, 2015). Due to the lack of affordable housing, many people build informal dwellings/shacks in areas which still lack basic facilities, such as adequate water, sanitation and electricity. The high migration levels, in the context of problems from Apartheid, together with current social and economic factors, means that people living in this area often face a precarious situation. Therefore, while regional data on social and economic indicators show that, in comparison to other regions, children in the Khomas region live in better situations (Namibia Statistics Agency, 2012a; RAISON, 2014); there is a large discrepancy within the region, with the poorest parts of the population living in this rapidly growing north-west area of the city. It is within this area that the current study takes place.

4. Conceptual framework

HIV is a medical reality; however, as we have seen, it is impacted by and impacts a range of factors in the environment. For this reason any research that investigates the impact of HIV has to include not only the individual characteristics, but also the broader economic, socio-cultural and political context within which individuals live and grow. This is important particularly in contexts faced with social and economic challenges, as in southern Africa (Richter et al., 2009; Richter, 2004). In this study child mental health is considered to be impacted on by the child's individual psychological and relational factors and also by larger structural factors, such as poverty and access to services. Bronfenbrenner's ecological theory (Bronfenbrenner, 1979; 1994) has been used as a framework to understand the impact of HIV on HIV-positive (Coetzee, Kagee, & Bland, 2015) and HIV-affected children (Cluver, 2007; Doku, 2012; Killian, 2004). It is considered as a conceptual framework for the current study.

Ecological theory proposes that child development is affected by the interaction between the "bio-psychological human organism" and its environment. The environment not only includes the people and objects in the child's immediate environment, but also broader contexts, such as social factors, cultural aspects and the political context (Bronfenbrenner, 1979; 1994). The model can be understood as a series of concentric layers or subsystems around the child (Figure 4). The subsystem closest to the child is called the microsystem. It includes the child's individual characteristics (child level factors) as well as the interactions with people in its system, such as parents, peers or teachers. In the case of an HIV-positive child, individual characteristics could include demographics such as age and gender and factors such as health status (e.g. CD4 count) or orphan status and also people involved in their treatment and care, such as caregivers, nurses or friends in their peer system. Children are often impacted by more than one microsystem: such as the family, the school and their peers.

The next layer is the mesosystem which considers the different microsystems and their interaction and impact upon one another and how this affects the development of the child. An example could be the communication between the child´s caregiver and the child´s teacher. For example, for HIV-positive children, language barriers between parents and health workers can be an important factor in the child´s treatment adherence (Coetzee et al., 2015).

The exosystem includes the different institutions of society which can indirectly affect the child’s development, although the child does not directly participate in them. The parent´s workplace is an example, but also broader systems, like the government. An example might be governments’ policies on assistance to be offered to vulnerable children, such as a school feeding programme, which can mitigate the effects of poverty on the child´s ability to learn. Further factors may include community violence, stigma towards PLHIV and availability and access to services (Cluver, Gardner, & Operario, 2008a). In the present study, the setting where the research is conducted will be very important, since a large urban hospital is likely to be better resourced than a rural community clinic in another part of the country.

The macrosystem refers to the larger socio-cultural context which impacts on the individual´s behaviour and beliefs. Beliefs can be influenced by socio-economic, cultural, political or religious structures. For example, in Namibia and South Africa, gender roles and rules of authority may create a social context in which young girls are made vulnerable to sexual abuse by older men (Jewkes, Penn-Kekana, & Rose-Junius, 2005). Young girls are to accord respect and be submissive to older men. Furthermore in the context of poverty, these norms may be linked to the widespread occurrence of inter-generational sexual relationships, which is considered to be one of the drivers of the HIV epidemic in sub-Saharan Africa (Leclerc-Madlala, 2008). For HIV-positive children, poverty and lack of resources can also have an effect on their neurocognitive development (L. K. Brown, Lourie, & Pao, 2000).

The final layer in the theory, the chronosystem, refers to changes that occur over time, both in the environment and also in the life of the child. An example might be that the transition from middle childhood to adolescence may bring different challenges to a child living with HIV, such as decisions about disclosure of their HIV status to potential sexual partners.

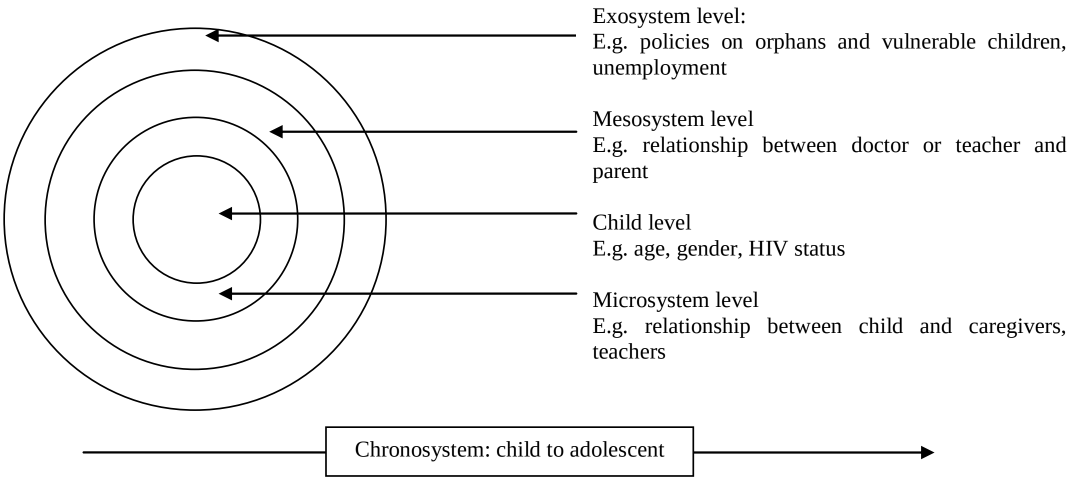

Figure 4 Bronfenbrenner's ecological framework

Bronfenbrenner’s model provides a framework in which the child’s functioning is seen as impacted by all these systems. Such an approach allows for the identification of multi-level contexts for intervention, broader than only the microsystem level as suggested by psychosocial theories (Elder et al., 2007). While the current study assesses the impact of particular risk factors in the child´s environment, we also look at the influence of certain experiences and the protective role they may play on the development of mental distress. Protective factors can be thought of as those experiences that “ameliorate or modify” a child’s adaptation to a particular environmental stressor (Rutter, 1985). These protective factors may exert influence across the different microsystems. As already noted, negative experiences at one microsystem may impact negatively on another, but protective factors may have the same effects across systems. For example a positive experience at the health centre or within a peer support group can mitigate the effects at home or help buffer the effects of a stigmatising community environment.

There are some limitations in applying the framework. It is impossible in one study to include all the criteria and assess each level of the ecological system (Bronfenbrenner, 1979). Recognising that this study assesses a fairly new demographic, we consider those factors immediately measureable and that have been suggested as more pertinent in the literature (see Chapter one) and through discussion with local experts (see Chapter two). Another limitation is the exclusion of particular psychological processes, such as coping style (Sopeña, Evangeli, Dodge, & Melvin, 2010), which may have important impact on children´s wellbeing. We also recognise that our outcome, child mental health, assesses only one aspect of the child’s functioning and only at one particular point in time.

5. Purpose of the study

Amongst some of the challenges facing Namibian children are high levels of violence, high levels of orphanhood and poverty. Children and adolescents living with HIV face the additional stressors of stigmatisation (Edusector AIDS response Trust, RAISON Namibia and TAMASHA Tanzania, 2008), living with an HIV-positive parent, disclosure and treatment adherence. This study contributes to our understanding of how the challenge of being ill, coupled with the many psychosocial stressors affects the wellbeing of this subpopulation and what implications this may have for their treatment.

The study has three general objectives. First, to examine the social and demographic characteristics of adolescents living with HIV and the effects of HIV status and its associated risk factors, e.g. HIV-related stigma, as well as other risk factors, e.g. poverty, on the mental health of adolescents living with HIV. We also examine the types and levels of social support available to adolescents living with HIV and its role as a potential protective factor in their mental health.

Second, to compare the mental health status of adolescents living with HIV to an age and gender matched sample from the same community. We examine which environmental variables differentiate the two groups and also, how these variables impact on the potential differences observed in their mental health. Finally, in the light of the scarce data on child and adolescent mental health in the country, this study contributes by providing more data on the prevalence of mental health among young people.

6. Overview of the thesis

The current chapter has presented the background for the study and outlined the general study objectives. The next chapter reviews relevant African and international research conducted with adolescents living with HIV, specifically empirical studies of mental health in this group. Our aim is to identify those risk factors which predict poor mental health outcomes in children and adolescents affected with and living with HIV. This will provide an empirical foundation for identifying relevant risk and protective factors to be included in the current study.

Since this is the first time a study on factors implicated in adolescent mental health is conducted in this context, it was important to ensure that the factors suggested by the literature review are in fact applicable to Namibia. Chapter two outlines the pilot work undertaken to ensure that the instruments and factors were appropriate to the local Namibian context. It also outlines the pilot work undertaken to assess the psychometric properties of the tool used to measure mental health. In chapter three we present the methodology and research approach used to answer the main study objectives. Chapter four presents the results of the analysis according to the study objectives outlined.

The findings and their implications will be discussed in Chapter five. We synthesise the findings from the study and discuss these in the context of previous research. We also discuss the findings specifically within the Namibian context and outline the major implications, both including clinical, policy and research implications. The chapter also considers the limitations of the study.

CHAPTER ONE: LITERATURE REVIEW

This chapter outlines important elements in paediatric and adolescent HIV infection and reviews relevant literature on mental health in adolescents living with HIV. The chapter begins by discussing the epidemiology of paediatric HIV, including its effects on children and their development, as well as treatment issues. Thereafter findings on mental health problems in HIV-positive populations are reviewed. Since research in adults living with HIV has been more common than with young people, an overview of the relevant findings in the adult literature is also considered.

The findings of a systematic review of international research on mental health in children and youth living with HIV, conducted in the last 10 years, are presented. The review includes findings on prevalence and types of mental health problems found in adolescents living with HIV and on risk and protective factors, identifying those factors that have been shown to predict worse or better outcomes for mental health. Both individual and microsystem factors as well as larger contextual factors will be considered. The purpose of this review is three fold. Firstly, it explores whether mental health problems are indeed more prevalent in HIV-positive adolescents when compared to their peers. Secondly, it identifies gaps in this research. Thirdly, the review identifies those risks and protective factors that may be relevant to the current context. Finally, the review considers how previous research could inform the design and selection of assessment tools for the current study.

1.1 HIV in adolescents and children

In this section we consider the epidemiology of HIV in adolescents, including how the epidemiology has evolved over time and the changes access to antiretroviral treatment (ART) has brought. The section also considers the consequences of being HIV-positive, not only the medical consequences, but also the social consequences.

1.1.1 Epidemiology and treatment

HIV infection in children occurs primarily through vertical transmission with most infections occurring at either at birth or through breastfeeding. In the last decade, however, considerable developments in the prevention of mother to child transmission have resulted in a notable decline in vertical transmission. These developments include administration of antiretroviral prophylaxis to HIV-positive pregnant women not yet eligible for antiretroviral therapy (ART) prior to pregnancy, postpartum treatment to infants born from HIV-positive mothers as well as more comprehensive interventions, such as increased testing of pregnant women and antenatal care and support to mothers before and after birth (MoHSS, 2008a; MoHSS, 2014a; Padian et al., 2011; WHO, 2007). According to UNAIDS (2013) there has been a 52% decline in infections among children worldwide between 2001 and 2012. Specifically, six high epidemic and priority countries, including Namibia and South Africa, achieved a decline of 40−59% in vertical transmissions between 2009 and 2011 (UNAIDS, 2012). Namibia, for example, provides antiretroviral medicine to 90% of pregnant women living with HIV (UNAIDS, 2013) and data indicates that the country is on target for reaching the WHO goal of reducing mother to child transmissions to 5% (Jonas et al., 2014).

However, many high prevalence countries still lag behind in reducing the transmission of HIV in children: these include Namibia’s northern neighbour Angola as well as Chad, the Democratic Republic of the Congo, Ethiopia, and Nigeria (UNAIDS, 2013). Of the 333 000 children that became newly infected in 2011, 90% were in sub-Saharan Africa (UNAIDS, 2012). Furthermore, previous high rates of vertical transmissions mean those children born before the advances in the prevention of mother to child transmission have started to reach middle childhood and adolescence.

Apart from declining vertical transmissions, developments in the treatment of HIV have also significantly changed the landscape of the disease for those surviving children and adolescents. HIV is no longer a disease where children have a high possibility of early mortality, but has become a chronic disease requiring lifetime management. Prior to developments of Highly Active Antiretroviral Therapy (HAART), for example, HIV progression in children was quite rapid with 20-30% of children developing AIDS or dying within the first year of life (Abrams & Kuhn, 2003). In Africa, as much as 50% of infected children did not survive their second year (Newell et al., 2004). Both early detection of HIV and early start of ART in babies have reduced mortality in infants and improved overall child survival (Judd et al., 2007; K. Patel et al., 2008).One study, for example found that early start with ART (at 6-12 weeks of age) improved infant survival by as much as 76% and decreased HIV progression by 75% (Violari et al., 2008). However, a recent analysis by UNICEF has suggested that adolescents living with HIV in low and middle income countries may remain at a high risk for AIDS-related mortality.

AIDS mortality in adolescents living with HIV

In 2012, there were an estimated 2.1 million adolescents living with HIV worldwide, of which 1.3 million were living in eastern and southern Africa. Statistics for AIDS-related mortality are generally reported for children (0-14) and adults (15+) both of which have shown a declining trend (UNAIDS, 2013). To examine and isolate adolescent specific trends in AIDS-related mortality, UNICEF conducted an analysis of the UNAIDS spectrum data from 2001- 2010 focussing specifically on the adolescent age range (10-19) (Kasedde, 2014; Porth, Idele, Suzuki, Kasedde, & Luo, 2014). The analysis showed that, while AIDS-related mortality decreased over the time period for all other age groups, it actually increased for adolescents (Figure 5). Between 2005 and 2012, for example, there was a 32% decline in mortality for other age groups, while for the same period there was a 50% increase (from 71, 000 to 110, 000) in AIDS-related deaths for adolescents (Idele et al., 2014).

Older adolescent males (15-19) appear to be most vulnerable, although this could also be because more girls in this age group tend to be newly infected, which could make male mortality rates appear more marked. It should be noted that this analysis is based on the HIV and AIDS spectrum estimates of UNAIDS, and, as explained previously, the accuracy of these estimations depends on the quality of information provided in country data. Furthermore, it is not clear what proportions of these deaths are for behaviourally or vertically infected adolescents or whether these trends replicate across different contexts. Further research will help unravel the causes for this trend and the factors that may increase vulnerability, whether adherence, treatment access, testing rates or potential biological or social factors. We now look at the consequences of HIV on the growing child and its development. The results of the increased risks in adolescents have resulted in a recognition of and increased effort required for this group, including more segregated and effective data collection (Idele et al.; 2014)

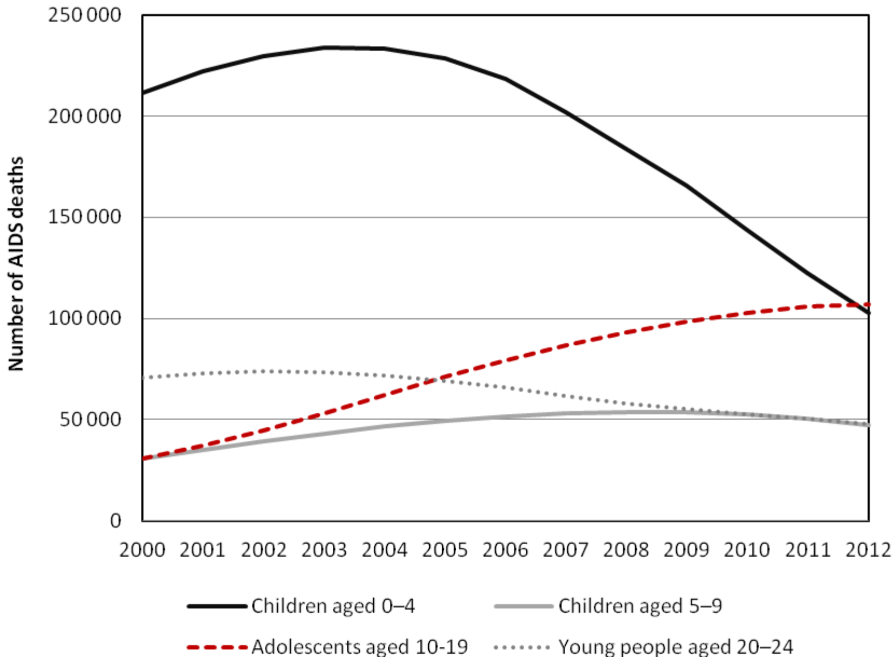

Figure 5 Annual AIDS deaths for children, adolescents and young people in low and middle income countries: 2001-2012 (Source: Kasedde, 2014).

1.1.2 Consequences of HIV in children and adolescents

We consider the neurodevelopmental, cognitive and psychosocial effects of HIV on children and adolescents.

Neurodevelopmental and cognitive effects of HIV

HIV invades the central nervous system producing widespread neurological and cognitive damage. In younger children, it can cause a loss of developmental milestones, poor motor development, cognitive delay and deficits in neuropsychological functioning (Havens & Mellins, 2008; Potterton, 2006). In older children, this includes lowered IQ scores, difficulties with language, attention, concentration and memory (Havens & Mellins, 2008; Smith et al., 2012). Neurodevelopmental effects are more pronounced in children with advanced stage illness (Laughton, Cornell, Boivin, & Van Rie, 2013; Smith et al., 2012) and are exacerbated by social and economic deprivation, poverty and poor nutrition (L. K. Brown et al., 2000). A major benefit of ART has been that these effects are significantly less common in children on treatment (Havens & Mellins, 2008). The latest WHO guidelines recommend that all children below five begin ART, irrespective of CD4 count, whereas children over five should start ART once CD4 count falls below $500mm^3$, higher than the previous level of $350mm^3$ (WHO, 2013).

According to WHO (2007):

> The pathogenesis of HIV infection is largely attributable to the decrease in the number of T cells (a specific type of lymphocyte) that bear the CD4 receptor (CD4+). The immune status of a child or adult living with HIV can be assessed by measuring the absolute number (per mm^3) or percentage of CD4+ cells, and this is regarded as the standard way to assess and characterize the severity of HIV-related immunodeficiency....For children over 5 years: CD4 > 500per mm^3 is classified as non-significant immunodeficiency; 350-499 $CD4/mm^3$ is classified as mild immunodeficiency; 200-349 $CD4/mm^3$ is classified as advanced immunodeficiency; <200 or <15% $CD4/mm^3$ is classified as severe immunodeficiency (p. 12)

While many countries in low resource settings find this recommendation quite stringent, Namibia has updated the guidelines for children to be in line with these recommendations. However, ART coverage for children lags behind that of adults; in the 2012/13 reporting period coverage was 67%, compared to 82% for adults (MoHSS, 2013). Many low and middle income countries may struggle with implementing these higher recommendations, largely due to the larger number of HIV-positive people requiring treatment which places a significant burden on the health systems (Davies, Egger, Keiser, & Boulle, 2010). Indeed there is still considerable debate regarding the correct starting point of ART for children over five years, particularly where the risks of poor adherence may be high (Mofenson, 2014; Tudor-Williams, 2014). Poor adherence could result not only in treatment failure but in the development of treatment resistance and the development of new strains of HIV (Gardner, Burman, Steiner, Anderson, & Bangsberg, 2009). Minimizing these potential consequences, adherence as high as 90% is recommended. This may be problematic for resource-limited countries (Elise et al., 2005; Mofenson, 2014) where both individual factors, such as drug exhaustion (Iroha, Esezobor, Ezeaka, Temiye, & Akinsulie, 2010) and structural factors, such as cost of medications (Paranthaman, Kumarasamy, Bella, & Webster, 2009) being an orphan (Vreeman, Wiehe, Ayaya, Musick, & Nyandiko, 2008) and poverty (Biadgilign, Deribew, Amberbir, & Deribe, 2009), are barriers to non-adherence. Thus while advancement in treatment has extended the lives of perinatally infected children and reduced the neurocognitive effects, poor coverage of ART in children and adolescents in low and middle income countries and poor adherence to treatment mean that the consequences of HIV still affect large numbers of children and adolescents.

Psychosocial consequences of HIV

Apart from the medical, treatment and adherence challenges faced by children and adolescents living with HIV in sub-Saharan Africa, they may also face many psychosocial consequences. These include, but are not limited to the death of a parent to AIDS, having to care for younger siblings and/or an HIV-positive parent, stigma and poverty. Orphanhood is more likely in HIV-positive children and adolescents as the parents are more likely to be HIV-positive resulting in an increased chance of .The consequential family reconfiguration as well as the loss of a parent may have serious consequences on the wellbeing of the child (Cluver & Gardner, 2007). In sub-Saharan Africa it is estimated that in 2012, 56 000 million children were orphaned in the year, of which an estimated 27% were due to HIV and AIDS (UNICEF, 2014).

Two surveys report statistics of orphanhood in Namibia: the Namibian Census (Namibia Statistics Agency, 2013a) and the Namibian Demographic and Health Survey 2013 (NDHS) (MoHSS and ICF International, 2014). An orphan in both surveys is defined as a child under 18 who has lost one or more parent.

Table 2 Prevalence of orphans in Namibia

National orphan prevalence	**Percentage (%)**	**Source**
Percentage of orphaned children in the general population	15.7% 14.0%	2011 Census 2013 NDHS
Percentage of orphaned children stratified by age:		
0-4	4.0%	2013 NDHS
5-9	10.0%	
10-14	21.9%	
15-17	26.8%	
Khomas region orphan prevalence		
Percentage of orphaned children in Khomas region (0-18)	11.1%	2011 Census

Note: The 2011 Census includes children aged 18 and below as orphans whereas the NDHS includes children below age 17 and below.

The census data covers the entire Namibian population, while the NDHS contains a representative sample of the Namibian population. The NDHS is included as it provides age-disaggregated data. The 2011 Namibian census reports that 150 589 children (15.7%) in Namibia are orphans, with 2.7% of these being double orphans (Namibia Statistics Agency, 2013a). The level in the 2013 NDHS is slightly lower at 14%. The proportion of orphaned children increases with age from 4.0% in the below five year-old age group to 26.8% in the 15-17 age group (Table 2). Although orphan prevalence in the Khomas region, where the current study is based, is lower than the National prevalence (11.1%), certain constituencies included in the current research have higher prevalence (Namibia Statistics Agency, 2013a). For example, orphan prevalence is 14.8% in the Katutura East constituency and 13% in Moses//Garoeb constituency. It is not known which proportions of orphans are due to HIV and AIDS, but it is estimated to be more than half (58.5%) (UNICEF, 2014). While there is no current data on proportions of children and adolescents living with HIV being orphans, it is expected that there will be higher percentages of orphans within that subgroup compared to the general child and adolescent population (Banerjee, 2007; Betancourt et al., 2014).

Parental HIV has social, economic and psychological effects on children. It can contribute to high migration of children between families (Lowenthal et al., 2014; Sherr et al., 2014) or, as a shown in a Namibian study, the assumption of responsibility for caring for the family

(Kizza, 2010). However, even when parents are still alive, statistics suggest that it is common in Namibia for children to live apart from their biological parents. For example, the 2013 NDHS found that approximately 28.3% of children do not live with either biological parent, despite both parents being alive (MoHSS and ICF International, 2014).

Added to this is the potential effect of poverty, which may be worsened by the death of an HIV-positive parent or breadwinner. In Namibia, households containing orphans tend to rate higher on poverty indices compared to households containing non-orphans (Namibia Statistics Agency, 2012a). Families with children and adolescents living with HIV also have the added costs, including travel expenses for treatment, and nutritional needs.

Further psychosocial challenges faced by children and adolescents living with HIV include HIV-related stigma, directed to themselves or towards family members which may be living with HIV. Research on educational needs of HIV-positive children and adolescents in Namibia and Tanzania suggests that stigma and discrimination was so pervasive that all participants at both study sites reported at least one instance of experienced stigma (Edusector AIDS response Trust, RAISON Namibia and TAMASHA Tanzania, 2008). Research shows that in Namibia, as elsewhere, HIV stigma is often internalised by HIV-positive populations (Keulder, 2007). Bearing in mind the challenges described above, as well as the fact that these adolescents need to cope with the reality of their disease, it has been suggested that children and adolescents living with HIV may suffer from increased prevalence of mental distress than their peers. Since this topic has been investigated in adults for some time, this research is briefly reviewed.

1.2 HIV and mental health in adults: overview and lessons learnt

The prevalence of mental illness in adults living with HIV has been studied for some time in high income countries (Ciesla & Roberts, 2001; Rabkin, 2008), and is increasing in low and middle income countries (Brandt, 2009; Breuer et al., 2011; Collins, Holman, Freeman, & Patel, 2006). In a review of studies conducted in sub-Saharan Africa between 1994 and 2008, for example, Brandt (2009) reported that more than half of the 24 studies found were published after 2005 (58%).

Research in both high income and low and middle income countries, including sub-Saharan Africa, tends to report high rates of mental health problems in PLHIV; however, there are big variations in the reported prevalence. Breuer et al. (2011) for example, found that prevalence of mental disorders in adults in sub-Saharan Africa varied widely across studies, from as low as 5% to as high as 83%. Similarly, Collins et al. (2006) found large variations in developing countries, particularly for depression (0-63.3%). The most prevalent mental disorder in people living with HIV (PLHIV), other than substance use disorders, tended to be depression, with more mixed findings for anxiety disorders (Brandt, 2009; Breuer et al., 2011).

However, studies included in the above reviews comprised participants as diverse as pregnant women, sex workers and the general population (Brandt, 2009; Collins et al., 2006). Furthermore, some studies did not specify the stage of illness and only a few studies included a control group (Brandt, 2009). Furthermore, randomisation in studies with HIV populations is not always feasible, practically or financially, since most studies are dependent on voluntary participation. There is also a concern with the lack of cross-cultural validation of the instruments in studies in sub-Saharan Africa (Brandt, 2009). Despite these methodological concerns, the evidence suggests that the prevalence of mental illness may be high in PLHIV. Research with adults has also shown the importance of this topic from a public health perspective, with mental health problems being linked to poor treatment adherence in PLHIV and also to HIV risk behaviour.

1.2.1 Mental health and treatment adherence

As noted in the previous section, treatment adherence is vital in extending life expectancy and quality of life of PLHIV. Non-adherence has been associated with increased risk for mortality (Lima et al., 2009; Nachega et al., 2006), decreased suppression of the virus (Gardner et al., 2008; Sherr et al., 2010) and subsequent development of treatment resistance (Gardner et al., 2009). Low or undetectable viral loads decrease the spread of the virus as individuals who achieve viral suppression are not as infectious. Mental illness and its role in adherence to treatment have been examined in high income countries and more recently in low and middle income countries.

In a review of 29 studies in sub-Saharan Africa, Nakimuli-Mpungu et al. (2012) found that the likelihood of good adherence was 55% lower among those with depression. Again the findings are interpreted with caution, due to the wide range of instruments used to assess mental illness and that no study reported any cross-cultural validation methods. However, similar findings are reported in high income countries (Tegger et al., 2008), particularly with depressive symptoms and non-specified mental disorders (Springer et al., 2012). The findings for anxiety disorders are less clear, since these disorders tend to be less prevalent in PLHIV (Springer et al., 2012). There is also evidence that the level of adherence improves following treatment for mental health problems, particularly for depression (Springer et al., 2012). This was true for treatment through medication and through increased follow-up visits.

1.2.2 Mental health and HIV risk behaviour

Research has also started to explore the relationship between mental illness and HIV risk behaviour (Breuer et al., 2011; Meade & Sikkema, 2005), particularly whether people who have a mental illness may be more likely to engage in risky behaviour which could lead to further HIV infections (Baingana, Thomas, & Comblain, 2005). This has been prompted by some evidence that HIV prevalence tends to be higher in psychiatric populations (Guimarães, McKinnon, Campos, Melo, & Wainberg, 2010), although this link has not been established in sub-Saharan Africa (Breuer et al., 2011).

Evidence suggests that HIV risk behaviour, such as multiple partners, unprotected sex and STI may be more common in populations with severe mental illness (Campos et al., 2008; Meade & Sikkema, 2005). However, as Meade and Sikkema (2005) point out, those with severe mental illness may also be in situations of poverty, possibly an indirect promoter of HIV risk behaviour. Furthermore, this research tends to be focused on chronic mental illness often requiring hospitalization and often in small and non-representative samples (Campos et al., 2008). The research in sub-Saharan Africa has mostly been limited to the use and abuse of alcohol; no study has looked specifically at the link between severe mental illness and HIV risk behaviour (Breuer et al., 2011). Therefore, while it may be possible that higher rates of HIV risk behaviour may be associated with mental illness, further research is needed to establish this link in sub-Saharan Africa.

Research with adults suggests that PLHIV may be at an increased risk for mental health problems; however there are important considerations to applying these findings to adolescents. Firstly, adolescence is a transitional developmental phase between childhood and adulthood and has particular tasks which differ from other phases. These tasks include the development of autonomy and self-identity (Kang, Mellins, Ng, Robinson, & Abrams, 2008). Having HIV can have implications for how an adolescent navigates these tasks. For example, as adolescents start to develop their autonomy and identity as separate from their family, peer relationships and acceptance by peers become important. Qualitative research has shown how having HIV may make HIV-positive adolescents question their identity and sense of belonging to their peer group, which may cause internal distress (Kang et al., 2008) and internalised stigma (Petersen et al., 2010). Secondly, HIV-positive adolescents differ from adults as they include those that have been perinatally infected, whereas adult populations have predominantly been infected behaviourally. Longstanding HIV infection acquired at birth may have different physical and psychological effects (Lowenthal et al., 2014). These differences need to be considered when examining adult literature. For this reason, the next section specifically reviews studies conducted with adolescents and young people living with HIV.

1.3 The mental health of adolescents living with HIV: review of research

This section considers recent published literature investigating mental health in adolescents and young people living with HIV. We were interested in establishing whether previous research has indeed shown young people living with HIV to have greater risk of mental health problems. The review therefore focused on the prevalence of mental health problems in adolescents living with HIV and also on how these rates compared to other adolescent groups. Later on, Section 1.5 will look specifically at risk and protective factors implicated in mental health of adolescents and young people living with HIV.

1.3.1 Search strategy and papers included

The literature reviewed in this section focuses on quantitative studies which examine mental health outcomes in children, adolescents and young people living with HIV. The review includes controlled studies, non-controlled studies and longitudinal studies published in the last decade. Studies were included in the review if they met the following criteria:

- A proportion of study participants fell in the 12-18 age range, although not limited to that age range. The current study focuses on adolescents in the 12-18 age range. However, it was not possible to only include studies in this age range due to the low number of studies. For a study to be included, the lower age limit was set at six years and the upper age limit at 25 years.
- Mental health outcomes were assessed.
- The studies were published between 2004 and 2014.
- The review includes studies from sub-Saharan African countries, other low and middle income countries and high income countries.

The review searched databases of *PsycINFO*, Medline and Google scholar using a combination of keywords for adolescents living with HIV ("adolescents or youth living with HIV/ALHIV/YLHIV", "HIV-positive adolescents or youth", "HIV-infected adolescents or youth"), mental health ("mental illness", "mental distress", "psychiatric illness/symptoms", "emotional/behavioural symptoms of distress"). In addition to online databases, grey literature and the reference lists of articles included in the review were examined for additional studies.

Studies were not included if they only focused on neurological delay or cognitive functioning and did not include mental health outcomes. While these may be important consequences of HIV in children and adolescents (Laughton et al., 2013; Lowenthal et al., 2014), this thesis only considers their role only as they are linked to mental illness. Studies that used qualitative techniques are not included in the review (Hodgson, Ross, Haamujompa, & Gitau-Mburu, 2012; Loos et al., 2013; Petersen et al., 2010). The search was expanded beyond Africa, mainly due to the low number of studies conducted in Africa. However, taking into consideration that the current study setting is in sub-Saharan Africa and owing to differences between this and other contexts, preference is given to studies conducted in this region.

Some authors have proposed that there may be "striking commonalities" between HIV-positive children in high income and low resource contexts suggesting that some extrapolation from these findings may be useful (Havens & Mellins, 2008). HIV infection in high income contexts, such as the U.S., often occurs in ethnic minorities, those living in difficult socio-economic situations or from mothers who have been injecting drug users. This makes these children and their families vulnerable to the effects of poverty, minority status and family reconfiguration, similar to challenges in low resource settings (Havens & Mellins, 2008). However there are important differences. In sub-Saharan Africa, the epidemic is generalised. Paediatric infection tends to affect the poor, as those in socio-economic hardships tend to struggle to access treatment to prevent vertical transmission and slow the effects of HIV once children have the virus. Furthermore, access to health-care and treatment has meant that paediatric infections have largely been eradicated in high income countries (Havens & Mellins, 2008). Better care and treatment availability in high income countries has reduced mortality as well as the neuro-developmental consequences of HIV. Additionally, treatment and care extends to other comprehensive services, such as counselling and other support services to individuals and families (Elkington et al., 2011) which may play a huge role in the mental distress of perinatally infected children. These factors need to be considered when extending findings from high income contexts to countries in sub-Saharan Africa.

Articles were included if they were published between 2004 and 2014. For studies conducted prior to 2004 and 2006, see Scharko (2006) and Havens and Mellins (2008) respectively. Two more recent reviews were conducted, one in 2011 (Palmer, 2011) and one in 2013 (Mellins & Malee, 2013). Palmer (2011) however, included fewer than 10 studies, and all were from the U.S. Mellins and Malee (2013) conducted the most comprehensive review to date to include both quantitative and qualitative publications. Our review only considers quantitative research conducted from 2004, whereas they reviewed studies as far back as 1999 and only included perinatally infected participants. We extend their review, by including 23 articles that were not included in that review, some because they were published after 2012 and others because they include behaviourally infected youth. Mellins and Malee (2013), refer to only two quantitative studies in sub-Saharan Africa, whereas we have included seven quantitative studies.

Forty-six publications were identified for the review (Figure 6). Of these publications, seven examined the mental health of adolescents living with HIV in sub-Saharan Africa, five publications were from other low and middle income (including upper middle income) contexts and 34 were from high income countries, predominantly from the U.S. For the studies in sub-Saharan Africa, all were cross-sectional studies with only one study having a control group. For the five studies from other low and middle income contexts, all were cross-sectional, with four of the five having a control group(s). For the 34 publications from high income contexts, most were cross-sectional (*n* = 28), of which 11 had control groups, while 4 studies were longitudinal, of which 2 had control groups. There were also two retrospective studies.

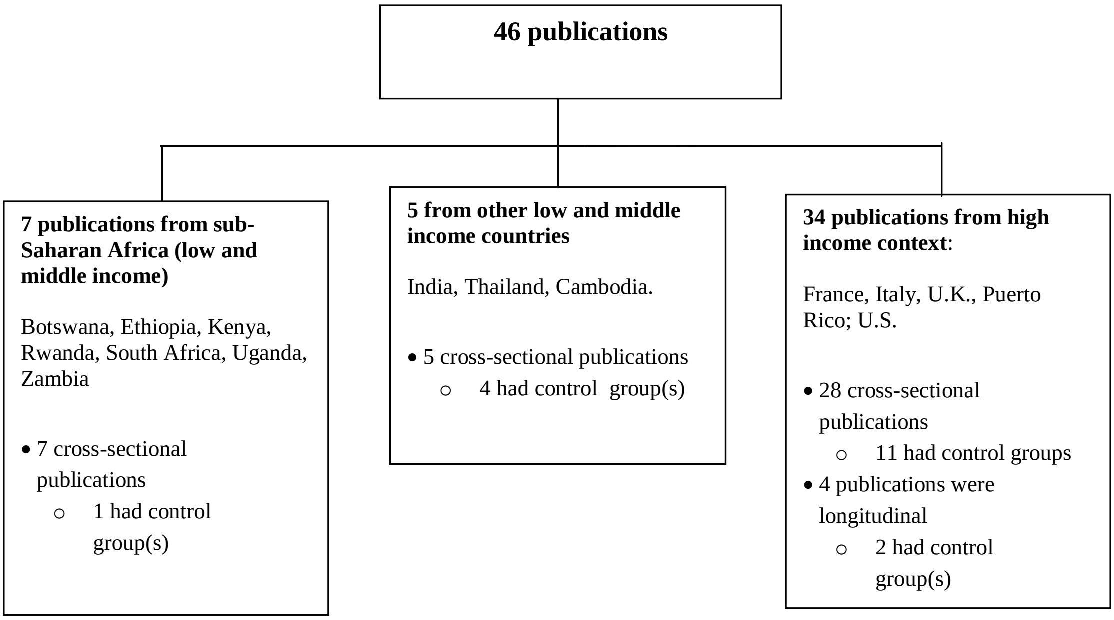

Figure 6 Breakdown of publications in the review by region

1.3.2 Results of the review

Findings from studies from sub-Saharan Africa will be considered first, followed by findings from other contexts.

Studies in sub-Saharan Africa

Sub-Saharan Africa includes central Africa, east Africa, southern Africa and west Africa. As this spans a large geographical area and potentially diverse contexts, we recognise that countries included may differ substantially in their social and economic conditions and with respect to HIV prevalence and dynamics.

Seven empirical studies examined the prevalence of mental health problems and the associated risk factors in adolescents living with HIV in sub-Saharan Africa, of which one was a controlled study. Five studies examined emotional and behavioural difficulties: one each in Zambia (Menon et al., 2007), Ethiopia (Tadesse et al., 2012), Botswana (Lowenthal et al., 2012), South Africa (Small et al., 2014) and Rwanda (Betancourt et al., 2014) and two studies examined prevalence of psychiatric disorders, one in Uganda (Musisi & Kinyanda, 2009) and one in Kenya (Kamau et al., 2012). Only the study conducted in Rwanda had a local comparison group (Betancourt et al., 2014). The studies are presented in Table 3.

Betancourt et al. (2014) was the only study in sub-Saharan Africa to date, to include a locally selected control group, comparing the mental health of HIV-positive adolescents (n = 218) with two groups: adolescents living with an HIV-positive caregiver or orphaned by AIDS (HIV-affected, n = 228) and HIV-negative and unaffected children (HIV-unaffected, n = 237) in three rural districts in Rwanda. A total of 683 children between the ages of 10 and 17 were assessed using a mixture of self-constructed and locally validated instruments (Achenbach & Ruffle, 2000; Radloff, 1991). It was found that both HIV-positive and HIV-affected children reported higher rates of depression, anxiety, conduct problems and functional impairment compared to HIV-unaffected children. There was no significant difference in mental health problems between HIV-positive and HIV-affected participants.

Kamau et al. (2012) examined the prevalence of psychiatric morbidities in 162 children and adolescents living with HIV between the ages of 6 and 18 at a clinic in Kenya. Psychiatric diagnosis was determined with the Mini International Neuropsychological Interview for Children (MINI-Kid) (Sheehan et al., 1998; Sheehan & Janavs, 2008). Seventy-nine (48.8%) participants qualified for at least one psychiatric disorder, the most common being anxiety disorders (32.2%), followed by major depression (17.8%). In the study with the largest number of HIV-positive participants in sub-Saharan Africa, Lowenthal et al. (2012) assessed emotional and behavioural problems in 692 HIV-positive youth between 8 and 17 in two urban sites in Botswana. Using the Paediatric Symptom Checklist (PSC) (Jellinek, Murphy, & Burns, 1986; Jellinek & Murphy, 1988; Jellinek et al., 1988), 17.3% of participant scored above the cut-off for clinical significant distress.

Menon et al. (2007) assessed emotional and behavioural symptoms of distress using the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) in 127 adolescents aged 11 to 15 years recruited through various clinics in Zambia. Since there were no local cut-offs, the authors did not report the number of participants with significant distress (mean Total Difficulties score: 11.9). Compared to an age and gender matched sample from the U.K., participants scored significantly higher on mental distress. Musisi and Kinyanda (2009) assessed both psychological distress and psychiatric disorders in 82 fully disclosed adolescents between the ages of 12 and 18 at a child and adolescent clinic in Uganda. Forty two participants (51.2%) showed significant distress based on a cut-off of >= 6 on the World Health Organisation Self report Questionnaire-25 (SRQ-25) (WHO, 1995). Using the International Classification of Diseases-10 (ICD-10) diagnostic criteria, the most common diagnosis was anxiety (45.6%), depression (40.8%) and somatisation (18.0%). Fourteen participants (17.1%) had attempted suicide.

Table 3 Empirical studies on mental health in HIV-positive adolescents in Africa

Country	**Sample**	**Study type and control group (if applicable)**	**Mental health measures: youth or caregiver (cg) administered**	**HIV group**	**Main Results**
Betancourt et al. (2014) Rwanda	*n* = 683 Age range: 10-17 Female: HIV+ group: 50% Control group: 52% rural site	Cross-sectional study with control group 218 HIV+ participants Control group (s): 228 HIV-affected (HIV+ caregiver or orphaned by AIDS) 237 HIV-unaffected	CES-DC: youth Conduct problem item scale): youth YSR internalising items and 10 internalising items from qualitative data: youth *Other domains*: socio-demographics, functional impairment, daily hardships, stigma, parenting	NO DATA	*Participant characteristics/Group differences* HIV+ and HIV-affected groups: greater levels of stigma and more likely to have experienced the death of a caregiver than HIV-unaffected HIV+ group: less likely to have mother as primary caregiver than HIV-affected or HIV-unaffected *Mental health* No difference between HIV-positive and HIV-affected children but both reported more mental health problems than HIV-unaffected. *Mental health: risk and protective factors* Once contextual variables (caregiver mental health, daily hardships, death of a caregiver, access to social service, harsh punishment and stigma) were controlled for: differences in mental health disappeared.
Kamau et al. (2012) Kenya	*n* = 162 Age range: 6-18 Female: 48.1%	Cross-sectional study	MINI-Kid: cg and youth *Other domains:* socio-demographics	30% knew their HIV status. 55% on ART 13.6% had CD4 count <350 cells/mm^3	*Participant characteristics/Group differences* 72.3% orphans , 34% double orphans *Mental Health* Prevalence of psychiatric morbidity: 48.8% 32.3% anxiety, 17.8% major depression, 12.2% attention deficit and hyperactivity disorder (ADHD), 12.2% oppositional defiant disorder *Mental health: risk and protective factors* No association between psychiatric disorder and socio-demographics. Significant association between male gender and major depressive disorder, and between female gender and specific phobia Major depression was significantly associated with immune suppression (CD4 < 350 mm^3), Knowledge of HIV status significantly associated with social phobia. Suicidality significantly associated with older age (children aged more than 11 years) No association between psychiatric morbidity and type of primary guardian or parental status (whether single mother, orphaned, both parents alive) or ART.
Lowenthal et al. (2012) Botswana	*n* = 692 Age range: 8-16.9 Female: 50.3%	Cross sectional study	PSC: youth *Other domains:* virologic failure, demographics, executive functioning	>90% perinatally infected (PIY) 100% on ART 6.8%: CD4 < 200mm^3 at the time of the study	*Participant characteristics/Group differences* 52.6% orphaned, 28% double orphans *Mental health* 17.3% had scores above the cut-off for distress *Mental health: risk and protective factors* Virologic failure more common in those with scores above the cut-off Virologic failure related depressive symptoms

Country	Sample	Study type and control group (if applicable)	Mental health measures: youth or caregiver (cg) administered	HIV group	Main Results
Menon et al. (2007) Zambia	*n* = 127 Age range: 11-15 Female: 45%	Cross-sectional study	SDQ: cg and youth *Other domains:* socio-demographics, disclosure status	96.9% PIY 37 % knew their HIV status 73.2% Receiving ART WHO: Stage III (28.3%), Stage IV (5.5%)	*Mental health* HIV+ group higher emotional difficulties than an age and gender matched sample in the U.K. *Mental health: risk and protective factors* Participants with more health problems reported higher SDQ scores No relationship between SDQ scores and WHO clinical stage or between those who knew their HIV status and those that did not. No relationship between orphan status and mental health
Musisi et al. (2009) Uganda	*n* = 82 Age range: 12-18 Female: 55.6%	Cross-sectional study	WHO-SRQ: youth Diagnostic assessment with psychiatrist using ICD-10 research diagnostic criteria: youth *Other domains:* socio-demographics	None receiving ART 60.9% WHO clinical disease stage III or IV	*Participant characteristics/Group differences* 97.6%: orphans of which 53.7% double orphans. 26.8% stayed with at least one biological parent, 24.4% with grandparents and 43.9% with other relatives. *Mental health* 51.2% significant psychological distress: 45.6% anxiety, 40.8% depression, 18% somatisation, 17.1 % attempted suicide within the last 12 months. *Mental health: risk and protective factors* Factors associated with distress were: younger age, being out of school, not being able to play sports at school, the HIV status of the caregiver Factors NOT associated with distress were: observable HIV-related physical signs and symptoms, sex, tribe, religion, academic grade, presence of parents, person with whom child is staying, attendance of counselling and HIV clinical stage
Small et al. (2014) South Africa 3 sites: Argentina, South Africa, U.S.	*n* = 111 Age range: 9-14 Female: South Africa: 49%	Cross-sectional study 111 HIV+ adolescents Argentina=22 South Africa=65 U.S.=24	SDQ: cg *Other domains*: Demographic information	100% knew their HIV status No other data	*Mental health* Percentage with abnormal scores for the South African site: Total difficulties (18%), Emotional symptoms (54%), Peer problems (11%), Conduct problems (10%), Hyperactivity (11%) and Prosocial (91%)
Tadesse et al. (2012) Ethiopia	*n* = 318 Age range: 6-14 Female: 52.5%	Cross-sectional study	CBCL: cg	11% knew their HIV status 100% on HAART 54.1% had a history of hospital admission for more than 5 days	*Participant characteristics/Group differences* 63.5% orphans; 26.7% double orphans. 57.9% have monthly income of less than 500 Ethiopian birr (ETB) (approximately 50 USD) *Mental health* 39.3% significant behavioural and emotional problems *Mental health: risk and protective factors* After controlling for the effect of socio-demographic variables, children with family monthly income of less than 500 ETB, children 10 years and above, and parental loss were significantly associated with behavioural and emotional problems

Small et al. (2014) assessed emotional and behavioural symptoms in 65 young adolescent (age: 9-14) at a hospital in South Africa. Using the SDQ (Goodman, 1997), it was found that 18% of the participants scored above the normal range for the total difficulties scale. For the subscales, 54% scored above the normal range for emotional symptoms, 11% for peer problems, 10% for conduct problems, and 11% for hyperactivity/inattention.

Tadesse et al. (2012) used the Child Behaviour Checklist (CBCL) (Achenbach & Rescorla, 2001) to assess the prevalence of emotional and behavioural symptoms of distress in children and adolescents living with HIV at a paediatric unit in Ethiopia (n = 318). Participants fell between the ages of 6 and 14. More than a third (39.3%) of participants qualified for significant emotional and behavioural symptoms of distress.

Summary and appraisal of studies in sub-Saharan Africa

Although only few studies were found, all had been conducted in the last seven years, suggesting that interest in this research area is growing within the region. Reported mental health problems ranged from 17.3% in Botswana (Lowenthal et al., 2012) to 51.2% in Uganda (Musisi & Kinyanda, 2009). Worldwide it is estimated that about 10-20% of children suffer from mental illness (WHO, 2001), whereas a review of studies in sub-Saharan Africa found that 14.3% of children suffer from psychopathology (Cortina, Soda, Fazel, & Ramchandani, 2012). Thus three of five studies had rates higher than upper WHO cut-off of 20% in children (39.3%, 48%, 51.2%) with the remaining two studies being in the upper range (17.3% and 18%). However, these studies used screening questionnaires assessing psychological symptoms of distress with cut-offs. Studies using screening questionnaires tend to report higher rates when compared to clinical diagnostic instruments (Cortina et al., 2012). The two studies that relied on psychiatric diagnosis found that depression and anxiety were the most common diagnoses (Kamau et al., 2012; Musisi & Kinyanda, 2009) which differs from adults where anxiety tends to be less commonly reported (Brandt, 2009; Breuer et al., 2011). However, it is consistent with literature that anxiety disorders are the most common in youth (Merikangas, Nakamura, & Kessler, 2009). Overall, while the studies point to elevated mental health problems in children and youth living with HIV compared to the general child and youth prevalence, these findings should be treated with caution, especially in the absence of local control groups. Furthermore, a few aspects of the sample selection and methodology need to be considered when interpreting these results.

With the exception of Small et al. (2014), all of the studies reported sample sizes over 100. However, studies also included high proportions of participants who, although HIV-positive, had not yet had their HIV status disclosed to them. The rate of non-disclosure was as high as 89% in the Ethiopian study (Tadesse et al., 2012) and 63% in the Zambian study (Menon et al., 2007). Only two studies had 100% fully disclosed participants (Musisi & Kinyanda, 2009; Small et al., 2014). Research supporting the benefits of disclosure to children’s mental health is accumulating; however, studies also show that if it is not handled properly, it may produce negative effects (Wiener, Mellins, Marhefka, & Battles, 2007). The mixture of disclosed and non-disclosed participants in the above studies make it difficult to draw specific conclusions about the effects of HIV status, since disclosure itself may be a confounding variable, although how it confounds depends on each specific context and case. That is, it may or may not have a positive effect depending on how it is approached (Lester et al., 2002; Meless et al., 2013; Wiener et al., 2007).

Sample groups also tended to be heterogeneous with respect to demographic and illness factors, such as age and disease stage. Only two studies focused exclusively on (WHO defined) adolescent age range (Menon et al., 2007; Musisi & Kinyanda, 2009), whereas two studies included participants as young as six years (Kamau et al., 201: Tadesse et al., 2012). Furthermore, different systems were used to classify the health of participants, which makes it problematic to compare the role of physical health on mental health differences across studies using either the WHO classification system or immune suppression as an indicators. Betancourt et al. (2014) and Small et al. (2014) did not report any data on biological markers or the illness stage of their participants. The section which follow looks at risk and protective factors in mental health, discusses the role of health status in mental health; however, the use of different indicators of health makes it hard to compare the illness stage of participants across studies.

Only one study, Betancourt et al., 2014, included a comparison group from the same context.

This study found that youth living with HIV have significantly more symptoms of distress, but more studies of this nature will be necessary to isolate HIV status as a risk factor in the context of other context related risk factors, such as poverty, particularly as the differences in the study by Betancourt et al. (2014) disappeared after taking account poverty (see Section on risk and protective factors). Given widespread resource poor settings in sub-Saharan Africa, comparison groups will be important to unravel the specific effects of HIV outside of social and economic hardships, a neglected area of study (Lund, 2014).

Other limitations include the range of instruments and administration formats used and the lack of information on the psychometric properties of the instruments used to assess mental health. The mixture of self-report and diagnostic assessment, as well as informants (self-report, caregiver, psychiatrist) complicates comparisons of the rates of disorders across the different studies. Furthermore, only three studies reported that the instrument was validated in the population it was used (Betancourt et al., 2014; Tadesse et al., 2012) and only one study reported the psychometric properties of the instrument used (Menon et al., 2007). This information is important to assess whether these instruments were reliable and valid tools for the respective contexts in which they were applied.

Another consideration is that only the Rwandan study was conducted in a rural setting (Betancourt et al., 2014). Given that the dynamics of rural populations may differ substantially, it limits the generalisation to all young people living with HIV in the region. It will also be important to separate the effects of co-occurring risk factors, such as orphanhood. In one study 97.6% of participants were orphans (Musisi & Kinyanda, 2009). Much research has documented the effects of orphanhood on the mental health of children and adolescents (Cluver & Gardner, 2007; Cluver, Gardner, & Operario, 2007; Doku, 2009). Since a large portion of children and adolescents living with HIV tend to be perinatally infected, it is expected that there will be higher rates of orphanhood in this population and it will be interesting to separate the effects of orphanhood and HIV status on mental health.

While the growing number of studies is encouraging, a lack of validation of the instruments, a lack of an adequate control groups and a mixing of disclosed and non-disclosed participants limit the conclusions that can be drawn from these studies regarding the specific influence of

HIV status. The next section considers the findings of research in HIV-positive adolescent and youth mental health in contexts outside of Africa.

Studies in non-African countries

Thirty-nine publications, reporting results of 32 studies conducted outside of Africa, were found. Five were from low and middle income contexts; one from India, three from Thailand and one combined a sample from Thailand and Cambodia (Table 4). For the studies in high income contexts, one was from the U.K., one from France, one from Italy, six were combined samples from U.S. and Puerto Rico, and the remaining 25 were from the U.S (Table 5). Most of the studies (33 publications) had a cross-sectional design. Four studies were longitudinal, although two of the longitudinal studies only report baseline findings, and two studies were retrospective. Fifteen of the cross-sectional publications and two of the longitudinal studies included control groups, either HIV-negative or HIV-affected (e.g. living with an HIV-positive parent or perinatally exposed to HIV but uninfected).

Mental health prevalence in cross-sectional research: Cross-sectional studies examined either psychiatric diagnosis or psychological symptoms of distress. No studies from low and middle income contexts outside of Africa examined psychiatric diagnosis (Table 4). Four studies from high income contexts (Table 5), reported prevalence of psychiatric diagnosis using either symptom inventories (Gadow et al., 2010; New, Lee, & Elliott, 2007), diagnostic interviews (Mellins, Brackis-Cott, Dolezal, & Abrams, 2006; Mellins et al., 2012; Wood, Shah, Steenhoff, & Rutstein, 2009) or diagnosis extracted from the medical file (Kapetanovic et al., 2011; Rudy, Murphy, Harris, Muenz, & Ellen, 2009). The lowest prevalence of psychiatric disorders was reported by New et al. (2007), who found that only 6% of HIV-positive participants met the criteria for a psychiatric diagnosis (*n* = 57). In that study, participants were only assessed for psychiatric diagnosis after meeting borderline or clinical scores on the Child Behaviour Checklist (CBCL) (Achenbach, 1991b). The majority of the remaining studies reported prevalence ranging from 48% to 68.7% (Kapetanovic et al., 2011; Mellins et al., 2006; Mellins et al., 2012; Wood et al., 2009) with two studies outside that range; Gadow, et al. (2010) found a prevalence of 27% and Rudy et al. (2009) found a prevalence of 38.3%.

The studies comprised samples which mixed participants which knew their HIV status with those who did not, those knowing their HIV status ranging from 44% (New et al., 2007) to 81.3 % (Mellins et al. 2012). Three studies did not report the proportion of participants who knew their HIV status (Kapetanovic et al., 2011; Rudy et al., 2009; Wood et al., (2009). The health of participants also varied. Few participants in Kapetanovic et al. (2011), Mellins et al. (2012) and Mellins et al. (2006) fewer participants showing advanced illness indicators, 22%, 10% and 9% respectively showing severe immunosuppression (CD4 < 200mm^3) whereas the study by New et al. (2007), about half of the participants (51%) met Centre for Disease Control and Prevention (CDC) criteria for an AIDS diagnosis at the time of the study.

Table 4 Empirical studies on mental health in HIV-positive adolescents in low and middle income countries (non-African)

Country	**Sample**	**Study type and control group (if applicable)**	**Mental health measures: youth or caregiver (cg) administered**	**HIV group**	**Main Results**
Banerjee (2007) India	*n* = 441 Age range: 4-16 Female: not reported	Cross-sectional with control group 140 HIV+ participants *Control group (s)* 301 participants in community control group	CBCL: cg *Other domains:* academic performance, orphanhood, family environment	NO DATA	*Participant characteristics/Group differences* HIV+ group reported higher rates of paternal death, and poorer academic performance. No group differences for: number of changes in school or residence HIV group and lower parental education level than control. *Mental health* HIV+ group had significantly more cg reported behaviour problems *Mental health: risk and protective factors* Being HIV-positive and having a disturbed family environment predicted more behaviour problems Boys aged 12-16: HIV infection was a major contributory factor towards behavioural disorder
Lee et al. (2011) Thailand	*n* = 219 Age range: ≥13 Female: HIV+ group: 50% Control group: 53%	Cross-sectional with control group 54 HIV+ participants *Control group(s)* 165 (from a local public school)	Thai CDI: youth *Other domains:* HIV status disclosure to others, substance use, sexual behaviour and knowledge	Vertically infected 100% knew their HIV status	*Participant characteristics/Group differences* No demographic differences, HIV group higher frequency of orphans (87% vs. 11.5%), double orphans (38.9% vs. 3.0%) *Mental health* HIV+ group had significantly lower mean CDI scores Fewer screened positive for depression; 27.8% of HIV group vs. 43% of control group (CDI ≥15) *Mental health: risk and protective factors* No association between HIV status disclosure to others and depression scores No association between CDI score and loss of a family member
Louthrenoo et al. (2013) Thailand	*n* = 106 Age: 11-18 Female: HIV+ group: 46%, Control group: 54%	Cross-sectional with control group 50 HIV + participants *Control group (s)* 56 participants (from local public school)	CBCL: cg YSR: youth	Mean CD4 count of 690 cells/mm^3 84% had complete suppression of viral load (< 50 copies/mL), 90% < 400 All on HAART	*Participant characteristics/Group differences* Fewer HIV+ participants lived with biological parent (46% vs. 90%) HIV+ group came from significantly poorer households *Mental health* No significant difference in the total difficulties score, although the trend was for HIV+ group to report more difficulties(p=0.07) HIV+ group more internalizing problems scores (self-report)) HIV+ group reported significantly more somatic complaints and social problems *Mental health: risk and protective factors* Significantly more total difficulties, internalising and externalising problems reported for HIV+ participants who lived with relatives or foster care compared to those who lived with at least one biological parent Higher viral load (> 50 copies/mL) significantly more withdrawn problems, aggressive behavioural problems, and thought problems

Country	**Sample**	**Study type and control group (if applicable)**	**Mental health measures: youth or caregiver (cg) administered**	**HIV group**	**Main Results**
Puthanakit et al. (2013) Thailand and Cambodia	*n* = 603 Age range: 6 to 12+ Female HIV +: 58% Control: 58%	Cross-sectional data from a longitudinal study (week 144) with control group 284 HIV+ participants *Control group(s)* 319 HIV-uninfected (155 perinatally exposed and 164 unexposed)	CBCL: cg *Other domains:* cognitive and intellectual functioning	Two groups of HIV + children according to whether ART was started early or deferred 65% of HIV+ group RNA < 50 copies (undetectable)	*Participant characteristics/Group differences* No group differences in gender, ethnicity, caregiver education or income Significantly fewer in the HIV unexposed were in low-very low socio-economic status group. *Mental health* HIV+ group had significantly higher total problems and externalising scores than both the HIV uninfected groups. HIV+ children also performed worse on cognitive and neurodevelopmental tasks than the control groups.
Rongkavilit et al. (2010) Thailand	*n* = 70 Age range: 16-25 Female:58.6%	Cross-sectional study 70 HIV+ participants	Thai GHQ12 *Other domains:* stigma, socio-demographics, HIV status disclosure to others, quality of life, alcohol use	100% knew their HIV status No other data	*Participant characteristics/ Group differences* HIV status disclosure to others: Men who have sex with men were more likely to have disclosed their HIV status to friends and less likely to family; women more likely to disclose their HIV status to family and less likely to friends *Mental health* 53% of participants had mental health problems in the clinically significant range. *Mental health: risk and protective factors* Stigma scores were significantly associated with mental health problems The public attitudes subscale w associated with poorer quality of life and mental health problems.

Table 5 Empirical studies on mental health in HIV-positive adolescents in high income countries

Country	Sample	Study type and control group	Mental health measures: youth or cg administered	HIV group	Main Results
Abramowitz et al. (2009) U.S.	*n* = 166 Age: 13-21 Female: 53%	Cross-sectional	BDI: youth *Other domains:* social support	60% perinatally infected and 40% behaviourally infected median CD4 count 450	*Participant characteristics/Group differences* 71% had someone to remind them to attend clinic, 60% had someone to bring them to clinic: mostly family (53%) and fewer friends (4%) 52.4% of youth relied on their family for help compared to 28.3 % for friends Behaviourally infected youth significantly more friends who knew their status. Behaviourally infected youth received significantly less help from family in accessing care. *Mental health: risk and protective factors* A significant negative relationship was found between social support and depression General perceived social support and behavioural mode of transmission were the best predictors of depression
Bomba et al. (2010) Italy	*n* = 54 Age range:6 -18 Female: HIV+ group: 51.9% Control group: 51.9%	Cross-sectional with control group 27 HIV + *Control group(s)* 27 control group from a local public school	CBCL: cg *Other domains:* physical, emotional, social and school functioning	Perinatally infected 100% on HAART 70%: complete viral suppression (< 50 copies/mL) 7% (*n* = 2) having moderate immune suppression (CD4% between 20 and 25%) the rest had adequate immune functioning	*Participant characteristics/Group differences* Poorer school functioning for HIV + group HIV + group significantly reduced physical functioning *Mental health* HIV+ group significantly higher scores for total problems and internalizing problems, but not significantly more externalising problems HIV + group had: higher scores for withdrawn, anxious/depressed, social problems, thought problems, attention problems and delinquent behaviour subscales. No differences in somatic complaints and aggressive behaviour between the groups *Mental health: risk and protective factors* HIV+ participants with viral load higher than 50 had higher scores on delinquent behaviour and school competence
Chernoff, Nachman et al. (2009) U.S. & Puerto Rico (IMPAACT study)	*n* = 575 Age range: 6-17 Female: HIV + group: 49% Control group: 52%	Cross-sectional with control group 319 HIV+ *Control group (s)* 256 Control (174 HIV-exposed but uninfected and 82 HIV living with HIV-positive person)	CI-4/YI-4R: youth CASI-4R: cg *Other domains*: life events and treatment	Perinatally infected 81% on HAART 7% had severe immune suppression, 19% moderate immune suppression. 60%: undetectable viral loads	*Participant characteristics/Group differences* HIV group less likely to live with biological caregiver (43% vs. 76%), more likely to live in a household with higher socio-economic status *Mental health* No significant group difference between level of psychiatric symptoms or level of impairment Control group living with HIV + person reported more conduct disorder problems than HIV- positive or perinatally exposed youth (HIV-negative)

Country	**Sample**	**Study type and control group**	**Mental health measures: youth or cg administered**	**HIV group**	**Main Results**
Elkingon et al. (2011) U.S. R&R and CASAH combined	*n* = 545 Age range: 9-16 Female: HIV+ group: 49.5% Control group: 49.5%	Cross-sectional with control group 196 HIV+ Youth *Control group (s)* 349 (either perinatally exposed, living with an HIV + or HIV- caregiver)	CBCL: cg CDI & STAIC: youth *Other domains:* caregiver mental health, parent-child communication, family functioning	70.4% knew their HIV status 84% on ART	*Participant characteristics/Group differences* 36% of HIV+ youth resided with a birth parent compared with 88% of HIV- youth Overall: almost 75% lived below poverty line for New York *Mental health* No significant difference between HIV+ group and comparison group for CBCL internalising and externalising problems Overall most youth fell in the normal range for CBCL, CDI and STAI Youth who reported symptoms of depression in the clinical range were more than twice as likely to be HIV+ *Mental health: risk and protective factors* Youth with HIV+ caregivers had better mental health, even after adjusting for youth HIV status and other contextual and social factors No interaction effect between youth and caregiver status Residing with a birth parent not associated with mental health outcomes
Elliot-DeSorbo et al. (2009) U.S.	*n* = 55 Age range:8-17 Female: 45%	Cross-sectional	BASC: cg and youth administered *Other domains*: stressful life events, demographics	Perinatally infected 100% knew their HIV status 100% on ART Mean CD4 = 612 31% had undectable viral load	*Participant characteristics/Group differences* 45.5% African American, 43.6% Caucasian, 45% lived with biological parent Youth living with a biological caregiver experienced more stressful life events *Mental health* Depression (self-report): 4% in the clinical range and 9% in the at risk range Anxiety (self-report): 4% in the clinical range and 7% in the at risk range *Mental health: risk and protective factors* Youth living with biological caregivers rated higher on depression (cg rated) e compared to non-biological caregivers School related stressors significantly predicted self-reported depression Children who had disclosed their diagnosis in the past six months were rated as more anxious by their caregivers than non-disclosers.
Gadow et al. (2010) U.S. & Puerto Rico IMPAACT study	*n* = 575 Age range: 6-17 Female: HIV+ group: 48.9% Control group: 52.3%	Cross-sectional with control group (baseline findings) 319 HIV+ participants *Control group (s)* 256 HIV-affected (174 HIV-exposed but uninfected and 82 HIV- living with HIV- positive person)	CASI-4R: cg YI4-R (ages 12-17) & CI-4 (ages 8-11): youth *Other domains:* processing speed, special education, whether youth received pharmacological or behavioural interventions	Perinatally infected 92% on ART 100% of older group knew their HIV status and 36% of the younger group 59% had HIV RNA viral load < 400 copies/mL; 73% had entry CD4% > 25%, 22% had prior AIDS defining diagnosis.	*Participant characteristics/Group differences* HIV+ group significantly less likely to have a biological parent as caregivers (43% vs. 76%) HIV+ group less likely to be living in financially impoverished environments. *Mental health* No group difference in psychiatric problems 73% of HIV+ group and 74% of control group did not currently have psychiatric problems Comparison group higher rates of aggressive and antisocial behaviour HIV+ group: higher rates and greater severity of somatisation symptoms Biological parents reported less symptoms of ADHD, conduct disorder, ODD and anxiety disorders than other caregivers. More HIV+ youth had been evaluated for special education (44% vs. 32%) HIV+ group had significantly lower processing speed scores

Country	Sample	Study type and control group	Mental health measures: youth or cg administered	HIV group	Main Results
Gadow et al. (2012) U.S. & Puerto Rico IMPAACT study	*n* = 573 Age range: 6-17 Female: HIV+ group: 49.0% Control group: 52.0%	Longitudinal study with control group HIV group=319 *Control group (s)* 254 HIV-affected (168 HIV-exposed but uninfected and 86 HIV- living with HIV+ caregiver)	CASI-4R: cg YI4-R (ages 12-17) & Child Inventory-4 (ages 8-11): youth *Other domains:* academic functioning, treatment history	Perinatally infected 83% on HAART At study entry: 75% had CD4% > 25% and 22% had prior AIDS defining diagnosis	*Participant characteristics/Group differences* HIV+ group: less likely to have biological parents as caregivers (44% vs. 77%), more likely to be living in advantaged households *Mental health (over time)* From study entry to the second-year follow-up visit, 69% HIV+ group and 70% of peer comparisons met DSM-IV criteria for at least 1 targeted psychiatric disorder. *Mental health: risk and protective factors* Greater HIV disease severity at study entry (CD4% <25% vs. 25% or more) had higher probability of depression symptoms (19% vs. 8%, respectively). Females had greater odds of developing anxiety and depression symptoms during follow-up
Kang et al. (2011) U.S. CASAH study	*n* = 325 Age range: 9-16 Female: HIV + group: 50% Control group: 50%	Cross-sectional with control group (baseline findings) 196 HIV+ participants *Control group(s)* 129 HIV- perinatally exposed	CDI: youth STAI: youth *Other domains:* neighbourhood stress, stressful life events, religiosity, social problem solving	Perintally infected 86% on HAART 35% undetectable viral load (≤ 400), % ≥100 000 copies/mL	*Participant characteristics/Group differences* No differences in age, gender, race/ethnicity between the two groups HIV+ youth reported significantly higher income than HIV- but exposed group HIV+ youth less likely to be living with a biological parent *Mental health: risk and protective factors* Depression and anxiety were significantly associated with neighbourhood stress, higher frequency of daily stressful events, and fewer social problem-solving skills.
Kapetanovic et al. (2011) U.S. LEGACY study	*n* = 197 Age range:13-24 Female: 55.8%	Cross-sectional data from a longitudinal study	Psychiatric disorder: medical record using ICD criteria *Other domains:* risky behaviours (adherence problems, substance use, pre-adult sexual activity)	Perinatally infected % that knew their HIV status: not reported 22% had severe immunodeficiency (CD4 < 200); 12% had advanced immune deficiency (CD4 200-350)	*Participant characteristics/Group differences* 74% had history of at least one risky behaviour Both substance use and pre-adult sexual activity was very low (9 % and 6% respectively) compared to surveys of youth 72% reported adherence problems *Mental health* 55% of participants had at least one psychiatric diagnosis Most common reported psychiatric disorder was depression (45%), ADHD (31%), disruptive behaviour disorders (ODD, conduct, NOS: 28%), HIV-related encephalopathy (20%), developmental disorders/delays (19%), anxiety disorders (9%) *Mental health: risk and protective factors* Psychiatric diagnosis not associated with presence of individual risk behaviour Psychiatric diagnosis associated with a history of at least one risky behaviour (ART adherence problems, pre-adult sexual activity and substance abuse) with adherence problems as the biggest contributor Presence of psychiatric diagnosis not associated with any health indicator (viral load, CD4 count, immune suppression)

Country	**Sample**	**Study type and control group**	**Mental health measures: youth or cg administered**	**HIV group**	**Main Results**
Lam et al. (2007) U.S.	*n* = 66 Age range:16-25 Female: 47%	Cross-sectional	BSI: youth *Other domains:* social support, HIV status disclosure to others	36% on ART Viral load average: 66,906	*Mental health* 50% of youth scored above the cut-off for clinically significant mental health problems on the Global severity index, (32% for depression and 29% for anxiety) *Mental health: risk and protective factors* Lower social support, higher viral load, HIV status disclosure to acquaintances, and being gay/lesbian/ bisexual were all significantly correlated with more symptoms No association with age HIV status disclosure to family and close friends were not associated with mental health symptoms, but disclosure to acquaintances was associated with increased distress. Higher viral load was associated with increased distress
Leonard (2007) U.S.	*n* = 20 age range: 14 - 17 Female: 60%	Cross-sectional	BDI: youth *Other domains*: adherence, attachment	100% vertically infected NO other data	*Participant characteristics/Group differences* 70% born to intravenous drug users, 60% had lost both parents (either not living with them or died), 40% lived with a birth parent. *Mental health* Only one participant scored in the clinical range for depression *Mental health: risk and protective factors* Adherent participants were less depressed
Malee et al. (2011) U.S.& Puerto Rico AMP & PHACS study	*n* = 416 Age range:7-15 Female: HIV + group: 55.6% Control group: 43.8%	Cross-sectional with control group (baseline findings) 295 HIV+ *Control group(s)* 121HIV- (HIV-exposed but uninfected)	BASC-2: cg and youth *Other domains:* caregiver functioning, parent-child relationship	Perinatally infected 67% knew their HIV status 32% had detectable viral load (>400mL) 21.4% :CD4 count <200mm^3 (qualifies for AIDS diagnosis WHO stage 4)	*Participant characteristics/Group differences* HIV + group: significantly more female, black, older age and households with higher income HIV+ group: significantly less likely to reside with biological mothers (38% vs. 78%) *Mental health* Control group had significantly higher rates of mental health problems (38% vs. 25%), higher behavioural problems (29% vs. 19%) and emotional problems (17% vs. 12%) than HIV + group *Mental health: risk and protective factors* HIV group: females more likely to have elevated emotional symptoms (18% vs. 5.9%) Factors associated with mental health problems (HIV+ group): female gender, younger age, lower child IQ, no prenatal antiretroviral (ARV) exposure, caregiver psychiatric disorder, ≥4 caregiver functional health limitations (vs. zero), and caregiver limit setting problems Factors not associated with mental health problems: HIV disease indicator or highly active antiretroviral therapy (HAART)

Country	Sample	Study type and control group	Mental health measures: youth or cg administered	HIV group	Main Results
Marhefka et al. (2009) U.S. CDC Adolescent impact study .	*n* = 164 Age range: 13-21 Female: 52%	Cross-sectional	YSR or ASR: youth *Other domains:* HIV status disclosure to others, abuse (physical and sexual), family violence	60% perinatally infected, 39.5% behaviourally infected 13.4% had severe immunodeficiency (CD4 (< 200 cells/mm^3)	*Mental health* 31% reported levels of internalizing, externalizing, or overall symptoms above cut-off for clinical psychopathology *Mental health: risk and protective factors* Global scores not associated with transmission type (PIY vs. BIY), but BIY higher internalising and externalising scores Factors associated with internalising symptoms: increase in age, as time since their HIV status was disclosed to them decreased. Factors not associated with internalising symptoms: gender, race, ethnicity or immune functioning for internalising symptoms Factors associated with externalising symptoms: as time since their status was disclosed decreased, behaviourally infected vs. perinatally infected, those who identified as gay, bisexual and CD4 counts above 200 to 500 and above 500 vs. less than 200 Participants who identified their sexual orientation as Bisexual or Questioning their sexuality were at greatest risk for emotional and behavioural problems
Martinez et al. (2009) U.S.	*n* = 174 Age range: 13-24 Female: 33%	Cross-sectional	CDQ: youth *Other domains*: violence, demographics	NO DATA	*Participant characteristics/Group differences* Black (78.8%), Latino (10.6%), White (5%), Mixed (5.6%) Identified heterosexual (42%), gay or lesbian (40%), bisexual (15%) Rates of violence: physical assault/ abuse (24% in childhood; 19% as adolescents), sexual abuse/assault (28% in childhood; 15% as adolescents), dating violence (i.e., physical abuse by sexual partner) (18%), and family violence (44%) *Mental health* Major depressive disorders (15%), generalized anxiety disorder (17%); posttraumatic stress disorder (28%); alcohol abuse disorder (19%); and substance abuse disorder (31%). *Mental health: risk and protective factors* Youth with physical abuse and family violence higher anxiety
Mellins et al. (2006) U.S.	*n* = 47 Age range: 9-16 Female: 47%	Cross-sectional study 47 HIV + participants	DISC-IV: youth and cg CBCL: cg CDI: youth *Other domains*: health, demographics, caregiver mental health	Perinatally infected 77% knew their HIV status 9% had severe immunodeficiency (CD4 < 200 mm^3) 73% viral load <10 000 copies/mL	*Participant characteristics/Group differences* African American (83%) 26% lived with biological caregiver, 38% with relative, 36% an adoptive non-relative *Mental health* 55% met criteria for a psychiatric disorder (either child or caregiver report) Anxiety disorders (40%), attention deficit hyperactivity disorders (21%), conduct disorders (13%) and oppositional defiant disorders (11%) 90% scored in normal range on emotional and behavioural functioning according to CBCL *Mental health: risk and protective factors* No association with age, gender, ethnicity, caregiver health, disclosure of HIV status, history of loss Caregiver depression associated with caregiver reported CBCL internalising, externalising and total problems. Caregiver anxiety was also associated with total problems on CBCL.

Country	Sample	Study type and control group	Mental health measures: youth or cg administered	HIV group	Main Results
Mellins et al. (2009a) U.S. CASAH study	*n* = 340 Age range: 9-16 Female: HIV+ group: 51% Control group: 52%	Cross-sectional with control group (baseline findings) 206 HIV+ participants *Control group(s)* 134 HIV- (perinatally exposed but uninfected)	DISC-IV: youth and cg *Other domains*: demographics, history of treatment, health	Perinatally infected 70% knew their HIV status 84% receiving antiretroviral therapy (ART) 10% had severe immunodeficiency (CD4 count <200mm^3)	*Participant characteristics/Group differences* Significantly fewer HIV+ youth live with biological parent, HIV+ youth higher income than control group Significantly more HIV+ youth lost a primary caregiver *Mental health* Significantly more youth in HIV+ group met criteria for a psychiatric disorder (61% vs. 49%) and ADHD (18% vs. 8.2%, OR: 2.45) HIV + Group: 49% anxiety disorders, 25.7% behavioural disorders (mostly ADHD:18%), 7.3% mood disorders *Mental health: risk and protective factors* No HIV variables (CD4, disclosure etc.) were associated with mental health
Mellins et al. (2009b) U.S. CASAH study	*n* = 320 Age range:9-16 Female: HIV+ group: 50% Control group: 50%	Cross-sectional with control group 193 HIV+ participants *Control group (s)* 127 HIV- perinatally exposed but uninfected	CDI & STAI: youth *Other domains*: risky behaviour (substance use and sexual behaviour*)*	Perinatally infected 70% of HIV+ youth knew their status 84% on ART No other data	*Participant characteristics/Group differences* HIV+ group had slightly higher average income than control group, however, average for both groups was under the NYC poverty line Fewer in the HIV+ group were living with a birth parent (36% vs. 70%) More HIV+ group reported that a long term carer had died (53% vs. 24%) *Mental health* No difference in mental health prevalence between the two groups 3% of youth met criteria for substance use disorder *Mental health: risk and protective factors* Mental health was a significant predictor of youth's onset of sexual behaviour and substance use. Caregiver mental health was also significantly associated with youth mental health, No direct association was found between family functioning and either child mental health
Mellins et al. (2011) U.S. PHACS study	*n* = 349 Age range: 10-16 Female: HIV group: 50% Control group: 52%	Cross-sectional study with control group/ case-control 238 HIV+ *Control group (s)* 111 perinatally exposed but uninfected	BASC-2: youth and cg *Other domains:* substance use, adherence problems, sexual activity	Perinatally infected 64.3% did not have a detectable viral load Do not report percentage disclosed.	*Participant characteristics/Group differences* 34% had missed ART at least once in the past 7 days *Mental health* Significant mental distress in HIV+ : 26% No significant difference between the two groups in mental health (26% for HIV+ group vs. 33% uninfected youth) *Mental health: risk and protective factors* HIV+ youth living with biological mother as primary caregiver: were 3 times more likely to have two or more comorbidities of risk factors (significant distress, substance use, sexual activity, adherence problems) than those with another relative or non-relative caregiver

Country	Sample	Study type and control group	Mental health measures: youth or cg administered	HIV group	Main Results
Mellins et al. (2012) U.S. CASAH study	*n* = 280 Age range: 9-16 Female:51%	Longitudinal study: baseline and 18 month follow up 166 HIV+ *Control group (s)* 114 HIV perinatally exposed but uninfected	DISC-IV: youth and cg *Other domains:* mental health over time	Perinatally infected 81.3% knew HIV status at follow-up <10%: severe immune compromise (CD4 < 200)	*Participant characteristics/Group differences* HIV+ youth: less likely to have lived in only one home, less likely to have lived with a caregiver who was a biological parent and more likely to live in a home with higher household incomes *Mental health*: No significant difference between the two groups on mental health outcomes 68.7% of HIV+ group (vs. 69.3% of control group) met criteria for any psychiatric disorder at either time point. No significant differences for anxiety disorders at baseline or follow-up. HIV+ youth were 3 times more likely to report a mood disorder at baseline Most common psychiatric disorders for HIV group baseline and follow-up: any anxiety (48.2% and 30.1% respectively), any behavioural (28.9% and 23.0% respectively), ADHD (21.8% and 15.8% respectively) and any mood (12.7% and 8.8% respectively) Between baseline and follow-up: the odds of having any psychiatric disorder decreased significantly among HIV+ youth, but remained relatively unchanged among control group. Anxiety disorders specifically decreased over time among both groups *Mental health: risk and protective factors (presented for entire sample)* Girls more likely to present with any psychiatric disorder and anxiety disorders, boys were more likely to present with behavioural disorders, specifically ADHD. Mood and behavioural disorders were more likely in older youth and anxiety disorders in younger youth No biological markers at baseline were significantly related to presence of psychiatric disorders over time for the HIV+ group
Misdrahi et al. (2004) France	*n* = 17 Age range:6-17 Female: 41%	Retrospective study 17 HIV+ participants	Clinical evaluation by psychiatrist *Other domains*: neurological complications	71% perinatal infection, 29% blood products 71% had severe immunosuppression (CD4% below 15%)	*Mental health* Youth were included on the basis of having a psychiatric diagnosis: 47% depression and 29% ADHD Major depression was associated with neurological abnormalities, whereas no association was found with ADHD
New et al. (2007) U.S.	*n* = 57 age= 6-12 Female: 49%	Cross-sectional	CBCL: cg C-DISC 4: to children with significant symptoms *Other domains:* effects of being disclosed their status	44% knew their HIV status 51% met CDC criteria for AIDS diagnosis Mean CD4 count: 28%,	*Participant characteristics/Group differences* 37% of caregivers were HIV+; Caregivers included biological mother (37%); grandparents (29%), adoptive parents (23%) and foster parents (2%) *Mental health* 20% fell in borderline or clinical range (clinical: 14%) for either internalising or externalising problems Of these 38% (n=6) met criteria for DSM diagnosis Prevalence of disorder consistent with what is reported in the general population 30% of caregivers endorsed symptoms that reached clinical significance. *Mental health: risk and protective factors* Disclosed participant more likely to present with internalising problems

Country	Sample	Study type and control group	Mental health measures: youth or cg administered	HIV group	Main Results
Orban et al. (2010) U.S. Adolescent Impact study	*n* = 166 Age range: 13-21 Female: 53%	Cross-sectional	YSR or ASR : youth BDI: youth *Other domains:* coping style, stressors	59.6% perinatally infected, 40.4% behaviourally infected 100% knew their HIV status ART: 82.5% of perinatally infected youth and 42% of behaviourally infected youth	*Participant characteristics/Group differences* Most common reported HIV-related stressors: medication (30%) and HIV status disclosure to others (28%) *Mental health* 27% of youth scored in the borderline or clinical range for total problems; 21% scored in the borderline or clinical range for the internalizing behaviour 30% scored in the borderline or clinical range for the externalising behaviour *Mental health: risk and protective factors* Youth with more emotional and behavioural problems endorsed fewer coping strategies than the better adjusted youth
Rudy et al. (2009) U.S. ATN & PACTG	*n* = 396 Age range: 12-24 Female: 65.5%	Cross-sectional 396 HIV+ participants	Mental health: medical chart review *Other domains:* adherence, barriers to adherence, environment	100% behaviourally infected Mean CD4 count: Adherent : 472.6 Non-adherent:293.2	*Participant characteristics/Group differences* Black (76%), White (11%), Other/mixed race (22%) *Mental health* 38.3% had a formal mental health diagnosis, mostly mood disorders (32.1%) No mental health outcome was associated with adherence/non-adherence
Salama et al. (2013) U.S. ALPHA study	*n* = 59 Age range: 14-23 Female:60%	Cross-sectional 59 HIV+ participants	BDI: youth Conduct disorder subscale of the ASI: youth *Other domains*: coping strategies, executive functioning	None were perinatally infected or infected via blood products 32% on ART CD4 counts <200 (5.1%)	*Participant characteristics/Group differences* African American (86.4%), Caucasian (3.4%), Asian (1.7%) Biracial (/other (8.5%) *Mental health* 24% above the cut-off for clinically significant depression *Mental health: risk and protective factors* Depression not related to coping, but negative coping was associated with conduct disorder symptoms Depressive symptoms negatively associated with executive functioning.
Santamaria et al. (2011) U.S. CASAH study	*n* = 196 Age range: 9-16 Female: 50%	Cross-sectional (baseline data) 196 HIV+ participants	CDI and STAI-C: youth CBCL: cg *Other domains*: stigma, demographics, intentions to self-disclose	Perinatally infected 70% knew their HIV status No data on biological markers	*Participant characteristics/Group differences* Black (58%) Hispanic (42%) *Mental health* Youth who knew their HIV status were significantly less anxious than non-disclosed youth. No significant difference for depression, internalising or externalising behaviour for disclosed vs. non-disclosed No demographic variables were associated with mental health outcomes.
Serchuck et al. (2010) U.S. & Puerto Rico IMPAACT 1055 study	*n* = 576 Age range: 6-17 Female: HIV+ group: 49% Control group: 52%	Cross-sectional with control group 320 HIV + participants *Control group(s)* 256 HIV-affected (perinatally exposed or living with a HIV+ person)	SI-4 Instruments *Other domains*: self-reported pain, demographic and household characteristics	Vertically infected 81% on HAART 23% had AIDS diagnosis (CD4 < 200mm^3) More than 50% had <400 copies/mL HIV RNA	*Participant characteristics/Group differences* No group differences in ethnicity: Black (49 %), Hispanic (36%), White (15%), HIV group household significantly higher income *Mental health* No prevalence or group comparisons reported HIV+ youth self-reporting pain had significantly higher mean symptom severity scores for generalised anxiety disorder, major depressive disorder and dysthymia

Country	Sample	Study type and control group	Mental health measures: youth or cg administered	HIV group	Main Results
Sopeña et al. (2010) U.K.	*n* = 30 Age range: 11-17 Female: 53%	Cross-sectional	SDQ *Other domains*: coping	Perinatally infected 100% knew their HIV status CD4: 1 participant severe immunodeficiency (CD4 <200); 1 participant advance immunodeficiency (CD4 200-350)	*Participant characteristics/Group differences* 10% (n=3) did not live with a biological parent, 4 (13.3%) lived with both parents *Mental health* No significant difference between the study participants and British norms Most scored within the normal range: 27 within the normal range, 3 in the borderline range, and non within the abnormal range *Mental health: risk and protective factors* Younger children had lower levels of psychological adjustment
Tanney et al. (2012) U.S.	*n* = 186 Age range: 16-24[3] Female:	Cross-sectional 186 HIV+ youth with at least one problem behaviour	BSI: youth *Other domains:* stigma, risky behaviour	Perinatal and behaviourally infected	*Participant characteristics/ Group differences* Participants were included if they qualified for at least one risky behaviour: problem-level substance abuse (65.6%), adherence issues (44.1%) or sexual risk factors (53.8%) *Mental health:* Depression was significantly associated with stigma and problem behaviours. Factors associated with higher depression scores: behavioural infection, older age, more problem behaviours, and higher stigma
Weinberger (2010) U.S.	*n* = 28 Age range: 12 – 22 Female: 46%	Cross-sectional	PDS & CPSS: youth *Other domains:* HIV-related and general trauma	46% perinatally infected and 54% behaviourally infected 75% on medication, 14% had CD4% below 20%	Participant characteristics/Group differences No group differences except perinatally infected youth were younger than behaviourally infected Mental health PTSS scores fell in moderate range of severity for both HIV- and general traumas. 82% of participants experienced at least one HIV-related trauma. 75% of participants experienced at least one non-HIV-related traumatic event. No differences found in PTSS symptoms of number of traumas based on mode of transmission An inverse relationship of provider ratings of adherence and PTSS
Wiener and Battles (2006) U.S.	*n* = 40 Age range: 13-24 Female: 62.5%	Cross-sectional	IES & BSI: youth *Other domains:* HIV status disclosure to others	65% perinatally infected; 35% infected via transfusion or blood clotting 29.3% had severe immunodeficiency (CD4 cells/mm^3 <200;	Participant characteristics/Group differences 27.5% had a high level of HIV status disclosure to others, 40% had a medium level of disclosure and 32.5% had a low level of disclosure Mental health 35% met criteria for "caseness" on the BSI Mental health: risk and protective factors Factors not associated with psychological distress age of learning the diagnosis, level of HIV status disclosure to others Those highest in HIV status disclosure had higher self-competence in their peer relationships than those with medium/low disclosure Those highest in HIV status disclosure had the lowest avoidant and total IES scores

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[3] Age range is not reported in this publication. It was taken from a previous publication (Naar-King, Kolmodin, Parsons, & Murphy, 2010)

Country	Sample	Study type and control group	Mental health measures: youth or cg administered	HIV group	Main Results
Williams et al. (2010) U.S. & Puerto Rico IMPAACT P1055 study	*n* = 299 Age range: 12-18 Female: HIV + group: 48% Control group: 52%	Cross sectional with control group 196 HIV+ participants *Control group(s)* 103 HIV-affected (living with an HIV+ person OR perinatally exposed but uninfected)	YI-4 and CASI-4R: cg and youth *Other domains:* substance use, demographics	100% perinatally infected 80% on HAART 22% had past or current AIDS diagnosis 54% had <400 copies/mL HIV RNA	*Participant characteristics/Group differences* No association between HIV status and substance use 14% reported substance use (either caregiver or participant report) *Mental health* No significant difference between the two group on mental health indicators Overall: Higher odds of substance use for those who had ADHD, major depression or dysthymia, oppositional defiant disorder or conduct disorders
Williams et al. (2013) U.S. and Puerto Rico IMPAACT P1055 study	*n* = 582 Age range:6-17 Female HIV+ group: 49% Control group: 52%	Cross-sectional with control group 323 HIV+ participants 259 HIV- (HIV-affected: either perinatally exposed or living with an HIV+ caregiver)	YI-4 and CASI-4R: cg and youth *Other domains*: participation at 1 and 2 year follow up, demographics and health	Perinatally infected 83% on HAART No other data in this article	*Participant characteristics/Group differences* HIV+ group: significantly older, less likely to live with biological parents and more likely living in households with higher household income and caregiver education than control group Retention for follow up (at 2years) was significantly higher for HIV group than control group *Mental health* Prevalence and group comparisons reported elsewhere Overall, youth with any psychiatric condition had higher odds of being lost to follow up compared to those with no psychiatric condition Among HIV+ youth, those with any psychiatric condition had 3-fold higher odds of being lost to follow up.
Wood et al. (2009) U.S.	*n* = 81 Age range:11-23 Female:47%	Retrospective cohort study	Conner's Rating scale: youth Clinician diagnosed psychiatric illness (confirmed by clinical psychologist): youth *Other domains*: IQ, health and demographics	93% on HAART 19.8%had severe immune suppression (CD4% <15%), 23% were moderately immunosuppressed (CD4% 15-24%)	*Participant characteristics/Group differences* African American (71.6%) *Mental health* 48% had a diagnosed psychiatric illness Mood disorder (30.8%), ADHD (18%), non ADHD behavioural disorder (13.6%), psychotic disorder (8.6%), eating disorder (2.5%) *Mental health: risk and protective factors* Significant association between Class C diagnosis and psychiatric illness, mood disorder, psychotic disorder and no association with ADHD or a behavioural disorder
Wright et al. (2007) U.S.	*n* = 48 Age range: 16-25 Female:46%	Cross-sectional	BSI: youth *Other domains:* stigma, social support, substance use	86% infected through sexual contact NO DATA on health	*Participant characteristics/ Group differences* 88% African American, 64% of males identified gay or bisexual *Mental health* 50% above the clinical cut-off for the General severity index (global distress score), 42% for depression, 42% for anxiety *Mental health: risk and protective factors* Global distress and the depression scale were significantly associated with the total stigma score and with the subscales for personalised stigma and negative self-image. Anxiety was significantly associated with personalised stigma and negative self-image.

Studies in low income countries outside of Africa and high income countries also assessed rates of significant psychological or emotional and behavioural symptoms of distress. Instruments included were from the:

- the Achenbach System of Behavioural Assessment (ASEBA), the parent, youth self-report and adult self-report checklist (CBCL/YSR/ASR) (Achenbach, 1991a; Achenbach & Rescorla, 2001; Achenbach & Rescorla, 2003) in six studies (Bomba et al., 2010; Elkington et al., 2011; Marhefka et al., 2009; New et al., 2007; Orban et al., 2010; Santamaria et al., 2011),
- the Behavior Assessment System for Children, Second Edition (BASC-2) (Reynolds & Kamphaus, 2004) in three studies (Elliott-DeSorbo, Martin, & Wolters, 2009; Malee et al., 2011; Mellins et al., 2011),
- the Child and Adolescent Symptom Inventory-4R (CASI-4R) (Gadow & Sprafkin, 2005) and the Youths' Inventory-4R (YI-4R) (Gadow & Sprafkin, 1999) in four studies (Gadow et al., 2010; Serchuck et al., 2010; Williams et al., 2013; Williams et al., 2010),
- the Brief Symptom Inventory (BSI) (Derogatis & Spencer, 1982; Derogatis, 1993) in four studies (Lam, Naar-King, & Wright, 2007; Tanney, Naar-King, & MacDonnel, 2012; Wiener & Battles, 2006; Wright, Naar-King, Lam, Templin, & Frey, 2007),
- the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) in one study (Sopeña et al., 2010),
- the Beck Depression Inventory (BDI) (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) in three studies (Leonard, 2007; Orban et al., 2010; Salama et al., 2013),
- the Impact of Events Scale (IES) (Horowitz, Wilner, & Alvarez, 1979) in one study (Wiener & Battles, 2006),
- the Child Depression Inventory (CDI) (Kovacs, 1992) in four studies (Elkington et al., 2011; Kang, Mellins, Dolezal, Elkington, & Abrams, 2011; Lee, Chhabra, & Oberdorfer, 2011; Santamaria et al., 2011) and,
- the State-Trait Anxiety Inventory for Children (STAIC) (Spielberger, 1973) in two studies (Elkington et al., 2011; Santamaria et al., 2011) and the State Trait Anxiety Inventory (STAI) (Spielberger, 1987)in two studies (Kang et al., 2011; Mellins et al., 2009b).

However, not all the above studies reported prevalence rates as they were either concerned with how the rates compared with a control group (section which follows) or how mental health was associated with risk factors (Section 1.5).

Four studies which examined prevalence of emotional and behavioural symptoms of distress in high income countries reported very low rates. Elkington et al. (2011) reported that most of the participants scored in the normal range for distress, Leonard (2007) found that only 5% had enough symptoms for depression, Sopeña et al. (2010) that only 10% met enough symptoms to fall in the borderline range for distress and New et al. (2007) reported that only 14% of HIV-positive participants fell in the clinical range.

Of the remaining studies, most prevalence fell within the range of 24% - 35% (Malee et al., 2011; Marhefka et al., 2009; Mellins et al., 2011; Orban et al., 2010; Salama et al., 2013; Wiener & Battles, 2006), although three studies reported prevalence over 50% (Lam et al., 2007; Rongkavilit et al., 2010; Wright et al., 2007). The latter studies all had smaller sample sizes (n = 66, 70 and 48 respectively), all were for older youth (16-25) and all of the participants knew their HIV status. Of the other studies, three reported that all the participants knew their HIV status (Marhefka et al., 2009; Orban et al., 2010; Wiener & Battles, 2006), and another that 67% of the participants knew their HIV status (Malee et al., 2011). Two did not report the proportion of youth that knew their HIV status (Mellins et al., 2011; Salama et al., 2013). Furthermore, of these studies, four reported the rate of severe immune suppression (CD4 < $200mm^3$) in their participants, with 29.3% in Wiener and Battles (2006), 21.4% in Malee et al. (2011), 13.4% in Orban et al. (2010) and 5.1% for Salama et al. (2013) being immune suppressed. Interestingly, and probably expectedly, it was the study with the highest rate of immune-compromised patients (Wiener & Battles, 2006) that reported the highest rate of symptoms (35%).

Twelve studies outside of Africa reported the prevalence of the specific psychiatric diagnosis or, if using psychological and emotional and behavioural distress, the prevalence of participants meeting the cut-off for a specific disorder. Depression and anxiety were the most commonly reported specific disorder and symptoms. The proportion of participants showing enough symptoms to qualify for depression ranged from 27.8% (Lee et al., 27.8%) to 32% (Lam et al.

2007). With those that had a psychiatric disorder, Kapetanovic et al. (2011) reported a rate of depression of 45% and Misdrahi et al. (2004) a rate of 47%.

Anxiety disorders were found to be the highest specific disorder in some studies Mellins et al. (2009) found that 48.2% of respondents qualified for anxiety, followed by attention deficit and hyperactivity disorder (ADHD, 21.8%) and mood disorders (12.7%). Similarly, Mellins et al. (2006) found 40% of anxiety and, Mellins et al. (2009) 49% anxiety with lower rates of depression (7.3%). Other studies also reported high rates for anxiety (29%, Lam et al., 2007), ADHD (31%, Kapetanovic et al., 2011) and also disruptive behaviour disorders (28%, Kapetanovic et al., 2011) and post-traumatic stress disorder (PTSD, 28%) (Martinez, Hosek, & Carleton, 2009).

Controlled studies: Controlled studies are important design to determine the specific effects of HIV status on mental health. Eleven studies included a control group, two of which were longitudinal, but only the baseline data are reviewed in this section. The four studies from low and middle income countries outside of Africa and will be discussed first (Table 4). In three of these studies, the control group was selected from the local community (Banerjee, 2007; Lee et al., 2011; Louthrenoo, Peninnah, & Sirisanthana, 2013) and in one the control group was a mixture of perinatally exposed but uninfected youth and HIV-unaffected youth (Puthanakit et al., 2013).

Using the CBCL (Achenbach & Edelbrock, 1983), Banerjee (2007) examined emotional and behavioural symptoms of distress in HIV-positive children and adolescents in India, compared to a local comparison group which was matched for age and monthly income. The HIV group reported significantly more symptoms than the comparison group. The study provided no medical data or the percentage that had been disclosed their status. In the second study, the mental health of 50 HIV-positive adolescents who all knew their HIV status (aged 11-18) from Thailand were compared to participants selected from a local public school (*n* = 56) (Louthrenoo et al., 2013). In this study, no significant differences were found in emotional and behavioural symptoms of distress as assessed by the YSR (Achenbach & Rescorla, 2001), although there was a trend for the HIV group to report more symptoms (*p* = .07). However, the HIV group reported significantly more internalising problems and also had significantly higher rates of somatic complaints and social problems. No significant differences were found in the caregiver administrated CBCL (Achenbach and Rescorla, 2001). All participants in the second study knew their HIV status and most (84%) of them were virally suppressed.

In contrast, the third study conducted in northern Thailand, found that significantly more participants in the control group from a local public school scored above the recommended cut-off for depression in Thai youth (≥ 15) as assessed by the CDI (Kovacs, 1992) compared to the HIV group (Lee et al., 2011). In the final study, Puthanakit et al. (2013) compared the psychological distress of 284 HIV-positive children and adolescents to 319 control group participants (of which 155 had been exposed to HIV perinatally and 164 unaffected), using the CBCL (Achenbach and Rescorla, 2001). Participants in this study were from Thailand and Cambodia. They found that HIV-positive group had significantly higher total problems and externalising problems than both the control groups (HIV-exposed and HIV-unexposed). The above studies show a trend for HIV-positive participants to score higher than either a local comparison group or perinatally exposed participants. However, one study found no differences, and another found that the control group had higher rates of distress when using the locally recommended cut-off for depression.

The remaining seven controlled studies were conducted in upper income countries. In a study in Italy, Bomba et al. (2010) compared the mental health of 27 HIV-positive participants to 27 participants from a local public school, using the CBCL (Achenbach, 2001). All participants in the HIV-positive group were perinatally infected and were fairly healthy, with 93% having adequate immune reconstitution (CD4% > 25). HIV-positive children had significantly higher scores for total problems and internalising problems, but not more externalising problems than the control group.

The International Maternal Paediatric Adolescent AIDS Clinical Trials Group study (IMPAACT) examined emerging psychiatric symptoms in 319 perinatally infected youth were compared to 256 youth in the U.S. and Puerto Rico using the CASI-4R and the YI-4R (Gadow et al., 2010; Serchuck et al., 2010; Williams et al., 2013; Williams et al., 2010) . The comparison group included youth that were exposed to HIV at birth, but not infected (*n* = 174), and youth that were living with an HIV-positive caregiver (*n* = 82) (Chernoff et al., 2009; Gadow et al., 2010). Youth from the HIV-positive group were not found to be at greater risk for psychiatric problems than either of the two comparison groups. In fact, the comparison groups tended to be at greater risk for aggressive and antisocial behaviour than the HIV-positive group. However, it was found that the HIV-positive group reported higher rates and a greater severity of somatic symptoms. Williams et al. (2010), also compared HIV-positive (*n* = 196) with a control group of HIV-affected youth (*n* = 103), (either living with an HIV-positive person or HIV-exposed but uninfected). Similarly there were no significant differences between the two groups on mental health outcomes.

In the U.S., Elkington et al. (2011) compared HIV-positive youth to comparison groups of HIV-affected youth (HIV-exposed but uninfected youth and HIV-negative youth which were living with either an HIV-positive or HIV-negative caregiver). Overall the authors found that the scores, as assessed by the CBCL (Achenbach, 1991a) fell in the normal range for both the HIV-positive group and the comparison groups. Being HIV-positive was not associated with higher scores. However, HIV-positive youth were more than twice as likely to report symptoms of depression in the clinical range as the comparison groups, as assessed by the CDI (Kovacs, 1992). In two more U.S.-based studies, one compared 193 HIV-positive youth with 127 HIV-exposed but uninfected youth (Mellins et al., 2009b) and another compared 238 HIV-positive youth with 111 youth, also perinatally exposed but uninfected (Mellins et al., 2011). Neither of these studies found any differences in mental health outcomes between the groups. The first study reported that 70% of HIV-positive youth knew their status although they did not report the health status of participants and the second study did not report the number of participants knowing their status.

The above studies in high income countries using HIV-affected control groups, found no differences between the groups. Only two studies found findings contrary to this (Malee et al., 2011; Mellins et al., 2009a). One study compared 206 perinatally infected participants with 134 HIV-exposed but uninfected, and found that significantly more youth in the HIV-positive group met criteria for a DSM IV-based psychiatric disorder (61% vs. 49%) and ADHD (18% vs. 8.2%)

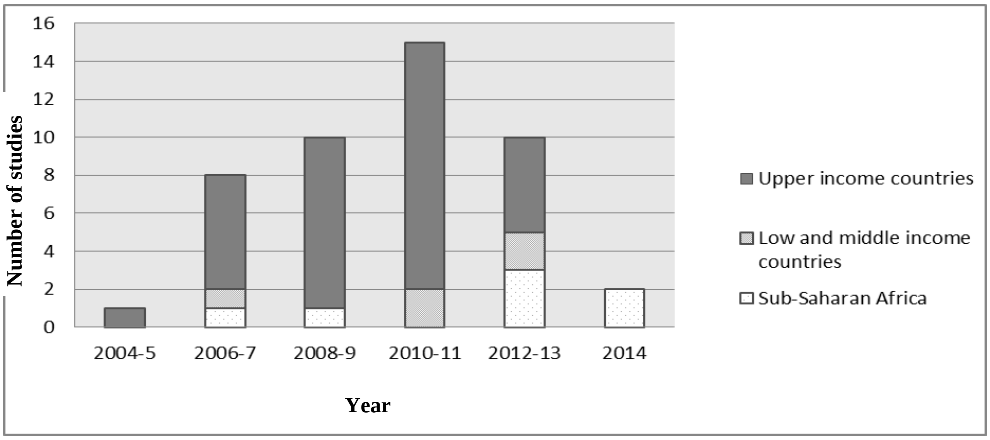
(Mellins et al., 2009a) using the DISC-IV (Shaffer et al., 1996). In this group 70% of youths had been disclosed their status. This was the only controlled study to assess psychiatric disorders. Finally, Malee et al. (2011) study found that HIV-positive group (*n* = 121) reported significantly lower rates of mental health problems, behavioural problems and emotional problems than the comparison group of perinatally exposed but uninfected youth (*n* = 295) as assessed by the BASC-2 (Malee et al., 2011; Reynolds & Kamphaus, 2004).

The above findings are contrary to expectation, being that most reported no differences with only one study, that the HIV group had higher scores for mental distress. There may be reasons for these findings. Firstly, youths from the comparison groups tended to be HIV-affected, either living with an HIV-positive parent or perinatally exposed to HIV. Secondly, youth were from the same environments and may be exposed to similarly difficult social and economic stressors, including family stressors, poverty and social problems facing inner city youth (Flisher & Dawes, 2009). Indeed, as we will see in section 1.5, many times youth from the comparison groups based in the U.S studies tended to come from lower socio-economic environments. The differences may also be related to the fact that HIV-positive adolescents may have more access to support services than the comparison groups, by virtue of being connected to clinics and support services (Bachanas et al., 2001; Elkington et al., 2011; Flisher & Dawes, 2009).

Longitudinal research: The prevalence of mental health symptoms over time was reported in two studies, both conducted in high income countries. Gadow et al. (2012) compared 319 HIV-positive participants to a control group consisting of 168 perinatally exposed but uninfected participants and 86 participants living with an HIV-positive caregiver. There were no significant differences between the groups, either at baseline or follow-up. Mellins et al. (2012) reported similar findings over time, when comparing 166 perinatally infected participants with 114 HIV-exposed but uninfected participants; with no difference between the two groups. However, the study reported that, for the HIV group, the odds of having a psychiatric disorder decreased over the time periods, whereas it did not change for the comparison group. More studies examining mental health prevalence of HIV-positive youth over time could help determine the effects of HIV status over the developmental life span, particularly as youth pass from middle childhood to adolescence, to young adulthood.

Summary and conclusions regarding prevalence of mental health

Previous reviews of mental health problems in adolescents living with HIV concluded that these disorders appeared to be "exceedingly common", however sample sizes were small (Scharko, 2006) and there was a lack of control groups (Palmer, 2011). Furthermore, few studies from low and middle income countries were included in these reviews. The current review looked at studies over the previous 10 years and identified 46 publications. Findings suggest that attention to this area has increased in the last decade and that much needed studies from sub-Saharan Africa and other low and middle income countries are emerging. Graph 1 shows the number of studies bi-annually in upper-middle income, low and middle income countries (excluding Africa) and sub-Saharan Africa. Most of the studies reviewed in low and middle income countries and sub-Saharan Africa examined in the review were published in the last 5 years (80% and 71% respectively).



Graph 1 Number of empirical studies on mental health in the different regions: sub-Saharan Africa, other low and middle income countries and upper income countries: 2004-2014

In the current review (2004-2014), psychiatric prevalence of HIV-positive adolescents and youth ranged from 6% to 68.7%, while the only study that assessed psychiatric prevalence in sub-Saharan Africa found a rate of 48.8% in Kenya (Kamau et al., 2012). Most prevalent specific disorders in adolescents living with HIV tended to be depression and anxiety. Finally psychological symptoms also varied with most reporting significant symptoms ranging from 26-35%. There may be many factors that explain the wide range of findings, some may be methodological, such as the differences in the instruments used, including different cut-offs, whereas others may have to do with differences in the study populations. This includes being at different stages of illness, not all youth being aware of their HIV status, age of the participant, and the type and number of contextual stressors to which youth are exposed, such as stigma, orphanhood or poverty. The next section reviews a range of risk factors that have been included to try to understand the role that these may play in mental distress.

In the current review, the few studies that used control groups with HIV-negative and unaffected youth tended to find that HIV-positive youth show higher rates of symptoms (Banerjee, 2007; Betancourt et al., 2014; Louthrenoo et al., 2013). Only one such study has been found in sub-Saharan Africa (Betancourt et al., 2014). Most studies in upper income countries used comparison groups affected by HIV. Controlled studies that used comparison groups of HIV-affected youth, either living with a HIV-positive caregiver, or having been exposed by HIV at birth, therefore also having an HIV- positive mother, tended not find any significant differences between the HIV-positive adolescents and their HIV-affected peers. In fact one study found that HIV-exposed but uninfected youth reported higher rates of mental health problems (Malee et al., 2011). Only in one study the HIV group reported significantly more somatic symptoms (Gadow et al., 2010) and another study found more depressive symptoms (Elkington et al., 2011).

The studies have limitations. Limitations for studies conducted in sub-Saharan Africa have been reviewed earlier in this section. Similarly, studies in non-African contexts have limitations such as the range of instruments used, heterogeneous samples, including mixing of disclosed and non-disclosed participants and different illness stages. Some of the studies reviewed also compose samples with wide age ranges, for example the study by Wiener and Battles (2006), spans an age range of 13-24 years.

1.4 Risk and protective factors in the mental health of HIV-positive adolescents: Review

This section reviews findings from empirical studies that reported on risk and protective factors for mental distress in children and young people living with HIV. The review provides empirical evidence to inform the inclusion of specific variables for the current study. Empirical studies which included a measure of mental health as well as assessed specific risk and protective factors in the last 10 years are included in this review. The search strategy has been described earlier (section 1.4.1) and the studies are presented in Table 3, Table 4 and Table 5. Following from the theoretical model presented in the previous chapter (Bronfenbrenner, 1979), we present the findings on individual and microsystem factors first, including family and caregiver factors, and thereafter will move to the broader contextual factors in the mesosystem and exosystem. A number of factors are not included in the review, amongst which are psychological factors, such as identity development (Loos et al., 2013). While these are important aspects of children's adjustment, they are beyond the scope of the current review.

1.4.1 Individual level factors

Age and gender: It is estimated that girls account for about 56% of adolescents living with HIV worldwide and 58% in sub-Saharan Africa (Idele et al., 2014). Most studies in this review from sub-Saharan Africa and elsewhere had roughly equal numbers of male and female participants living with HIV, with female participants ranging from 45% to 55%. The proportion of females fell outside of this range in only six studies; four reporting higher rates and two reporting lower rates. In the U.S., Wiener and Battles (2006) and Leonard (2007) reported that 60% of their samples were female and Rudy et al. (2009) reported a rate of 65.5%, whereas, in Thailand and Cambodia, Puthanakit et al.'s (2013) study included 58% of females in their sample. Of the two studies that reported lower rates of females, Martinez et al. (2009) had a rate of 33% in the U.S. and Misdrahi et al. (2004) reported 41% in France. It should be remembered that the estimate that 56% of adolescents living with HIV being female, included both perinatally and behaviourally infected adolescents, whereas the studies in this review predominantly refer to perinatally infected youth. In fact, the study with the highest number of females was from a sample of behaviourally infected youth in the U.S. (Rudy et al., 2009). Higher numbers of new/behavioural infections in adolescents occur amongst girls (Idele et al., 2014); up to two thirds of new infections are among girls (UNICEF, 2013). Furthermore, the current review included studies with age ranges extending outside of the adolescent age range, which could account for the variations.

Overall, few studies found associations between gender and mental health. In the general child health literature, girls tend to report higher levels of internalising problems, whereas boys tend to report higher levels of externalising problems (Merikangas et al., 2009). In sub-Saharan Africa, while Kamau et al. (2012) found no association between overall psychiatric morbidity and social demographic characteristics they did report an association between male gender and major depression and female gender and specific phobia. For studies outside of Africa, only three studies found females to be at greater risk: Gadow et al. (2012) in their longitudinal study, found that, at the follow up, females had greater odds of presenting with anxiety and depression than boys and Malee et al. (2011) report that females were more likely to have elevated scores for emotional symptoms. Mellins et al. (2012) found that girls were more likely to present with any psychiatric disorder and also anxiety disorders, while boys tended to present with behavioural disorders, especially ADHD. In India, Banerjee (2007) found that for the HIV group those in the 12-16 age range, being a boy contributed significantly to having a behavioural disorder. So while the majority of studies did not report any associations between gender and mental health, of those that did, in all, except one study, the findings were consistent with the general child psychology literature.

In the general literature on child mental health, psychological problems tend to increase with age, although different mental health problems are also present in different developmental stages. For studies in sub-Saharan Africa, Tadesse et al. (2012) found that older age was associated with increasing symptoms (age range: 6-14), after controlling for the effect of socio-demographic variables, whereas Kamau et al. (2012) found that suicidality was related to age, with older children more likely to be suicidal (age range: 6-18). Musisi and Kinyanda (2009), in contrast, found that younger age was associated with psychological distress (age range: 12-18).

For studies outside of Africa, mixed findings were reported for the association between age and mental health, with most studies not reporting any association. Three studies, however did find that symptoms in youth living with HIV increased with age. Marhefka et al. (2009) reported that while externalising symptoms showed no association with age, internalising symptoms increased significantly as age increased (age range: 13-21). Mellins et al. (2012) reported increasing mood and behavioural disorders in older participant, but higher frequency of anxiety disorders in younger participants (age range: 9-16) and Tanney et al. (2012) reported that older age was one of the variables that predicted higher depression scores (age range: 6-17). Age could be an important factor in the mental health of children and adolescents living with HIV as the understanding of the implications of HIV may cause a higher level of symptoms. However one study, by Sopeña et al. (2010) in the U.K., similar to Musisi and Kinyanda (2009) in Uganda, found that younger children reported more psychological problems than older children (age range: 11-17).

Ethnicity and sexual orientation: Ethnicity was examined as a risk factor in three studies in the U.S. (Gadow et al., 2012; Kapetanovic et al., 2011; Malee et al., 2011; Marhefka et al., 2009; Mellins et al., 2006), whereas only one study in sub-Saharan Africa reported this variable (Tadesse et al., 2012). Ethnicity was not found to be significantly related to mental health in any of the studies. The current study will focus almost predominantly on black children. Similarly a few studies in the U.S. considered the influence of sexual orientation as one of the risk factors for mental health problems, finding that those identified as gay, bisexual or questioning their gender tended to report higher levels of emotional distress (Lam et al., 2007; Marhefka et al., 2009). This variable will not be considered in the current study, mostly because HIV in sub-Saharan Africa is not limited to this group.

Health status: The health status of participants was reported using a variety of HIV-related markers and stages, including either

- Biological markers, such as CD4 cell counts (see Section 1.2.2) or Ribo-nucleic Acid (RNA) viral load. RNA viral load is the estimation of the amount of virus in the body fluid,
- Disease stage, either using the WHO clinical stages (WHO, 2007) recorded as asymptomatic (Stage 1), mild symptoms (Stage 2), advanced symptoms (Stage 3), severe symptoms (Stage 4), or the CDC stage of HIV infection (CDC, 2008), which, for adults is

defined as Stage 1 (HIV infection with CD4≥500 cells/µL or ≥29%); Stage 2 (HIV infection with CD4 count of 200-400µL or 14-28%) and Stage 3 (AIDS with CD4 count <200µL or <14% (CDC, 2008), or finally

- Whether the criteria for an AIDS diagnosis were met.

Such a variety of indicators makes it complicated to compare health status across studies. Where possible, reference is made to CD4 cell counts as this was the most consistently used indicator.

Based on the indicators presented, the health of participants in the different studies varied from good health to advanced disease stages. Examples of studies with healthy participants were the study in Thailand (Louthrenoo et al., 2013), where 84% of participants had complete viral suppression and the UK study (Sopeña et al, 2010), where only two participants (6.7%) were reported to have moderate to severe immune suppression (CD4 < 350 mm^3). More advanced disease status was reported in the Uganda study, where 60.9% were reported to be in WHO clinical stage III or IV (Musisi & Kinyanda, 2009), and in the U.S. by both Wiener and Battles (2006), where 29.3% or participants were reported to have severe immune suppression (CD4 < 200mm^3), and New et al. (2007), where 51% of participants in that study met an AIDS diagnosis.

A few studies reported the relationship between health status and mental illness. In Africa, no association was reported between WHO clinical stage and mental health or between observable HIV-related symptoms (Menon et al., 2007; Musisi & Kinyanda, 2009). However, Kamau et al. (2012) found an association between immune suppression (CD4 < 350mm^3) and major depression, whereas Menon et al. (2007) reported a relationship between self-reported health problems and higher scores of emotional and behavioural distress. Finally, Lowenthal et al. (2012), in Botswana, found that those with a history of virologic failure (23% of participants) were significantly more likely to score above the cut-off for the Paediatric Symptom Checklist (Jellinek et al., 1988).

Of studies conducted outside of Africa, many did not report whether they assessed the associations of health status with mental health. This may have been due to little variability in the health status of the sample. However of the studies that reported this association, findings were mixed. Five found a negative relationship with health indicators and mental health, four did not find any association and one found an unexpected positive association. Lam et al. (2007) found an association with higher viral load, an indicator of poor health, and increased symptoms of psychological distress. Similarly, Louthrenoo et al. (2013) found that increased viral load (> 50mL) was associated with three YSR sub-scales (Achenbach & Rescorla, 2001): withdrawal problems, aggressive behaviour problems and thought problems and using the same indicator, Bomba et al. (2010) found an association of viral load (> 50mL) with the delinquency subscale of the CBCL (Achenbach & Rescorla, 2001). Wood et al. (2009) in a study where 47% of participants had a history of an AIDS defining illness (Class C diagnosis), found a significant association between Class C diagnosis and psychiatric illness, mood disorder and psychotic disorder.

In a longitudinal study, Gadow et al. (2012) found that greater disease severity at baseline, according to CD4 percentage, predicted a higher probability of depressive symptoms at follow-up. On the other hand neither Kapetanovic et al. (2011), Malee et al. (2011) nor Mellins et al. (2009a) found any association between mental health problems and disease indicators and Mellins et al. (2012), in another longitudinal study, did not find that the severity of the biological markers at baseline predicted occurrence of mental distress at the follow-up. Finally, only one study (Marhefka et al., 2009) found that moderate and high immune functioning (200-500mm^3 and > 500mm^3) was associated with higher externalising symptoms compared to low immune functioning, as assessed by the YSR (Achenbach and Rescorla, 2001) and ASR (Achenbach & Rescorla, 2003). It would be expected that a more advanced disease stage would predict worse outcomes, and a few studies did find that (Gadow et al., 2012; Lam et al., 2007; Louthrenoo et al., 2013; Menon et al., 2007). However, biological markers, such as viral load tend to vary over time making it hard to draw conclusions at one specific time point.

Educational performance: Given the potential effects of the HIV virus on children's cognitive and neuro-development, a few studies examined whether HIV-positive children may have worse educational outcomes. Kamau et al. (2012), in Kenya, found that 81 (50.3%) participants were two or more classes below their age appropriate grade. Most cited poor health (41%) and poor performance (34%) as the reason for their poor performance. Unfortunately without an adequate community control group it is not possible to know whether these rates are different from other children in the community.

Outside of Africa, in Thailand and Cambodia, Puthanakit et al.(2013) found that HIV-positive children performed worse on cognitive and neurodevelopmental tasks than the control group of 319 uninfected youth (of which 155 had been exposed to HIV and 164 were unexposed). Finally, in Italy, Bomba et al. (2010), although with a small sample (*n* = 54), found that HIV-positive participants had significantly lower school functioning (attention ability, concentration, memory, and school absences) than a local control group.

1.4.2 Caregiver and family factors

Studies also examined factors related to HIV-positive youth's microsystem, including risk factors such as parental loss, caregiver HIV status, caregiver mental health, negative family environment and protective factors such as social support. Studies also examined the effects of participants' experiences of HIV-related stigma and HIV status disclosure to others.

Parental loss, orphanhood and not living with a biological caregiver: Studies examined the prevalence of parental death (loss of father, mother or both), prevalence of participants living with a biological parent and also whether this was a risk factor for mental distress. This section presents findings on reported orphan prevalence in children and adolescents living with HIV, how this prevalence compares to other peer groups and whether orphanhood or living with a non-biological parent is associated with increased symptoms of distress.

The prevalence of parental loss in studies in sub-Saharan Africa in HIV-positive children was reported in three studies. The rates varied from 52% in Botswana (Lowenthal et al., 2012), 63% in Ethiopia (Tadesse et al., 2012) and a high 97.6% in Uganda (Musisi & Kinyanda, 2009), with double orphans ranging from 26.7% (Tadesse et al, 2012) to 53.7% (Musisi and Kinyanda, 2009). Studies conducted outside of Africa reported either whether participants had lost a parent or whether participants lived or did not live with a biological parent. However, half of the studies did not reported neither (Abramowitz et al., 2009; Bomba et al., 2010; Kapetanovic et al., 2011; Lam et al., 2007; Marhefka et al., 2009; Martinez et al., 2009; Mellins et al., 2011; Misdrahi et al., 2004; Orban et al., 2010; Puthanakit et al., 2013; Rongkavilit et al., 2010; Rudy et al., 2009; Salama et al., 2013; Santamaria et al., 2011; Serchuck et al., 2010; Tanney et al., 2012; Weinberger, 2010; Wiener & Battles, 2006; Williams et al., 2010; Wood et al., 2009; Wright et al., 2007). Two studies reported the frequency of orphanhood: one study in the U.S. reported that 60% of participants in their study had lost both parents (Leonard, 2007) and, in Thailand, another study reported the prevalence of orphans as 87%, including both single and double orphans (Lee et al., 2011).

In other studies the percentage of participants living with at least one biological parent ranged from 26-45% (Elkington et al., 2011; Elliott-DeSorbo et al., 2009; Gadow et al., 2010; Gadow et al., 2012; Mellins et al., 2006; Mellins et al., 2009b; Mellins et al., 2012), with New et al. (2007) only reporting the number of children living with a biological mother as 37%. Only Sopeña et al. (2010) fell outside of this range: reporting that only 10% of participants were not living with at least one biological parent, although only 13.3% lived with both parents.

Controlled studies assessed whether HIV-positive participants were more likely to have lost a parent compared to HIV-negative or HIV-affected youth (Banerjee, 2007; Betancourt et al., 2014) or, the extent to which HIV-positive participants resided with biological parents compared to the comparison groups (Elkington et al., 2011; Gadow et al., 2010; Gadow et al., 2012; Louthrenoo et al., 2013; Mellins et al., 2009b; Mellins et al., 2012). In the only controlled study in sub-Saharan Africa, Betancourt et al. (2014) compared three groups: HIV-positive youth, HIV-affected (either having an HIV-positive caregiver or being orphaned by AIDS) and HIV-unaffected youth. Both the HIV-positive and HIV-affected groups were significantly more likely to have experienced the death of a caregiver as compared to the HIV-unaffected group. However, the odds of this happening for the HIV-positive groups were much higher, 1.78 for HIV-affected and 6.26 for HIV-positive youth. HIV-positive children in this study were also less likely to have a mother as primary caregiver.

Similarly, in India, Banerjee (2007) found that participants in the HIV-positive group had higher rates of orphans, specifically paternal orphans, compared to the community control group, whereas, Lee et al. (2011) report a similar finding in Thailand, 87% of orphans in the HIV group versus only 11% in the control group. Louthrenoo et al. (2013), also in Thailand, reported that significantly fewer participants in the HIV-positive group lived with a biological parent, 46% compared to 90% of the community control group. Of the reviewed U.S.-based studies, the only study that compared orphanhood, found that significantly more youth in the HIV-positive group had lost a primary caregiver than the control group of HIV-exposed but uninfected (Mellins et al., 2009a). In controlled studies assessing whether youth resided with a biological parent the rate of HIV-positive youth residing with a birth parent ranged from 36% to 43%, whereas the range of participants in the comparison group living with a birth parent ranged from 70% to 88% (Elkington et al., 2011; Gadow et al., 2010; Gadow et al., 2012; Mellins et al., 2009b; Mellins et al., 2012). All studies found that significantly more participants in the comparison groups were living with a biological parent.

Studies examining the association of orphanhood with mental health had more mixed findings. In sub-Saharan Africa, neither Menon et al. (2007) nor Kamau et al. (2012) found any association between orphan status and mental health problems. Tadesse et al. (2012) was the only study in sub-Saharan Africa that reported a significant association between parental loss and emotional and behavioural symptoms of distress, finding that HIV-positive participants who had experienced parental loss reported evidenced more symptoms of distress.

Outside of Africa, two studies, one in Thailand and one in the U.S., did not find an association between a history of loss of a family member and mental health outcomes, although they did not specify whether the loss was a biological parent (Lee et al., 2011; Mellins et al., 2006). A few other studies reported the effects of living with a biological parent or non-biological parent on mental health. Louthrenoo et al. (2013) reported that HIV-positive participants who lived with relatives or in foster care presented with significantly more symptoms of distress (total symptoms, internalising and externalising symptoms) than those who lived with at least one biological parent. Similarly, Mellins et al. (2009a) found that youth living with a biological parent reported lower rates of ADHD and Gadow et al. (2010) that participants who had biological parents as caregivers, had less caregiver reported symptoms of ADHD, conduct disorder, ODD and anxiety disorders than youth who did not have biological parents as caregivers. However, two studies (Elkington et al., 2011; New et al., 2007) found that residing with a biological parent or having a biological parent as a caregiver respectively produced no effect on mental health, whereas Elliot-De Sorbo et al. (2009) found that youth living with biological parents had higher scores on caregiver rated depression.

Few studies outside of Africa reported the prevalence of parental loss. Only two studies assessed this and one had a low sample size (Leonard, 2007, *n* = 20). Nevertheless, rates of orphanhood appear to be high in Africa, with all studies reporting rates of at least 52%. Studies conducted outside of Africa did report high rates of participants not living with a biological parent with prevalence ranging from 54-64%, only one reporting that only 10% of participants did not live with a biological parent (Sopeña et al., 2010). However, in that study, we do not know whether the biological parents had died or simply were not living with their children. What is consistent in all studies, is that participants living with HIV had higher rates of orphanhood and were less likely to be living with a biological parent, when compared to either community control groups or HIV-affected peers.

The mixed findings on the association between orphanhood and psychological distress are surprising, given that previous studies report an association between being an orphan, especially due to AIDS (presumed HIV-negative), and mental distress, particularly internalising problems (Cluver et al., 2007; Cluver & Gardner, 2007; Doku, 2009). This is an important variable for future studies as the number of orphaned children has grown, especially in sub-Saharan Africa, owing to previously high AIDS mortality.

HIV status of caregiver: Parental HIV has been shown to have immediate negative consequences on child outcomes, including mental health (Sherr et al., 2014). A few studies included in the review assessed the impact of caregiver HIV status on participant mental health. HIV status of the caregiver was associated with increased symptoms of mental distress in one study, although this association did not depend on whether the participant was aware of the caregiver HIV status (Musisi & Kinyanda, 2009). It should be noted that in this case many of the caregivers were not biological parents. Mellins et al. (2011) found that HIV-positive youth living with their biological mother as primary caregiver, were 3 times more likely to have two or more comorbidities of risk factors (significant distress, substance use, sexual activity, adherence problems) than those living with another relative or non-relative caregiver. In this case, since all the youth were perinatally infected, it can be assumed that all the caregivers were HIV- positive. In contrast, Elkington et al. (2011) compared HIV-positive youth and HIV-negative youth living with either an HIV-positive or HIV-negative caregiver, and found that youth with HIV-positive caregivers had better mental health, even after adjusting for differences in youth HIV status and other contextual and social regulation factors.

Caregiver mental health: Two studies, both in the U.S., examined the association between caregiver mental health and participant mental health, both finding associations between caregiver mental health problems and child and adolescent mental health problems. Malee et al. (2011) found that caregiver psychiatric disorder was associated with increased mental health problems in adolescents and Mellins et al. (2006) found that caregiver depression was associated with an increase in caregiver=rated total difficulties, internalising problems and externalising problems on the CBCL (Achenbach & Rescorla, 2001)

Negative family environment: Three studies assessed different aspects of family environment and its association with participant mental health. In India, Banerjee (2007) found an association between disturbed family environment and mental health; whereas, in the U.S. Gadow et al. (2012) found that family stressors were associated with higher rates of mental health problems. On the other hand, Mellins et al. (2009), also in the U.S. found no association with family functioning (caregiver communication and caregiver involvement) and child mental health.

Social Support: Social support is implicated in a variety of outcomes, including psychological health (House, 1987). Three aspects of social support have generally been assessed: its existence and quantity, its formal structure and its function (House, 1987). Social support can also be present at different levels for children: for example the family network, or, particularly for adolescents, within the peer group. Furthermore, for PLHIV, social support can also include the extent to which someone supports them when they experience HIV-related stress. Despite the importance of social support, only two studies examined its role in the mental health of children and adolescents living with HIV. In the first study, Abramowitz et al. (2009) explored the presence of both HIV-specific support (e.g. whether someone helps them attend clinic appointments) and general functional support as assessed by the Medical Outcomes Study (MOS) Support Survey (Sherbourne & Stewart, 1991) in a sample of behaviourally and perinatally infected youth. For support regarding their HIV, most youth reported that they had someone to remind them to attend clinic appointments (71%), or to bring them to the clinic (60%), mostly family (53%). More youth (52.4%) reported that they relied on family for help than on friends (28.3%). The authors reported that general social support and the two subscales of support (positive emotional support and tangible support) were significantly and negatively related to depression. Furthermore, whether someone facilitates access to care (e.g. brings them to the clinic) was also associated with fewer symptoms of depression.

In the second study, Lam et al. (2007) assessed the role of social support in symptoms of mental distress, using the Social Provisions Scale (Cutrona & Russell, 1987), which assesses the perceived functional content of support. They found that low social support was associated with poorer mental health. Understanding the role of social support is important as it may serve as an important protective factor for this group.

Stigma: Four studies assessed the role of HIV associated stigma in children and adolescents living with HIV. In Rwanda, Betancourt et al. (2014) assessed the amount of stigma children may feel regarding an HIV-affected person in their family with the Stigma-by-association scale (Boyes, Mason, & Cluver, 2013). They reported significantly higher levels of stigma in HIV-positive and HIV-affected youth compared to HIV-unaffected youth. In addition, group differences in mental distress disappeared when taking into account specific contextual variables which included the level of stigma.

Three studies (Rongkavilit et al., 2010; Tanney et al., 2012; Wright et al., 2007) used the 10-item Berger stigma scale (Berger, Ferrans, & Lashley, 2001; Wright et al., 2007) to assesses the role of HIV-related stigma in mental health of HIV-positive youth on four aspects of stigma, personalized stigma, disclosure concerns, negative self-image and public attitudes. All three studies found that stigma was associated with increased mental health problems. Wright et al. (2007) found that stigma was associated with mental distress as assessed by the Brief Symptom Inventory, with anxiety and depression in particular significantly associated with personalised aspects of stigma. Tanney et al. (2012) found that stigma was associated with depression, with higher stigma scores predicting higher depression scores. Finally, in Thailand, Rongkavilit et al. (2010) found that both the total stigma score and the public attitudes subscale were significantly associated with higher mental health problems.

Disclosure of status to others (HIV status disclosure): Three studies assessed the extent of HIV status disclosure to different people in the participants' environment and whether this was associated with mental health outcomes. HIV status disclosure can be helpful as it may open up avenues of support. Lam et al. (2007) assessed whether participants disclosed their status to immediate family, extended family, close friends, and acquaintances. Interestingly they reported that while HIV status disclosure to acquaintances was significantly associated with increased symptoms of distress, disclosure to family and close friends showed no association to mental health symptoms. Wiener and Battles (2006) classified the level of disclosure to immediate family, other family, friends and other people in the participant's life as low, medium and high. In their sample of HIV-positive youth between ages 13-24, they found that 27.5% had a high level of HIV status disclosure ("most people in my life"), 40% had a medium level of disclosure and 32.5% had a low level of disclosure. While psychological distress as assessed by the BSI (Derogatis, 1993), was not associated with level of HIV status disclosure, findings did show that those highest in disclosure had the lowest avoidant and total IES scores, as assessed by the IES (Horowitz et al., 1979). Finally, Elliot-DeSorbo et al. (2009) found that participants who had disclosed their diagnosis in the past six months were rated as more anxious by their caregivers than the non-disclosers. However, it should be noted that overall, in this final study, only 4% of participants scored in the clinical range and an additional 11% in the at risk range for caregiver rated anxiety on the BASC (Reynolds & Kamphaus, 1988). Given the few studies examining this factor, and the mixed findings, this is an important area for future research, particularly as youth enter into romantic relationships.

1.4.3 Economic factors, poverty and deprivation

Poverty factors such as low education, food insecurity, sub-standard housing and socio-economic status have consistently shown a positive relationship with mental health problems in low and middle income countries (Lund et al., 2010). Furthermore HIV and AIDS affected households are more seriously affected by poverty (Richter, 2004). In Ghana, for example, Doku (2009) found that children with HIV-positive parents had significantly lower socio-economic status than children of HIV-negative parents from the same community. Children orphaned by AIDS causes have also been reported as presenting lower on socio-economic status and poverty indicators, like food security and material affluence, than children orphaned by other causes (Cluver, Gardner, & Operario, 2008b; Doku, 2009).

Two studies in sub-Saharan Africa assessed the relationship between mental health outcomes and poverty (Betancourt et al., 2014; Tadesse et al., 2012). For the remaining studies, two reported that participants were from low socio-economic contexts (Kamau et al., 2012; Menon et al., 2007) and three studies did not report any data regarding the socio-economic status of their participants (Lowenthal et al., 2012; Musisi & Kinyanda, 2009; Small et al., 2014). Tadesse et al. (2012) assessed monthly family income and found that 57.9% of the participants earned less than 500 Ethiopian Birr, the equivalent of 50 U.S. Dollars per month. Children whose families earned less than this amount were more likely to have significant symptoms of emotional and behavioural distress, after controlling for sociodemographic variables.

In the other study, Betancourt et al. (2014) compared HIV-positive and HIV-affected (HIV-positive caregiver or AIDS orphans) youth with HIV-unaffected peers. They found that, although the HIV-unaffected group scored lower on poverty indicators than both HIV-affected groups, these differences were not significant. Furthermore, although they found that HIV-positive and HIV-affected youth had significantly more mental health problems than HIV-unaffected youth, these differences disappeared when they controlled for contextual variables, which included daily hardships such as food insecurity. This suggests that poverty may play a strong mediating role in observed differences in mental health problems.

Only one study in another low and middle income country compared socio-economic differences between youth living with HIV and a comparison group. In Thailand, Louthrenoo et al. (2013) reported that the HIV-positive group came from significantly poorer households, measured in family income, compared to the community comparison group. Of the studies conducted in the U.S., four studies included data on socio-economic indicators (Gadow et al., 2012; Kang et al., 2011; Malee et al., 2011; Mellins et al., 2009b; Mellins et al., 2012) comparing HIV-positive participants to youth that were perinatally exposed, but uninfected or HIV-affected. Contrary to expectations, all studies found that the HIV-positive groups were more likely to be living in more advantaged households compared to the comparison groups.

These findings suggest that it is not certain that HIV-positive children are necessarily in worse socio-economic situations than their peers. Overall, for studies using comparison groups, where the comparison groups were from HIV-affected participants (either perinatally HIV-exposed, living with an HIV-positive caregiver or AIDS orphans), the HIV-positive group were either from better socio-economic situations, or, as in Rwanda, there was no difference between the groups. Only one study used a locally matched community comparison group and this study found significantly lower socio-economic status for the HIV group (Louthrenoo et al., 2013). It is of concern that so few studies reported on the effects of poverty and socio-economic factors on youth mental health. Given the extent of poverty in countries like Namibia, and its effects on different aspects of the children’s environment, including nutrition, parental stress and even sexual risk behaviour in adolescents (Cluver, Orkin, Boyes, & Sherr, 2014), it will become more important for future studies to avoid this shortcoming.

1.5 Summary of main findings and gaps in the research

Despite the growing body of research investigating the mental health of children and young people living with HIV, only seven out of a total of 46 publications were conducted in sub-Saharan Africa. While advances in treatment have meant that perinatal infection has virtually been eliminated in high income contexts, this population will remain of interest for some years to come in sub-Saharan Africa. Findings from this review suggest that mental health problems in this population tend to be quite high: 39.9% – 51.2% in sub-Saharan Africa, but the mixing of disclosed and non-disclosed participants in particular makes it difficult to separate isolated effects. To answer the question of whether being HIV-positive is indeed a risk factor for mental health problems, more studies that include local comparison groups are needed, especially in sub-Saharan Africa where only one such study was found (Betancourt et al., 2014).

The review shows that a variety of risk factors are present, at an individual level, but also at different microsystems, such as the child’s family, educational settings and community level. Fewer contextual factors were examined in the studies with only two studies in sub-Saharan Africa examining this variable (Betancourt et al., 2014; Tadesse et al., 2012). While the extent and variety of risk and protective factors included is encouraging for this growing body of research, the same factors and measures are not consistently present in all studies, complicating overall comparisons. Nevertheless, many of the findings are consistent with the broader literature on child and adolescent mental health. The effects of being HIV-positive may be worsened in the context of certain risk factors: in particular poor health, caregiver vulnerabilities, poverty, orphanhood and stigma. In particular:

- The high rate of orphanhood in sub-Saharan Africa and particularly in children and adolescents living with HIV are consistent in studies assessing this variable, although the effect of parental loss on mental health is mixed. It seems imperative for all future studies, particularly those in sub-Saharan Africa, to assess both the presence and the effects of orphanhood on mental health outcomes for children, as this region contains 85% of the world’s AIDS orphans (UNICEF, 2013).
- Although only four studies examined the effects of HIV-related stigma on mental health, the findings consistently showed that HIV-related stigma had negative effects on mental health. Furthermore three studies used the same stigma scale and all were consistent. However, only one study was conducted in sub-Saharan Africa, suggesting this as a potential area for future investigation.
- Relatively little research has examined the effects of HIV status disclosure on mental wellbeing, and no studies have been conducted in sub-Saharan Africa. The findings on this variable were mixed.
- Evidence on social support as a potential protective factor is promising as it provides avenues for particular leverage points. None of the studies in sub-Saharan Africa reported any findings on social support.
- Few studies in sub-Saharan Africa include poverty and its role in mental distress.

1.6 Limitations of the review

The review includes studies which cover a wide age range for participants, from as young as six years to as high as 25 years. It would have been optimal to include only studies which focus on the adolescent age range (12-18) or the WHO defined range of 10-19 (WHO, 2003b). However, very few studies concentrate specifically on this age range. Since adolescence presents such a unique period with its own specific challenges and developmental issues, this means that there is a particular gap in research. Indeed as the analysis by UNICEF on the high AIDS mortality in adolescents shows (Kasedde, 2014), not only mental health research, but also HIV statistics need to be stratified for adolescents, especially by gender and also younger (10-14) and older (15-19) adolescents (Lowenthal et al., 2014).

Apart from wide age ranges, another limitation mentioned previously, is the wide variety of sample groups: mixing disclosed and non-disclosed, different health status and perinatally and behaviourally infected youth. Variations in mental health may be influenced by these differences. Limitations in tools used to assess mental health have also been mentioned. This includes the lack of comparative tools for assessing mental health and a lack of validation in non-Western contexts. This review has focused on empirical studies, but it is necessary to emphasise the added value that qualitative studies can bring to the understanding of the experiences of children and adolescents living with HIV. Particularly studies that combine quantitative with qualitative methods can be helpful.

The studies reviewed are based on a very few countries in Africa, which calls into question the generalizability of the results to other African contexts. Although research in sub-Saharan Africa is increasing in this area, it should be a concern that so few studies were found in comparison with high income countries. Low publication of African research occurs in other areas, with research studies from high-income countries nearly six times more likely to be accepted in influential journals compared to studies from low and middle income countries (Singh, 2006). Singh (2006) suggests that it is not only the quantity, but also the quality of research in Africa that needs to be improved. Research on children in Africa is a particularly neglected area (Jonsson, 2010). In this specific area however, it may be that other problems are considered more urgent in African context; HIV prevention research or research focused on material or basic health care needs may be considered more urgent than mental health needs. It becomes more important to emphasise the link between mental health and HIV-prevention, through the mechanisms discussed earlier.

This literature review has provided an overview of the risk and protective factors that can be included in the current study. We now provide an overview of Namibian studies that specifically examined issues with adolescents living with HIV.

1.7 Namibian-based studies with adolescents living with HIV

Five publications reporting the findings of four studies were conducted with adolescents living with HIV in Namibia (Baxen and Haipinge, 2015; Edusector AIDS response Trust, RAISON Namibia and TAMSHA Tanzania, 2008; O'Malley et al., 2015, Sisheho, 2011; Ward and Mendelsohn, 2008). These studies have not been included in the main review as they did not meet the inclusion criteria, either because they are not quantitative studies or because they do not assess mental health problems. However, they provide information about the context within which HIV-positive adolescents live, and highlight some specific challenges that these adolescents face in Namibia.

Two studies examined the experience of HIV-positive adolescents within educational settings. The first study, conducted in two urban and two rural settings, reports the findings of qualitative interviews with 76 respondents, of which 30 were HIV-positive children and adolescents. The study was published in two reports (Edusector AIDS response Trust, RAISON Namibia and TAMASHA Tanzania, 2008; Ward & Mendelsohn, 2008) and was interested in understanding the specific educational needs of HIV-positive learners. In the second study Baxen and Haipinge (2015) studied the school experiences of eight HIV-positive adolescents at a school through qualitative interviews in Windhoek, an urban setting. A third study, commissioned by UNICEF Namibia, was a survey conducted at an urban hospital (the Katutura Hospital) to understand the behaviour and attitudes of HIV-positive adolescents and to identify their needs for a group support (Siseho, 2011). The final study investigated the utility of a disclosure tool with HIV-positive adolescents (O'Malley et al., 2015). This final study is reported in Chapter three. The following themes emerged from these three studies.

Stigma and discrimination: The presence and experience of stigma and discrimination was a cross-cutting theme in all studies, particularly in the school settings. There was a pervasive fear in HIV-positive adolescents, a consequence of intolerant attitudes at school and in the community regarding people living with HIV. In the most extreme form this was illustrated by reports of negative experiences by participants when they disclosed their HIV to others. Baxen and Haipinge (2015) found that participants reported considerable bad experiences, including name calling and inability to access resources. Similarly, all participants in the report by (2008) had bad experiences with disclosing their HIV status and found that there was "greater safety in silence" (p. 4). This was confirmed by the findings from the survey, with 45% of adolescents in the 15-19 age range saying that they would want their friends to know their HIV status (Siseho, 2011).

Educational and school environment: Participants reported a general lack of trust in teachers (Baxen & Haipinge, 2015); with one study even reporting isolated cases of non-consensual disclosure from teachers (Edusector AIDS response Trust, RAISON Namibia and TAMASHA Tanzania, 2008). HIV-positive adolescents did not feel protected in the school setting. Secondly, the handling of the HIV and AIDS curriculum was found to be problematic, with participants reporting that teachers had a lack of sensitivity in handling this topic. Baxen and Haipinge (2015) also reported that some participants reported a lack of privacy for taking medication at school. On a positive note, there were isolated cases where HIV-positive adolescents were able to form a supportive relationship with a teacher or a counsellor at school (Baxen and Haipinge, 2015; Edusector AIDS response Trust, RAISON Namibia and TAMASHA Tanzania, 2008). However, this tended to be an exception.

Home environment: HIVpositive children and adolescents are often in precarious home situations, due to a loss of parents and, as a consequence, there may be little family support available (Baxen & Haipinge, 2015). Families of HIV-positive children are often adversely affected and may therefore struggle to provide support to the family (Edusector AIDS response Trust, RAISON Namibia and TAMASHA Tanzania, 2008). Additional stressors include poverty and deprivation.

Mental health: While no structured assessment of mental health was conducted by any of the studies, some data was reported that reflected on mental health issues. Siseho (2011) reports that

38% of the participants that took part in the survey reported that they often get depressed about their HIV status and 56% of those asked worry about their HIV status. Baxen and Haipinge (2015) in the qualitative interviews noted feelings of rejection, shame, embarrassment and a loss of self-worth as consequences of negative disclosure experiences and loss of self-worth.

The above studies highlight particular challenges that children and adolescents face in the Namibian context, mainly stigma and discrimination, poor support at school, negative consequences of orphanhood and poverty which may put strain on the support available to HIV-positive children from the home. Non-governmental organisations (NGO) were mentioned as an important source of support for participants (Edusector AIDS response Trust, RAISON Namibia and TAMASHA Tanzania, 2008). The studies provide important contextual information about the experiences of adolescents living with HIV in the Namibian context. However, it should be noted that only one study included participant from rural areas, all studies being conducted in the capital, Windhoek, thus limiting the generalisation to adolescents in other places, in particular to rural areas. The qualitative methodology used in two studies allowed detailed information to emerge regarding adolescents’ experiences. However, this also limits the generalizability of the results to the wider population of adolescents living with HIV population.

1.8 Research objectives and hypothesis

The current research will examine the mental health of adolescents living with HIV and determine which risk factors (e.g. stigma, poverty) and which protective factors (e.g. social support) may predict mental health outcomes in Namibia. The review of literature on adolescents living with HIV, suggested that research in high HIV prevalence countries, such as Namibia is lacking. Furthermore there may be difficulties in applying findings from other settings to low income countries. The chapter also examined Namibian-based studies to have a better understanding of contextual factors that may play a role in adolescent mental health in Namibia.

The specific objectives of this study are:

1. To determine the basic socio-demographic composition of HIV-positive adolescents and to assess differences in these factors between HIV-positive adolescents and a matched community comparison group.
2. To assess the level of mental distress in HIV-positive adolescents and to determine whether they have more mental health problems than adolescents from the comparison group.
3. To determine whether HIV-positive adolescents present with more risk factors, such as parental death, when compared to the community comparison group.
4. To assess the association between risk factors, such as poverty and parental bereavement, and mental distress and to assess whether any risk factors may mediate mental health differences between the two groups.
5. To assess the role of social support on the mental health of HIV-positive adolescents and whether there are any differences in social support between the two groups and to assess whether social support may mediate differences between the two groups.
6. To determine which variables are the best predictors of mental distress in HIV-positive adolescents, including the role of HIV-specific factors, such as stigma and HIV status disclosure to others.

The research hypotheses are that:

- HIV-positive adolescents show higher levels of mental distress than a matched community control group.
- HIV-positive adolescents present with more risk factors, including higher levels of parental loss, than participants in the comparison group.
- Risk factors, including poverty, parental bereavement and HIV-related stigma, are associated with increased mental health problems.
- HIV-positive adolescents receive/perceive lower levels of social support than adolescents in the comparison group. Social support has a protective effect on mental health.
- For HIV-related variables, stigma experiences are associated with higher levels of mental distress in adolescents living with HIV and HIV status disclosure to others is not associated with mental distress.

Despite the fact that the literature review also identified risk and protective factors for this group, a pilot study was undertaken to assess local perspectives on specific risk and protective factors. This was important as no research into risk factors for mental health had been previously conducted. The methods and results are presented in Chapter two. Chapter two also discusses methods employed to select and adapt the instrument to assess mental health.

CHAPTER TWO: PILOT STUDY METHODOLOGY AND RESULTS

Early scholars in the field of cultural psychology questioned the appropriateness of constructs developed in the West, such as the psychiatric diagnostic system, to contexts other than where they were developed (Dowdney, 2007). These authors emphasized the importance of recognizing that current diagnostic or bio-medical systems have been developed within a particular historical and cultural context (Bracken, Giller, & Summerfield, 1995). Whilst the debate around the validity of the importing of Western diagnostic systems into the African context remains important, there is now sufficient consensus that there are serious mental health consequences for children exposed to difficult and stressful events (Dowdney, 2007). However, social and cultural contexts influence and shape the ways in which mental health symptoms are experienced and talked about (Tol, Komproe, Jordans, Susanty, & de Jong, 2011). Kirmayer (2001), for example, observes that while only a small number of emotions may exist, they may be both experienced and expressed in a variety of ways. Activities, symptoms and behaviours captured in tools that assess mental health, may have different meanings and have different values attached in different settings (Tol et al., 2011). Ruiz-Casares et al. (2009) for example, explain how appetite change, a symptom of depression captured by the Child Depression Inventory (CDI), needed further clarification in their work in a low resource setting in the north of Namibia. After consultation with local professionals, it became apparent that it was necessary to add the phrase “when there was food available” to take into account the contexts of deprivation. Tools developed in one context should not be applied to new and different contexts without considering their relevance and applicability to the new context. However, developing instruments from scratch to suit each specific context is expensive and time consuming; an additional disadvantage being that it will not allow for comparison with studies from other countries or contexts (van Widenfelt, Treffers, de Beurs, Siebelink, & Koudijs, 2005).

As mentioned above, the CDI assessing depression has been adapted in Namibia (Ruiz-Casares et al., 2009); however no tool assessing emotional and behavioural distress has been adapted or validated. A pilot study, using both qualitative and quantitative methods was thus incorporated into this study in order to select an appropriate mental health tool and to assess its psychometric properties in the local context. Furthermore, in order to gain a better understanding of context-specific risk and protective factors for mental distress in Namibia, the qualitative phase also included methods to explore these factors with adolescents and local experts. While the literature reviewed in the previous chapter provides a list of potential variables that could function as risk factors for mental distress, this pilot phase provided information specific to Namibia. These locally identified factors were considered alongside those identified in the literature for the selection of variables to be included in the main study.

2.1 Aims of pilot work

In this chapter we describe qualitative and quantitative phases of pilot work undertaken before the main study. The aims of the pilot study were to:

1. Identify contextually relevant risk and protective factors for mental distress.
2. Explore local constructs and expressions for mental distress. These could then be later used to guide the selection and adaptation of an existing mental health measure.
3. To explore the ecological validity and psychometric properties of the selected mental health instrument.

Aim one and two were addressed by qualitative methods, which included group discussions and key informant interviews, and aim three was addressed with quantitative methods. As part of the outcome of the quantitative phase, a supportive aid was developed for improving item comprehension in the selected instrument, the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997). Furthermore, the pilot study also allowed for the identification of local services and resources that could be useful during the main study phase, such as referral options for adolescents.

2.2 Qualitative methods: perspectives on mental health, risk and protective factors

In order to explore perspectives on risk and protective factors and mental health problems, group discussions were held with 34 adolescents and key informant interviews with 13 adults were conducted.

2.2.1 Participants and procedure

Adolescent participants: Four group discussions were conducted with 34 adolescents in the 12-18 age range, with 7 to 11 participants per group, between September and October 2012.

Participants were selected from four sites located in northern Windhoek in the area proposed for the main study. Half (47.1%) of the participants were selected from two community centres in the Katutura area whereas the remaining were from two schools in an adjoining community (Khomasdal). About 30% of the participants were in the 12-14 age range and 70% were in the 15-18 age range, while less than half (41%) were female. Most of the participants spoke Oshiwambo as their main home language (70%) followed by Afrikaans (11.8%), Herero speakers (5.9%), with the remaining 12.3% speaking various other languages.

Procedure for adolescent participants: Participants were identified by teachers and/or community leaders. Groups were held either at the school or community centre where parental/caregiver consent was obtained. Chapter three provides a detailed discussion on the ethical procedures followed throughout the research. *Free-listing* exercises were used to prompt children to draw on their own perspectives. The three main questions focussed on stressors (risk factors), symptoms of distress and coping mechanisms (protective processes). The questions were:

1. Can you identify anything that makes young people's lives difficult or stressful in the settings where you live? (adapted from Miller et al. (2009)
2. How would you know when a child is not coping/doing well after a difficulty?
3. What do you think a child experiencing such a difficulty or stressful event (see above) would do?

Information was recorded using a flipchart and worksheets which participants completed. The flipchart provided a visual stimulus to facilitate the discussion and also allowed participants correct their responses and elaborate on them. The technique of *free-listing* was used to generate responses to the questions. As suggested by Bolton and Tang (2002), in this technique the interviewer probes the respondents to give as many suggestions as they can think of. When this is completed, the interviewer ensures they understand the meaning of each term. The technique has been used in conflict and cross-cultural settings to explore and develop tools for assessing stressors (Betancourt et al., 2011; Miller et al., 2009) and the impact of mental health on functioning (Bolton & Tang, 2002). More participatory techniques were also included, such as a ranking exercise to indicate which difficulties described in the first question were the most common. In this case, the difficulties were written down and spread on the floor and each participant was given three beans to indicate the three most commonly occurring difficulties. After the meetings the data was transferred to electronic format for analysis. A full outline of the group format can be found in Appendix 3.2. The groups took about 1 hour and 30 minutes and were conducted in English by the main researcher (S Gentz).

Adult participants: Interviews were also conducted with eight key informants, including community workers and professionals working directly with adolescents living with HIV, researchers or specialists in either HIV or child and adolescent mental health. The findings discussed refer specifically to children and adolescents living with HIV.

Procedure with adult participants: Interviews included open-ended questions regarding informants' experiences with adolescents living with HIV, their challenges and coping techniques as well as informants' observations of signs and symptoms of distress. The interview schedule used is included in Appendix 3.3. Interviews took place at hospital, non-governmental organisations (NGO) or University settings and were conducted by the main researcher (S Gentz). Information was captured manually with the interviewer taking notes during the interview. These were transferred to electronic format for analysis.

2.2.2 Analysis strategy

The interviews and discussions resulted in qualitative information on risk factors, mental distress and protective process which were sorted into categories and given a frequency count. Data was analysed manually using the techniques of thematic analysis (Aronson, 1995) extracting themes and categories which recur. Attention was paid to those categories that appeared to be consistent across the groups and interviews. Stressors were categorised according to the level at which they occur (e.g. peer, family microsystem or broader exosystem factors, such as poverty), mental health was categorised in the general categories of internalising and externalising symptoms and social support was categorised according to those used in previous research (Cluver, 2007; Ruiz-Casares, 2006): emotional support, recreational support, practical or material support, advice and positive feedback/validation.

2.2.3 Results

Stressors

A few key themes emerged as being causes of stress for adolescents in Namibia. These included stressors in the family system, peer system factors, environmental factors such as poverty and living conditions, as well as violence and abuse.

Parental/familial and caregiver factors: All groups and key informant interviewees identified the importance of parental and caregiver environment as a risk factor for children's distress. Factors identified as particularly stressful in the groups included domestic and family violence (4 groups), parental loss and orphanhood (3 groups), separation of children from their parents (3 groups) and parents being HIV-positive (2 groups). Two groups specifically mentioned physical abuse from parents as stressors. Emotional abuse was also mentioned as a stressor by 2 groups ("rejection from parents"). For the three groups asked, these were identified as either high intensity or very traumatic stressors for children. One group was not asked due to time restrictions.In the key informant interviews, all informants mentioned that for children and adolescents living with HIV, the home and family situation were the most important factor: "Social circumstances at home are the main determining factor of how a child copes with their diagnosis. If there is no support from caregivers it becomes difficult for the child" (Medical doctor working with children and adolescents living with HIV). Parental loss and orphanhood were also mentioned by key informants as being a big stressor for adolescents living with HIV. One informant (medical doctor) raised the issue of a mobile population, such as moving between caregivers or moving between rural and urban areas during school holidays; such mobility has negative effects on treatment follow-up and adherence

Poverty and living conditions: Material poverty was identified as an important stressor by 3 of the groups and was also mentioned by key informants as an important determinant for distress in adolescents living with HIV. This included lack of money for basic needs (food, electricity, water, school uniform, and school shoes), hunger as well as "lack of money to buy things that your peers have, such as cell phones, nice clothes, entertainment" (Participant, 15-18 age range). Three groups also mentioned living conditions, such as living in a noisy or overcrowded neighbourhood, although the former was rated as a low intensity stressor. Key informants mentioned how poverty has an important influence on adherence to treatment for children and adolescents living with HIV, as well as the impact of poor nutrition on children's health.

Peer problems: All groups mentioned peer problems as a source of stress for young people in Namibia. This included bullying (3 groups) as well as the negative effects of peer pressure (3 groups). For adolescents living with HIV, peer problems were also mentioned by key informants: fears that their peers will discriminate against them, in the school and in the community. As mentioned by one key informant, these fears may lead to children not wanting to carry their medications around at school for fear of being discovered, as well as their HIV status contributing to shyness around their peers.

Violence and abuse: Apart from domestic and family violence, violence was also mentioned to occur in other systems, including community violence ("not feeling safe in your street", 2 groups) and rape/sexual violence in unsafe communities (3 groups).

*Other risk factors***:** Other risk factors identified in the groups included teenage pregnancy (2 groups), divorce/parental separation (2 groups), drug and alcohol abuse and addiction (3 groups) and HIV and AIDS and other illnesses (3 groups). It is noteworthy that HIV and AIDS were mentioned in this sample of young people who were not HIV-positive or HIV-affected. School factors, such as exam stress, school routine, school failure and school work, were identified by all groups, although they were rated as low intensity stressors. Key informants also mentioned fear of discrimination at school as an important issue for adolescents living with HIV: "children are afraid that teachers will label them". Adherence problems were brought up by all key informants as an important issue for adolescents living with HIV.

Symptoms of mental distress

At this stage, an instrument to assess mental distress had not been selected, although a few had been identified through the literature review. A combination of findings from the groups and stakeholder interviews provided a list of locally observed and frequent symptoms which could be categorised and used to compare with existing instruments. The symptoms were categorised according to broad clusters of "Internalising" (denoting whether they were depressive or anxious symptoms) and "Externalising" problems (denoting whether they were "conduct/aggressive/oppositional" or "hyperactive/inattentive"). A full list of symptoms is provided in Appendix 3.4.

Internalising symptoms: Depressive symptoms: All groups identified depressive symptoms as consequences to distress. This includes feelings of sadness (depressed, "feeling down or sad", feeling unhappy), moodiness ("gets upset quickly", moodiness, "you can just snap at your friends"), withdrawal ("wants to be left alone"), loneliness, suicidal behaviour, vegetative symptoms (sleeps a lot, no appetite, low energy) as well as cognitive symptoms (negative thoughts "thinks parents do not care about him" "feels like no-one cares") and low self-esteem. The three groups that were asked to define depression understood and were able to articulate its meaning: "the person feels as if they have no future, no hope, alone, a part of you gone, you feel like you are no use to people, stressed, you have suicidal feelings" (group 1), "Always alone, loses concentration, always crying, never interested to do things" (group 2), "person feel miserable, always sad, wants to be alone all the time, the person does not want to do anything, you always have stress, you have stress when you don't want it" (group 3).

The fourth group were not asked due to time limitations. Depressive symptoms were also mentioned by key informants as a symptom that HIV-positive children and adolescents experience: "unhappiness, and regret", "kids can become depressed, quiet and withdrawn." Suicidal ideation was mentioned, although it was highlighted that it occurs in the context of other contributing problems, specifically family problems and poverty.

Anxiety related symptoms: Anxiety related symptoms were identified by all groups, although less frequently than depressive symptoms. These included feeling stressed and worried as well as feelings of fear ("afraid to be seen in public" if there are problems at home) and shyness/shame. Fear related symptoms were mentioned by key informants as potential reactions for adolescents living with HIV ("Fear of losing friends if they disclose", "fear kids will discriminate against them at school and in the community"). Furthermore there was a high distrust from the children and a need to keep their status a secret. Rumination about their HIV ("thinking too much about their illness") was also brought up by a counsellor who works with adolescents living with HIV.

Externalising symptoms: Conduct/oppositional/aggressive symptoms: All four groups mentioned symptoms of conduct/oppositional/aggressive behaviour as a reaction to stressful situations. These symptoms included aggressive behaviour ("person may become violent", "commit crime"), delinquent behaviour (stealing, vandalism like breaking windows), drug and alcohol use ("smoking and other social evils"). Oppositional and aggressive symptoms were also mentioned by key informants and it was suggested that these were consequences of finding out about their HIV status: "kids may start drinking, picking fights on the street, become careless", "kids start to feel anger and aggression, blaming others for their problems". Oppositional behaviour can also affect treatment: "Teenagers are clever and can easily mislead you" (about whether or not they were taking their medications). The interviewee felt that this may be fuelled by denial as kids "start to doubt that they have HIV".

Hyperactivity and inattention: Symptoms of hyperactivity and inattention were mentioned in all groups, although less commonly than other symptoms: lack of concentration was mentioned by 3 groups ("the child can't concentrate and their grades begin to drop") and hyperactivity by one group ("you talk a lot/keep busy"). One of the three groups, directly linked concentration problems to the stressor of poverty ("the child is worrying about food and can't concentrate on his school work"). Hyperactivity and inattention were not mentioned by key informants.

Support

To assess participants' opinions on the type of social support that young people in distress might need, and to provide contextual information on support structures and protective processes to help formulate the questionnaire, participants in two groups were asked to complete a short worksheet providing their opinion on what type of assistance a child experiencing particular stressors might need. Responses were categorised according to emotional support, recreational support, practical or material support, advice and positive feedback/validation. The findings (Appendix 3.5) show that:

- All of the categories of social support were mentioned, although emotional and practical/material assistance were the most commonly cited.

- The prominent sources of help for adolescents in distress included parents, family and close relatives, friends, and some professionals (counsellors, psychologists, doctors) and the police.
- Many children in the groups referred to a local NGO (Lifeline/Childline) as a place of support.

In this pilot phase children, adolescents and adult key informants provided their opinions on particular stressors for Namibian youth, as well as the symptoms children facing these stressors experience. It was not meant to provide a deep qualitative analysis of these factors, but rather a list of factors that could be used to select an appropriate tool for the context. The findings show that the broad categories of mental health (depressive and anxiety for internalising symptoms and aggressive/oppositional and hyperactivy/inattention for externalising symptoms) were shown to be present among Namibian youth as reactions to stressful situations.

2.2.4 Limitations

The above methods have some limitations. The number of children included in the groups was small and participants were sampled only from two urban low income areas which limits the generalizability to children from other areas. Furthermore there were no adolescents living with HIV in the groups. There were two reasons for this decision. Firstly, we were conscious of the limited number of participants available for the HIV group and wanted to preserve those participants for the main study. Secondly, and more importantly, it would have been challenging to maintain anonymity of HIV-positive participants in a group setting. Themes were explored in groups for children in general and no questions were specifically asked for perspectives on HIV-affected or infected children. The main reason for this was that there remains a general stigma around talking about HIV and AIDS (Cluver, 2007; Van der Riet, Hough, & Killian, 2005) especially in school settings with HIV-affected children experiencing such discussions as a negative experience due to the insensitivity of teachers and peers (Baxen & Haipinge, 2015). As Van der Riet et al. (2005) in their research in South African schools explain: “Exploration of sensitive, possibly stigmatizing topics inevitably raises tension between the need to collect data and the child’s need to be offered a contained context in which to express their feelings and experiences” (p. 84).

2.3 Exploring the psychometric properties of the SDQ in Namibian adolescents

For the current study it was important that the selected instrument assessing mental distress had sound psychometric properties, was fairly easy to administer and was well-established in the field of child mental health. The Strengths and Difficulties Questionnaire (SDQ) was selected due to ease of administration, wide use in African contexts and being a cost-effective tool for resource limited settings. The SDQ was therefore selected as it captured the issues we were interested in assessing in the local context (see pervious section). Once an instrument was selected, it was necessary to explore the psychometric properties to ensure that it was reliable for use in Namibia. This section begins with a brief background of mental health research with children and adolescents in Namibia followed by a description of the methods and findings in a quantitative pilot phase which assessed the instrument.

2.3.1 Background: mental health in children and adolescents in Namibia

Few Namibia-based studies were found that included mental health indicators specifically for children. The Namibian School-based Student health survey, a multi-country study conducted in 2004 contained 4 questions looking at psychological distress in 6367 adolescents across the country with most (67%) between the ages of 13 and 15 years (D. W. Brown, Riley, Butchart, & Kann, 2008; MoHSS, 2008c; Page & Hall, 2009). The mental health findings of the 2013 Schools based Health Survey were not available at this point. Questions focussed on: loneliness, worry, sadness/hopelessness and suicidal planning. In another study, Ruiz-Casares et al. (2009) explored depression and depressive symptomology in 157 children in the north-east of Namibia (Caprivi/Zambezi and Kavango) using the Child Depression Inventory (Kovacs, 1985). Finally, Shaanika (2009) assessed the mental health of 61 adolescents between 11 and 19 years, living in long-term residential care in Namibia using the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997).

The tool used in the 2004 Schools–based Student health survey was not a rating scale and data on each question was reported separately. Findings show that 11.5% of participants felt lonely most of the time or all of the time, and 19.8% feeling worried most of the time or all of the time to the extent that they could not sleep; and 10% of youth worrying to the extent of using alcohol or drugs to feel better. With regards to suicide: 32.2% of children had made a plan for suicide in the past 12 months (MoHSS, 2008c). While the data should raise concern, especially the finding on suicide, the psychometric properties of the indicators measuring psychosocial distress were not reported for Namibian youth. It is not possible to say how reliable and valid this tool is as an indicator for mental health. Furthermore, because the questionnaire relied only on 4 questions, it does not provide a complete picture of mental health.

In the second study, Ruiz-Casares (2009) found that 1 in 6 children were at risk for depression using the standard cut-off point of ≥19 for the CDI (Kovacs, 1985). Before administration, the tool was piloted and adapted to the local context, translated into local languages and the final version was found to have acceptable reliability (α = 0.71). However, the tool had not been standardised for use in Namibia (Ruiz-Casares et al., 2009) and the sample was small and limited to only two regions in the north of the country. Finally, Shaanika (2009) reported high rates of significant distress in adolescents in long-term residential care, with 70.5% of the participants qualifying for significant distress on the SDQ total problems scale, 52.5% having abnormal scores peer problems (52.5%), 49.2% for conduct problems, 34.4% for hyperactivity, and 31.1% for emotional symptoms. High rates would be expected in this sample of youth living in residential care for long times. However, this study does not provide any data on the psychometric properties of the SDQ.

While few data exist regarding mental health prevalence in Namibia, the few previous studies suggest that at least certain groups of vulnerable children are at risk for mental health problems: with 16.7% of children in the north of Namibia qualifying for depression (Ruiz-Casares et al., 2009), 32.2% of a country wide representative sample having suicidal ideation (MoHSS, 2008c) and 70% of children in residential care in Windhoek (which is also the site for this study) having symptoms to qualify for significant distress (Shaanika, 2009). These findings suggest that this is an important area to explore. However it is important to have valid and reliable tools for child mental health to identify at risk children and adolescents, to establish prevalence and risk factors and to assess the impact of mental health interventions in the local context. This study will add to the existing data on mental health, and report on the appropriateness of the SDQ to assess mental distress in Namibian adolescents.

The Strengths and Difficulties Questionnaire.

The SDQ was developed by Robert Goodman from the Department of Child and Adolescent Psychiatry in King´s College, London and consists of a 25 item behavioural screening questionnaire covering the following components:

- Emotional symptoms (e.g. "I am often unhappy, downhearted or tearful")
- Conduct problems (e.g. "I get very angry and often lose my temper")
- Hyperactivity/inattention (e.g. "I am restless, I cannot stay still for long")
- Peer relationship problems (e.g. "Other children or young people pick on me")
- Prosocial behaviour scale (e.g. "I often volunteer to help others")

Qualitative data generated in group discussions and key informant interviews supported the broad categories of the problems scales of the SDQ: emotional symptoms, conduct problems and hyperactivity/inattention, whereas difficulties of peer relationship problems were supported by the findings on risk factors. The prosocial scale was not explored in group discussions as the main aim of the research was to identify negative consequences of stressors in Namibian youth. However, the decision was made to retain this scale in order to maintain the completeness of the instrument.

The instrument is well-validated in a wide variety of cross-cultural contexts and has been translated into 51 languages, including Afrikaans, has excellent psychometric properties and has been widely used in epidemiological studies. In sub-Saharan Africa, for example, the SDQ has been used with orphans and vulnerable children in South Africa (Cluver, Operario, & Gardner, 2009) and Ghana (Doku, 2009) and with adolescents living with HIV in Zambia (Menon et al., 2007). As mentioned, the tool had also been used in a small sample in Namibia (Shaanika, 2009). The SDQ is useful for a variety of purposes including screening, epidemiological research, clinical assessment and evaluating outcomes and has been found to be as good as longer scales, such as the CBCL (Achenbach & Rescorla, 2001), in detecting internalising and externalising problems (Goodman & Scott, 1999). As the psychometric properties of the SDQ were not known for Namibia, this pilot phase was incorporated to assess its psychometric properties.

2.3.2 Objectives

The objectives of this pilot phase was to

- Assess the reliability of the SDQ in a sample of Namibian adolescents by testing the internal consistency of the overall scale and the 5 subscales (emotional, hyperactivity, peer problems, conduct problems, prosocial behaviour scale).
- Conduct a preliminary hypothesis testing: assess whether socio-demographic factors (gender, age, socio-economic status, orphan status, presence of a supportive other) were related to the emotional and behavioural difficulties as assessed by the SDQ.

2.3.3 Data collection procedure and participants

In order to be comparable to the participants in the main study, participants were selected from four schools in the Katutura area and corresponding to the proposed 12-18 age range. A two stage cluster sampling method was utilised. Two primary schools (and one back-up) and two secondary schools (and one back-up) were selected randomly, with probability proportion to size, from a list of eligible schools in the study area. The second stage involved the random selection of 2 to 3 classes in each school, from the grades corresponding to the required ages. The required sample size for the analysis for this pilot study set at least 150 participants, using the programme Decision Analyst STATA 2.0 (Decision Analyst Inc.). Participation rates for classroom-based research efforts vary widely from as low as 40% to 80% (Fletcher & Hunter, 2003). Since no local data was available to estimate participation rate, it was decided to use a conservative estimate of 50% and to approach approximately 300-350 learners.

Permission was obtained from the Ministry of Education (Appendix 2), the school management and written consent was obtained from parents. Some 72.6% of the consent forms were returned with a higher return rate for primary schools (82.2% vs. 63.9%). It was not possible to determine whether the non-return of forms was a result of parental refusal or whether the children neglected to deliver the forms. Of the returned forms, five parents (2%) refused participation. In total, 236 learners completed the questionnaires. For each session, a facilitator was present and read out the questions while each participant completed the questionnaire in private. The administration took between 30 and 45 minutes.

Ethical procedures: Ethical principles and procedures followed throughout the research are more fully described in Chapter three. Participants only took part if parents and participants themselves provided written consent. Parent consent forms were available in English, Oshiwambo and Afrikaans (Appendix 4.2). Questionnaire responses were anonymised and participants' survey questionnaires and the consent form were linked together by identifiable reference codes known by only by the main researcher (S Gentz). Group administration took place within the classes so as to cause minimum disruption to learners. An information sheet explained the details of the study and procedures. Prior to the administration a brief class discussion was held to assess participants' comprehension of the study procedures, to reinforce the voluntary nature of the study and to provide opportunity for questions. Five learners (2%) did not wish to participate. No incentives were provided. At the end of each administration, participants were provided with a list of local resources, printed on coloured paper, in case they needed further help (Appendix 6.1). A total of seven learners contacted the researcher after the sessions by text message; of these seven, two participants needed a referral to a counselling centre, one was referred to the life-skills teacher and one learner was helped over the phone. The remaining three participants contacted the researcher to say that they had enjoyed taking part in the study.

Participant characteristics: A total of 236 participants completed questionnaires. The mean age was 14.0 years (SD = 1.80) with about half (54.2%) falling in the younger age group (12-14). There were slightly more female participants (59.7%). Although statistics from the Education Management Information system (EMIS) show slightly higher female enrolment in the Khomas region where the schools are located (Ministry of Education, 2012), the difference in gender composition is more likely due to female learners being more likely to return the parent consent forms.

2.3.4 Instruments

The following variables were assessed by the questionnaire (Appendix 4.3):

Demographic and background variables: A number of demographic variables, including age, date of birth, grade at school, gender, home language, main caregivers and orphan status were assessed. Primary caregiver was identified as the person who ‘stays with you and takes care of you at home’.

Poverty indicators: Poverty was assessed with the following indicators: whether anyone in the household was working, food security, housing conditions and the presence of certain assets (television, radio, electricity) in the household. These indicators have been used in previous studies with vulnerable children in southern Africa (Cluver & Orkin, 2009; Doku, 2012) and to assess poverty in Namibia (Namibia Statistics Agency, 2012b).

Mental health: Mental health was assessed by the SDQ self-report version (Goodman, 1997).

Other variables: The Ministry of Education was interested in data on children’s opinions on life-skills teachers. For this reason, a few questions were included regarding participants’ perception of life-skills teachers. This information is not reported in this thesis, but was forwarded to the Ministry representative.

2.3.5 Results

The demographic and social characteristics of the participants are presented in Table 6.

Caregiver information and orphanhood: About one-fifth of participants were orphaned (21.6%), of which 2.1% were double orphans. Most of the participants identified a biological parent as their main caregiver (69.9%), followed by other relative (28.7%), such as aunts or grandparents. Only 3 participants were cared for by non-relatives.

Poverty: About one third of participants (31.2%) lived in informal dwellings (shacks), and 24.2% used a public tap with one participant’s family using a nearby dam for water. Forty children (16.9%) did not have electricity in their home. For 73 (31.5%) participants there was at least one day where there was not enough food in the house in the past 7 days.

Table 6 Demographic and social characteristics of participants in pilot study

Demographic variable	***n* (valid %)**	**Socio-demographic variables**	***n* (valid %)**
Age		**Suburb**	
Mean (SD)	14 (1.8)	Katutura	218 (93%)
		Khomasdal/Otjomuise	11 (4.6%)
Gender		Other[b]	7 (4%)
Male	95(40.3%)		
Female	141 (59.7%)	**Housing**	
		Formal housing	161 (68.8%)
Current grade		Informal housing	73 (31.2%)
Grade 6	58 (24.6%)		
Grade 7	76 (33.5%)	**Assets**[c]	
Grade 9	49 (20.8%)	Mean (SD)	5.01 (1.4)
Grade 10	50 (21.2%)		
		Access to water	
Home language		Own tap	178 (75.4%)
Oshiwambo	122 (51.5%)	Public tap	57 (24.2%)
Otjiherero	62 (26.3%)	River or dam	1 (0.4%)
Afrikaans	16 (6.8%)		
English	14 (5.9%)	**Electricity**	
Nama/Damara	12 (5.1%)	No	40 (16.9%)
Other[a]	10 (4.2%)	Yes	196 (83.1%)
Orphan status		**Days no food (last 7 days)**	
Orphan	51 (21.6%)	None	159 (68.5%)
Non-orphan	184 (78.3%)	One day	34 (14.7%)
		2-3 days	26 (11.2%)
Main identified carer		4 or more days	13 (5.6%)
Biological parent	165 (69.9%)		
Other relative	68 (28.7%)	**At least 1 working adult**	
Non-relative	3 (1.2%)	Yes	216 (91.5%)
		No	20 (8.5%)
Age of caregiver			
Under 25	9 (5.3%)		
25-60	154 (91.1%)		
60+	6 (3.6%)		

[a] Rukwangali (*n* = 4), Portuguese (*n* = 3), Nyemba (*n* = 2), Silozi (*n* = 1)
[b] Dorado Park (*n* = 2), Academia (*n* = 2), Windhoek North (*n* = 1), Eros (*n* = 1), Rocky Crest (*n* = 1)
[c] List of assets radio: television, fridge, telephone/cell phone, stove, car, bicycle, electricity (Namibia Statistics Agency, 2012a)

Psychometric properties of the Strengths and Difficulties Questionnaire: Table 7 presents the Cronbach's α for the total score and the five SDQ subscales. While the total difficulties score is adequate (0.67), the prosocial behaviour, emotional symptoms and conduct problems subscales have low reliability (0.47-0.53) and the hyperactivity and peer problems subscales should raise concern (0.31-0.35).

Table 7 Cronbach's α for SDQ subscales

	Cronbach's α	**Items whose omission improves Alpha**[a]
Emotional Symptoms (items = 5, n = 228)	0.53	
Conduct Problems (items = 5, n = 232)	0.47	
Hyperactivity/inattention (items = 5, n = 227)	0.35	"fidgety"
Peer Problems (items=5, n = 229)	0.31	"better with adults"
Prosocial behaviour (items=5, n = 231)	0.51	"considerate"
Total difficulties (items 25, n = 219)	0.67	"better with adults"

[a]Improvement in Cronbach was between 0.01 and .136

Table 8 compares the Cronbach α to scores obtained to two other studies which have used the SDQ self-report questionnaire, including the study by Goodman (2001) with 3 983 British youths as well as a study conducted in Zambia with 127 adolescents living with HIV (Menon et al., 2007). Comparing the Cronbach α from the current study to previous studies suggests that reliability for the total difficulties is adequate (0.67). Although it is somewhat lower than the British sample (Goodman, 2001) it is higher than the Zambian study (Menon et al., 2007). While the reliability for the emotional symptoms subscales is lower in the Namibian sample, it may still be adequate when compared to the Zambian study.

Table 8 Comparison of SDQ Cronbach´s α with previous studies

	Namibian PILOT study **N = 236**	**British sample (Goodman, 2001)** **N = 3 983**	**Zambian sample (Menon et al., 2007** **N = 127)**
Emotional Symptoms	0.53	0.66	0.51
Conduct Problems	0.47	0.60	0.61
Hyperactivity / Inat.	0.35	0.67	0.18
Peer Problems	0.31	0.41	0.31
Prosocial behaviour	0.51	0.66	-
Total difficulties	0.67	0.80	0.51

The peer problems subscale has the lowest Cronbach *α* of all the subscales in the current study. It is also the scale with the lowest reliability in the British (Goodman, 2001) study and is comparable to the Zambian study. The reliability of the conduct problems is lower than both the British and Zambian studies. The Hyperactivity/inattention subscale in the Namibian sample is lower than the British and should raise concern. A lower reliability for this scale was also obtained in the Zambian study.

Preliminary associations between risk factors and mental health outcomes

Preliminary associations between various socio-demographic factors and poverty factors and the continuous psychological outcomes were examined using t tests and Pearson bivariate correlations for continuous variables. For mental health outcomes continuous scores for the total difficulties scale were used.

Age, gender and orphan status: No significant associations were found with gender or age group with regards to distress. Although orphans tended to report more symptoms of emotional and behavioural distress, in this sample, the differences were not statistically significant.

Poverty: There was a significant difference in symptoms of distress according to whether children lived in formal or informal housing (*t* (216) = -1.99, *p* <.05). Children living in informal housing were significantly more likely to report emotional and behavioural symptoms of distress than children living in formal housing (*M* = 13.37 vs. 14.87). Children who reported problems with food security (at least one day without enough food in the home) reported higher scores on the total difficulties scale than children who had no problems with food security in the past 7 days (*t*(216) = -4.67, *p* < .001, *M* = 12.73 vs. 16.15). Similarly, children who reported not having had breakfast due to a lack of food in the home, reported significantly more total difficulties than children who had breakfast (*t*(209) = 3.15. *p* < .01; *M* = 16.52 vs. 13.28). There was no association between the number of assets in the home and the symptoms of distress.

2.4 Improving comprehensibility of SDQ items for the main study

Despite the fact that the SDQ is a simple tool requiring a reading level of around the 5th Grade, the low reliability in some subscales raised concern. The next step in the research process therefore involved exploring the potential for comprehension difficulties with some items. Two approaches were used. Firstly, cognitive interviewing was incorporated during pilot interviews. Pilot interviews were conducted at different points prior to the main study for the testing of the entire instrument and administration procedure (See Section 3.4 for more information). In this case cognitive interviewing techniques were employed during the final round of pilot interviews after the SDQ had been tested and before the main study was conducted. Before the questionnaire was administered, participants were asked to indicate to the interviewer if there were any words or phrases that they did not understand and again after the administration of the questionnaire. They were also asked the meaning of potentially difficult words, such as “restless”, “hyperactive”, “fidgety”, “squirming” and phrases like “lose my temper”. Participants were also asked whether they understood the instructions and the response categories.

Secondly, comprehension and semantic difficulties were further explored in 3 group discussions with younger children. Two of the discussions were held at one of the community centres and the third at a primary school located in the study area. Qualitative comments regarding difficult words and items were collected during the pilot interviews and group discussions. The final stage involved establishing a children´s reference group, selected from the primary school, to generate alternatives for problematic phrases and words. This led to the generation of a list of standardised explanations. As a final step the list of standardised explanations were reviewed by an external academic familiar with the SDQ to ensure that the explanations did not deviate from the original item. These explanations did not replace the pen and paper versions of the SDQ which were administered to the participants as recommended (www.sdqinfo.org), but rather served to provide verbal support which could be used by interviewers to clarify or elaborate on specific questions. Standardised explanations meant that all interviewers would provide the same explanations to problematic items. For example, during pilot interviews, many interviewees indicated that they did not understand the term "lose my temper" for item x ("I get very angry and often lose my temper"); one participant indicated that it meant that "I just need to be quiet". Many children were also not familiar with the word "often". After discussion with the reference group, the following standardised explanation was added: "I get very angry and I lose control of myself a lot. I lose control of myself many times." Further, examples of this process are included in Appendix 3.6. The full list of standardised explanations is included in Appendix 5.6.

Apart from semantic difficulties, previous research in low resource settings (van Widenfelt et al., 2005) have shown that participants may also have difficulty completing questionnaires if they were not familiar with the response formats employed. This was therefore explored in the pilot interviews and the group discussions. It was found that some participants had difficulty interpreting the response format and often needed further explanation. Furthermore, participants also found the instructions of the impact supplement quite long and difficult. For this reason, in order to ensure ease of administration, a simple practice example was included before administering the SDQ (Figure7), and visual aids were introduced to facilitate understanding of the impact response categories (Figure 8). The Cronbach's α scores in the final study improved on the total difficulties and all the subscales suggesting the addition of standardised explanations, practice example and visual aids were helpful in improving the comprehension of the SDQ (see Chapter 3).

The next part is about children´s Strengths and Difficulties. We are going to read some questions together. Think about yourself and say if it´s "Not true" "Sometimes true" or "Certainly true". Some words might be difficult. If there is a difficult word, please tell me which word so that I can explain it to you. Let´s do one example together:

"I like sweets"

Think about yourself. Do you like sweets?

- If you do not like sweets then you would mark "No" or "Not true"
- If you sometimes like sweets then you would mark "Somewhat true"
- If you like sweets then you would mark "Yes" or "Certainly true"

Not true or No	Somewhat True (This is like Sometimes or In the middle)	Certainly true or Yes
☐	☐	☐

Figure 7 SDQ practice example

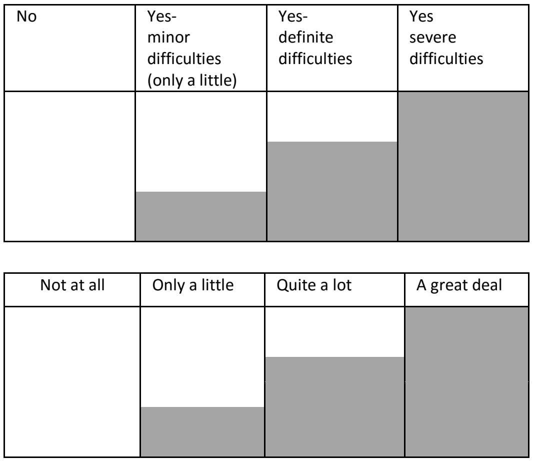


Figure 8 Visual aids for the SDQ impact supplement

2.5 Summary and conclusions

The aims of the qualitative phase were to provide a list of the factors implicated in mental distress and also to gain a deeper understanding of how mental distress is understood in the local context. This phase helped established the semantic equivalence of the items of the SDQ, after the initial qualitative phase established that the symptoms are expressed. However, a larger and more representative study will need to confirm that it is more widely applicable. Quantitative methods supported this, but also identified specific items that may be problematic due to comprehension difficulties.

This pilot study was valuable in suggesting areas where comprehension of SDQ could be improved prior to the main study. The quantitative pilot study showed that

- The overall scale (total difficulties) of the SDQ showed an acceptable reliability of just under 0.70 (Cronbach's α).
- However the 5 subscales were not as strong. The subscale with the highest reliability was the "emotional symptoms" which showed a reliability of 0.51.

This pilot phase allowed us to take into account the contextual and cultural facets in understandings of key variables, especially mental health (Canino, Lewis-Fernandez, & Bravo, 1997). In the light of these findings, a decision was made to retain the SDQ as the instrument, particularly the total difficulties scale, and to retest the reliability of the subscales after the main study for improvement. While effort was made in this study to take into account local constructions of mental health, the decision to use the SDQ needs to be considered in the context of the general criticism against the use of standardised measures in contexts of cultural and social diversity. The next section describes the methodology for the main study.

CHAPTER THREE: RESEARCH METHODS

The review of empirical studies in Chapter one highlighted the limited data available on mental health in HIV-positive children and adolescents, particularly in sub-Saharan Africa, whereas Chapter two showed the limited data on child mental health in Namibia. A quantitative methodology was selected to answer the research questions outlined at the end of Chapter one as the fundamental approach which allows the researcher to collect data that can be generalized from a sample to a population, useful in the light of limited mental health data. Secondly, the approach allows one, amongst other things, to assess the relationships among variables (Kazdin, 2003). This allows us to assess the effects of certain variables (microsystem and macrosystem) on other variables (mental health outcomes) at a specific point in time. A case-control design was adopted to assess the specific effects of HIV status on mental health and to conduct comparisons between HIV-positive adolescents and adolescents who are not known to have HIV (Kopec & Esdaile, 1990). Comparison groups were found to be lacking in mental health research with HIV-positive adolescents in sub-Saharan Africa. The design can also be described as observational or non-experimental.

In this chapter we describe the quantitative methods employed to test the study objectives outlined at the end of Chapter one. Data collection for the main study was conducted after the completion of the pilot work, from July 2013 to March 2014. The case-control design compares two study groups, in this case an HIV-positive group and a community control group. Participants were selected from two study sites: the HIV group from a hospital setting and the comparison group from four local schools in the study area.

3.1 HIV-Positive group

Participants in the HIV group were accessed from the Paediatric ARV clinic of the Katutura State Hospital, located on the outskirts of Katutura in Windhoek (Appendix 1). Katutura, an area designated to the black community during Apartheid, still suffers from hugely inadequate services and participants using the state hospital are mainly from low socio-economic backgrounds.

All patients attending the paediatric ARV clinic are seropositive, having predominantly (>90%) been infected via mother to child transmission (Dr. N. Rukato[4], personal communication, 12 October 2012). Participants were included in the HIV group if they satisfied the following criteria:

- They knew their HIV status.
- They were within the 12-18 age range.
- They spoke English.
- Their parents/guardians provided written informed consent for participation.
- Participants provided written informed consent that they agreed to participate.

Participants were excluded if they were unable to complete the questionnaire due to mental or cognitive difficulties (based on medical provider clinical judgement).

Sample size

The clinic services approximately 700-800 active paediatric patients between the ages of 0 and 19 (Cox & Siseho, 2011). Clinic records showed that approximately 194 participants were eligible for participation at the time of the study (June 2013). Table 9 shows that about 51% if eligible participants at the clinic were female and that just over half of the participants (n = 100, 51.5%) were in the 12-14 age group. The statistical programme GPower 3.1, developed by Erdfelder, Faul and Buchner in 1996, was used to determine the required sample size for this study (Faul, Erdfelder, Lang, & Buchner, 2007).

Table 9 Age and gender composition of eligible participants

	Age range			
	12-14	15-16	17-18	Total
Females	48 (48%[a])	30 (55.6%)	21 (52.5%)	51%
Males	52 (52%)	24 (44.4%)	19 (47.5%)	49%
	100	54	40	

[a]Percentages within the column

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[4] Dr Nguni Rukato is the medical doctor at the paediatric ARV clinic and this information was communicated during one of the Key informant interviews.

The study compares two groups and the effects of various predictors on mental health. Based on a General Linear Model involving six predictors and working at a 0.05 level of significance, it was estimated that a minimum of 98 participants per group was sufficient to obtain power of 95% and to detect a small effect (0.15 effect size) (Appendix 7.1).

3.1.1 Recruitment and data collection procedures

Although all 194 participants were eligible, it was not possible to obtain a list of names from which to randomly select participants due to confidentiality concerns. A recruitment procedure was developed in consultation with the ARV paediatric clinic staff. After a patient has been judged as stable, their follow-up appointments are scheduled once every three months. It was decided that clinic staff would inform participants about the study during this routine follow-up. At this appointment the medical doctor or nurse briefly explained the research to eligible participant(s) and their caregiver(s) and provided information forms (Appendix 5). Interested participants/caregivers were invited for an information session with a member of the research team. Where caregivers were not present, information and consent forms were sent to them via the participant, including the contact details of the researcher. Participants were approached until the required sample size was obtained. Only participants who had gone through all the stages of HIV status disclosure were approached to take part in the study. An additional recruitment process was conducted with the support group for adolescents who know their HIV status. With the permission of its members, I visited one session of the support group to explain the research, provide information sheets/ consent forms and answer any questions or concerns. Participants could return the forms at the next follow-up appointment.

Once parental/caregiver consent was obtained and participants agreed to be interviewed, an appointment was set for the interview. Where possible, appointments for interviews were scheduled to occur the same day as the clinic appointment, so as to minimise the number of visits participants had to make to the clinic. A protocol was developed to deal with missed appointments and non-attendance. Once an adolescent missed two scheduled appointments, the researcher would no longer contact them. In total 138 participants were approached of which 99 completed interviews, representing a participation rate of 71.7% (Table 10).

Table 10 Participation rate for the HIV group

	Frequency	**Percentage**
Participants interviewed	99	71.7%
Incomplete interviews[a]	8	5.8%
Participants who declined	12	8.7%
Lost to follow-up[b]	10	7.2%
Number unreachable/wrong contact details/not legible	9	6.5%
Total	138	100%

[a] Uncertain whether participant had been disclosed their status, Language difficulties

[b] At least two missed appointments or participant did not return calls or messages

Thirty-nine participants did not complete the interviews, of which 12 participants (8.7 %) declined, 19 participants (13.7 %) could not be obtained for interviews (either because of missed appointments, unreturned calls or incorrect contact details) and eight interviews were terminated due to suspicion that the participant had not been disclosed their status (n = 4) or due to intellectual and language difficulties (n = 4).

Interviews were conducted by the main researcher (S Gentz) and three research assistants, fourth year Bachelor of Psychological Counselling students (BPsych) recruited from the Psychology Department at the University of Namibia (UNAM). Psychological counsellors in their fourth year have already received training in counselling skills and working with PLHIV. The questionnaire (Appendix 5.3), described more fully in section 3.3, was administered in one sitting. Before the questionnaire was administered, participants were given time to read the information sheets and consent forms after which they were asked a few short questions to assess their comprehension. The questions included: “From what you have read can you tell me what is the study about?”, “What will happen if you decide that you do not want to take part in the study?”, “Will what we talk about be kept private?”, “Do you have any questions before you sign the form?” Researchers used this opportunity to reinforce situations where privacy may be broken. This introduction also allowed the research assistant to get an idea of the participants reading ability (for administering the SDQ). It was found that this section also enhanced rapport between the interviewer and participant. When it was determined that the participant understood the process and signed the consent form the questionnaire was administered in a face to face interview format. Pilot interviews demonstrated this to be the most effective and efficient format. A self-report method was found in the pilot interviews to be more time consuming and fatiguing especially for younger participants and slow readers. However, since the face to face format may offer less privacy, the SDQ and HIV-related stigma questionnaire were completed by assisted self-report. Sensitive questions were placed towards the latter sections of the questionnaire, to allow for rapport to develop. Furthermore, putting non-HIV questions first ensured that comparability of administration sequence between the control group and HIV group. The questionnaire was administered in a private space where interruption was minimised. Although the administration occurred in English, where clarifications were necessary they were sometimes provided in the local dialect of the participant. With the SDQ, standardised translations were provided in Oshiwambo and used when required.

A short debriefing session was conducted at the close of the interviews to assess the need for follow-up or referral. In all cases, participants were provided with a list of referral agencies and their numbers. While no incentives were given, participants received a snack consisting of an energy dense bar, a fruit and a fruit juice. In addition, taxi money was provided for each participant and caregiver (equivalent of 2Euros/person).

Protecting participants from unintended disclosure: One of the concerns was that participants who had not known their HIV status may inadvertently be referred for the interview. For this reason, before beginning the HIV section of the questionnaire, all participants were asked a few open ended questions to ascertain whether they had been disclosed and also to assess the level of comfort they felt about talking about their status. These questions included: “Why did you come to the hospital?” “Have you ever heard about the support group?” The clinic uses a structured disclosure procedure developed by the MoHSS in collaboration with a local non-governmental organisation (NGO), the International Training and Education Centre for Health. The disclosure process includes the application of a disclosure booklet “Why I take my medication?” (Appendix 6.2). The book, which contains cartoons, is made up of five chapters taking children from six years of age through the various stages of disclosure (O’Malley et al., 2015). Interviewers also had a copy of the disclosure booklet and, without going into the content of the book, asked participants whether they had ever discussed the book with their doctor. The booklet was found to be an especially useful resource as it put the participant more at ease and also guided the interviewer as to the most appropriate vocabulary to use with each participant. In total four interviews were terminated as it could not be established that the participants had been disclosed their HIV status.

3.2 Comparison group

The comparison group consisted of adolescents who are not known to be HIV-positive. In a case-control design, the control group should match the study group in terms of age, gender and socio-demographic background (Wacholder, Silverman, McLaughlin, & Mandel, 1992). Selecting participants for the control group directly from the hospital setting where HIV-negative status could be ensured, was discarded due to the difficulties of matching for age and gender. Furthermore, there would be less motivation for participants or caregivers selected at testing centres to participate in the research and this expected high refusal rate would potentially add bias to the case-control design (Kopec & Esdaile, 1990). Interviews and discussions with medical staff at the Paediatric clinic indicated that most of the patients using the clinic live and/or school in Katutura. The comparison group was therefore selected from schools in this geographical area, and had the same inclusion criteria as the HIV group, apart from their HIV status.

Sample size

Apart from the GPower calculations outlined in the previous section, sample size guidelines specific to case-control designs were also considered. Wacholder et al. (1992), for example, recommend a one to one ratio to the case group, when determining the size of the control/ comparison group. Others recommend that the researcher enrol more than one control participant for every case, in order to increase the power of the study (Lewallen & Courtright, 1998). However, “there is little gained by adding more than two controls per case” (Lewallen and Courtright, 1998, p.58). The target for the control group was therefore set at 150-200 participants or 1.5 to two times the size of the case group. Participation rates for classroom-based research efforts vary widely from as low as 40% to 80% (Fletcher & Hunter, 2003). Our pilot research in schools indicated return rates of about 72% (82% for primary schools and 64% for high schools). Based on the estimated average return rate of 70%, it was necessary to target between 214 and

285 learners. Furthermore, as the pilot phase indicated that return rate from primary schools were higher, proportionately more learners were targeted in secondary schools. Sampling for the comparison groups was conducted in three stages:

Stage 1: A list of all schools in the Katutura area with the number of learners in each school (obtained from the Ministry of Education) was stratified into primary (19 clusters) and secondary schools (five clusters). The lower number of secondary schools may be attributed to the high number of learners that leave school particularly in grades eight, nine and ten (Ministry of Education, 2012). From these lists, three primary schools and three high schools were selected using a random number generator and using probability proportional to size. One school in each group was a back-up in case any school declined participation.

Stage 2: Statistics for Khomas Region showed that eligible learners for the lower age range (12-14) were in Grades 5 - 7 and eligible learners for the upper age range (16-18) were in Grades 8-12 (Ministry of Education, 2011). Khomas school statistics were used to estimate the ages due to the high learner repetition rates. In each school, 3 - 4 classes were randomly selected from the list of eligible classes.

Stage 3: A list of learners with their ages and genders were obtained for each selected class. Learners were selected randomly from this list, matching age and gender characteristics of the list of eligible participants from the clinic (Table 11). Cluster sampling was selected as a quick, cost-effective and practical technique which would cause less disruption to participants and participating schools. Selection from four different schools and the random sampling of learners at stage three increased the chances of having a more diverse sample. From Table 11 we can see that, although the return rate was higher than expected (78.4%), participant refusal (*n* = 13), unsuitableness (*n* = 12) and practical difficulties at two schools preventing the completion of interviews (*n* = 19), meant that the final sample size was 159.

Table 11 Participation rate for comparison group

	Eligible	Return rate (%)	Refusal (%)	Unsuitable[c]	Practical difficulties[d]	Final participation
School 1[a]	90	74 (82.2%)	8 (10.8%)	2	13	51
School 2[b]	50	45 (90%)	0 (0%)	6	0	39
School 3[a]	68	42 (61.8%)	2 (4.8%)	2	6	32
School 4[b]	51	42 (82.4%)	3 (7.1%)	2	0	37
TOTAL	**259**	**203 (78.4%)**	**13 (6.4%)**	**12**	**19**	**159**

NOTE: [a]High school; [b]Primary school

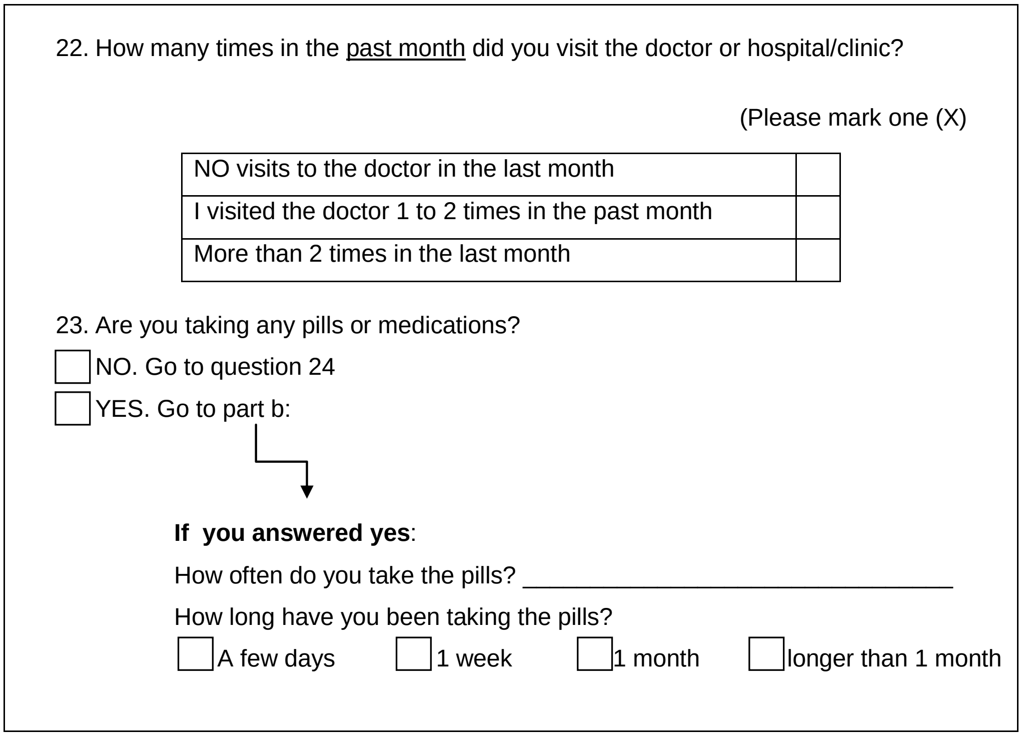
[c]Eight cases were determined as potential HIV cases by proxy questions (see below) and four cases did not meet the age criteria as they had turned 19 by the time of the interview

[d]Unable to complete interviews due to exam and scheduling difficulties

3.2.1 Recruitment and data collection procedures

Recruitment with participants at schools occurred simultaneously to the HIV group. Identified participants met with the research team to discuss the main aspects of the study, allow participants to ask questions and hand out consent and information sheets (Appendix 5). Once consent forms were returned, interview days were set in consultation with the life-skills teachers at each school. Each school provided a private space where participants could be interviewed. The same interviewing procedure was applied as with the HIV group, the only difference being that the section containing the HIV questions (Section 2) was omitted and screening questions were included to determine youth's awareness of their HIV status.

Determining HIV status in the comparison group: The comparison group should differ from the case group in not having the selected "exposure condition" (Schultz & Grimes, 2002), in this case being HIV-positive. While the surest way of determining HIV status would be to conduct an HIV test, the feasibility and costs associated with testing HIV samples within the limited study budget was not possible. Furthermore, exposing participants in the comparison group to the blood analysis is difficult to justify, particularly since the interviews were conducted in school settings. Therefore it was not possible to determine HIV status through testing.



22. How many times in the past month did you visit the doctor or hospital/clinic?

(Please mark one (X))

NO visits to the doctor in the last month	☐
I visited the doctor 1 to 2 times in the past month	☐
More than 2 times in the last month	☐

23. Are you taking any pills or medications?

☐ NO. Go to question 24

☐ YES. Go to part b:

If you answered yes:

How often do you take the pills? ________________________________

How long have you been taking the pills?

☐ A few days ☐ 1 week ☐ 1 month ☐ longer than 1 month

Figure 9 Proxy screening questions for HIV status

Owing to the stigma surrounding HIV and the sensitivity attached to talking about HIV, particularly in a school setting, it was neither possible nor reliable to ask learners about their HIV status. Due to these difficulties, the possibility of determining HIV status through a series of proxy questions was considered in consultation with stakeholders working with adolescents living with HIV (including medical doctors and NGO staff). Since no precedent could be discovered in the literature at the time, a list of questions was developed, centring on hospital and doctors' visits and medications (Figure 11). One stakeholder raised concern that adolescents living with HIV may be reluctant and unwilling to disclose that they are taking medication. This should be taken into account in the findings. These proxy questions resulted in the exclusion of 8 cases, predominantly on the basis of taking medication twice daily for longer than a month.

Potential biases in the selection of the comparison group

Using only proxy questioning, it is impossible to absolutely determine the known HIV status of participants in the comparison group. It may also be that participants who know their status as seropositive are not any treatment regime. Since the proxy questions focus on treatment (number of visits to medical facility, medication) there would be no way of detecting these adolescents that are not receiving treatment. With this method, there was also chance that participants taking medication or attending regular clinic appointments for other medical conditions may be excluded from the study. However, this was necessary in order not to inadvertently include participants who may be living with HIV. Many participants taking medications often volunteered the reasons for the medications, for example, the medications are "painkillers and antibiotics" or "flue medication". Furthermore, responses about timing and length of time on treatment ("I only take them when I feel sick"), "I only take them some days" provided additional information on whether to exclude the participant.

3.3 Ethical issues and concerns

This study has been approved for ethics by the Institutional Review Board of the *Universidad Complutense de Madrid,* and three Namibian ministries: Ministry of Health and Social Services, the Ministry of Education and the Ministry of Gender Equality and Child Welfare. Approval letters are included in Appendix 2. Approval from the *Universidad Complutense de Madrid* was a requirement for PhD studies and was necessary prior to applying for approval at Namibian Institutions. Permission to interview participants from the paediatric antiretroviral (ARV) clinic was obtained from the Namibian Ministry of Health and Social Services, to access and interview participants from school permission was obtained from the Ministry of Education and to access participants from children's homes permission was obtained from the Ministry of Gender, Equality and Child Welfare (Appendix 2).

The ethical protocol described below was developed after reviewing key protocols for ethical procedures with vulnerable children, including guidelines for biomedical research (The Council for International Organizations of Medical Sciences, 2002), International guidelines for working with vulnerable children by Family health international (Schenk & Williamson, 2005), Namibian professional ethics guidelines (Health Professionals Council of Namibia, 2010) and ethical guidelines used in previous studies with vulnerable children in sub-Saharan Africa.

Informed consent

Informed written consent was requested from both caregivers and participants. All children and parents/caregivers were provided with information sheets describing the study, the procedures involved, the approximate time taken and that their participation was voluntary and could be terminated at any time without negative consequences (Appendix 5.2). Participants were assured that refusing participation would not mean that they would not receive services. Interviewers ensured that prospective participants understood the possible risks and benefits that may result from taking part in the project, including that they would not receive individual feedback. To take into account literacy levels for guardians, caregiver consent forms were a reading level of Grade 4.3 and participant consent forms were at a Grade 5 reading level. In addition caregiver consent forms were translated into both Oshiwambo and Afrikaans. Since the official language at schools is English, participant consent forms were only provided in English. In total 25 participants declined to take part, 13 for the comparison group and 12 from the HIV group.

Confidentiality and anonymity

Confidentiality was promised to all participants, except when a child was shown through the research to be at risk (see protocol below). For the HIV group, to protect confidentiality of the participants from the stigma associated with HIV, interviews were conducted in a private and quiet space at the Hospital, but removed from the actual clinic. At the school settings, all interviews were conducted in a private space, mostly in the counselling room of the life skills teacher or an unused classroom. Procedures for protecting adolescents living with HIV at the hospital from unintended disclosure have been outlined in the previous section.

As soon as interviews were completed, the questionnaire responses were anonymised with the selection of a numerical reference code. The questionnaires and the consent forms were linked by this reference code. In reporting the findings of this study, names are omitted and only the locations which the study took place are mentioned. Data were stored in an anonymised version; with the numerical reference code. Only the principal researcher (S Gentz) knew the names to which the codes refer. Original questionnaires were stored in a safe space, and after data entry were stored in sealed boxes in a locked room.

In research, especially with potentially vulnerable children, there is always a small possibility that participants take the opportunity to disclose difficult living circumstances. It is recognised that researchers have a responsibility toward participants who may disclose information that shows them to be at risk. The following protocol, used in previous studies with AIDS-affected children in South Africa (Cluver et al., 2007), guided decisions about participants discovered to be at risk:

1. All participants were informed at the consent stage that everything said will be confidential unless it becomes clear that they are at risk of significant harm.
2. If information was disclosed that suggests that the child is at risk of significant harm, the researcher discussed the concerns with the child at the end of the interview.
3. In this case and with the child's consent, the caregiver would then be informed (unless this is thought to put the child at risk) and the interviewer would discuss the possibilities for referral to appropriate services, etc. If the child does not consent to sharing of information, and the harm was not considered to be significant, the child was given information about self-referral agencies. However, if the harm was considered to be significant the researcher would consult with social services or other organisations. If the decision is made to take action, the participant(s) were informed

Training of the research assistants

Interviews for the main study were conducted by the lead researcher, who is a clinical psychologist, and three research assistants. Research assistants (Fourth year Psychological Counsellor students) received full training in all aspects of the study procedures, the ethical considerations including informed consent, anonymity, confidentiality and privacy, and doing no harm, particularly as they apply to working with vulnerable children. The importance of maintaining a supportive and encouraging approach and avoiding moral judgement was also emphasized. As part of the training, each research assistant observed an interview conducted by myself for both a comparison group and HIV group participant. Thereafter, I observed each research assistant conduct an interview for each group. In addition, bi-weekly supervision was conducted to ensure quality of the interview protocol and also to provide support to the research assistants. Research assistants were also required to sign statements agreeing to protect the security and confidentiality of identifiable information.

Potential Benefits

The findings of the study will not be of direct benefit to participating children except in the long run as it will provide information to inform programme and policy development. The MoHSS research policy states that findings and recommendations are to be reported to the relevant Ministries (MoHSS, 2003). Preliminary findings and recommendations have been presented to stakeholders and local NGOs working with adolescents living with HIV, paediatric clinic staff and Development Partners for their consideration for programmes and policy development (n =8). In addition, an adolescent friendly presentation was given to interested adolescents living with HIV at the ARV clinic (n = 12). The research has also been presented at local and international conferences.

No financial incentives were provided in this study. Participants and caregivers were provided with a stipend to cover transport costs (value = ±2Euro/person) as well as a snack consisting of nuts, an energy dense bar, a fruit and fruit juice.

Potential Harm

No invasive medical procedures were necessary in this study as only adolescents with a previously confirmed HIV diagnosis were included in the HIV group. Furthermore, HIV-negative status was determined by proxy questions for the comparison group.

It was necessary to minimise the potential emotional distress produced by some sensitive questions. For example, adolescents living with HIV were asked questions around their HIV diagnosis and about their experiences of stigma. Furthermore, all children were asked about additional life stressors. Interviewees needed to be aware that participants may experience negative emotions such as guilt, shame or embarrassment. While these feelings may be considered normal and understandable, it was necessary to ensure that they were transitory and did not produce psychological harm (Kassam-Adams & Newman, 2002).

In order to maximise a safe and empathic space for interviewees, the following protocol was applied:

- Only psychological counsellors trained to offer counselling were used as research assistants.
- Prior to the start of data collection, connections were established with relevant government ministries, local NGO's and other service providers informing them about the study and enquiring about the services offered. For example, Lifeline\Childline, a local NGO's, offers psychotherapy and counselling to socio-economically disadvantaged children and adults needing clinical assistance. At the end of each interview all participants that took part in the study were provided with a list of referral points, if they did not want to discuss their difficulties with the research team.
- The research team offered participants in the HIV group the option to come for a follow-up appointment on a specified day at the hospital. The primary aim of this appointment was to provide a space to facilitate referral and to deal with any emotional response that may have come about from the interview. Since the hospital setting is familiar, it was felt that it would be easier for participants to come to this setting for initial help and assessment. For a child that would not otherwise have been able to discuss their concerns and be offered help, this counselling was likely to be of benefit.
- At the school settings, the life-skills teachers were consulted as to the best place to conduct the interviews. Participant who showed distress could be referred to the life-skills teachers for counselling.
- As part of this process it was also necessary to be aware that working with distressed and vulnerable populations may elicit strong feelings in interviewers, including feelings of helplessness or guilt at asking difficult questions (Derry & Baum, 1994). Ongoing supervision with the lead researcher, a clinical psychologist, was essential to deal with these experiences.

3.4 Instruments

A structured questionnaire was developed to assess child mental health outcomes and the selected risk and protective factors that may influence child outcomes. Risk and protective factors were based on a review of the literature (Chapter one) and focussed on understanding which factors play a role in child distress in sub-Saharan Africa and specifically in Namibian children and adolescents living with HIV. Furthermore, the group discussion and key informant interviews (Chapter two) with Namibian children and informants working with vulnerable children in the Namibian context provided further support for the selection of specific risk and protective factors. Finally, the decision was influenced by the ability to find suitable instruments as well as their feasibility to assess particular factors within the Namibian context. For example, the literature review identifies caregiver/maternal HIV status as an important factor for predicting mental distress in children. In our case, we did not include this variable, as it would have been impossible to ascertain the HIV status of caregivers of the comparison group with the selected study design. Pilot interviews, in which the instrument was tested, were also important to guide the inclusion of certain variables.

3.4.1 Pilot interviews

Pilot interviews with adolescents were incorporated to optimize the procedure (e.g. administration time) as well as the appropriateness and comprehension of the proposed instruments. These interviews (n = 20) were conducted in addition to the pilot phase discussed in Chapter 2. Fifteen pilot interviews were conducted very early in the process (7 in March 2012 and 8 in November 2012). These interviews allowed us to refine the procedure, to determine the order in which the interviews should be administered, to test the ease of the recruitment process and feasibility of the inclusion criteria for the HIV group. It also helped us to refine some of the risk and protective factors. A final round of interviews (n = 5) were conducted again after the completion of the quantitative phase of the pilot study (June 2013), mainly to focus on identifying problematic items for the SDQ and to assess the HIV sections of the interview protocol.

The initial pilot interviews (2012) allowed for the identification of specific questions that participant did not understand or know (see Instruments for specific examples). Furthermore, while violence, including domestic and family violence, community violence and sexual violence, as well as bullying were identified as important risk factors for mental distress in the group discussions and key informant interviews, these pilot interviews indicated that asking children about these sensitive topics in addition to the potentially sensitive topic of HIV would be an additional burden, particularly for the HIV group. As such, only two questions on family violence were included. Finally face to face interviewing was more effective, as opposed to self-completion of questionnaire. Self-completion took longer and, with self-report, questions were sometimes skipped or instructions misread. Most children were not familiar with certain testing procedures, such as completing check boxes. Reading difficulties also contributed to these problems. Assisted self-report was included only for sensitive sections (mental health tool and HIV stigma questions) where participants may benefit from privacy. Key informant interviews with the medical staff supported the decision not to do self-report.

3.4.2 Final Instrument

The following variables were assessed with the final version of the questionnaire (Appendix 5.3):

Outcomes: Mental wellbeing (emotional and behavioural symptoms of distress)

Mental health was assessed with the SDQ (Goodman, 1997). The SDQ was developed by Dr Robert Goodman from the Department of Child and Adolescent Psychiatry in King´s College, London and consists of a 25 item behavioural screening questionnaire covering the following components: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and prosocial behaviours (See 2.3.2). See chapter two for the pilot phase to examine the psychometric properties of the instrument.

Internal consistency, as assessed by Cronbach's alpha co-efficient showed improvement from the pilot study for the "Total difficulties" score and also for all the subscales. For the SDQ the final Cronbach alpha scores were acceptable for the Total Difficulties ($\alpha = .71$), emotional symptoms ($\alpha = .57$) hyperactivity ($\alpha = .51$) and prosocial behaviour ($\alpha = .52$). Cronbach's alpha was low for conduct problems ($\alpha = .49$) and peer problems ($\alpha = .32$).

Risk and protective factors

Basic demographic and background variables: A number of demographic variables were assessed. These included age, gender, home language and residential suburb.

Caregiving, orphanhood and bereavement factors: Participants were asked to identify their primary caregiver which was defined as the person who ‘stays with you at home and is mainly responsible for you. Parental bereavement as well as the age at which bereavement occurred was assessed. If the biological parent was alive and not living with the child, this was also recorded.

Educational variables: Educational variables included current school, current grade and whether any grades were repeated.

Health status: All participants were asked the number of visits they had made to the doctor in the last month, whether they ever had tuberculosis and the number of days missed from school due to illness. With permission from parents and the MoHSS, specific health indicators for the HIV group were accessed from the medical records, including date when antiretroviral therapy (ART) was initiated, WHO clinical stage, viral load and CD4 count at the last blood analysis.

Access to medical and psychosocial services: Participants were asked the number of visits they had made to a doctor or medical facility in the last month, as well as whether they had accessed any other types of psychosocial services: such as a psychologist or social worker, a life-skills teacher, teen support groups etc. Cognitive interviewing during pilot interviews demonstrated that asking participants to recall for periods longer than one month was too demanding especially for younger children. Participants in the HIV group were asked whether they attended the hospital support group or any other HIV-related support services.

Economic factors, poverty and deprivation: Due to challenges in assessing actual household income, poverty in this study was assessed using various related indicators of deprivation found relevant in other studies and local research (Cluver et al., 2008b; Namibia Statistics Agency, 2012b). Pilot testing helped to isolate and assess the reliability of indicators for the Namibian context.

For example, while parental education level has been found to be a consistent indicator of mental health (V. Patel & Kleinman, 2003), this indicator was removed as pilot work showed that many adolescents could accurately report their parents’ educational status. A study with vulnerable children in Ghana also reported a high rate of missing data for this indicator, as well as a large discrepancy between parent and child reports of parental education level (Doku, Koivusilta, & Rimpelä, 2010). Whether or not the family was receiving a social welfare grant, was also removed as pilot work showed that many children reported that they did not know this information. Indicators of poverty included in the final questionnaire were household employment, household assets, food security and dwelling/housing information.

- Household employment was assessed by asking whether any person in the household was working.
- Household assets were assessed through and asset index. This method has been applied to Demographics and Health surveys and other large scale child studies (Booysen, van der Berg, Burger, von Maltitz, & du Rand, 2005; Cluver, Fincham, & Seedat, 2009; Doku et al., 2010). The approach assesses the presence of a number of different assets/materials. The list of assets used in this study was taken from the Namibia Household and Income expenditure Survey (Namibia Statistics Agency, 2012a) which includes: radio, television, refrigerator, telephone/cell phone, stove, motor vehicle, bicycle and electricity. After the quantitative pilot study (see Section 2.3), telephone and bicycle were removed as they were found not to be relevant indicators for urban households. Most urban households in the pilot study owned a telephone and a bicycle is more relevant as an asset in rural regions. These items were replaced by three child relevant items: two items from the OECD Programme for International Student Assessment (2009) questionnaire: "ownership of books" and "a desk to study" and one item from a larger study on vulnerable children in southern Africa: "enough clothes to keep you warm and dry" (Cluver, 2007). The asset index had an acceptable alpha (α=.68).
- Food security was assessed by asking participants the number of days they went to bed hungry in the last 7 days (Cluver, 2007) and whether they had breakfast in the morning. The importance of this indicator was substantiated in the quantitative phase of the pilot study.
- Type of dwelling (informal/formal) and number of children and adults who live in the house (indicator for overcrowding).

Access to education/schooling was not used as previous research with adolescents at the paediatric clinic showed that 98.5% of adolescents were in school and 1.5% in tertiary education (Siseho, 2011). Pilot interviews indicated that most adolescents (99.6%) in an urban area had access to clean water. This is supported by data which shows that 99% of urban households in Namibia have access to piped water (Namibia Statistics Agency, 2012b).

Social support: The presence and amount of perceived support (instrumental, emotional, informational and recreational) was examined in the caregivers and peer Microsystems. Participants could also choose one additional person which they perceived as providing important support. The questions are an adaptation of the Social Support Scale (Seidman et al., 1995) and have been previously used in a study with AIDS orphans (Cluver et al., 2009).

The adaptations made in the study by Cluver et al. (2009) were retained in the present study. These include changing “mother” or “father” with caregiver and putting together the categories of “kids you own age” and “your group of close friends”. Furthermore, the categories of “siblings”, “teacher/principal” and “community” were collapsed into one category and participants were given the option of choosing who of these people “were helpful in their lives”. This was to simplify the scale as pilot interviews showed that it was quite fatiguing for participants. The scales that were collapsed: teacher/principal and “siblings” were also the ones that showed the lowest internal consistency in previous research (Cluver et al, 2009).

Each of the microsystems was assessed for support in the dimensions of instrumental, emotional, informational and recreational[5] on a three point Likert-scale (not at all/sort of/very). Similar aspects of social support were included in a study with Namibian youth (Ruiz-Casares, 2010). The scale produces a global score of perceived social support as well as scales of scores for each group: caregivers, peers and perceived supportive other.

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[5] Pilot work showed that youth distinguished between “emotional support” and “advice/information”. It was therefore decided to separate, the category of “helpful when I have a personal problem” into “gives advice/information” and “understands me and listens to me”.

Cluver et al. (2009) report a reliability of 0.76 in their study with AIDS orphans. In the current study, an acceptable reliability was obtained for the Total scale (α = .71) and also for the caregiver (α = .58), friends (α = .59) and other persons scales (α = .75).

Other indicators of support: Participation in age and context appropriate activities (sports, church or youth groups) was also assessed as well as participant satisfaction with support received from family and friends.

HIV-specific support: In addition to the above, HIV-specific social support was assessed for participants in the HIV group. Instrumental support was assessed by asking participants about the support they received for attending clinic appointments and the support they received in adherence to their ARVs. Structural support was assessed by asking whether they have friends who know their HIV status and also whether they had any friends who were also HIV-positive. These aspects of support have been assessed in a previous study with adolescents living with HIV (Abramowitz et al, 2009).

Negative family processes[6]: Negative family interactions was measured by selecting specific questions from the Traumatic Events Screening Inventory (TESI- Self Report Revised) (Radcliffe et al., 2007) Participants were asked about domestic violence experiences in the family and whether the particular experience caused them to feel bad, sad or upset. An introduction section from the national Primary Schools' violence survey in South Africa (2007) was added to normalise and reduce possible stigma that a child may feel reporting family violence (Cluver, 2007).

HIV disclosure and adherence: Participants in the HIV-positive group were asked details of when they were disclosed their HIV status, including the age of disclosure and the person who disclosed their status to them.

Measuring adherence to ART in people living with HIV is a major challenge (Simoni et al., 2007). Self-report measures of adherence are the most widely used and practical way to assess

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[6] This data was not included in the final analysis due to lack of variability.

adherence and have been used with adolescents in sub-Saharan Africa in Nigeria (Iroha et al., 2010) and Botswana (Tippett Barr, 2006). In these studies, participants were asked to recall the number of doses missed in the last three days. After consultation with medical doctors working with adolescents living with HIV, the numbers of days were extended to 7 days, as service providers felt that it would be important to include both week days and week-ends. Participants were asked: “How many times in the last 7 days have you forgotten to take your ARV medication?” in order to not stigmatise forgetting behaviour. Complete adherence will be defined as taking all doses of ARV medication in the previous seven days. With permission from the MoHSS, the above self-report measure of adherence was combined with provider adherence as recorded by the medical doctor in the participants’ medical file, recorded for the preceding month as “poor”, “fair” and “good”.

HIV & AIDS related stigma: Experience of stigma in HIV-positive persons has been linked to negative mental health outcomes (Betancourt et al., 2014; Logie & Gadalla, 2009; Rongkavilit et al., 2010; Tanney et al., 2012; Wright et al., 2007) and stigma was found to be pervasive in Namibia (Baxen & Haipinge, 2015; Edusector AIDS response Trust, RAISON Namibia and TAMASHA Tanzania, 2008). Stigma experiences were assessed with a shortened version of Berger´s HIV stigma scale (Berger et al., 2001). The 10 item scale, which was an adaptation for adolescents from the original 40 item version, assesses the following domains:

- personalized stigma (“I have lost friends by telling them I have HIV”),
- disclosure (“I worry that people who know I have HIV will tell others”),
- negative self-image (“I feel that I am not as good a person as others because I have HIV”) and
- public attitudes (“Most people think that a person with HIV is disgusting”).

Adolescents express agreement with particular statements based on a 4-point Likert scale ranging from “strongly agree” to “strongly disagree”. The shortened 10 item scale showed good internal consistency, with Cronbach’s alphas ranging from 0.72 for public attitudes to 0.84 for the negative image, as well as good validity with youth living with HIV in the U.S. (Berger et al., 2001).

For the current study the total scale acceptable reliability (α = .75) was shown to the total scale, the personalised stigma subscale (α = .79), the negative self-image subscale (α = .57) and the public attitudes subscale (α = .59). The disclosure subscale had a problematic internal consistency (α = .14) and analysis were not conducted with this subscale. This subscale consisted on only two items and an item analysis revealed that for one of the items "I am careful who I tell about my HIV status", all participants were in agreement with this by selecting either "agree" or "strongly agree".

HIV status disclosure to others: The disclosure of one´s own status to others is often considered as a proxy measure for stigma and discrimination (WHO, 2007) and can have both positive and negative outcomes (Thoth, Tucker, Leahy, & Stewart, 2014). The following questions are included to assess HIV status disclosure to others: "Have you told anyone about your HIV status?", "Who have you told?", "How did your friends react when you told them?", "If you did not tell your friends, how would they react if you told them?"

Wrap-up and closing questions: In order to provide a platform to include children´s opinions on the type of assistance needed to help Namibian children in general and children living with HIV, participants were asked an open-ended question on their opinions on assisting children in their situation. Two follow-up questions assessed participants' level of distress and whether a debriefing session or referral was required. Firstly, interviewees scanned answers given to key SDQ questions (e.g. "I worry a lot", "I am often unhappy, downhearted or tearful", "Other people my age pick on me or bully me") to determine whether distress was present as indicated by a score of two ("certainly true"). Finally interviewees gave participants a chance to reflect on their experience of completing the interview by asking participants how they felt during the interview.

3.5 Data analysis

3.5.1 Data entry and data cleaning

Data from questionnaires were entered into SPSS version 20.0 for Windows. Each questionnaire was given a unique code to protect the identity of participants. Thus identifying information did not appear on the questionnaires. This unique code linked the questionnaires to consent/assent forms containing identifying information but which were stored, with only the main researcher having access this information. Accuracy of data entry was checked at regular intervals for all questionnaires. After all data were entered, data were checked for errors, irregularities, missing values, duplicates etc., using descriptive statistics/frequencies, scatterplots and histograms.

3.5.2 Data analysis assumptions

The data are mainly analysed using parametric tests and generalised linear models. Parametric tests make assumptions that data are on a ratio or interval scale of measurement, that the distribution is normal, the variance is homogenous and errors are independent. Normality was tested using Shapiro Wilks and by looking for skewness and kurtosis in the distribution. For mental health outcomes, the tests of Shapiro Wilks were significant for peer problems, conduct problems, hyperactivity/inattention, prosocial behaviour scale, impact supplement and also for the social support scales, suggesting that the distributions for these data were not normal.

Levene’s test for homogeneity of variance showed that the following scales had unequal variances: peer problems, caregiver support and friend support. In cases where assumptions for parametric data were violated, we use non-parametric tests (e.g. Mann-Whitney U test, Spearman’s correlation coefficient) to confirm the findings. While it is argued that non-parametric tests have less power than parametric tests, this is only true if the “assumptions of parametric data are met” (Field, 2005, p.551).

Both multiple linear regression and binary logistic regression were used in the analysis. Assumptions were checked following the recommendations of Field (2005) and Martinez Arias (2015). For multiple linear regression:

- Outliers and influential statistics were checked using standardised residuals ensuring that 95% of cases had residuals ±2. Cases with a residual above 3.0 were considered as outliers (Field, 2005). Mahalanobis Distance and Cooks distance were used to check for influential cases using the recommendations of Field (2005).
- Adequate sample size was considered as at least 15 cases per predictor variable.
- Multicollinearity was checked by examining correlations between predictor variables and by examining collinearity diagnostics ensuring that tolerance was not below 0.1

- Normality of the residuals was examined with a P-P plot and histogram of residuals.
- The assumption of linearity was assessed by examining the graph of* ZRESID plotted against* ZPRED as recommended by Field (2005)

Levene's test for homogeneity of variances was conducted for the categorical variables and the outcome variable. In the case of emotional symptoms, the control variable, gender, did not meet the condition for homogeneity of variance. These findings are treated with caution.

For the Logistic Regression model assumptions were examined as follows:

- Linearity of the Logit was tested by running the logistic regression and including the interaction with the continuous predictors with the log of itself (Field, 2005)
- Sample size was at least 20 cases per predictor.
- The assumption of independence of errors was met.
- To examine the presence of multicollinearity, we checked tolerance (not less than 0.1) and the standard errors (not larger than 2.0) (Martinez Arias, Castellanos López, & Chacón Gomez, 2015)
- Outliers and influential statistics: Standardised residuals greater than 2.58 were removed if the predictive power without outliers was improved by more than 2%.
- To examine whether incomplete information could be exerting an influence we examined cross-tabulations of the dependent variable with each of the categorical predictors to ensure that none of the cells had frequency of 0. (Martinez Arias et al., 2015)

3.5.3 Data analysis strategy

The data analysis was performed using SPSS 20.0 for Windows. All inferential statistical analysis was set at a 95% level and was two-tailed, except for hypothesis testing differences in mental health between the two groups. In this case, a one tailed hypothesis was set as the scores were expected to be higher for the HIV group.

Factors were grouped according to demographic factors, poverty level factors, social support factors and HIV-specific variables. For statistically significant findings effect sizes were calculated and using Cohen´s categories for classifying magnitude of effect as small (eta squared

= 0.01, r: 0.1 – 0.29), medium (eta squared = 0.06, r: 0.3 to 0.49) or large (eta squared = 0.139, r: 0.5 to 1.0) (Cohen, 1988). The next section discusses the analysis strategy for each research objective.

Question: **What is the basic demographic composition of the HIV group? Are there any differences between the HIV and comparison group on basic socio-demographic characteristics?**

Basic frequencies, percentages and means with standard deviations are presented to examine the descriptive characteristics of the HIV group for such variables as age, gender and parental loss. To compare the HIV and comparison group on socio-demographic characteristics information was presented as basic frequencies, percentages and means with standard deviation. Group differences were assessed using chi-squared tests, independent sample t-tests or Mann-Whitney U test where appropriate.

Question: **What is the level of mental distress experienced by adolescents living with HIV? Do adolescents in the HIV group experience more mental health problems than the comparison group? What is the association between mental health outcomes and socio-demographic characteristics? Do mental health differences persist independently of basic demographic factors?**

The first step established the level of mental distress experienced in the HIV group. In the absence of Namibian normalised cut-off scores, the recommended cut-offs for each mental health outcome is used (www.sdqinfo.com). Analysis establishes the proportion of adolescents living with HIV who would qualify for significant mental distress.

- For total difficulties, borderline scores fall between 16-19 and abnormal scores >19.
- For emotional symptoms and hyperactivity, borderline scores are from 5 to 6 and abnormal scores from >7.
- For the conduct problems scale a score of 4 indicates borderline and a score >4 suggests abnormal scores.
- For peer problems, scores from 4 to 5 qualify as borderline and scores >5 are considered abnormal.
- Finally, for prosocial behaviour, a score of 5 is considered borderline and scores <5 are abnormal.

Secondly, using continuous scores we assess whether adolescents in the HIV group experience more mental health problems, for each of the mental health outcomes. These were assessed using independent t-test, and confirmed with Mann-Whitney U tests for data that did not meet all the assumptions of parametric data. A one-tailed test was used as the hypothesis tested whether adolescents living with HIV would experience more mental health problems. The first analysis tested the association without controlling for socio-demographic factors.

In the next section analysis we determined whether there was any association between mental health outcomes and socio-demographic outcomes, including age, gender and orphan status. These were assessed using Pearson bivariate correlations, independent t-test, and confirmed with Mann-Whitney U tests for data that did not meet all the assumptions of parametric data.
A model was also developed in order to test the association of HIV group status with mental health outcomes, controlling for relevant socio-demographic factors, of age, gender and language. Multiple linear regression analysis was performed, controlling for these socio-demographic factors

Question: **Do adolescents living with HIV come from poorer households than adolescents in the comparison group? Is there an association between poverty indicators and mental health outcomes in the overall sample? Do the differences in mental health outcomes persist after controlling for the effects of socio-demographics, poverty and orphan status?**

The analyses first explored the relationship between HIV group status (HIV and comparison group) and poverty, and secondly, between poverty and mental health outcomes. Differences between the two groups on poverty indicators were assessed using independent sample t-tests, chi-squared tests. Mann-Whitney U test confirmed findings for non-parametric data. Associations between poverty indicators and mental health outcomes were examined with bivariate correlations, independent sample t-tests and Mann-Whitney U test.

Finally, using linear regression, models were developed to control for socio-demographic and poverty indicators, to see if differences between the two groups persist. Poverty variables showing the strongest association were selected for the analysis.

Question: **Do participants in the HIV group experience lower levels of perceived social support compared to participants in the comparison group? Is there an association between social support and mental health outcomes? Do differences in levels of mental distress between the HIV and comparison group persist after controlling for perceived social support?**

The analyses first explored the relationship between HIV group status (HIV and comparison group) and social support, and secondly, between social support and mental health outcomes. Differences between the two groups on social support were assessed using Mann-Whitney U test for non-parametric data. Associations between social support and mental health outcomes were examined with bivariate correlations

Finally, using linear regression, models were developed, controlling for socio-demographic, poverty indicators and social support, to see if mental health differences between the two groups persist. Poverty variables showing the strongest association were selected for the analysis.

Question: **Which variables are the best predictors for determining potential clinical cases?**

Logistic regression analysis was conducted to select the best subset of predictor variables for whether a participant had scores in the "abnormal range" (scores indicating potential clinical distress), using the recommended cut-offs by Dr Goodman (www.sdqinfo.com). After controlling for socio-demographics, the analysis tested the potential for the variables showing the strongest association with mental health continuous scores.

Question: **What are the risk factors for mental distress in the HIV group?**

Analyses were conducted to assess the unique factors associated with mental distress in the main group of interest, adolescents living with HIV. Associations were conducted between mental health outcomes socio-demographic factors as well as poverty indicators.

This section also assessed the unique role of HIV-specific variables, such as health and stigma, on the mental health of adolescents living with HIV. Finally, using multi-variate analysis, we examined the extent to which variables predicted mental distress in the HIV group. Variables with significant bivariate correlations or associations were retained for the analysis.

***Question:* Which variables best predict symptoms of emotional and behavioural problems in the HIV group?**

Using multiple regression analysis, we examined the extent to which variables predicted mental distress for the HIV group. The analysis was conducted using continuous scores, instead of dichotomous variables. Variables with significant bivariate correlations or associations were retained for the analysis and entered simultaneously into the model. These were: social support, stigma and poverty. Since demographic variables were not significantly associated with this outcome they were not controlled for in the analysis, except for emotional symptoms, where gender was controlled for.

Having outlined the methodology, the next chapter presents the findings from the analysis, starting with the socio-demographic findings.

CHAPTER FOUR: RESULTS

4.1 Socio-demographic findings

Question: What is the basic demographic composition of the HIV group? Are there any differences between the HIV and comparison group on socio-demographic factors?

Summary: There were no statistically significant differences in age (overall mean age = 14.4yrs) and gender (53.1% female overall) between the HIV and comparison groups. Most of the participants in the HIV group were healthy, with only about 5% having a high viral load (>10 000 copies/mL) and less than 5% showing advanced-severe immunosuppression (CD4 < $350mm^3$). Significantly more participants in the HIV group were orphaned (62.6% vs. 20.8%), $\chi 2$ (1, *N* = 258) = 45.98, *p* < .001, and fewer lived with biological parents (75.5% vs. 57.6%), $\chi 2$ (1, *N* = 258) = 9.072, *p* = .003. Participants in the HIV group were significantly younger at the age of first parental loss (median age = 4 vs. 6), U = 596.5, z = -2.42, *p* = 0.016. There was a significant difference in main home language spoken between the two groups, $\chi 2$ (5, *N* = 258) = 50.06, *p*<.001, and more participants in the comparison group lived in the various Katutura suburbs (96.9% vs. 81.8%; $\chi 2$ [2, *N* = 258] = 18.416; *p* < .001).

Grade repetition rates in school was high for both groups, with almost half of the participants having repeated a grade at least once (47%), although there were no statistically significant differences between the two groups. Participants in the HIV group missed significantly more days from school in the past six months (*M* = 2.69 vs. 1.44), however, when only considering days missed due to illness, there was no statistically significant difference.

This section describes the social and demographic characteristics of the HIV and the comparison groups and assesses whether there are any differences in any of these factors between the two groups. Table 12 presents the main demographic characteristics of the HIV group, whereas Table 13 presents the findings when the two groups are compared.

Age and gender: The mean age of the 99 participants in the HIV group was 14.33 (*SD* = 1.80) with most (61.6%) falling in the younger age group (12-14). There was no significant difference in age between the two groups with the overall mean age being 14.44 (*SD* = 1.86). There were roughly equal numbers of male and female participants in both the HIV and comparison groups, with 53.1% of the overall sample being female. These results confirm that participants in the two groups were successfully matched for age and gender.

Language: Overall, 54.7% of the participants in the two groups identified the Oshiwambo language group as the main home language, followed by 21.3% that identified Otjiherero (Table

13). There was a significant difference in the main language spoken at home between the two groups, χ^2 (5, N = 258) = 50.06, $p < .001$, with more participants in the HIV group identifying Oshiwambo as their main home language (65.7% vs. 47.8%) and more participants in the comparison group identifying Otjiherero as their main home language (32.7% vs. 3.0%). The higher proportion of Otjiherero speakers in the comparison group occurred as one of the four randomly selected schools fell within an area with predominantly Otjiherero speakers. Whether or not these translate to differences in other factors will be determined in later analysis.

Orphan status, age of bereavement and caregiver information: Overall, 95 (36.8%) participants were orphaned. Significantly more participants in the HIV group were orphaned (62.6% vs. 20.8%), χ^2 (1, N = 258) = 45.98, $p < .001$, with 17.2% (vs. 2.5%) of children in the HIV group having lost both parents. Participants in the HIV group were 6 times more likely to be orphaned than participants in the comparison group (OR = 6.37). In the HIV group, 24 (24.2%) were paternally bereaved, 21 (21.2%) were maternally bereaved and 17 participants (17.2%) had lost both parents (*Table 12*).

Participants in the HIV group were significantly younger at the first parental bereavement (mean age = 4.5 vs. 6.8, *Mdn* = 4 vs. 6), U = 596.5, z = -2.42, p = 0.016, compared to participants from the comparison group. Not surprisingly, significantly more participants in the comparison group lived with a biological parent (75.5% vs. 57.6%), χ^2 (1, N = 258) = 9.072, p = .003. In addition, the analysis showed that significantly fewer participants in the HIV group identified their biological parent as their primary caregiver (55.6% vs. 71.6%), $\chi 2$ (2, N = 258) = 17.495, $p < .001$.

Health information: All participants in the HIV group were on antiretroviral therapy (ART) with the mean time being 6.99 years and 80% having been on ART for over 5 years. All of the participants with available data (n = 91) were in WHO stage 1 (asymptomatic), according to the provider rating (Table 12). The most recent blood analysis (conducted every 3 months) indicated that 5 participants (5.6%) had a high viral load (>10 000 copies/mL) and 3 participants (3.9%) showed advanced - severe immune suppression (CD4 < 350mm^3).

Disclosure information: Most participants in the HIV group (66.3%) had been told their status by a family member (predominantly by their mother) followed by a service provider (31.6%), either a doctor or nurse. The mean time since disclosure was 4 years, with just over half (54.3%) having known their HIV status for over three years. Forty (43.5%) participants reported that they were told their status before their 11th birthday.

Residence: The majority of participants in both groups lived in the various Katutura suburbs (91.1%). However, significantly more participants in the comparison group lived in the Katutura suburbs (96.9% vs. 81.8%); χ^2 (2, N = 258) = 18.416; $p < .001$, compared to the HIV group. In addition 9 participants in the HIV group lived in children's homes.

School related factors: Just under half (47.7%) of participants in the entire sample reported that they had repeated at least one grade at school. Although more participants in the HIV group repeated a grade (52.5% versus 44.7%), the differences were not statistically significant. Participants in the HIV group reported that they missed significantly more days from school (M = 2.69, SD = 3.36) compared to participants from the comparison group (M = 1.44, SD = 2.25), U = 5777.9, Z = -3.76, $p < .001$. For those participants that reported missing school in the HIV group, the most common reasons for missing were: hospital appointments for follow-up/pharmacy to pick up pills (54.4% of those that missed school) and illness (41.2% of those that missed school). When only considering days missed due to illness, there was no significant difference between the two groups.

Visits to the doctor: Participants in the HIV group reported significantly more visits to the doctor in the past month, with only 12.1% of participants in the HIV group not reporting any visits to the doctor, versus 74.4% in the comparison group, χ^2 (2, N = 258) = 106.505, $p < .001$.

Table 12 Socio-demographic characteristics of the HIV group

	n (%)	*Mean (SD)*
Age (years)		
12-14	61 (61.6%)	14.33 (1.80)
15-18	38 (38.4%)	
Gender		
Male	47 (47.5%)	
Female	52 (52.5%)	
Parental loss:		
Non-orphan	37 (37.4%)	
Loss of father	24 (24.2%)	
Loss of mother	21 (21.2%)	
Loss of both parents	17 (17.2%)	
Average time on ART (years)		6.99 (2.47)
Viral load[a] (copies/mL)		
Very low/ suppressed (Undetectable to <50)	59 (66.3%)	
Low-moderately low (50-10,000)	25 (28.1%)	
High (>10,000)	5 (5.6%)	
Immune suppression[a] (CD4/mm^3)		
Not significant >500/mm^3	59 (75.6%)	
Mild 350-499/mm^3	16 (20.5%)	
Advanced-severe <350/mm^3	4 (3.9%)	
Age HIV status was disclosed (years)		10.38 (2.8)
Time since HIV status was disclosed (years)		4.05 (2.69)
Person who disclosed HIV status to participant		
Family	63 (66.3%)	
Provider	30 (31.6%)	
Friend	1 (1.1%)	
Don´t remember	1 (1.1%)	

[a] Reduced *n* because of missing data.

Table 13 Differences between groups on socio-demographic factors

	HIV group (*n* = 99)	**Comparison group (*n* = 159)**	**P value**		**HIV group (*n* = 99)**	**Comparison group (*n* = 159)**	**P value**
Mean Age				Age of first parental bereavement	(n=58)	(n=30)	
years (*SD*)	14.33 (1.80)	14.52 (1.89)	ns	Mean (*SD*)	4.5 (3.96)	6.8 (4.49)	.05
Gender				Residence			
Male	47 (47.5%)	74 (46.5%)	ns	Katutura	81 (81.8%)	154 (96.9%)	.001
Female	52 (52.5%)	85 (53.5%)		Other	18 (18.2%)	5 (3.1%)	
Home language				Repeated ≥ 1 grade			
Oshiwambo	65 (65.7%)	76 (47.8%)	.001	no	47 (47.5%)	88 (55.3%)	ns
Otjiherero	3 (3.0%)	52 (32.7%)		yes	52 (52.5%)	71 (44.7%)	
Other	31[a] (31.3%)	31[b] (19.5%)					
Lives with a biological parent				Days absent from school (6months)			
Yes	57 (57.6%)	120 (75.5%)	.01	Mean (*SD*)	2.69 (3.36)	1.44 (2.25)	.001
No	42 (42.4%)	39 (24.5%)					
Main identified caregiver				Days missed due to illness (6months)			
Biological parent	55 (55.6%)	114 (71.7%)	.001	Mean (*SD*)	0.86 (1.88)	0.69 (1.59)	ns
Another relative	33 (33.3%)	44 (27.7%)					
Non-relative	11 (11.1%)	1 (0.6%					
Orphan status				Visits to doctor			
Orphan	62 (62.6%)	33 (20.8%)	.001	No visits	12 (12.1%)	123 (77.4%)	0.001
Non-orphan	37 (37.4%	126 (79.2%)		1 – 2	74 (74.7%)	26 (16.4%)	
				> 2 visit	13 (13.1%)	10 (6.3%)	

[a] English = 13, Afrikaans = 9, Nama/Damara = 6, Other language= 3

[b] English =3, Afrikaans =3, Nama/Damara =16, Other language = 9

4.2 Mental health

Question: What proportion of participants in the HIV group experience clinically significant mental distress? Do participants in the HIV group experience more mental health problems than the comparison group? Do any socio-demographic factors mediate the association between mental health and HIV group status?

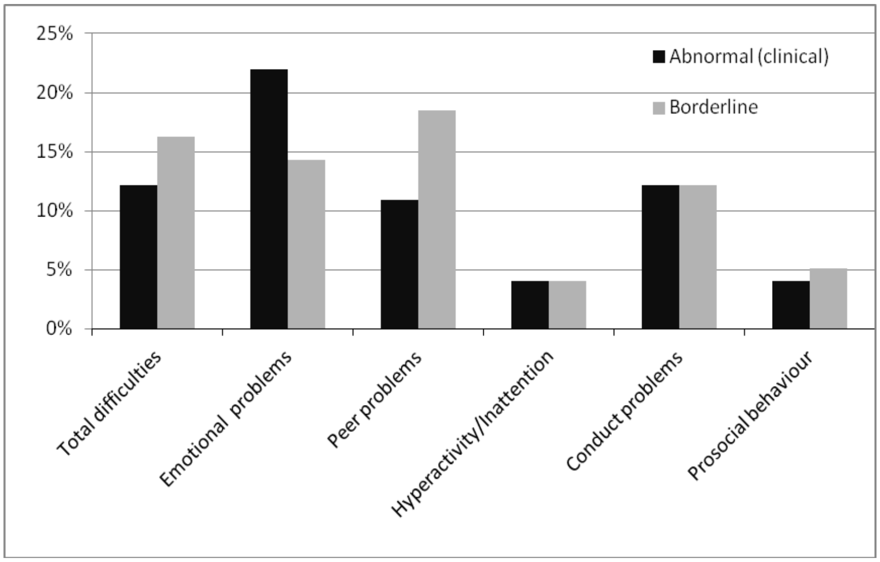
Summary: The proportion of participants at risk for emotional and behavioural problems in the clinical range was relatively low in the HIV group, with 12.2% having scores in the abnormal/clinical range on the total difficulties scale. For the subscales, the highest proportion of participants scoring in the clinical range, was for emotional problems (22%), followed by conduct (12.2%) and peer problems (10.9%). Participants in the HIV group reported more total emotional and behavioural problems (p = .027) and more conduct problems (p = .025), than the comparison group, although with small effect sizes. The differences remained significant after controlling for socio-demographic factors (age, gender, language). For the two groups, males reported significantly less prosocial behaviour (p = .008) and more conduct problems (p = .031) than females. Age was positively correlated with hyperactivity/inattention (p = .014) and conduct problems (p = .009) in the two groups. For the two groups combined, there were significant differences in mental health outcomes between orphans and non-orphans, with orphans reporting significantly more total emotional and behavioural problems (p = .007) and more peer problems (p = .016).

Mental distress was calculated by summing the scores of the 20 problem items that signal emotional and behavioural problems on the SDQ. Scores were also calculated for each of the five subscales: emotional problems, conduct problems, hyperactivity/inattention, peer problems and the prosocial behaviour as well as the impact supplement.

4.2.1 Mental health in adolescents living with HIV

Using the recommended SDQ self-report cut-offs for indicating clinical level mental distress (see section 3.4.3), 71.4% of participant in the HIV group fell within the normal range for the total difficulties score. Only 12.2% of participants were at risk for clinically significant mental distress, with 16.3% in the borderline range (Graph 1). When comparing different subscales, a higher number of participants were at risk for clinically significant scores for emotional problems (22%), with an additional 14.4% in the borderline range. In comparison, fairly low numbers had abnormal scores on the hyperactivity/ inattention scale (4.0%) and prosocial behaviour scale (4.0%).

Since there are no norms available for cut-offs indicating clinically significant distress for Namibian adolescents, these results are treated with caution. However, they are included here so as to provide some indication of the level of distress experienced by adolescents living with HIV. However, to compare the level of distress between the two groups and to assess the role of risk and protective factors, we use continuous scores.



Graph 2 Percentage of participants in the clinical/abnormal and borderline range for the HIV group: SDQ self-report

4.2.2 Group differences

Differences in continuous scores for mental health outcomes were assessed between the HIV and comparison group using student t test and confirmed with the Mann-Whitney U test (if appropriate) using a one-tailed test with significance set at $p < .05$. The outcomes are presented in Table 14. Participants in the HIV group were more likely to report more total emotional and behavioural problems, t (255) = 1.95, $p = .027$, and more conduct problems, t (255) = 1.98, $p = .025$, and peer problems, t (179) = 1.83, $p = .035$. However, the group differences with regard to peer problems were not confirmed as statistically significant when assessed using the Mann-Whitney U test for non-parametric data, U = 6987.5, $p = .062$. Although the HIV group reported more emotional problems and more problems of hyperactivity/inattention, these differences did not reach statistical significance. Similarly there was no statistically significant difference in the scores on the prosocial behaviour and impact supplement scales. Since there were so many comparisons, these findings are treated with caution.

Effect sizes: The magnitude of difference in the means for the two scales showing significance was small: for total difficulties (mean difference = -1.36, 95% CI: -2.47 to 0.02) eta squared was .015, and for conduct problems (mean difference = -.446, 95% CI: -.89 to -.002) eta squared was .015.

Table 14 Association between HIV group status and SDQ scores

	HIV group (n = 99)	**Comparison Group (n = 159)**	**Mean difference 95% CI**	**P value**
Total difficulties	12.74 (5.86)	11.38 (5.18)	-1.36 (-2.47 to 0.02)	$p < .05$
Emotional symptoms	4.74 (2.47)	4.48 (2.39)	-0.22 (-.89 to 0.39)	ns
Peer problems[a]	2.76 (2.01)	2.31 (1.67)	-.443 (-.921 to 0.03)	$p < .05$
Hyperactivity/ inattention	2.93 (2.03)	2.68 (1.84)	-.24 (-0.73 to 0.24)	ns
Conduct problems	2.35 (1.90)	1.90 (1.67)	-.446 (-.89 to -.002)	$p < .05$
Prosocial behaviour	8.25 (1.71)	8.39 (1.52)	0.13 (-0.27 to 0.54)	ns
Total impact	1.21 (1.88)	1.01 (1.89)	-0.21 (-0.68 to 0.27)	ns

[a] This was not significant with Mann-Whitney U test (U = 6987.5, $p = .062$)

4.2.3 Associations with socio-demographic factors and caregiver factors

The relationships between mental health outcomes and various socio-demographic and caregiver factors were examined using either t-tests (or Mann-Whitney U test if appropriate) and Pearson bivariate correlations (or Spearman's rho if appropriate) for continuous variables and chi-squared for categorical variables for the two groups combined ($n = 257$). The findings of these analyses are presented in Table 15.

Gender and age: Gender was associated only with conduct problems and prosocial behaviour, with male children reporting significantly more conduct problems $t(255) = 2.167$, $p = .031$, and significantly less prosocial behaviour, $t(256) = -2.676$, $p = .008$. The eta squared statistic (.018

and .027 respectively) indicated small effect sizes. Age was positively correlated with hyperactivity/inattention (*r* = .152, *p* = .014) and conduct problems (*r* = .163, *p* = .009), suggesting that these symptoms increase with age. The correlation coefficient indicated a small effect size for both correlations.

Orphan status, age of bereavement and caregiver information: Orphans reported significantly more total emotional and behavioural problems, *t*(255) = -2.70, *p* = .007, and significantly more peer problems, *t*(256) = -2.43, *p* = .016. Effect size for the magnitude of the differences in the means for total difficulties (mean difference = -1.89, 95% CI: -3.27 to .0.513) was small (eta squared = .028). Similarly for peer problems the magnitude of the difference in the means (-0.55, 95% CI:-1.02 to -0.108) was small (eta squared = .023). Although there was a tendency for orphans to show more problems in the remaining scales, these did not achieve statistical significance (conduct problems: *p* = .055 and total impact *p* = .068). There was no association between mental health outcomes and age at first bereavement. Although there was a tendency for participants who lived with biological parents to have lower mean scores for distress, these differences were not statistically significant.

Language: Due to differences in languages in the HIV and comparison group, we also explored whether language was associated with any of the mental health outcomes. To meet the requirements of the ANOVA, it was necessary to combine the groups. A disadvantage is that this may obscure differences in languages in group which combined languages. Language was significantly associated with the hyperactivity/inattention scale, F(2,255) = 5.27, *p* = .006.

School related variables: Participants that repeated at least one grade had significantly more total emotional and behavioural problems, *t*(255) = -3.25, *p* = .001, more emotional problems, *t*(255) = -2.86, *p* = .005, and more conduct problems, *t*(255) = -2.09, *p* = .038. For the remaining scales, there was a tendency for participants who repeated a grade to score higher on distress although it did not achieve statistical significance (hyperactivity = .077, peer problems = .051). There was a significant positive correlation with the number of days missed from school and total difficulties (*r* = .138, *p* = .027), conduct problems (*r* = 166, *p* = .008) and total impact scores (*r* = .189, *p* = .002). Similarly for days missed due to illness, there was a significant positive correlation between number of days and emotional symptoms (*r* = .135, *p* = .030), prosocial behaviour (*r* = 131, *p* = .036) and total impact scores (*r* = .127, *p* = .041). The correlation coefficient indicates small effect sizes for all these associations.

Visits to the doctor: Finally there was a significant association between number of visits to the doctor and emotional problems, with more visits indicating higher scores, F(2,254) = 3.07, *p* = .048.

Table 15 Association between demographic factors and mental health outcomes

	Total difficulties *M (SD)*	***p***	**Emotional symptoms** *M (SD)*		**Peer problems** *M (SD)*	***p***	**Hyperactivity/Inat.** *M (SD)*	***p***	**Conduct problems** *M (SD)*	***p***	**Prosocial scale** *M (SD)*	***p***	**Total impact** *M (SD)*	***p***
Gender[a]														
Male	11.89 (5.23)	ns	4.31 (2.16)	ns	2.61 (1.78)	ns	2.65 (1.86)	ns	2.32 (1.88)	.05	8.06 (1.75)	.01	1.02 (1.86)	ns
Female	11.91 (5.71)		4.80 (2.62)		2.37 (1.85)		2.89 (1.97)		1.85 (1.65)		8.58 (1.40)		1.14 (1.92)	
Age[b]														
r^2	0.188	ns	0.036	ns	-0.012	ns	0.152	.05	0.163	.05	-.035	ns	0.117	ns
Orphan status[a]														
orphan	13.09 (5.47)	.01	4.89 (2.37)	ns	2.84 (2.01)	.05	3.01 (2.15)	ns	2.35 (1.81)	ns	8.28 (1.68)	ns	1.38 (2.07)	ns
non-orph	11.20 (5.38)		4.38 (2.44)		2.28 (1.67)		2.64 (1.76)		1.91 (1.73)		8.36 (1.55)		0.91 (1.75)	
W/biological parent														
no	12.65 (5.55)	ns	4.96 (2.53)	ns	2.49 (1.97)	ns	3.04 (2.02)	ns	2.16 (1.89)	ns	8.40 (1.66)	ns	1.23 (2.16)	ns
yes	11.56 (5.43)		4.39 (2.35)		2.48 (1.75)		2.66 (1.86)		2.03 (1.72)		8.31 (1.57)		1.02 (1.75)	
Language[c]														
Oshiwambo	11.26 (5.45)		4.37 (2.41)		2.35 (1.75)		2.47 (1.87)		2.06 (1.79)		8.39 (1.60)		1.04 (1.92)	
Otjiherero	12.00 (5.05)	ns	4.84 (2.40)	ns	2.42 (1.56)	ns	2.85 (1.80)	.01	1.89 (1.58)	ns	8.44 (1.38)	ns	1.33 (2.15)	ns
Other	13.27 (5.73)		4.76 (2.46)		2.84 (2.13)		3.40 (2.00)		2.25 (1.89)		8.13 (1.75)		0.95 (1.53)	

[a] Confirmed with Mann-Whitney U test, for those data that were not parametric.

[b] Confirmed with Spearman's correlation coefficient, for those data that were not parametric

[c] Confirmed with Kruskall-Wallis, for those data that were not parametric

4.2.4 Group differences when controlling for socio-demographic factors

Section 4.2.2 reported that there was a statistically significant difference between the HIV group and comparison group on the total difficulties and conduct problems scale. Hierarchical multiple regression analysis was conducted to assess whether these differences remain after controlling for socio-demographic factors. The analysis therefore controls for age, gender and language (Table 16 and Table 17). Language was included due to group differences in the main home language spoken by participants (Section 4.1.2).

Total difficulties (total emotional and behavioural problems): After controlling for age, gender and language, the statistically significant difference between HIV and comparison groups on total difficulties remained, meaning that HIV status remains a statistically significant predictor of total difficulties. In fact, the significance level is stronger when controlling for the effects of socio-demographics (F (4, 252 = 3.73, *p* = .006).

Conduct problems: After controlling for socio-demographic characteristics of age, gender and language, HIV status remains statistically significant for predicting conduct problems (F(4,252) = 4.37, *p* = .002, r^2 = .065.

Table 16 Regression analysis examining the effects of HIV status on total difficulties, while controlling for socio-demographics

Step	**Independent Variables**	**R^2**	**R^2 change**	**F change**	**β^a**	**B**
1	Gender,	.038	.038	3.37*	-.002	-.017
	Age,				.127	.374*
	Language				.157	1.03*
2	Gender,	.055	.017	4.66*	.000	.001**
	Age,				.133	.393*
	Language,				.162	1.061**
	HIV group status				.132	1.49*

F(4,252) for entire model = 3.73, *p* = .006

[a] Standardised Beta coefficient.

*denotes significance at the .05 level, ** denotes significance at the .01 level

Significant predictors in the final model are: age (*p* = .031), language (*p* = .009) and HIV group status (*p* = .032)

Table 17 Regression analysis examining the effects of HIV status on conduct problems, while controlling for socio-demographics

Step	Independent Variables	R^2	R^2 change	F change	β	B
1	Gender,	.048	.048	4.22**	-.138	-.491*
	Age				.169	.161**
	Language				.046	.097
2	Gender	.065	.017	4.61*	-.137	-.485*
	Age,				.175	.167**
	Language				.050	.106
	HIV group status				.131	.477*

F(4,252) for entire model = 4.37, *p* = .002
*denotes significance at the .05 level, ** denotes significance at the .01 level, *** denotes significance at the .001 level
Significant predictors in the final model are gender (*p* = .026), age (*p* = .005) and HIV group (*p* = .033).

4.3 Poverty

Question: Do adolescents in the HIV group come from poorer households than the comparison group? Is there an association between poverty indicators and mental health outcomes? Do differences in mental health outcomes between the groups persist after controlling for the effects of socio-demographics, poverty and orphan status?

Summary: There were no significant differences between the groups on poverty factors, including food insecurity, number of assets in the home and type of dwelling. The reported household unemployment levels were lower than expected for Windhoek (10% overall). Poverty factors were associated with poorer mental health, particularly for food insecurity and household assets. Participants reported more total emotional and behavioural problems and more emotional problems if they did not have breakfast that morning due to no food in the house (p = .003 and p = .007 respectively), or if there was one or more days in the last week when there was not enough food for everyone (p = .001 and p < .001 respectively), if they had fewer assets (p = .012 and p < .001 respectively) and specifically, if they had fewer child centred assets (p < .001 for both). Participants reported significantly more peer problems if they had at least one day where there was no food in the house (p = .027), had fewer assets (p = .041) and child centred assets (p =.042) and more conduct problems if they reported fewer child centred assets (p = .004). Finally, significantly higher impact scores were reported in participants that did not have breakfast that morning (p = .007) and participants that reported fewer child centred assets (p < .001).

After controlling for the effects of poverty (food insecurity and child centred assets), mental health differences between the two groups remained. This suggests that poverty did not mediate the differences between the HIV and comparison groups for total difficulties and conduct problems. However, after controlling for poverty indicators and orphan status, the differences observed between the two groups disappeared. This suggests that orphanhood may mediate the differences observed between the HIV and the comparison groups.

4.3.1 Group comparisons

The following indicators were used to assess poverty: food security, assets, household size, dwelling type and household employment status. Table 18 shows the findings for the HIV and the comparison groups on different poverty indicators.

Food security: To assess food security, participants were asked how often, in the last 7 days, there was not enough food for everyone in the house. Secondly, participants were asked whether they had breakfast that morning before leaving the house to go to the school/come to the hospital and, if so, whether it was because there was no food in the house. Overall, 169 (65.5%) participants reported that there were no days when there was not enough food in the house, meaning that 89 (34.5%) participants had at least one day in the last week where there was not enough food for everyone in the house. About 12.7% of participants reported that they did not have breakfast that morning, due to there not being any food in the house. The analysis did not detect any significant differences between the HIV and the comparison groups with respect to either question.

Assets: An asset index approach was also used to assess poverty. The list of assets was taken from relevant assets for an urban household in Namibia (See Chapter 2). Three specific child-centred assets used in research in southern Africa were also assessed. Overall participants reported a mean of 6.49 (*SD* = 1.99) assets (out of 9) and 1.89 (*SD* = .97) child centred assets (out of 3). There were no significant differences between the HIV and the comparison groups for either the total assets or child centred assets.

Dwelling type, employment status and number of people per household: No significant differences were found between the two groups for dwelling type, with 46.1% of participants overall living in informal housing/shacks. Similarly, there were no group differences between household employment status (whether at least one household member was working) or the number of people living in the household. Overall, 10% of children lived in households where there was no household member working. However, the definition of employment used in this study was particularly broad and only determined whether there was any type of income. In some cases it may have meant self-employment or low paid work, such as domestic work, meaning that the household would still earn very little income. Finally, there were not differences in household size between the two groups.

Table 18 Differences between HIV and comparisons group on poverty indicators

	HIV group (*n* = 99)	**Comparison group (*n* = 159)**	***p***
Days no food in the past week			
none	67 (67.7%)	102 (64.2%)	
1 day	16 (16.2%)	28 (17.6%)	ns
2-3 days	12 (12.1%)	25 (15.7%)	
4 or more days	4 (4.0%)	4 (2.5%)	
Days no food in the past week			
none	67 (67.7%)	102 (64.2%)	ns
at least one day	32 (32.3%)	57 (35.8%)	
Breakfast			
No (No food)	9 (9.1%)	23 (15.0%)	ns
Yes	90 (90.9%)	130 (85.0%)	
Employment in household			
yes	82 (91.1%)	140 (88.1%)	ns
no	8 (8.9%)	19 (11.9%	
Assets[a] (out of 9)			
Mean (*SD*)	6.30 (2.11)	6.61 (1.91	ns
Child centred assets[b] (our of 3)			
Mean (*SD*)	1.84 (0.93)	1.93 (0.99)	ns
Dwelling type:			
Formal	50 (50.5%)	89 (56.0%)	ns
Informal (Shack)	49 (49.5%)	70 (44.0%)	
Household size			
mean (*SD*)	6.36 (5.12)	6.45 (2.75)	ns

[a] Radio, television, refrigerator, stove, motor vehicle, electricity, books of your own, enough clothes to keep you warm, desk or table to study.

[b] Books of your own, enough clothes to keep you warm, desk or table to study.

4.3.2 Poverty and mental health outcomes

Analyses were conducted to test the associations between mental health outcomes and the following indicators of poverty: number of assets in the home, food security, number of household members, household employment and dwelling type. The findings are presented in Table 19.

Food security: There was a significant association between mental health outcomes and the two measures of food security. Participants who reported that they did not have breakfast due to there being no food in the house reported significantly more total emotional and behavioural problems, *t*(249) = 2.99, *p* = .003, emotional problems, *t*(249) = 2.70, *p* = .007, and impact scores, *t*(35) = 2.84, *p* = .007. Whereas the magnitude of the difference between the means for impact scores (mean difference=1.39, 95% CI: 0.39 to 2.37) was medium (eta squared=0.059), it was small for the total emotional and behavioural problems (mean difference = 3.08, 95% CI: 1.06 – 5.11, eta squared = .035), and for emotional problems (mean difference = 1.23, 95% CI: 0.33 – 2.13, eta squared = .028).

Participants who reported at least one day in the past week where there was not enough food in the house, reported significantly more total emotional and behavioural problems, *t*(255) = -3.26, *p* = .001, emotional problems, *t*(255)= -4.08, p < .001, and peer problems, *t*(150) = -2.24, p = .027. Small effects were present for peer problems (mean difference = -0.56, CI 95%:-1.6 to -0.07, eta squared = .022), whereas medium effects were present for total emotional and behavioural difficulties (mean difference = -2.31, CI 95%: -3.70 to -0.92, eta squared =.040) and emotional problems (mean difference = -1.87 to -0.65, CI 95%: eta squared = 0.061)

Assets in the home: A negative association was found with total assets and total emotional and behavioural difficulties (r = -.157, *p* = .012), emotional problems (*r* = -.205, *p* < .001) and peer problems (*r* = -.127, p = .041), meaning that participants with fewer assets experienced more mental health problems. When just considering child centred asset, having fewer assets was associated with increased total emotional and behavioural difficulties (*r* = -.268, p < .001), emotional problems (*r* = -.286, *p* < .001), peer problems (*r* = -.127, *p* = .042), conduct problems (*r* = -.181, p = .004) and impact scores (*r* = .212, *p* < .001). However, the association with peer problems was not significant when the analysis was repeated with Spearman's rank order correlation. The correlation coefficient indicated small effect size for all associations, with slightly larger effects for child centred assets.

Household size, dwelling and household employment status: There was a significant positive correlation between household size and symptoms of hyperactivity/inattention (r = .210, p < .001) with a small magnitude of effect. There were no significant differences in mental health outcomes for dwelling type (formal or informal housing) or whether at least one household member was working

Table 19 Associations between poverty and mental health outcomes

	Total difficulties	***p***	**Emotional symptoms**	***p***	**Peer problems**	***p***	**Hyperactivity/ inat.**	***p***	**Conduct problems**	***p***	**Prosocial behaviour**	***p***	**Total Impact**	***p***
Total assets (9)[ab]	-.157	.05	-.205	.01	-.127	.05	.019	ns	-.096	ns	.078	ns	-.080	ns
Child centred assets[ab]	-0.268	.001	-.286	.001	-.127	.05	-.111	ns	-.181	.01	-.106	ns	.0.212	.01
Food insecurity[cd]														
no days	11.11 (5.39)	0.01	4.14 (2.22)	.001	2.29 (1.66)	.05	2.65 (1.93)	ns	2.04 (1.88)	ns	8.33 (1.61)	ns	0.97 (1.82)	ns
at least 1	13.42 (5.52)		5.40 (2.60)		2.85 (2.05)		3.02 (1.88)		2.14 (1.55)		8.35 (1.57)		1.30 (2.00)	
Breakfast[cd]														
no (no food)	14.56 (5.58)	.01	5.63 (2.50)	0.01	3.06 (2.20)	ns	3.31 (2.26)	ns	2.56 (1.87)	ns	8.19 (1.45)	ns	2.31 (2.68)	.001
yes	11.48 (5.42)		4.39 (2.40)		2.41 (1.75)		2.69 (1.85)		1.99 (1.76)		8.38 (1.57)		0.93 (1.70)	
Household size[ab]	0.084	ns	-.035	ns	.046	ns	.210	.001	.033	ns	-.040	ns	0.090	Ns

Note: Household size, formal/informal housing and household employment did not show any significant association with any variables.

[a] Pearson's Correlation coefficient, [b]Non parametric data was confirmed with Spearman's correlation co-efficient. Peer problems were not significant with Spearman's correlation.

[c] Confirmed with Mann-Whitney U test for those data that were not normally distributed

[d] "Food insecurity" categorised as at least one day in the last 7 days where there was not enough food for everyone in the house

4.3.3 Group differences when controlling for poverty and orphan status

Earlier results showed that HIV group status was associated with total difficulties and conduct problems (Table 14). Associations were also found between indicators of poverty and mental health. This section considers whether differences in mental health between the two groups persist after controlling for socio-demographic variables and poverty. In addition, we also consider the effect of orphan status after controlling for socio-demographic factors and poverty indicators. Food security (breakfast) and child centred assets were included as indicators for poverty as they showed the strongest effect sizes. Each outcome is considered separately.

Total difficulties: After controlling for socio-demographic and poverty indicators the differences between the HIV and comparison group remained significant (*p* = .041, Table 20). However after controlling for the effects of orphanhood, there was no longer a significant difference in the number of total emotional and behavioural difficulties reported by the HIV and the comparison groups (
Table 21).

Conduct problems: In a model which controlled for socio-demographic variables, and poverty indicators the differences between the HIV and the comparison groups remained significant (Table 22). However after controlling for the effects of orphanhood, there was no longer a significant difference in the number of symptoms reported by the HIV and the comparison groups (
Table 23).

Poverty did not mediate the differences between the HIV and the comparison groups for total difficulties and conduct problems. However, after controlling for poverty indicators and orphan status, the differences observed between the two groups disappeared. This suggests that orphanhood may play a mediating role in the observed mental health differences between the groups.

Table 20 Regression analysis examining the effects of HIV status on total difficulties, controlling for socio-demographics and poverty

Step	Independent Variables	R^2	R^2 change	F change	β	B
1	Gender,	.038	.038	3.32*	.005	.055
	Age,				.135	.396*
	Language				.148	.969*
2	Gender,	.138	.100	14.47***	-.036	-.390
	Age,				.171	.504**
	Language				.151	.989*
	Food security				.135	.773*
	Assets				-.244	-1.379***
3	Gender,	.152	.014	4.22*	-.035	-.378
	Age,				.176	.518**
	Language				.155	1.018**
	Food security				.139	.796*
	Assets				-.239	-1.348***
	HIV group status				.120	1.351*

ANOVA for final model: F(6,249) = 7.45, *p* < .001; *denotes significance at the .05 level, ** denotes significance at the .01 level, *** denotes significance at the .001 level

Table 21 Regression analysis examining the effects of HIV status on total difficulties, controlling for socio-demographics, poverty and orphan status

Step	Independent Variables	R^2	R^2 change	F change	β	
1	Gender,	.038	.038	3.32*	.005	055
	Age				.135	.396*
	Language				.148	.969*
2	Gender,	.138	.100	14.47***	-.036	-.390
	Age				.171	.504**
	Language				.151	.989*
	Food security				.135	.773*
	Assets				-.244	-1.379***
3	Gender,	.153	.015	4.31*	-.031	-.336
	Age				.154	.453*
	Language				.147	.965*
	Food security				.146	.833*
	Assets				-.227	-1.279***
	Orphan status				.123	1.396*
4	Gender,	.158	.006	1.65	-.032	-.344
	Age				.162**	.478**
	Language				.151*	.992*
	Food security				.145*	.832*
	Assets				-.228***	-1.287***
	Orphan status				.087	.982
	HIV group status				.083	.935

ANOVA for Final model (step 4): F(7,248) = 6.65, *p* < .001;*denotes significance at the .05 level, ** denotes significance at the .01 level, *** denotes significance at the .001 level

Table 22 Regression analysis examining the effects of HIV status on conduct problems, controlling for socio-demographics and poverty

Step	Independent Variables	R^2	R^2 change	F change	β	B
1	Gender,	.048	.048	4.22**	-.136	-.483*
	Age				.171	.163**
	Language				.042	.090
2	Gender,	.095	.047	6.53**	-.160	-.568**
	Age				.195	.186**
	Language				.052	.110
	Food security[a]				.011	.020
	Assets[b]				-.216	-.396**
3	Gender,	.110	.015	4.16*	-.159	-.564**
	Age				.200	.191**
	Language				.056	.120
	Food security				.015	.027
	Assets				-.210	-.386**
	HIV group status				.122	.446*

F(6,249) for entire model = 5.12 , *p* < .001;*denotes significance at the .05 level, ** denotes significance at the .01 level, *** denotes significance at the .001 level

[a] Days no food in the last week [b] Child centred assets

Table 23 Regression analysis examining the effects of HIV status on conduct problems, controlling for socio-demographics, poverty and orphan status

Step	Independent Variables	R^2	R^2 change	F change	β	N
1	Gender,	.048	.048	4.22**	-.136*	-.483*
	Age				.171**	.163**
	Language				.042	.090
2	Gender,	.095	.047	6.53**	-.160**	-.568**
	Age				.195**	.186**
	Language				.052	.110
	Food security				.011	.020
	Assets				-.216**	-.396**
3	Gender,	.100	.005	1.32	-.157*	-.558*
	Age				.185**	.177**
	Language				.050	.106
	Food security				.017	.031
	Assets				-.206**	-.378**
	Orphan status				.070	.259
4	Gender,	.110	.010	2.90	-.158**	-.562**
	Age				.197**	.188**
	Language				.055	.118
	Food security				.016	.030
	Assets				-.208**	-.381**
	Orphan status				.020	.075
	HIV group status				.114	.415

ANOVA for Final model (step 4): F(7,248) for entire model = 4.39 , *p* < .001; *denotes significance at the .05 level, ** denotes significance at the .01 level, *** denotes significance at the .001 level

4.4 Social support

Question: Do participants in the HIV group perceive lower levels of social support compared to participants in the comparison group? Is there an association between social support and mental health outcomes? Do differences in levels of mental distress between the HIV and comparison group persist after controlling for differences in perceived social support?

Summary: Participants in the HIV group perceived lower levels of global social support (*p* = .043) and lower levels of caregiver support (*p* = .026) using the Social Support Scale. There were no group differences with either perceived friend support or perceived support from another person.

Perceived social support was associated with mental health outcomes, with higher scores on perceived social support being associated with better mental health. The global perceived social support (*r*: -.212 to -.313), perceived caregiver support (*r*: -.152 to -.286)) and perceived friend support (*r*: -.130 to -.309) had a significant negative correlation with all mental health outcomes, except emotional problems and impact scores. After controlling for the effects of perceived social support, the differences in mental distress between the HIV and comparison group were no longer significant for total difficulties and conduct problems.

Participants rated the level of perceived support received from their main caregiver, friends and one "other" person from their environment that they felt was supportive producing a global score of perceived social support as well as scores for each of the three subscales (caregiver, friend, other), with higher scores reflecting more supportive environments. The "other" subscale allowed participants to select a person who the considered as "helpful in (their) life" – a person from their family, school or any other context. Most participants chose a parent (24.4%), that is, the parent who was not the main caregiver, followed by a sibling (15.9%) or another family member (34.5%), such as a grandmother or an aunt/uncle. About 10.1% of participants chose their teacher, 5% chose a neighbour, 6.6% did not choose anyone and 6.6% chose other people (e.g. pastor/counsellor/doctor etc.).

4.4.1. Perceived social support: Group comparisons

Group differences in total perceived social support, as well as for each of the sub-scales (caregiver, friend, other) were assessed with Mann-Whitney U test (Table 24). The tests were two tailed and significance was set at 95% (*p* < .05). Overall, participants in the HIV group perceived significantly lower global social support (*Mdn* = 20.0, *M* = 18.31, *SD* = 4.16) than participants in the comparison group (*Mdn* = 19.0, *M* = 19.44, *SD* = 3.60), *U* = 6625.5, *Z* = -2.02, *p* = .043, *r* = -0.126. Similarly, for caregiver support, participants in the HIV group perceived significantly less support (*Mdn* = 7.0, *M* = 6.22, *SD* = 1.81) than participants in the comparison group (*Mdn* = 7.0, *M* = 6.74, *SD* = 1.49), *U* = 6622.0, *Z* = -2.22, *p* =.026, r = 0.138. There were no significant group differences for perceived friend support and perceived support from the self-selected supportive "other",

Table 24 Association between social support and HIV group status

	HIV Group (n = 99)		**Comparison Group (n = 159)**		***P* value**
	M (SD)	*Mdn*	*M(SD)*	*Mdn*	
Social support	18.31 (4.16)	20.0	19.44 (3.60)	19.0	*p* < .05
Caregiver support	6.22 (1.81)	7.00	6.74 (1.49)	7.00	*p* < .05
Friend support	6.12 (1.89)	7.00	6.51 (1.53)	7.00	*ns*
Other support	5.97 (2.42)	7.00	6.20 (2.07)	7.00	*ns*

4.4.2 Social support and mental health

Bivariate correlations assessed associations between mental health outcomes and the global social support score as well as each of the subscales for the two group combined (Table 25).

Total social support: The global perceived social support had a significant negative correlation with all mental health outcomes, except emotional symptoms and impact scores. Participants who reported higher overall social support reported fewer total difficulties (*r* = -.275, *p* < .001), peer problems (*r* = -.313, *p* < .001), hyperactivity/inattention (*r* = -232, *p* < .001), conduct problems (*r* = -.212, *p* =.001) and more prosocial behaviour (*r* = .310, *p* < .001). The correlation coefficient showed medium effect sizes for peer problems and prosocial behaviour, with the remaining scales showing small effect sizes.

Support from caregiver: There was a significant negative correlation between mental health outcomes and perceived caregiver support for all the outcomes except emotional problems and the impact scale. Participants who perceived more caregiver support had significantly fewer symptoms for total difficulties (*r* = -.286, *p* < .001), peer problems (*r* = -.161, *p* = .009), hyperactivity/inattention (*r* = -.275, *p* < .001), conduct problems (*r* = -256, *p* < .001), total impact score (*r* = -.152, *p* = .014) and more prosocial behaviour (*r* =.258, *p* < .001). The correlation coefficient showed small effect sizes for all associations.

Support from friends: Participants who perceived more support from their friends had significantly fewer total difficulties (*r* = -.224, *p* < .001), peer problems (*r* = -.309, *p* < .001), hyperactivity/inattention (*r* = -.130, *p* = .037) conduct problems (*r* = -.137, *p* = .028) and more prosocial behaviour (*r* =.278, *p* < .001). The correlation coefficient showed small effect sizes for all associations. For non-parametric data, when the analysis was repeated with Spearman rank-order coefficient the association between perceived friend support and hyperactivity/inattention was no longer significant.

Support from others: Support from others had a significant negative correlation with peer problems (*r* = -.189, *p* = .002) and a significant positive correlation with the prosocial behaviour scale (*r* = .137, *p* = .028). The correlation coefficient showed small effect sizes for both correlations.

Table 25 Correlation between social support and mental health outcomes

	Total difficulties	**Emotional symptoms**	**Peer problems**	**Hyperactivity/inatt.**	**Conduct problems**	**Prosocial behaviour**	**Total Impact**
Total support[ab]	-.275***	-.048	-.313***	-.232***	-.212***	.310***	-.111
Caregiver[ab]	-.286***	-.121	-.161**	-.275***	-.256***	.258***	-.152*
Friend[ab]	-.224***	-.071	-.309***	-.130*	-.137*	.278***	-.096
Other[ab]	-.098	.058	-.189**	-.103	.076	-.137*	-.007

[a] Pearson correlation coefficient
[b] Confirmed with Spearman’s correlation coefficient for non-paramatric data. The association with hyperactivity/inattention and friend support was no longer significant
*denotes significance at the .05 level, ** denotes significance at the .01 level ***denotes significance at the .001 level

4.4.3 Group differences when controlling for the effects of social support

Section 4.2 described how the HIV group reported higher levels of total difficulties and conduct problems than the comparison group, even after controlling for socio-demographic variables and poverty indicators. This section considers whether the differences in mental health outcomes (total difficulties and conduct problems) persist after controlling for the effects of total perceived social support and caregiver support, the two scales in which group differences were present.

Total difficulties: We examined the association between total difficulties and HIV/comparison group, after controlling for the effects of socio-demographics, poverty variables and perceived social support (Table 26). After controlling for the effects of total perceived social support, there were no longer significant differences in total difficulties scores between the HIV and comparison group. Similarly, after controlling for the effects of caregiver support the group differences in reported total difficulties are no longer significant (Table 27)

Conduct problems: In a model which controlled for socio-demographic variables and poverty related variables, the differences in conduct problems between the HIV and the comparison groups remained significant, with participants in the HIV group having higher scores. However after controlling for the effects of total perceived social support, there was no longer a significant difference in the number of symptoms reported between the HIV and the comparison groups (Table 28). Similarly, after controlling for the effects of caregiver support the groups differences in reported conduct problems are no longer significant (Table 29).

Table 26 Regression analysis examining the effects of HIV status on total difficulties, controlling for socio-demographic factors, poverty and total support

Step	**Independent Variables**	**R^2**	**R^2 change**	**F change**	**β**	**B**
1	Age, Gender	.015	.015	1.82	.127 .006	-085 .359
2	Food security (breakfast) Assets (child)	.105	.091	12.41**	-.092 -.220	-1.82 -1.43**
3	Perceived total support	.147	.042	11.93**	-.195	-.302**
4	HIV group status	.154	.008	2.17	.089	1.001

F(6,243) for entire model = 7.40, $p < .001$

*denotes significance at the .05 level, ** denotes significance at the .01 level *** denotes significance at the .001 level

Table 27 Regression analyses examining the effects of HIV status on total difficulties, controlling for socio-demographics, poverty and caregiver support

Step	Independent Variables	R^2	R^2 change	F change	β	B
1	Age, Gender	.015	.015	1.820	.109 -.001	.359 .085
2	Food security (breakfast) Assets (child)	.105	.091	12.406***	-.110 -.211	-1.824 -1.429***
3	Caregiver support	.150	.045	13.014***	-.204	.766***
4	HIV group status	.157	.007	1.985	.085	.959

F(6,243) for entire model = 7.56, *p* < .001
*denotes significance at the .05 level, ** denotes significance at the .01 level *** denotes significance at the .001 level

Table 28 Regression analysis examining the effects of HIV status on conduct problems, controlling for socio-demographics, poverty and total support

Step	Independent Variables	R^2	R^2 change	F change	β	B
1	Age, Gender	.041	.041	5.274**	.168 -.139	.152* -.477*
2	Food security Assets	.091	.050	6.714**	-.030 -.188	-.196 -391**
3.	Perceived total support	.110	.019	5.185**	-.124	-.066*
4	HIV group status	.120	.010	2.794	.103	.376

F(6,243) for entire model = 15.84 , *p* < .001
*denotes significance at the .05 level, ** denotes significance at the .01 level,
*** denotes significance at the .001 level

Table 29 Regression analyses examining the effects of HIV status on conduct problems, controlling for socio-demographics, poverty and caregiver support

Step	Independent Variables	R^2	R^2 change	F change	β	B
1	Age, Gender	.041	.041	5.274**	.150 -.142	.152* .133*
2	Food security Assets	.091	.050	6.714**	-.038 -.177	-.196 -.391**
3.	Perceived caregiver support	.123	.032	8.903**	-.167	-.209**
4	HIV group status	.131	.008	2.334	.094	.342

F(6,243) for entire model = 17.37, *p* < .001
*denotes significance at the .05 level, ** denotes significance at the .01 level,
*** denotes significance at the .001 level

4.5 Predictors of mental distress

Question: Which variables are the best predictors for indicating potential clinical distress for the two groups combined?

Summary: After controlling for the effects of sociodemographic factors, orphanhood (OR: 7.09, 95% CI, 1.03 to 48.5, *p* = 0.047), food insecurity (OR: 14.44, 95% CI, 1.68 to 124.15, p = 0.015), child centred assets (OR: 0.21, 95% CI, .06 to .71, *p* = .012) and social support (OR: 0.68, CI, 0.52 to 0.88, *p* = 0.003) were significant predictors of whether or not a participant had scores in the clinical range for total difficulties.

Gender (OR: 0.33, 95% CI, 0.15 to 0.72, *p* = .005) and child centred assets (OR: 0.43, 95% CI, .29 - .63, *p* < .001) were significant predictors of whether or not a participant had scores in the clinical range for emotional problems. For conduct problems, age (OR: 1.54, 95% CI, 1.07 to 2.20, *p* = .019), child centred assets (OR: 0.14, 95% CI, 0.05 -0.37, *p* < .001) and social support (OR: 0.85, 95% CI, 0.74 to 0.98, *p* = .029) significantly predicted whether or not a participant scored in the abnormal range.

Logistic regression analysis was conducted to select the best subset of predictor variables for determining emotional and behavioural problems in the two group combined (*n* = 256). After controlling for socio-demographic factors, the potential of the following variables to predict scores in the “abnormal/clinical range” were tested: HIV status, orphan status, poverty and social support. Variables were selected based on their association with mental health continuous scores (See Section 4.3 and 4.4). Only scales which satisfied all the assumptions of binary logistic regression were included. These were the total difficulties scale, the emotional symptoms scale, the conduct problems scale and the peer problems scale[7].

4.5.1 Total difficulties

Using the hierarchical method, and controlling for age and gender, we examined the predictive power of HIV status, orphanhood, poverty and social support to determine total difficulties scores. Poverty variables showing the largest effect sizes (i.e. child centred assets and food security as measured by whether the participant ate breakfast that morning) were included in the analysis. The result of the hierarchical logistic regression analysis with all predictors is shown in Table 30. The full supplementary tables are included in Appendix 7.2. The analysis showed that

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[7] Hyperactivity was not included in the analysis due to low number (n = 8) of participants that fell in the abnormal range (3.1%). The prosocial behaviour scale was not included as the focus was to identify predictors of emotional and behavioural problems.

after controlling for age and gender, orphan status (OR: 7.09, 95% CI, 1.03 to 48.5, p = 0.047), food security (OR: 14.44, 95% CI, 1.68 to 124.15, *p* = 0.015), child centred assets (OR: 0.21, 95% CI, .06 to .71, *p* < 0.012) and social support (OR: 0.68, CI, 0.52 to 0.88, *p* = 0.003) significantly predicted whether a participant had scores in the clinical range for total difficulties. Participants who were orphaned were 7 times more likely to have scores in the clinical range and participants who did not have breakfast that morning (because there was no food in the house), were 14 times more likely to have scores in the clinical range. Having child centred assets and higher levels of social support decreased the odds of having scores in the clinical range. For every additional child centred asset there was a 0.21 chance of having a score in the clinical range, or, inverting the odds, every fewer child centred asset, increases the odds of having scores in the clinical range by 4.7. Finally, for every one point increase in social support there is a 0.68 chance of having scores in the clinical range, or inverting the odds, for an every one point increase in social support there is a 1.47 times chance that a participant does not have scores in the clinical range. The predictive power of the model improved from 95.4% at the baseline to 95.8% and the total explained variance as suggested by Pseudo r^2 (Nagelkerke´s *r*) improves from .0002 to .601 when all the predictors are included.

Table 30 Logistic regression analysis for total difficulties on socio-demographics, HIV status, orphan status, poverty and social support

		95% Confidence interval		
Variables	**Odds ratio**	**Lower limit**	**Upper limit**	***p*- values**
Age	0.86	0.56	1.32	.489
Gender	1.97	0.33	11.61	.454
HIV Group	4.12	0.51	33.23	.184
Orphan status	7.09	1.03	48.75	.047*
Food security	14.44	1.68	124.15	.015*
Child centred assets	0.21	0.06	.71	.012*
Social support	0.68	0.52	.88	.003**

*denotes significance at the .05 level, ** denotes significance at the .01 level

4.5.2 Emotional symptoms

The results of the logistic regression analysis with all predictors included are shown in Table 31. with supplementary tables included in Appendix 7.2. Gender (OR: 0.33, 95% CI, 0.15 to 0.72, *p* = .005) and child centred assets (OR: 0.43, 95% CI, .29 -.63, *p* < 0.001) were significant predictors of whether or not a participant had scores in the clinical range for emotional problems. Females were 3.03 times more likely to score in the clinical range for emotional problems (males having a 0.33 chance of having scores in the clinical range). For every additional child centred assets there was a 0.43 increase in odds of scoring in the clinical range, or, inverting the odds, for every decrease in child centred assets there is a 2.3 increase in the odds of scoring in the clinical range. The predictive power of the model did not improve, and the total explained variance according as suggested by Pseudo r^2 (Nagelkerke´s r) improves from .071 at the baseline model to .223 when all the predictors are included.

Table 31 Logistic regression analysis of total difficulties for socio-demographics, HIV status, orphan status, poverty and social support

		95% Confidence interval		
Variables	**Odds ratio**	**Lower limit**	**Upper limit**	***p*- values**
Age	0.99	0.81	1.22	.951
Gender	0.33	0.15	0.72	.005**
HIV Group	1.17	0.53	2.57	.706
Orphan status	1.22	0.55	2.71	.631
Food security	1.42	0.51	3.89	.502
Child centred assets	0.43	0.29	0.63	.000***
Social support	1.09	0.98	1.21	.100

** denotes significance at the .01 level***denotes significance at the .001 level

4.5.3 Peer problems

The result of the hierarchical logistic regression analysis, with all predictors included for peer problems, is shown in **Error! Reference source not found.**, with full supplementary tables included in Appendix 7.2. The analysis showed that after controlling for socio-demographic factors, orphanhood (OR: 11.74, 95% CI, 1.31 to 105.53, $p = 0.028$) and decreased social support (OR: 0.64, 95% CI, 0.49 to 0.83, $p < 0.001$) were significant predictors of whether or not a participant had scores in the clinical range for peer problems. Orphans were 11 times more likely to have scores in the clinical range for peer problems.

Table 32 Logistic regression of peer problems on socio-demographics, HIV status, orphan status, poverty and social support

		95% Confidence interval		
Variables	**Odds ratio**	**Lower limit**	**Upper limit**	***p*- values**
Age	0.77	0.49	1.20	.247
Gender	0.43	0.07	2.85	.381
HIV Group	1.45	0.21	10.29	.708
Orphan status	11.74	1.31	105.53	.028*
Food security	2.13	0.26	17.30	.480
Child centred assets	0.37	0.13	1.10	.074
Social support	0.64	0.49	0.83	.0006***

*denotes significance at the .05 level, ** denotes significance at the .01 level

Furthermore, every increase in social support there was a 0.64 chance of having scores in the clinical range, or alternatively, for an every one unit decrease in social support there is a 1.56 times chance that participants scored in the clinical range for peer problems. The predictive power of the model improved from 96.1% at the baseline to 97.0% and the total explained variance as suggested by Pseudo r^2 (Nagelkerke's r) improves from .004 to .535 when all the predictors are included.

4.5.4 Conduct problems

The result of the logistic regression analysis with all predictors included for conduct problems is shown in Table 33 with supplementary tables in Appendix 7.2. In the final model, age (OR: 1.54, 95% CI, 1.07 to 2.20, p = .019), child centred assets (OR: 0.14, 95% CI, 0.05 -0.37, p < 0.001) and social support (OR: 0.85, 95% CI, 0.74 to 0.98, p = .029) significantly predicted whether a participant had scores in the abnormal range for conduct problems. With every increase in age, there is a 1.54 chance of having scores in the clinical range for conduct problems. Inverting the odds ratio for child centred assets, every decrease in child centred assets increases the chance of having scores in the abnormal range by 7.14 and for social support, every one unit decrease in social support increases the odds of scoring in the clinical range by 1.18. Although the predictive power of the model did not improve, the total explained variance according to the Pseudo r^2 (Nagelkerke's r) improves from .086 at the baseline model to .503 when all the predictors are included.

Table 33 Logistic regression of conduct problems

		95% Confidence interval		
Variables	**Odds ratio**	**Lower limit**	**Upper limit**	***p*- values**
age	1.54	1.07	2.20	.019*
gender	3.19	0.77	13.14	.109
HIV Group	2.38	0.56	10.15	.242
Orphan status	2.47	0.58	10.47	.221
Food security	1.05	0.22	4.98	.949
Child centred assets	0.14	0.05	0.37	.000***
Social support	0.85	0.74	0.98	.029*

** denotes significance at the .01 level***denotes significance at the .001 level

4.6 HIV group: Risk factors and mental health

Question: What are the risk factors for mental distress in the HIV group?

Summary: In the HIV group, females reported higher scores on the emotional symptoms scale (*p* = .046). When only considering the HIV group, there were no significant differences in mental health for orphans versus non-orphans or age. Poverty indicators assessing food insecurity and assets, particularly child centred assets, was associated with mental health outcomes, having medium effect sizes. Fewer child centred assets was associated with more total difficulties (*r* = -.324, *p* = .001), emotional problems (*r* = -.317, p =.002) and conduct problems (*r* = -.338, *p* = .001), whereas food insecurity (having at least one day without enough food for everyone) was associated with more total difficulties, *t* (96) = -2.63, p = .010, and more emotional symptoms, *t* (96) = -3.45, *p* = .001.

There was an association with total perceived social support, perceived caregiver support and perceived friend support and mental health outcomes, with higher scores on social support being associated with poorer mental health. No health indicator was associated with mental health for HIV-positive participants. Self-reported non-adherence was associated with total difficulties (*p* = .034) and higher rates of conduct problems (*p* = .025), both with medium effect sizes. HIV status disclosure to others was associated with more total difficulties, (*p* = .007) and higher scores on the hyperactivity/inattention scale (*p* < .001). Participants reporting scores indicating higher stigma experiences reported significantly more total difficulties (p = .001), emotional symptoms (*p* < .001), peer problems (*p* < .030) and conduct problems (*p* = .025).

In this section, we only consider the HIV group (*n* = 99) and examine the association between different factors and mental health outcomes. This includes associations between mental health and socio-demographic factors, poverty and social support as well as HIV-specific variables, such as health status, stigma and HIV status disclosure to others. The findings for these analyses are shown in Table 34 and Table 35.

4.6.1 Mental health and socio-demographic factors

There was an association between emotional symptoms and gender, *t* (93) = -2.02, *p* = .046, with female participants showing higher rates of emotional symptoms, with magnitude of the difference between the two means (Mean difference = -0.98, 95% CI: -1.95 to -0.018) being medium (eta squared = .040). No association was found in the HIV group between mental health outcomes and age, orphan status, age of bereavement or whether participants lived with a biological parent (see Appendix 7.3).

4.6.2 Mental health outcomes and poverty

Food security: Participants in the HIV group who reported being food insecure, tended to report more emotional and behavioural problems. HIV-positive participants who did not have breakfast that morning due to lack of food, reported significantly more total difficulties, *t* (96) = 2.47, *p* = .015, and more symptoms of hyperactivity/inattention, *t* (97) = 2.97, *p* = .004. The magnitude of the difference between the means for both associations was medium: for total difficulties (mean difference = 4.94, 95% CI: 0.96 to 8.90) eta squared was .06 and for hyperactivity/inattention (mean difference =2.03, 95% CI: 0.67 to 3.39) eta squared was .083.

Similarly participants who reported one or more days when there was not enough food for everyone in the house reported significantly more total difficulties, *t* (96) = -2.63, p = .010, and more emotional symptoms, *t* (96) = -3.45, *p* = .001, than those that had sufficient food every day. The magnitude of the differences in the means was medium (eta squared = .067) for total difficulties (mean difference = -3.25, 95% CI -5.70 to 0.80) as well as emotional symptoms (mean difference = -1.75, 95% CI: -2.76 to -0.74; eta squared = 0.11).

Assets: Pearson bivariate correlations did not detect any statistically significant association between the total assets and any of the mental health outcomes (Table 34). However, there was a statistically significant negative correlation between child centred assets and mental health. Participants with fewer child centred assets reported higher scores on total difficulties (*r* = -.324, *p* = .001), emotional symptoms (*r* = -.317, p =.002) and conduct problems (*r* = -.338, *p* = .001), with all significant correlations having medium effect sizes (*r* > 0.3).

Household size, dwelling or household employment: There was a significant positive association between household size and hyperactivity/inattention (*r* = .304, *p* = .002) meaning that participants with larger household sizes reported higher scores on the hyperactivity/inattention scale. However, this association was not significant with Spearman's rank correlation coefficient. There was no association between remaining mental health outcomes and household size, dwelling type or whether any household member was working.

4.6.3 Mental health and social support

The associations between perceived social support and mental health outcomes are presented in Table 35.

Total social support: Higher scores on the global perceived social support was significantly associated with fewer total emotional and behavioural difficulties (*r* = -.328, *p* = .001), peer problems (*r* = -.408, *p* < .001), hyperactivity/inattention (*r* = -.280, *p* = .005) and conduct problems (*r* = -.224, *p* = .028) and more prosocial behaviour (*r* = .288, *p* = .004). The association between hyperactivity/inattention and total perceived support was not significant with Spearman's rank correlation coefficient. The correlation coefficient indicated a medium effect size for total difficulties and peer problems and a small effect size for conduct problems and prosocial behaviour.

Support from caregiver: Perceived support from the main caregiver was significantly associated with all outcomes, except emotional problems. Higher perceived caregiver support was associated with fewer total emotional and behavioural difficulties (*r* = -.337, *p* = .001), peer problems (*r* = -.256, *p* = .010), hyperactivity/inattention (*r* = -.300, *p* = .003), conduct problems (*r* = -.294, *p* = .003), and total impact (*r* = -.224, *p* = .026) and more prosocial behaviour scale (*r* = .203, *p* = .044). The association between total impact, and prosocial behaviour and support from a caregiver was not significant with Spearman's rank correlation coefficient. The correlation coefficient indicated a medium effect size for total difficulties and hyperactivity/inattention and a small effect size for the remaining scales.

Support from friends: Higher scores on perceived support from friends was associated with fewer total difficulties (*r* = -.316, *p* = .002), peer problems (*r* = -.415, *p* < .001) and conduct problems (*r* = -.219, *p* =.030) and more prosocial behaviour (*r* = .375, p < .001). The correlation coefficient indicated a medium effect size for all the associations, except conduct problems which had a small effect size.

Support from other: For the HIV group there was no association between scores on the support received from the participant selected supportive "other" and mental health outcomes.

4.6.4 Mental health and HIV-specific variables

The outcomes for the analysis assessing associations with HIV-specific factors and mental health outcomes are shown in Table 36. Non-significant findings are reported in Appendix 7.3.

Health indicators, disclosure of HIV status and adherence: No association was found between mental health outcomes and any of the health variables (CD4 count, viral load, time on ART), the age at which disclosure occurred or time since disclosure (Appendix 7.3). To assess medication adherence, participants were asked how often they forgot to take their medication over the last 7 days. The question is not a reflection of actual adherence as the participant may still have remembered to take the dose at a later time. About half the participants (52.6%) reported that they did not forget any doses; whereas 23 participants (23.7%) forgot to take one dose on time and a further 23 (23.7%) forgot to take two or more doses of their medication on time (Figure 10).

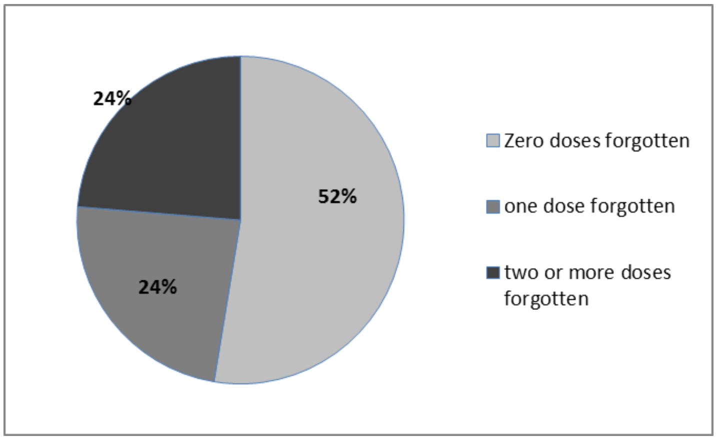

Figure 10 Percentage of participants who forgot doses in the last seven days.

The most cited reasons for poor adherence were being late for school or oversleeping (29.5%), playing (27.3%) and some change in the normal routine (27.3%), such as going away for the weekend or attending a wedding. There were no gender differences in adherence and, while older children remembered a little bit better than younger children, this difference was not statistically significant. Participants who reported that they had missed one or more doses of medication on time, reported more total difficulties (t (94) = -2.15, p = .034) and conduct problems (t (84) = -2.29, p = .025), with medium effect sizes for both total difficulties (mean difference = -2.5, 95% CI: -4.90 to –0.196 ; eta squared = .047) and conduct problems (mean difference = -0.88 , 95% CI -1.64 to -0.115, eta squared = .054).

HIV status disclosure to others: Participants were asked whether they had disclosed their HIV status to anyone. About 30% reported that they had disclosed their HIV status to at least one person. Of these, 50% had disclosed to friends and 42.9% to family members (of which 17.9% were siblings). Only one participant had disclosed to a teacher and another reported that s/he had disclosed to the HIV community.

Participants who had disclosed their status to at least one person, reported more total difficulties, t (93) = -2.74, p = .007, higher scores on the hyperactivity/inattention scale, t (94) = -4.36, (p<.001) and higher impact scores, t (94) = -2.56, (p<.05) than participants who had not disclosed their status. However, when confirmed with Mann Whitney U test these differences were not significant for Impact scores. The magnitude of the difference in the means for total difficulties (mean difference = -3.49, 95% CI -6.01 to -0.96) was medium (eta squared = 0.075) and for hyperactivity/inattention (mean difference = -1.81, 95% CI: -2.63 to -0.98) was large (eta squared = 0.168).

Support group attendance: Fifty one participants (52.0%) had attended the teen support group hosted at the hospital at least once. Of those, 43.1% reported that they attend all sessions. There was no association between mental health outcomes and whether participants attended the teen support group, even after controlling for age (participants who attended the teen support group tended to be older). There was also no association between whether participants had at least one HIV-positive friend and mental health outcomes.

Stigma: Stigma experiences were assessed with the Berger stigma scale. The scale produces a global stigma score and scores for each subscale for personalised stigma, negative self-image and public attitudes. Associations between mental health outcomes and stigma experiences, as well as the sub-scales for personalised stigma, negative self-image and public attitudes, were assessed using Pearson bivariate correlation. There was a positive correlation between the total stigma scores and total difficulties (*r* = .356, *p* = .001), emotional problems (*r* = 360, *p* < .001), peer problems (*r* = .226, *p* < .030) and conduct problems (*r* = .235, *p* = .025). The correlation coefficient indicated medium effects size for total difficulties and emotional problems (*r* > .3) and small effect size for peer and conduct problems (*r* < .3).

For the personalised stigma scale, the only association was a positive correlation with peer problems – participants with higher scores on the personalised stigma scale reported significantly more peer problems (*r* = .294, *p* = .005), with a small effect size. For the remaining scales, statistically significant positive correlations were detected between mental health outcomes and the negative self-image scale and the public attitudes scale. Participants with higher scores on the negative self-image scale reported significantly more total difficulties (*r* = .379, *p* < .001), emotional problems (*r* = .399, *p* < .001) and conduct problems (*r* = .236, p = .025), with medium effect sizes for total difficulties and emotional symptoms and small effect sizes for conduct problems. Participants who reported higher scores on the public attitudes scale reported higher scores for total difficulties (*r* =. 285, *p* = .006), emotional symptoms (*r* = .304, *p* = .003) and conduct problems (*r* = .216, *p* = .040). The correlation coefficient indicated medium effect for emotional symptoms and small effects for total difficulties and conduct problems.

Table 34 Associations between mental health outcomes and socio-demographics and poverty indicators[8]

	Total difficulties M (SD)	***p***	**Emotional symptoms M (SD)**	***p***	**Peer problems M (SD)**	***p***	**Hyperactivity/inat. M (SD)**	***p***	**Conduct problems M (SD)**	***p***	**Prosocial beh. M (SD)**	***p***	**Total Impact M (SD)**	***p***
Gender[a]														
Male	12.34 (5.70)	ns	4.19 (2.08)	.05	2.83 (1.98)	ns	2.74 (1.81)	ns	2.57 (2.02)	ns	8.06 (1.77)	ns	1.09 (1.59)	ns
Female	13.12 (6.03)		5.18 (2.72)		2.69 (2.06)		3.10 (2.23)		2.14 (1.78)		8.42 (1.65)		1.33 (2.12)	
Total assets[b]	-.129	.ns	-.184	ns	-.111	ns	-.115	ns	-.164	ns	-.103	ns	-.032	ns
Child centred assets[b]	-.324	.01	-.317	.01	-.072	ns	-.146[a]	ns	-.338	.01	-.080	ns	-.189	ns
Days no food[a]														
none	11.72 (5.66)	.01	4.15(2.23)	.00	2.60 (1.86)	ns	2.66 (1.94)	ns	2.31 (2.05)	ns	8.33 (1.66)	ns	1.06 (1.65)	ns
1 or more	14.97 (5.76)		5.90 (2.57)		3.09 (2.31)		3.50 (2.14)		2.42 (1.54)		8.09 (1.82)		1.53 (2.29)	
Breakfast[a]														
no	17.22 (6.87)	.05	5.55 (3.05)	ns	3.44 (2.60)	ns	4.78 (2.54)	.01	3.44 (2.35)	ns.	7.33 (1.50)	ns	2.67 (2.65)	ns
yes	12.29 (5.59)		4.62 (2.41)		2.69 (1.95)		2.74 (1.90)		2.23 (1.83)		8.34 (1.71)		1.07 (1.74)	
Household size[b]	.161[a]	ns	-.040	ns	.126	ns	.304	.01	.088	ns	-.132	ns	.132	ns

[a] Confirmed with Mann-Whitney U test for nonparametric data
[b] Pearsons Correlation coefficient and confirmed with Spearman's correlation coefficient where data did not meet parametric assumptions

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[8] Non-significant findings are reported in Appendix 7

Table 35 Correlations between social support and mental health outcomes (HIV group)

	Total difficulties	**Emotional symptoms**	**Peer problems**	**Hyperactivity/inattention**	**Conduct problems**	**Prosocial behaviour**	**Total Impact**
Total support[a]	-.328**	-.045	-.408***	-.280**	-.224*	.288**	-.179
Caregiver[a]	-.337**	-.113	-.256*	-.300**	-.294**	.203*	-.224*
Friend[a]	-.316**	-.108	-.415**	-.159	-.219*	.375***	-.154
Other[a]	-.061	.093	-.168	.130	008	.069	-.017

Note: Association between Hyperactivity/inattention and total support, between caregiver support and prosocial behaviour and total impact was not significant with Spearman's correlation coefficient.

[a] Pearson correlation coefficient. Confirmed with Spearman's correlation coefficient where data did not meet parametric assumptions. *denotes significance at the .05 level, ** denotes significance at the .01 level ***denotes significance at the .001 level

Table 36 Associations between HIV variables and mental health outcomes (HIV group)[9]

	Total difficulties M(SD)	*p*	Emotional symptoms M (SD)	*p*	Peer problems M (SD)	*p*	Hyperactivity/inat. M (SD)	*p*	Conduct problems M (SD)	*p*	Prosocial behaviour M (SD)	*p*	Total Impact M (SD)	*p*
Doses missed[a]														
no doses	11.61 (6.02)	.05	4.27 (2.47)	ns	2.57 (1.97)	ns	2.80 (2.29)	ns	1.96 (1.65)	.05*	8.22 (1.69)	ns	0.88 (1.52)	ns
1 or more	14.16 (5.52)		5.20 (2.46)		2.98 (2.10)		3.12 (1.75)		2.84 (2.08)		8.26 (1.77)		1.59 (2.21)	
HIV status disclosure [ab]														
no	11.79 (5.82)	.01	4.39 (2.52)	ns	2.73 (2.17)	ns	2.43 (1.81)	.001[d]	2.24 (1.98)	ns	8.25 (1.61)	ns	0.88 (1.49)	.05[d]
yes, at least 1	15.28 (5.46)		5.45 (2.37)		2.86 (1.75)		4.24 (1.99)		2.72 (1.73)		8.17 (2.00)		1.93 (2.49)	
Stigma														
Total[c]	.356	0.01	.360	.001	.226	.05	.123	ns	.235	.05*	-.048	ns	.170	ns
Pers. Stigma[c]	.194	ns	.141	ns	.294	.01	.040	ns	.051	ns	-.075	ns	.094	ns
Neg. self-image[c]	.379	.001	.399	.001	.176	ns	.187	ns	.236	.05*	-.019	ns	.167	ns
Public attitude[c]	.285	.01	.304	.01	.056	ns	.175	ns	.216	.05*	-.004	ns	.114	ns

[a] Confirmed with Mann-Whitney U test for nonparametric data
[b] Whether participant has disclosed their status to another person
[c] Pearson correlation coefficient, confirmed with Spearman's correlation where data was not parametric.
[d] Not significant with Mann Whitney U test

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[9] Non-significant findings are reported in Appendix 7

4.7 Predictors of distress in the HIV group

Question: Which variables best predict emotional and behavioural problems in the HIV group?

Summary: Analysis examined which variables were the strongest predictors for symptoms of distress in the HIV group, selecting variables which had significant associations. Variables included social support, poverty and stigma. For the HIV group, child centred assets (β = -.213, *p* = .023) and stigma (β = .268, *p* = .009) were the best predictors for symptoms of emotional and behavioural distress on the total difficulties scale, with social support (β = -.189, *p* =. 061) just outside of significance.

For emotional problems, the only significant predictors was stigma (β = .314, *p* = .002), with child centred assets just outside of significance (β = -.193, *p* = .055). Social support had a significant protective effect on peer problems (β = -.349, *p* = .001). For conduct problems, the only significant predictor was child centred assets (β = -.309, *p* = .004) with stigma just outside of significance (β = .204, *p* = .054).

Section 4.5 the set of variables which best predicted whether a participant was likely to have scores in the clinical range for the two groups combined was examined. In this section multiple regression analysis examined the extent to which variables best predict mental distress in the HIV group, using continuous scores. Variables with significant bivariate correlations or associations were retained for the analysis and entered in a hierarchical fashion into the model. These were: poverty, social support and stigma. Since demographic variables were not significantly associated with this outcome they were not controlled for in the analysis, except for emotional symptoms, where gender was controlled for. Findings are presented in Tables 37 – 40.

4.7.1 Total difficulties

A significant result was obtained, F(4,85) = 6.07, $p < .001$, $r^2 = .222$, with the model containing the predictors of child centred assets, food security, social support and HIV-related stigma explaining 22% of the variance in total difficulties scores for the HIV group (Table. 37). Child centred assets, t = -2.32, *p* = .023, β = -.231, and stigma, t = 2.67, *p* = .009, β = .268, significantly predicted total difficulties scores, with social support just outside of significance, β = -.189, *p* = .061.

4.7.2 Emotional symptoms

After controlling for the effects of gender, a significant result was obtained F(5,84) = 6.165, $p < .001$, $r^2 = .268$, with the model containing food security, child centred assets, social support and HIV-related stigma, explaining 26.8% of the variance (Table 38). The only significant predictor was stigma, t = 3.18, $p = .002$, $\beta = .314$, with child centred assets just outside of significance, t = 1.94, $p = .055$, $\beta = -.193$.

4.7.3 Peer problems

A significant result was obtained, F(4,86) = 4.150, $p = .004$, with the model including child centred assets, food security, social support and HIV-related stigma explaining 16% of the variance in peer problems scores (Table 39). The only significant predictor was social support, t = -3.395, $p = .001$, $\beta = -.349$.

4.7.4 Conduct problems

A significant result was obtained with the model containing food security, child centred assets, social support and HIV-related stigma explaining 16% of the variance in conduct problems scores, F(4,85) = 4.058, $p = .005$ (Table 40). It was found that child centred assets, was the only significant predictor, t = -2.988, $p = .004$, $\beta = -.309$, with stigma just outside of significance ($p = .054$).

4.7.5. Hyperactivity/inattention

The model containing the predictors was not significant, F(4,86) = 2.028 , $p > .05$, with the model containing the predictors child centred assets, food security, social support and HIV-related stigma explaining only 8% of the variance.

Table 37 Regression analysis examining predictors for total difficulties (HIV group)

Step	**Independent Variables**	**R^2**	**R^2 change**	**F change**	**β**	**B**
1	Food security	.105	.105	5.077**	.145	1.792
	Child Centred assets				-.254	-1.588*
2	Food security	.157	.051	5.337*	.093	1.153
	Child Centred assets				-.256	-1.601*
	Social support				-.234	-.334*
3	Food security	.222	.065	7.126**	.046	.562
	Child Centred assets				-.231	-1.447*
	Social Support				-.189	-.269
	Stigma				.268	.292**

Overall model F(4,85) for entire model = 6.066 , $p < .001$; $R^2 = 0.222$, Adjusted $R^2 = 0.185$
*denotes significance at the .05 level, ** denotes significance at the .01 level, *** denotes significance at the .001 level

Table 38 Regression analysis examining predictors for emotional symptoms (HIV group)

Step	**Independent Variables**	**R^2**	***R*^{2} change**	**F change**	**β**	**B**
1	Gender,	.062	.062	5.84*	.249	1.269*
2	Gender,	.179	.117	6.120**	.145	.739
	Food security				.223	1.223*
	Child centred assets				-.227	-.630*
3	Gender,	.180	.001	.105	.141	.715
	Food security				.232	1.267*
	Child centred assets				-.227	-.632*
	Social support				.033	.021
4	Gender,	.268	.088	10.15**	.172	.876
	Food security				.169	.924
	Child centred assets				-.193	-.535
	Social support				.082	.052
	HIV stigma				.314**	.153**

Overall model F(5,84) for entire model =6.165 , $p < .001$
R^2 = 0.268, Adjusted R^2= 0.225
*denotes significance at the .05 level, ** denotes significance at the .01 level, *** denotes significance at the .001 level

Table 39 Regression analysis examining predictors of peer problems (HIV group)

Step	**Independent Variables**	**R^2**	***R*^{2} change**	**F change**	**β**	**B**
1	Food security	.001	.001	.039	.023	.096
	Child Centred assets				-.013	-.027
2	Food security	.137	.136	13.704***	-.059	-.244
	Child Centred assets				-.020	-.041
	Social support				-.377	-.181***
3	Food security	.162	.025	2.557	-.086	-0.36
	Child Centred assets				-.008	-0.02
	Social Support				-.349	-0.17**
	Stigma				.165	0.06

Overall model F(4,86) for entire model = 4.150, $p = .004$
*denotes significance at the .05 level, ** denotes significance at the .01 level, *** denotes significance at the .001 level

Table 40 Regression analysis examining predictors of conduct problems (HIV group)

Step	**Independent Variables**	**R^2**	***R^2* change**	**F change**	**β**	**B**
1	Food security	.100	.100	4.809*	-.102	-.409
	Child Centred assets				-.326	-.664**
2	Food security	.123	.023	2.275	-.137	-.548
	Child Centred assets				-.328	-.667**
	Social support				-.156	-.072
3	Food security	.160	0.38	3.806	-.173	-.693
	Child Centred assets				-.309	-.629**
	Social Support				-.122	-.056
	Stigma				.204	.072

Overall model F(4,85) for entire model = 4.058 , *p* = .005
R^2 = 0.160, Adjusted R^2 = 0.121 *denotes significance at the .05 level, ** denotes significance at the .01 level, *** denotes significance at the .001 level

4.8 Summary

Although a statistically significant difference was found between the mental health of adolescents living with HIV and children from a community comparison group, the findings are interpreted with caution, bearing in mind the small effect sizes. In addition, multivariate analysis suggested that orphanhood and social support may be some of the factors that mediate this observed difference. Participants in the HIV group perceive/receive significantly less social support than the comparison group and have a 6 times greater odds of being orphaned.

Various poverty indicators, particularly food insecurity and child centred assets, showed a significant association with mental health outcomes, for both the two groups combined and also for the HIV group alone. For the HIV group, stigma, poverty factors and social support emerged as significant predictors for emotional and behavioural symptoms of distress. The implications of these findings are discussed in the next chapter.

CHAPTER FIVE: DISCUSSION AND CONCLUSION

This study sought to determine the level of mental health problems in adolescents living with HIV and to evaluate context specific factors that may impact mental health outcomes in Namibia, a high HIV prevalence country. To do this a group of HIV-positive adolescents at an urban clinic were compared to a locally selected and matched comparison group. It is the first time such a study has been conducted in the Namibian context. This chapter discusses the key research findings and outlines the key clinical and policy implications. It also provides a discussion of the major limitations and strengths of the study. Finally the chapter presents some recommendations for future investigations.

5.1 The mental health of adolescents living with HIV

Using the SDQ self-report tool, 12.2% of adolescents qualified for significant clinical distress, with an additional 16.3% in the borderline range, using Western-established norms, which, nonetheless had been used in other studies in the region (Cluver, 2007; Devries et al., 2014; Kinyanda, Kizza, Abbo, Ndyanabangi, & Levin, 2013; Menon et al., 2007; Mueller, Alie, Jonas, Brown, & Sherr, 2011; Small et al., 2014). Unfortunately there are no established epidemiological data available for adolescent mental health in Namibia with which to compare this prevalence. However, the finding are consistent with estimated prevalence (10-20%) of mental illness in adolescents worldwide (WHO, 2001) and in sub-Saharan Africa (14.3%) (Cortina et al., 2012), but lower than majority of previous studies with HIV-positive adolescents both in sub-Saharan Africa (17.3% to 51.2%) and worldwide (majority in the 24-35% range).

Important characteristics of participants in the current study may explain the comparatively lower rates of participants scoring in the clinical range compared to previous studies. Firstly, participants were fairly homogeneous with respect to health factors. Fewer than 5% of the participants had advanced to severe immune suppression and all participants were rated by the provider to be the WHO clinical stage 1 (asymptomatic, *n* = 91). Better health has served as a protective factor for HIV-positive adolescents in some previous studies (Kamau et al., 2012; Menon et al., 2007). Secondly, participants were sourced from a paediatric clinic of an urban hospital providing adolescent-friendly services where participants are in regular contact with service providers. This may be an important community level support structure (Petersen et al., 2010). Since majority of participants (+90%) in the current study were perinatally infected, they would have been using the services at the clinic from a young age. To what extent the hospital/clinic setting serves as a protective space for participants was not directly investigated, but should be considered when interpreting these findings, and will be important for future investigations. No empirical study reviewed in Chapter one examined this variable, although its importance has been suggested in qualitative research (Petersen et al., 2010; Kang et al., 2008). Thirdly, participants report knowing their status for an average of four years and have gone through a very structured and age-appropriate disclosure process (See Appendix 6.2) (O'Malley et al., 2015), which may have lessened the emotional and psychological impact of being HIV-positive. Finally, just over half the participants in the current study (52.0%) attended the hospital support group for adolescents. Future research should explore the potential protective effects of these factors as they may highlight aspects of the environment that could be strengthened and lead to a reduction in the psychological impact of the disease. Given that one of the priorities for Namibia is to "deliver comprehensive, adolescent-focused, clinical HIV services to all adolescents living with HIV" (MoHSS, 2012c), determining which of the site-specific factors mentioned above may play a role as a protective factors would strengthen the evidence base for the implementation of such services across Namibia.

Nevertheless, a high proportion of participants scored in the clinical (22%) and borderline range (14.3%) range for emotional problems. This is consistent with previous research both in studies in sub-Saharan Africa (Kamau et al., 2012; Musisi & Kinyanda, 2009) and elsewhere (Kapetanovic et al., 2010; Lam et al., 2007; Lee et al., 2011; Mellins et al., 2006; Mellins et al., 2009a), where emotional problems such as depression and anxiety tend to be the most widely reported symptom cluster and disorder. Internalising problems, particularly depression, have been linked to low adherence in people living with HIV (Nakimuli-Mpungu et al., 2012), and, although less consistently, to sexual risk behaviour in adolescents, most likely through mechanisms of low self-esteem and decreased assertiveness (L. K. Brown et al., 2010; Flisher & Dawes, 2009; Lehrer, Shrier, Gortmaker, & Buka, 2006). The identification and treatment of emotional problems is therefore important from a preventative and public health perspective.

While internalising symptoms tended to be reported more frequently, the current study also found relatively high rates of conduct problems in the clinical (12.2%) and borderline range (12.2%). Conduct and externalising problems have been found to contribute to risk taking behaviour, such as sexual risk behaviour, which includes low condom use or substance use (Donenberg, Emerson, Bryant, Wilson, & Weber-Shifrin, 2001; Williams et al., 2010), as well as problems with treatment adherence (K. Malee et al., 2011). In the context of the above concerns and the impact mental health problems have on the individuals' quality of life, the findings from the current study provides justification to increase awareness of and address the mental health needs of adolescents living with HIV. The implications of this will be further addressed in Section 5.5.

5.2 Group differences in mental health

In line with the study hypothesis, the study found that participants in the HIV group had more total difficulties and more conduct problems than a matched community group adding to evidence that having HIV is a risk factor for increased mental health problems. These differences persisted after controlling for differences in socio-demographic and poverty factors between the two groups. However, the findings are treated with caution as the size of the effect of the difference was small. No group differences were found for emotional problems, peer problems, hyperactivity/inattention, prosocial behaviour or impact scores, although the HIV-positive group tended to report more problems on all scales and lower prosocial behaviour.

The review in Chapter one highlighted the scarcity of research examining mental health in adolescents living with HIV in sub-Saharan Africa, particularly an absence of studies with comparison groups. The only previous controlled study similarly found higher prevalence of mental health problems in adolescents living with HIV compared to an HIV-unaffected local comparison group (Betancourt et al. 2014). Our study did not determine whether participants in the comparison group may be HIV-affected, either living with an HIV-positive caregiver/relative or orphaned by AIDS causes. This may have influenced the small effect sizes found, as research shows that HIV-affected children, either through parental death or parental HIV, have increased risk of experiencing mental health problems (Betancourt et al., 2014; Cluver & Gardner, 2007; Sherr et al., 2014). However, as mentioned, the small differences detected may also be linked to specific characteristics of the HIV-positive group (health, length of time they knew their HIV status, structured disclosure process, access to support group, regular contact with services providers). While Betancourt et al. (2014) found higher rates of mental health problems in HIV-positive participants, findings in other low and middle income contexts were more mixed. Some studies found higher prevalence of mental health problems in HIV-positive adolescents (Banerjee, 2007; Puthanakit et al., 2013), others found higher prevalence in the comparison group (Lee et al., 2011) and others did not find any group differences (Louthrenoo et al., (2013). While the current study adds to the literature that shows a tendency for HIV-positive adolescents to have more mental health problems, more research in low and middle income countries, particularly in sub-Saharan Africa, is necessary to understand the conditions under which HIV exerts specific negative effects, and how this may differ across regions. While being HIV-positive may put an adolescent at risk for mental health problems, it is not always the case –there may be context specific factors that influence the extent to which being HIV-positive is a risk factors. The current study was also interested in identifying which of those factors were important in Namibia.

5.3 Risk factors, protective factors and mental health outcomes

HIV-positive adolescents had significantly higher rates of orphanhood and received less social support than the comparison group. Furthermore, poverty, orphanhood and social support showed association with mental health outcomes in both groups and HIV-related variables, such as stigma, adherence and HIV status disclosure to others was associated with mental health outcomes in the HIV group.

5.3.1 Orphanhood

HIV-positive adolescents had exceptionally high rates of being orphaned (62.6%), almost two thirds of the entire group, with 17.2% being double orphans, compared to 2.7% reported for children/adolescents below 18 in the general population (Namibia Statistics Agency, 2013a). Indeed, adolescents living with HIV were 6 times more likely to be orphans than participants in the comparison group. The proportion of orphans in the comparison group (20.8%), although slightly lower than the national prevalence for this age range (21.9% and 26.8% for 10-14 and 15-17 age ranges respectively), is comparable to national statistics when considering that Khomas region, where the research was conducted, tends to have fewer orphans overall (9.3%) when compared to the national prevalence (15.7%) (MoHSS and ICF International, 2014).

This is in line with other studies in sub-Saharan Africa, where orphan rates in HIV-positive adolescents varied from 52% to 97.6% (Lowenthal et al., 2012; Musisi & Kinyanda, 2009; Tadesse et al., 2012), and with studies outside of Africa, where orphanhood in HIV-positive adolescents was more common than HIV-unaffected comparison groups (Banerjee, 2007; Lee et al., 2011). However, only half of the studies reviewed in Chapter one report orphan statistics and our findings underscore the importance of future studies to include this variable when conducting studies with HIV-positive children and adolescents. This is particularly important due to the role orphanhood has been found to play in mental health problems (Cluver et al., 2014). Indeed, research show that children and adolescents orphaned by AIDS are the most vulnerable compared to orphanhood by other causes (Cluver et al., 2007; Doku, 2009). Furthermore, after controlling for orphan status, the group differences in mental health disappeared, suggesting that orphanhood may play a mediating role in mental health differences. HIV-positive adolescents have additional risk factors, which includes being orphaned, increasing the chances of developing mental health problems, over and above their HIV status. This was the first study that specifically considered the role that orphanhood contributes to differences in mental health problems between HIV-positive adolescents and those from the community. It will be important for those providing services to HIV-positive and other affected children to enquire about parental bereavement. Namibia has some specific policy initiatives for orphans and vulnerable children (Ministry of Education, 2008; Ministry of Gender, Equality and Child Welfare, 2010), and these will be discussed in the context of reducing the overall effects of poverty (Section 5.3.3)

5.3.2 School performance

While grade repetition rates for this sample are high (47%), HIV was not found to be a specific risk factor for poorer educational performance as assessed by grade repetition. However, there was a tendency for HIV-positive participants to have repeated a grade more than the comparison group. Unfortunately, grade repetition in the current study cannot be compared to national statistics, as lifetime repetition rates are not available, although statistics show that repetitions are high (e.g. 20.6% in grade 1 and 31.6% for grade 8) (Ministry of Education, 2012. The role of being on long term treatment needs to be considered as a protective facter given that all of the HIV-positive participants are on ART. In fact majority (80%) have been on ART for more than 5 years potentially reducing the cognitive and neurological effects of HIV (Laughton et al., 2013; Smith et al., 2012). Although grade repetition may be a simple form of assessing differences in school performance, this is the first study in sub-Saharan Africa which has compared the school performance of HIV-positive adolescents with a matched comparison group. School performance can have effects on future quality of life, employment prospects and future drop-out rate (Laughton et al., 2013) and has been found to predict non-adherence in HIV-positive adolescents (Williams et al., 2006). More research into the factors influencing school repetition and how to identify those at risk are important in order to adequately plan educational support to learners. Other methods, such as cognitive or neurological tests may be added in future studies to detect more subtle differences (Bomba et al., 2010; Puthanakit et al., 2013).

5.3.3 Poverty

While some research has suggested that certain groups of HIV-affected children, such as AIDS orphans, may live in poorer conditions (Cluver et al., 2008b), adolescents living with HIV may not necessarily be worse off than their peers from the same community. The current study did not find any differences on poverty indicators between HIV-positive adolescents and a community comparison group. Betancourt et al. (2014) similarly found that neither youth living with HIV nor HIV-affected youth from the same community were worse on poverty indicators when compared to HIV-unaffected youth in Rwanda. However, the literature on this is particularly sparse. In addition, this may not necessarily apply to other contexts. Louthrenoo et al. (2013), for example, using family income as an indicator; found that, in Thailand , HIV-positive youth came from poorer households whereas, in contrast, studies from the U.S. found that the HIV-positive youth tend to live in more advantaged households than comparison groups of HIV-affected youths (Gadow et al., 2012; Kang et al., 2011; Malee et al., 2011; Mellins et al., 2009b; Mellins et al., 2012). However, our findings and that of Betancourt et al. (2014) suggest that in sub-Saharan African contexts, the same toxic effects of poverty may be present in both HIV-positive and HIV-unaffected groups.

A total of 46.1% of children lived in a shack (informal settlement) which is higher than what is expected in the Khomas region (25.7%) (RAISON, 2014). However, this may be due to the study being focussed in a low income geographical area where informal settlements are more likely to occur. Of particular concern are the high rates of food insecurity, with 35.5% of participants indicating at least one day in the past week when there was not enough food for everyone in the house, and 17.4% reporting at least two days without enough food. Furthermore, 12.4% of the sample did not have breakfast that morning due to there not being anything in the house to eat. Food insecurity is clearly not only an issue for younger children, but also for adolescents. These insecurities are likely to be heightened in rural areas, where children tend to be more affected by poverty (Namibia Statistics Agency, 2012a).

Although the effects of nutritional vulnerability may not be as challenging for adolescents as for infants and younger children, inadequate nutrition can retard their growth and sexual maturity (WHO, 2005). Adolescence can be an important window period during which the nutritional imbalances of childhood can be corrected. For adolescents living with HIV, particularly those on ART, food insecurity has been associated with decreased adherence (Dewing et al., 2015), reduced immunity and incomplete virologic suppression as well as mortality (Anema, Vogenthaler, Frongillo, Kadiyala, & Weiser, 2009). Other adverse health effects for HIV-positive adolescents include increased hospitalisations and malnutrition (Anema et al., 2009; Weiser et al., 2011). Focussing on food insecurity therefore has direct public health benefits, since virologic suppression, associated with optimum adherence, is an important factor in the transmission of HIV. The effects of poverty may also increase the risk for HIV transmission through other mechanisms. Poverty, for example, may make young girls' more vulnerable to engage in transactional sex or age-disparate sex; specific situations that reduce young women's power to negotiate safer sexual practices such as condom use (Andersson & Cockcroft, 2012). Indeed, research in South Africa showed that cash transfers in the form of a grant to vulnerable children as a method for poverty reduction, reduced both the incidence and prevalence of transactional and age-disparate sex in adolescent girls (Cluver et al., 2013). Poverty alleviation programmes, especially those focussed on alleviating food insecurity, may have a host of positive impacts, in addition to improved mental health.

In the current study, poverty did not mediate differences in mental health between the two groups, but poverty indicators, particularly food insecurity and a lack of child-centred assets were associated with increased mental health problems, showing small to medium effects in both groups. Participants experiencing food insecurity were 14 times more likely to have scores in the clinical range for total difficulties, irrespective of HIV status, and a lack of child centred assets was a significant predictor of total difficulties, emotional problems and conduct problems for HIV-positive participants. Again there is a paucity of rigorous research examining the association of poverty factors with mental health (Lund et al., 2010; Lund, 2014), particularly in HIV-positive children and adolescents, although food security has been linked to psychological problems in other vulnerable children (Cluver et al., 2008) and

Betancourt et al. (2014) showed that “daily hardships”, which included food insecurity, explained mental health differences between HIV-positive and a comparison group of non-affected children.

A range of policies to combat poverty are in place in Namibia, including Child Welfare Grants through Ministry of Gender Equality and Child Welfare and nutritional support for orphans and vulnerable children though the Ministry of Education (Ministry of Education, 2008; Ministry of Gender, Equality and Child Welfare, 2010). Child welfare grants in Namibia are provided as cash-based transfers and include:

- a Maintenance Grant for a biological parent of a child younger than 18 years whose other parent (a) is receiving an old-age pension or disability grant, (b) has passed away, or (c) is serving a prison sentence of six months of longer,
- a Foster Care Grant for any person who undertakes the temporary care of any child who has been found to be in need of care,

The current study did not assess the uptake of grants in adolescents living with HIV as pilot work showed that many participants, especially participants in the younger age groups, were not familiar with the terminology. Future studies that include caregiver interviews, should include this variable as it would be informative to determine the proportion of children and adolescents accessing grants and what impact this could have on their health and wellbeing.

Empirical analysis has revealed that the receipt of the Maintenance Grant or Foster Care Grant did not have a statistically significant poverty-reducing effect (Levine, van der Berg, & Yu, 2009). One of the reasons for this may be due to the low uptake of grants (Namibia Statistics Agency, 2012a) or that the amount provided is insufficient to meet the needs of children (approximately 14Euros/ month). Furthermore, multiple barriers include problems with monitoring that the grant reaches its intended recipients, the length of time to process the application and an abuse of the system (Biemba et al., 2009; Kanjeke, 2009). Further research is required to assess the effectiveness of the current grant system and improvements in mechanisms for monitoring and follow-up are required (Kanjeke, 2009). In addition, no mention is made of HIV-positive children and whether the current grant system would reach and fulfil the requirements of children and adolescents living with HIV.

There is a debate around whether to make a child support grant available to all children and not only for specific vulnerable children, like orphans. The argument is that the vulnerabilities driven by poverty and socioeconomic factors are commonly found in all children within the same contexts (Levine et al., 2009; Meintjies, Budlender, Giese, & Johnson, 2003). The proposed Universal child grant, a cash transfer initiative, would be available for all children and therefore would benefit all adolescents living with HIV, not only those that are orphaned or in need of care.

Nevertheless, the ability of such a Universal grant to meet the basic costs of the nutritional and other needs of those on ARV has not been discussed. Moreover, there are other costs, for example the transport costs associated with travelling to hospital appointments. Indeed many adolescents mentioned taxi fares as a barrier to attending the hospital support. The form in which assistance should reach HIV-positive children and adolescents requires clear strategies, due to the stigma attached to identifying and recording the data of HIV-positive adolescents. There are strong and relevant arguments against formulating mainstream interventions specifically targeting AIDS affected children. It may be more justifiable to provide assistance through the services offered through MoHSS, rather than other Ministries, as this may protect HIV-positive children and adolescents from the potential adverse effects of stigma and labelling. These are tricky questions and require debate amongst service providers, policy makers, advocates, researchers and stakeholders.

5.3.4 Social support

Social support was examined as a factor that may buffer adolescents from the adverse psychological effects of having HIV. This study found that adolescents living with HIV receive/perceive lower global support and, specifically, lower caregiver support compared to participants in the comparison group. Few previous studies have compared the level of social support that adolescents living with HIV receive/perceive (Abramowitz et al., 2009; Lam et al.; 2007) and none have examined this variable in empirical research in sub-Saharan Africa. HIV-positive adolescents may receive/perceive less support from their caregivers since many of the caregivers may be biological parents whose own HIV status may compromise their caregiving abilities. More than half (56.6%) of the participants in the HIV group identified a biological parent as their caregiver. Not only the caregivers' own HIV status, but also the challenges of stigma, illness and treatment adherence may render them less able to provide support to children and adolescents (Doku, 2012). Although our study did not include caregiver HIV status, previous studies have generally shown that caregiver HIV status is associated with negative adolescent mental health (Sherr et al., 2014) and risk behaviours in adolescent living with HIV (Mellins et al., 2011) even if the participant does not know the HIV status of the parent (Musisi & Kinyanda, 2009). Furthermore, the stresses of living with HIV may also increase mental health problems experienced by caregivers who in turn will have negative effects on child and adolescent mental health (Malee et al., 2011; Mellins et al., 2006). There were no group differences in perceived friend support between the two groups. It may be that HIV-positive adolescents, through peer support networks are able to connect with other adolescents.

Although analysis found that adolescents living with HIV had significantly more mental health problems, when taking into account the effects of both global social support and caregiver support, these differences were no longer significant. Furthermore social support was negatively associated with practically all mental health outcomes; this was true for global perceived social support, caregiver support and support from friends for the overall group and the HIV group. These findings are consistent with the few previous studies that examined the effect of this variable on the mental health of HIV-positive adolescents (Abromowitz et al., 2009; Lam et al., 2007), although all were conducted in high income countries. This is an important and encouraging finding as it highlights the role that social support can play in reducing levels of mental distress for adolescents overall, but specifically for HIV-positive adolescents. Improving the social support systems, especially caregiver support and structures available to adolescents living with HIV is an important step to buffering the mental health of adolescents.

Contrary to expectations, neither attending the hospital support group for adolescents nor having HIV-positive friends was associated with any mental health outcomes for the HIV group. This was surprising, as qualitative data showed overwhelming positive experiences with the support group. Participants mentioned that the support group had been beneficial for:

- information/knowledge: “I am now used to talking about things like CD4 count, before I did not know” (female, 14),
- Personal growth: “I have changed a lot, especially my confidence. Before I was a shy person. Through facilitation of the groups I got my confidence and how to talk in front of other people” (male, 17),

- problem sharing: “You can share your problems with others and with the doctors (female, 16) and
- Friendship/community: “I have met new friends. Now all my close friends are (HIV) positive” (male, 17).

These benefits have been noted in qualitative studies with HIV-positive children in sub-Saharan Africa (Menon et al., 2007; Midtbø, Shirima, Skovdal, & Daniel, 2012; Mupambireyi, Bernays, Bwakura-Dangarembizi, & Cowan, 2014). However, rigorous research which systematically evaluates the effects of support groups in HIV-positive children and adolescents is absent. One study that evaluated the effectiveness of a peer-support group for orphans in Uganda found that the group was effective for decreasing psychological problems (Kumakech, Cantor-Graae, Maling, & Bajunirwe, 2009). Since support groups can take a variety of formats, research should focus on understanding which components would be effective for improving mental health. For example, support groups can be peer-led (Kumakech et al; 2009; Menon et al., 2007) or they may be led by medical staff or semi-professionals. Their aims may be health education, reduction of risky behaviours or decreasing stigma and isolation, all of which in turn may be linked to mental health. Groups let by medical staff and/semi-professionals can provide a space to disseminate accurate information on medical issues, such as adherence, and dispel any myths around HIV and medication issues. One study in Zimbabwe found that participating in group sessions led by a professional facilitator was significantly associated with excellent adherence (Gross et al., 2015). However, the feasibility of requiring staff with already high workloads to lead groups must be given serious consideration in each context. Peer led groups on the other hand may have the benefit of being participant driven and foster the development of youth leadership, important factors for resilience promotion and the development of agency (Greifinger & Dick, 2011; Skovdal & Daniel, 2012). As noted by Kang et al., (2008) in a qualitative study, “the shared experience of being born with HIV becomes and unspoken and powerful source of affiliation” (p. 231) for group participants. Similarly, one participant in the current research reflected on his experience in the support group: “It opens up the person and there is a bond. You might feel that you are the only one infected and when you join you see there are other kids and you feel so relieved” (Male, 18). Pitfalls of these groups also need to be understood. Peer led groups may be vulnerable to exclusion and confidentiality concerns and the formation of cliques (Kang et al., 2008). Good training of peer leaders can help create awareness and mitigate these pitfalls. Furthermore, stable funding is necessary as these groups have been found to be vulnerable to collapse in low resource settings (Mupambireyi et al., 2014).

Given that the support group attendance had no association with mental health outcomes in the current study, it should be considered that children and adolescents living with HIV with severe mental health needs may require help beyond what can be provided by a support group. In this case, the groups could serve as an avenue where those in need of more individualised help can be identified. Support groups have been an important resource for people living with HIV in low income contexts (Greifinger & Dick, 2011; Skovdal & Daniel, 2012). These structures are a valuable mechanism particularly in the light of limited health professionals available in low and middle income contexts (V. Patel et al., 2007).

5.3.5 HIV-related variables

Biological markers of health

No association was found with any health variable assessed in this study and any of the mental health outcomes. Previous studies have found a negative relationship between biological markers and mental distress (e.g. Kamau et al, 2012; Lam et al., 2007, Lourthrenoo et al, 2013), although other studies did not find any association (Kapetanovic et al., 2011; Malee et al., 2011). However, the lack of association with biological markers in the current study is not unexpected as there was very little variability in the sample, with most participants being relatively healthy. Future studies could perhaps also consider a history of AIDS defining illness, a history of virologic failure or changes in immune functioning over time to predict current mental distress.

Adherence

About half (52.6%) of participants reported complete adherence (taking all doses on time) with about a quarter (23.7%) forgetting to take two or more doses on time in the past 7 days. These findings should not be taken to indicate actual adherence as participants could still have remembered to take the doses within the window period. Studies using self-report methods tend to report complete adherence levels of between 20-58% in paediatric populations (Simoni et al., 2007) and quite a big range (16-99%) in adolescents in low and middle income countries (Hudelson & Cluver, 2015). The levels recorded in the current study are therefore consistent with previous studies. However it will be important for future studies to combine self-report formats for assessing adherence with other measures, such as pill counts (Simoni et al., 2007).

Participants reporting higher total difficulties and more conduct problems reported higher rates of non-adherence, although, as with cross-sectional research, causality cannot be determined. This association has important implications. Adolescents living with HIV have exceptionally high mortality rates compared to other age groups (Idele et al. 2014) and finding ways to improve adherence is a major priority for this group. Perinatally infected adolescents often began treatment as children and therefore have been taking the drugs for longer periods than adults, which further heighten the chances of treatment resistance (Lowenthal, 2014). There is an absence of effective interventions for improving adherence in low-income settings (Lowenthal, 2014). The finding of higher levels of conduct problems in non-adherent participants is important, given the link between risky behaviour and conduct problems (Donenberg et al., 2001; Williams et al., 2010)). What is also encouraging is that previous studies with adults have shown that improving mental health, particularly depression, can improve levels of adherence (Springer et al., 2012).

HIV status disclosure to others

About a third of participants (30%) had disclosed their HIV status to at least one person, either a friend or family. HIV status disclosure to others was associated with increased mental health problems, particularly total difficulties and hyperactivity/inattention with medium and large effect sizes respectively. Findings from previous research has been mixed some finding no association between HIV status disclosure to others and mental health outcomes (Wiener & Battles, 2006) and others finding an association with disclosure in the past 6 months and symptoms of anxiety (Elliott-DeSorbo et al., 2009). Lam et al. (2007) found that HIV status disclosure to acquaintances, but not family and friends, was associated with higher levels of distress.

HIV status disclosure to others has been recommended as it may increase the social support network of the person (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003) and lead to strengthening of family relationships and help with medical care (Li et al., 2007) and to prevent the spread of HIV in sexual relationships (Thoth et al., 2014). Findings from this study suggest that interventions that assist adolescents with their decision-making about HIV status disclosure are necessary. This would include understanding and identifying the motivators for HIV status disclosure. Adolescents should not feel pressured to disclose and decisions not to disclose should be recognised as valid. Since causality cannot be determined, it may be that those adolescents with higher emotional and behavioural distress were more likely to disclose their status.

A qualitative study which included 30 HIV-positive youth in Namibia reported that “every HIV-positive child interviewed cited personal and continuing experience of the negative consequences of disclosure, and emphasized greater safety in silence” (Ward and Mendelsohn, 2008, p. 4). Future studies should explore the factors which are likely to impact negative outcomes, such as stigma, discrimination and rejection and those factors that are likely to produce positive outcomes. No interventions aimed at assisting youth with HIV status disclosure has been assessed in the literature (Thoth et al., 2014). HIV status disclosure has also been taken as a proxy for stigma and discrimination based on the belief that HIV status disclosure to others will be more prevalent where stigma and discrimination is not (Nyblade & MacQuarrie, 2006). The findings on the negative effects of HIV status disclosure with mental health outcomes are consistent with high levels of stigma found in this and other studies.

Stigma

The negative effect of stigma on mental health is one of the main findings of this study. Mental health outcomes (total difficulties, emotional symptoms, peer problems, conduct problems) were associated with overall stigma, as well as the scales assessing negative self-image and public attitudes, assessed by the Berger stigma scale. This is not surprising as previous studies in Namibia have reported high levels of stigma in people living with HIV in Namibia (Baxen & Haipinge, 2015; Keulder, 2007; Nghifikwa, 2011; Ward & Mendelsohn, 2008). Furthermore the findings are consistent with previous studies using the same instrument, all conducted outside of sub-Saharan Africa (Rongkavilit et al., 2010; Tanney et al., 2012; Wright et al., 2007). Regression analysis confirmed that stigma was the strongest for total difficulties and emotional problems and showed a tendency to predict conduct problems. Stigma and discrimination are particularly common in educational settings in Namibia, including incidents of non-consensual disclosure by teachers (Baxen & Haipinge, 2015; Ward & Mendelsohn, 2008). In adolescence, the peer group becomes increasingly important. Adolescents increasingly look towards their peers for support and affirmation. In contexts of high stigma, fear of rejection from the peer group, has negative effects on their mental health (Kang et al., 2008). Developmentally adolescents are already at risk of feelings of mistrust, shame, doubt, guilt and inferiority (Wenar & Kerig, 2006) and internalised HIV-related stigma will heighten the chances of developing these vulnerabilities.

From a public health perspective, research has found that high levels of stigma and discrimination may delay HIV testing (Keulder, 2007; Pulerwitz, Michaelis, Weiss, Brown, & Mahendra, 2010), decrease the chances of HIV status disclosure to others (Pulerwitz et al., 2010) and decrease treatment adherence (Rao, Sagar, Kabra, & Lodha, 2007). Reducing HIV-related stigma can reduce some of the obstacles to healthy behaviour (Tanney et al. 2012). Unfortunately, only a small number of studies have assessed the effectiveness of interventions aimed at stigma reduction (Mahajan et al., 2008) particularly in developing countries (L. Brown, Macintyre, & Trujillo, 2003). Some mechanisms that have been shown to be effective include inducing interventions aimed at developing empathy for people living with HIV, but there is a lack of rigorous intervention in low and middle income countries.
Apart from reducing HIV-related stigma towards people living with HIV, interventions should also focus on assisting people living with HIV, who may experience distress as a result of the internalisation of negative attitudes directed towards them. Furthermore, there is a need for having effective tools to assess the effects of these programmes (Rongkavlit et al., 2010). The Berger stigma scale has shown good psychometric properties for assessing stigma experienced by HIV-positive youth in Namibia and translating the scale into local languages should be considered. Further implications are addressed in Section 5.5.

We have identified some areas at different ecological levels that could be the target of interventions and may reduce level of mental distress. We now consider some limitations of the study.

5.4 Study limitations

This section discusses the methodological, conceptual and practical limitations of the study.

Sample group limitations: Generalizability of results is limited by the purposeful and volunteer nature of the recruitment of the HIV group. Volunteer recruitment is the most practical and cost-effective option for this type of study, and the ethical way to recruit participants where confidentiality is such an important consideration. Given the sensitivity of the research, it was useful to recruit and interview adolescents within the familiar setting of the paediatric unit. However, recruitment from this clinic also meant that those adolescents who have not undergone testing or choosing not to use this type of clinic, or use private medical facilities or those not attending due to illness, were not included in the research.

Most participants (>90%) at the paediatric unit have been infected via vertical transmission, a small number being through either sexual abuse or accidental transmission (1 known case). These findings therefore may not apply to adolescents infected by early sexual debut or to adolescents that are newly diagnosed. Furthermore, the findings are limited to adolescents living with HIV at a specialised urban paediatric clinic, yet the majority of HIV-positive adolescents in Namibia may reside in rural areas (67% of Namibians live in rural areas) (Namibia Statistics Agency, 2013a). Important differences between urban and rural areas include a higher HIV prevalence (15.0% vs. 13.3%) and differences in the presence of risk factors that emerged as important in this study. Rural areas tend to have more orphaned children (10.7 vs. 14.2%) and children tend to fare worse on poverty indicators (Namibia Statistics Agency, 2012a). Future studies should consider including rural samples especially since most previous research in this area has been conducted in urban settings (Baxen and Haipinge, 2015; Siseho, 2011). However, in the context of high stigma there may be additional ethical considerations when conducting this research in rural areas. Urban areas may provide more anonymity to HIV-positive research participants.

Furthermore, the findings must be cautiously generalised beyond Khomas region, particularly regions that have higher HIV prevalence compared to Khomas (11.9%), as for example the Zambezi region (previously Caprivi, 23.7%). Some regions, especially northern regions (Ohangwena, Oshana, and Oshikoto) have almost double the rate of orphans compared to Khomas (Namibia Statistics Agency, 2013a).

Comparison group limitations: Non-HIV status in the comparison group could not be confirmed by an HIV test due to practical and ethical considerations. These include the cost of HIV tests and the ethics of exposing children to medical procedures in school settings. We were also unable to match the comparison group beyond age and gender as the characteristics of the HIV group, such as language, were not known and are not recorded in medical files.

Methodological limitation: In case-control methodologies it is recommended that interviewers are blinded as to whether participants are in the case or control/comparison group (Schultz & Grimes, 2002). The concern is that interviewers may elicit information differently if they know that status of the participant. It was impossible to conceal from the interviewers whether a participant belonged to the HIV or comparison group. To minimise this potential source of bias the main study aims and hypotheses were concealed from the interviewers. Furthermore, the training protocol emphasised that interviewees elicit information in the same manner from the case group and the comparison group.

Psychometric properties of the SDQ: The internal consistency of the SDQ total difficulties and scales showed improvements from the pilot phase, although certain scales, particularly the peer problems and conduct problems scales, have internal consistency that should raise concern. Furthermore, although the study used continuous scores in the analysis, Western-based cut-offs were used to estimate the number of adolescents living with HIV at risk of clinical distress. These findings should be treated with caution. Future studies will be needed to confirm the above findings.

Potential biases in the study: Some sources of adversity are only applicable to the HIV group. For example, comparison group participants were not exposed to antiretroviral therapy (ART). Being on ART has been found to be an additional burden for children and youth living with HIV and all the medical, behavioural and cognitive effects of ART need to be considered. Furthermore, adolescents living with HIV have access to support groups and continuous care and contact with medical and other health workers and may be more “fluent” in psychological terminology. This may have resulted in them interpreting and answering questions differently to the comparison group. Snider and Dawes (2006) for example, noted HIV-positive participants have more ease with questions about emotional distress in comparison to HIV-negative participants in South Africa. HIV-positive respondents were receiving counselling and had gained an emotional fluency allowing them to be more expressive in talking about emotional distress.

Variables chosen: In any study, not all variables can be included. In particular, this study did not explore sexual and reproductive health needs and behaviour, such as first-time sexual encounters, condom use or multiple and concurrent partnerships, important topics from a prevention perspective. There is very little research exploring the link between mental distress and these behaviours in HIV-positive adolescents in sub-Saharan Africa.

Conceptual limitation: Quantitative instrumentation is “by nature narrow, reducing complex phenomena down to simpler, measurable constructs” (MacMullin & Loughry, 2004, p. 470) reflecting an incomplete picture of the psychological phenomena we are interested in (Howitt & Cramer, 2005). Despite the value of quantitative techniques to provide broad based data, qualitative research, and particularly mixed-methods research provide a more complete picture of complex phenomena. In the present study interviews in the pilot phase helped to ensure that the concepts used in the instruments were understood and phrased in relevant ways for Namibian adolescents.

Cross-sectional research design: Adjustment is a fluid concept and may change over time causing mental health itself to fluctuate. There may be moments of stress and vulnerability and moments of good functioning. A cross-sectional study is a snapshot into a certain point in time of an individual´s life and does not capture the fluxes and changes that occur in how an individual copes (MacMullin & Loughry, 2004).

Lack of triangulation of informants: The current study relied only on self-report data from adolescent participants. Three other informants were discarded–caregivers, doctors and teachers. Given the large percentage of orphans in the HIV group, and the different types of caregivers, consistency of information was not ensured from caregivers. Previous research with vulnerable children found that the data yielded by caregivers was not reliable for mental health (Menon et al., 2007) or poverty (Doku, 2012). While doctors may have been an option for the HIV group, it would have been impossible to obtain doctor reports from participant in the comparison group. Teachers, on the other would have been too sensitive for adolescents living with HIV, given their concern with stigma regarding their HIV status. Multiple informants would improve the triangulation of findings, but this is complex when researching such sensitive topics.

Despite these limitations, the study makes important contributions to the literature on the mental health of adolescents living with HIV in sub-Saharan Africa. We have included a large sample of fully disclosed HIV-positive adolescents (aged 12-18) and this is only the second study in sub-Saharan Africa to date to contain a matched community comparison group. A further strength is that the study is conducted in a high HIV prevalence country. It is imperative that more research is conducted in sub-Saharan Africa where over 90% of the world's HIV-positive adolescents live. One of the criticisms of previous studies has been the inclusion of diverse samples and particularly the mixing of disclosed and non-disclosed samples. The homogeneity of study participants with respect to having a 100% fully disclosed and generally healthy group is another advantage. Previously only two studies consisted of fully disclosed participants, (Musisi & Kinyanda, 2009; Small et al., 2014).

The study design included a pilot phase which explored local and contextual risk factors as well as and mental health symptoms in the Namibian context. The latter resulted in the improvements in the psychometric properties of the SDQ. In addition, many study variables which had been identified in qualitative research but had not yet been considered as factors in the mental health of HIV-positive adolescents in sub-Saharan Africa were included. These included data on HIV-related stigma and its link with mental health problems as well as on the protective effect of social support on mental health. Finally despite the fact that orphanhood in HIV-positive adolescents tends to be high, this was the first study that considered the role that orphanhood contributes to differences in mental health problems between HIV-positive and comparison group children. We now consider the implications of these findings.

5.5 Implications

5.1 Clinical and policy implications:

This study has shown that there are multiple factors that put children and adolescents at risk for mental health problems, yet their mental health needs are not sufficiently recognised in Namibia (D.W. Brown et al., 2008; MoHSS, 2008c; Page & Hall, 2009; Ruiz-Casares et al., 2009). Developments in the area are hampered by a lack of epidemiological data and an absence of a clearly articulated mental health policy for children, despite the latter being a WHO recommendation (MoHSS, 2005). Furthermore, a lack of adequate services and few professionals working in the state, mean that children requiring services often cannot access them (MoHSS, 2005; MoHSS, 2008b; Shifiona, Poggenpoei, & Myburgh, 2006). Other barriers include: a lack of public awareness of available services and a lack of resources to access these services (Coomer, 2011). Public awareness about mental health problems in children is needed and a mental health policy for children should be developed, or integrated into the existing policy (Coomer, 2011). The current study has also drawn attention to the mental health needs of adolescents living with HIV. Treating mental health problems in adolescents living with HIV, apart from improving their quality of life, can have other benefits, including improved adherence and reduction of risky behaviour. There are adolescents living with HIV that are at risk for clinical distress and these adolescents are in need of services.

The study also found that there are participants who, despite the challenge of being diagnosed with HIV, are functioning within the normal range. Care should therefore be taken not to pathologise all adolescents living with HIV (Skovdal, 2012). However, it is important to identify those needing clinical intervention. Interventions for this group include behavioural treatment, individual, family and group counselling, behavioural modification, after-school tutoring and psychiatric hospitalization; although few studies have evaluated the effectiveness of these mental health interventions in low and middle income countries (Mellins & Malee, 2013).

Although there are limited health professionals available, it may be fruitful to explore the value that a psychologist/psychological counsellor or social worker can have at the paediatric clinic, even if for one or two days in the week. Any service providers, such as social workers, teachers, psychologists and doctors, should enquire about risk factors, such as orphan status, poverty and deprivation, social support networks and stigma and HIV status disclosure to others, as these were found to be the strongest predictors of mental health problems. Although a screening tool, like the SDQ is not a substitute for clinical assessment, the tool can be useful to identify at risk adolescents (Ruiz-Casares, 2009).

The study found that adolescents living with HIV came from 44 different schools throughout Windhoek. While participants in our study may use the Katutura hospital, they were not confined to a specific geographical location. One possible avenue for intervening could be through the life skills and teacher counsellor programme of the Ministry of Education. Each school in Namibia above 250 learners should have a life-skills teacher. Sensitizing life-skills teachers to the needs of adolescents living with HIV, including adherence needs, dealing with stigma and personalized aspects of stigma, may help these learners feel more confident to approach for help and support.

Interventions should be context appropriate. Two interventions focussing on mental health have been evaluated for low and middle income contexts. Small et al. (2014) evaluated the effects of the Collaborative HIV prevention and Adolescent Mental health Project which strengthens familial relationships as a mechanism for addressing youth risk taking behaviours. The programme was found to improve adolescent mental health in South Africa, Brazil and the U.S. Another intervention, tailored to be participatory and culturally tailored, the VUKA family intervention, had effects not only on mental health, but also behaviour, stigma and adherence in South Africa (Bhana et al., 2014). Both interventions were family-based and may be useful since HIV has multiple effects on family networks. Families of HIV-positive children face many challenges and we should consider ways to improve the support networks of these families, whether through school or other community networks, such as home-based care. Previous research has highlighted the fact that families of HIV-positive adolescents in Namibia may already be stretched (Baxen & Haipinge, 2015; Edusector AIDS response Trust, RAISON Namibia and TAMASHA Tanzania, 2008).Family interventions and those aimed at supporting caregivers of HIV-positive youth may have benefits which indirectly reach the children, particularly if these interventions mitigate some of the stressors that caregivers face. This is imperative in the light of the lower levels of caregiver support reported by HIV-positive adolescents in the current study. Indeed, one of the recommendations in the MoHSS policy for adolescents living with HIV includes the establishment of a group for caregivers or a “Guardian Club…to provide group education and psychosocial support to guardians" (MoHSS, 2012c, pg. 29). However, research examining the effectiveness of these interventions should be integrated into the policy. In the current study 10% of the participants in the HIV group identified their teacher as a supportive "other", an encouraging finding, since previous studies reported negative experiences with support from the school environment (Baxen & Haipinge, 2015; Edusector AIDS response Trust, RAISON Namibia and TAMASHA Tanzania, 2008).

Although our study did not detect significant differences in school repetition, HIV-positive adolescents showed a tendency for higher grade repetition. School support or assistance from and educational psychologist or occupational therapist can be helpful in improving any cognitive or neurodevelopmental delays (Potterton, 2006). Laughton et al. (2012) describe and intervention where caregivers are trained to provide educational assistance to children and adolescents. The input of an occupational therapist and educational psychologist to design a training programme may be useful if the children themselves cannot be referred for occupational therapy. Liaison with Ministry of Education to provide assistance with educational placements and assessments is also recommended.

Stigma reduction is an important issue for people living with HIV, but specifically for adolescents living with HIV. Unfortunately, "although stigma is considered a major barrier to effective responses to the HIV/AIDS epidemic, stigma reduction efforts are relegated to the bottom of AIDS program priorities" (Mahajan et al, 2008, p.67). One major limitation in developing a set of recommendations to combat stigma relates to the complexity of the field and the lack of rigorous research evaluating stigma reduction efforts, including both stigma towards people living with HIV and stigma felt by people living with HIV (Brown et al., 2003). Given that previous qualitative research has pointed to difficulties in school and educational settings (Edusector AIDS response Trust, RAISON Namibia and TAMASHA Tanzania, 2008) and the fact that adolescents spend a significant amount of their time at schools, this would be an apt setting for targeting interventions aimed at reducing stigma. Interventions such as the provision of information around HIV, counselling for HIV-positive people, group desensitisation towards HIV and contact with HIV-positive people have had some benefits in reducing stigma, although their effectiveness have not been evaluated in low and middle income countries (L. Brown, Macintyre& Trujillo, 2003). Any stigma reduction interventions need to be monitored to ensure their effectiveness. As such appropriate tools which assess changes in levels of stigma need to be tested and incorporated into these programmes (Nyblade & MacQuarrie, 2006). The Berger stigma scale, for example, showed good psychometric properties in the current study.

Echoing the recommendations of previous research, effective policy for HIV-positive children and adolescents in educational settings should be developed to include the promotion of their right to unimpeded access to services (Edusector AIDS response Trust, RAISON Namibia and TAMASHA Tanzania, 2008) including freedom from discrimination (United Nations, 1989). Mechanisms to monitor the implementation of these policies should be put in place. Furthermore, the present study found that adolescents in the HIV group tended to miss more days from school, particularly for treatment reasons which may make them more susceptible to poorer performance at school. Educational support for these participants will be beneficial.

Ophanhood emerged as an important risk factor for mental distress and a mediating factor for the differences in mental health between adolescents living with HIV and the comparison groups. Orphans and vulnerable children, including HIV-positive children and adolescents will benefit from government-led initiatives and policies such as those addressing school related expenses, providing health care and nutritional support, ensuring a safe and non-discriminatory environment, providing counselling and support (Ministry of Education, 2008). Since many HIV-positive adolescents are orphans, they would benefit from these interventions. However, it is important that they are assisted to ensure access to those benefits (Cluver, 2007). For example barriers to accessing child welfare grants have been recorded including transport costs, lack of awareness of eligibility criteria, beaurocratic challenges and problems with having adequate documentation (Ministry of Gender, Equality and Child Welfare, 2010). Cash transfers, such as child welfare grants, have been shown to be beneficial for improving health status (Lagarde, Haines, & Palmer, 2007) and also reducing HIV risk in girls (Cluver et al., 2014). Unfortunately, the current study also found that at least two schools out of the eight we were involved in, reported barriers to implementing some policies, such as the school feeding system and school fee exemption.

Children and adolescents can be linked to existing and appropriate community services and support mechanisms. An example of two such programmes run by NGO’s include a parent training programme to support caregivers, run by Lifeline/Childline, and an educational support programme for younger children, run by KAYEC. The key to integrating HIV positive children and adolescents into these services is to safeguard and protect them from the unintended disclosure of their HIV status. Information about such services could be disseminated through the hospital support group or through service providers. Peer support group leaders might be involved in information gathering and development of links to community resources.

It will be useful to obtain the advice of stakeholders and participants to determine the practicality and usefulness of any of the recommendations of this research. Preliminary findings of the research have been presented in two meetings, one with staff, and one with HIV-positive adolescents who took part in the study, as well as at local and international conferences. Findings will also be disseminated to the three ministries who gave permission for the research (Ministry of Health and Social Services, Ministry of Education, Ministry of Gender, Equality and Child Welfare), as well as local development partners and NGO's working with young people living with HIV.

5.5.2 Research implications:

- The study should be extended to include samples from rural areas, particularly as they may face different risk and protective factors.
- Qualitative data on the adolescent support group showed that it was helpful for personal growth, knowledge sharing, and reducing isolation. However, more rigorous research should investigate whether incorporating any components, such as the presence of a mental health professional, may extend these benefits to mental health.
- Future studies could include caregiver factors shown by previous research to be important for adolescent mental health. These include caregiver mental health and caregiver HIV status.
- Further exploration of potential protective factors and resilience factors should be promoted. Factors in the current research that could be implicated include peer support, a structured disclosure programme and being an urban adolescent friendly clinic. However, research needs to validate this, so that these could be important areas to develop in other areas.
- The current study, through qualitative and quantitative methods, evaluated the SDQ as a tool to assess mental health in children and adolescents living with HIV. The introduction of standardised explanations improved the psychometric properties

between the pilot study and the main study. However, the reliability of some scales is still a concern. Therefore, a larger scale validation study will help identify whether Western cut-offs are applicable to the Namibian context. While it may also be recommended to translate the SDQ, this is complicated in Namibia, due to the large number of local languages spoken. Future research with SDQ or other mental health tools, might consider the addition of standardised explanations as we found that this improved the reliability.

- While the current study adds to the limited data on adolescent mental health, it is limited by being focussed on one urban area in Namibia. Larger scale epidemiological research into the mental health needs of children and adolescents in Namibia remains a priority. Such research is vital to plan and target appropriate service delivery. Epidemiological research is vital for effective monitoring of policy implementation.

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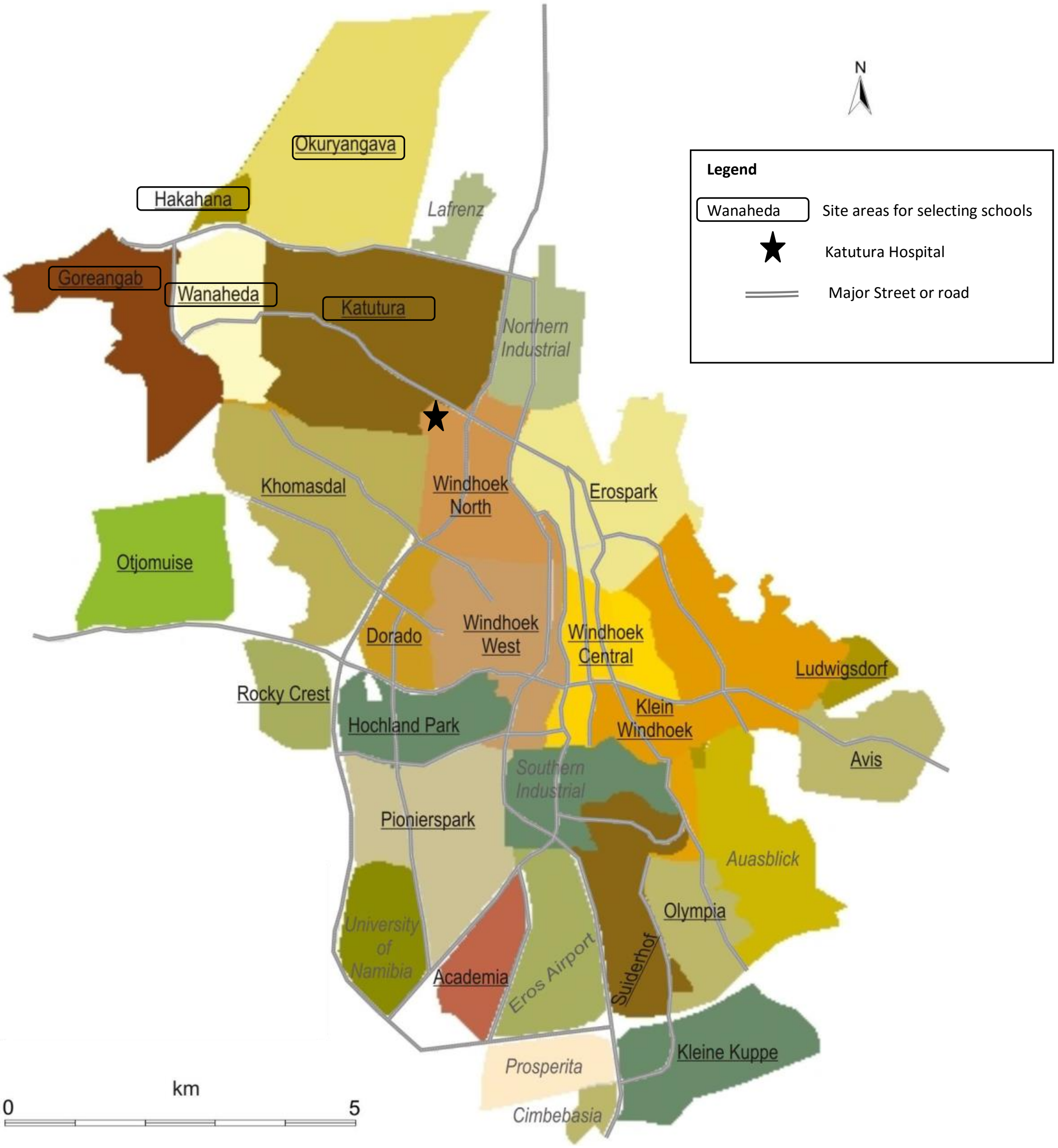
List of Appendices

Appendix 1: Map of the greater Windhoek area



Appendix 2: Ethics committee approval letters (UCM and government ministries)

2.1 Universidad Complutense de Madrid (Complutense University of Madrid)
2.2 Ministry of Education (Namibia)
2.3 Ministry of Health and Social Services (Namibia)
2.4 Ministry of Gender, Equality and Child Welfare (Namibia)

UNIVERSIDAD COMPLUTENSE DE MADRID

FACULTAD DE PSICOLOGIA

Leído el proyecto de investigación co-dirigido por la Dra. Isabel Calonge Romano con el título de "THE PSYCHOLOGICAL ADJUSTMENT OF ADOLESCENTS LIVING WITH HIV IN NAMIBIA AND ITS RELATIONSHIP TO ADHERENCE" **la Comisión Deontológica de la Facultad de Psicología de la Universidad Complutense emite** INFORME FAVORABLE **sobre los aspectos éticos relacionados con el estudio, toda vez que el Investigador Responsable se compromete expresamente a seguir las recomendaciones que aparecen en la carta de compromiso que se adjunta al presente informe.**

Madrid, 27 de junio de 2012

FACULTAD
DE
PSICOLOGIA

Fdo. Luis Enrique López Bascuas

Vicedecano de Investigación y Equipamiento Docente

Presidente de la Comisión Deontológica de la Facultad de Psicología

UNIVERSIDAD COMPLUTENSE DE MADRID

REPUBLIC OF NAMIBIA

MINSTRY OF EDUCATION

Enquiries: Mr. M. Gqwede
Tel: 061 2933278
Fax: 061 2933219

Private Bag 13186
Windhoek

25 March 2013

Ms S. Gentz
P.O. Box 6357
Ausspannplatz
Namibia

Dear Ms Gentz

Re.: The psychological adjustment of adolescents living with HIV in Namibia and its relationship to adherence

1. Reference is made to your application to conduct the above-mentioned study.

2. The proposal has been evaluated and the ministry agrees with the importance of having valid and reliable tools that can be used within the Namibian context. It is through research that the Ministry is able to plan interventions more efficiently and appropriately for the targeted community. Your proposal for evaluating the psychometric properties of the Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997) has thus been found to have merit.

3. **Kindly be advised the permission to conduct the study has been granted under the following conditions:**

   3.1 That the Directors of Education in the respective Regions are notified of this permission and that their consent is obtained for the selected schools to participate in this research;

   3.2 That the teaching and learning in schools should be disrupted as ***minimally*** as possible;

   3.3 That consent is received from all school Principals of sampled schools;

   3.4 That informed consent is received from all parents of learners participating in the study, and ensure that no learner without letter of consent participates;

   3.5 That preliminary findings from Phase 1 of the study are to be submitted and discussed with the representative from the Ministry of Education before proceeding to Phase 2;

3.6 Should findings at any point of the study indicate that there are signs of distress for the school learners, that the researcher makes arrangements for interventions together with the school and other relevant stakeholders, in an appropriate manner, that maintains the confidentiality of the learners;

3.7 The researcher will have to show proof upon completion of Phase 1 that these arrangements have been made and are adhered to in the implementation, before proceeding to Phase 2;

3.8 Final report is to be submitted upon completion of the study;

3.9 Separate permission should be sought from the Ministry of Education for the publication of the findings.

The Ministry wishes you success with your studies.

Yours Sincerely,

Office of the Permanent Secretary
26 MAR 2013

………………………………………
Mr A. M. Ilukena
PERMANENT SECRETARY

9 - 0/0001

REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198 **Ministerial Building** **Tel: (061) 2032552**
Windhoek **Harvey Street** **Fax: (061) 222558**
Namibia **Windhoek** **E-mail:** tkakili@yahoo.com

Enquiries: Ms. T. Kakili **Ref:** 17/3/3 **Date:** 07 August 2012

OFFICE OF THE PERMANENT SECRETARY

Shelene Gentz
P.O.BOX 6357
Auspannplatz
Windhoek

Dear Ms Gentz

Re: The psychological adjustment of adolescents living with HIV in Namibia and its relationship to adherence.

1. Reference is made to your application to conduct the above-mentioned study.

2. The proposal has been evaluated and found to have merit.

3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**

3.1 The data to be collected must only be used for completion of your PHD in Clinical Psychology, Forensics and Health;
3.2 No other data should be collected other than the data stated in the proposal;
3.3 A quarterly report to be submitted to the Ministry's Research Unit;
3.4 Preliminary findings to be submitted upon completion of study;
3.5 Final report to be submitted upon completion of the study;
3.6 Separate permission should be sought from the Ministry for the publication of the findings.

Yours sincerely,

PERMANENT SECRETARY
2012 -08- 0 8

MR. ANDREW NDISHISHI
PERMANENT SECRETARY

"Health for All"

REPUBLIC OF NAMIBIA

MINISTRY OF GENDER EQUALITY AND CHILD WELFARE

Tel: + 264 61 283 3111
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E-mail: genderequality@mgecw.gov.na

Private Bag 13359
Windhoek
Namibia

Our Ref.: 9/3/13
Your Ref.: ....
Inquiries: Ms. H. Andjamba

05 August 2013

Ms. Shelene Gentz
Clinical Psychologist
P. O. Box 6357
Ausspanplatz

Dear Ms. Gentz

RE: APPROVAL FOR RESEARCH: RESIDENTIAL CHILD CARE FACILITIES

Your letter dated 22 November 2012 has reference.

Permission to conduct research at the Namibian Children`s Home (NCH) and other Residential Child Care Facilities is hereby granted by the Ministry, hence we would like you to take note of the following conditions:

1. A meeting be conducted with the Children Home`s Superintendent and Caregivers (Child Care Officers) of NCH prior to meetings with the children in order to ensure that children are prepared accordingly.

2. All interviews should be conducted at the Anti-Retroviral Clinic and not at the facility where the child resides.

3. The ultimate decision to interview or not to interview shall remain the prerogative of the Superintendent (Director) of the facility in question, as a primary caretaker and guardian of the children.

4. Upon completion, a final copy of research report must be shared with the Ministry of Gender Equality and Child Welfare.

Lastly, the Ministry would like to thank you for the interest shown in our children and takes this opportunity to wish you all the best in your future endeavors.

Yours sincerely,

Mr. Erastus I. Negonga
PERMANENT SECRETARY

PERMANENT SECRETARY
2013 -08- 05
MINISTRY OF GENDER EQUALITY & CHILD WELFARE

Appendix 3: Forms and questionnaires for pilot study: qualitative procedures

- 3.1 Consent and information forms
- 3.2 Group discussion guide
- 3.3 Key informant interview guide
- 3.4 Signs and symptoms of mental distress (Groups & Informant interviews)
- 3.5 Social support findings
- 3.6 Explorations of comprehension and semantic difficulties for the SDQ

CAREGIVER CONSENT FORM

Dear Parent/Guardian

We would like to invite your teenager to take part in discussion group for a research project.

- This form explains what the study is about
- Please read it carefully. Take as much time as you need.
- The project has been approved by the Ministry of Health and Social Services in Namibia.

What will we talk about in the groups?

We want to find out more about the lives of Namibian children so that we can know how to help them. We will be talking to about 80 teenagers in Windhoek. We will ask young people to tell us how they see the lives of Namibian children:

- We will ask teenagers to tell us what difficulties teenagers in their communities have
- We will ask teenagers how youth react to these difficulties
- We will ask teenagers their opinion on what will help to improve the situation of youth

What will happen if I give my permission?

If you give permission,

- Your child will take part in a discussion group with about 6-8 other teenagers.
- This will take about an hour and will take place at the School.
- Young people can choose whether they want to take part or not.
- They can stop the discussion at any time.
- Everything we are told will be treated as entirely confidential unless children are at risk of serious harm, in which case we will try to help them.
- The information we get from teenagers will be stored in a safe place.
- When we report about this study no names of children will be given.

Your decision to have your child participate is voluntary. If you choose not to consent, all the services you and your child receive will not be affected. If you have any questions or worries about the research, please feel free to contact me and I will be very happy to discuss or explain further to you.

Please fill in the slip below and give to your child to give to the class teacher.
Thank you,

Shelene Gentz (Researcher)
Telephone: 0813033171
Email: shelenegentz@yahoo.co.uk

If you have any complaints about this study, please contact Shelene Gentz at 0813033171

I have read and understood the above information, or it has been read to me.
I consent voluntarily for my child to participate as a participant in this study

Name of Child .... Child’s grade..............
Can your child take part in this study? YES ☐ NO ☐

Name of parent/guardian...
Signature............................. Date...

Appendix 3.2 Group Discussion Guide

Topic Theme	**Activity**	**Aim of activity**
Introduction & Icebreakers 10 minutes	Introduce myself and the reason for the study, Set up boundaries regarding confidentiality; Completion of participant information sheet and consent forms	Introductions. How does a FG work Material: Name badges, Information sheets and consent forms
PART 1: Stressor scale for Namibian youth Time: 20 minutes	Group work Can you identify anything that makes young people´s lives difficult or stressful in the settings where you live? (Develop list on flipchart, probing for explanations and clarity of definitions; e.g. if they say "physical violence" ask what they mean, from whom etc) With the assistance of children, divide items into: traumatic events, highly stressful events and lower intensity stress. (Draw three columns on a flipchart, Make notes on discussions) Frequency of events: Each child is given three beans and instructed to put on the three stressors s/he thinks are most common (Cards will be laid down on a table or the floor with the names of the stressors written on them)	Aim: Generate and rank stressors experienced by youth to ensure inclusion of youth-generated relevant stressors in questionnaire) Material required: Beans, Flipchart paper, Cards to write stressors on.
REFRESHER	Short refresher game to get kids moving.	Word list: War, peace, tree, happy, sad, school, party, cat
PART 2: Mental health Time: 25 minutes	**Group Discussion: Exploring Mental Health** Think about the stressors and problems we generated: How would you know when a child is not coping? (*Probe: What would the child feel/ think? How would the child behave? What other symptoms would you see?) If anyone brings up specific terms like "depression" or "anxiety" explore meanings* **Review SDQ\YSR:** Go through meanings of the items of SDQ/YSR items (*"Do you think that a child who has a problem/depression/anxiety could experience this symptom?")*	Aim: To explore any local expressions of distress and to explore the local relevance of items on standard tools. Material required: SDQ and YSR questionnaires
PART 3: Social Support and resilience Time: 20 minutes	**Individual worksheets: Social support and protective processes** "Pick one stressors on the list. What do you think a child experiencing such a difficulty would do?" Who would they ask for help?" Which people? Which organisations? What kind of help would they need? (perhaps it would help to think about someone you know who had such a problem) *Each child completes their own worksheet.*	Aim: Material required: Worksheets for each child
Closing Activity	What part of the session did you enjoy the most? Why? What part of the session did you enjoy the least? Why? Resilience: younger kids (I am/I can/I have) OR Where will I be in 2013 (older kids)	Choose as appropriate to age, group feel

Appendix 3.3: Key informant interview guide

Date:

Name and position of person:

Name of organisation:

"Hi my name is Shelene Gentz, I am a clinical psychologist and researcher. I am interested in conducting a study which looks at the psychosocial wellbeing of Adolescents living with HIV in Namibia. The study has been approved by the Ministry of Health and Social Services. I am talking to professionals and lay people working with vulnerable children in Namibia to find out the difficulties that may impact on a child´s psychosocial wellbeing and to find out more about the situation of children prior to conducting my field work with affected teenagers. I am interested in the difficulties facing Namibian children in general, as well as the specific challenges that children living with HIV face. I will use the information generated from these discussions to inform the development of my questionnaires and interview guides. These discussions will help to ensure that the study takes into consideration the context within which Namibian children live and to ensure that I am covering all the important issues that affect children. This discussion will focus on: Identifying the challenges that Namibian children face, potential sources of protection and signs and symptoms of child distress. Finding out about the support systems or networks on which children draw in difficult times. I may also be asking you to comment on different indicators (e.g. SES, or adherence)

PSYCHOSOCIAL INFORMANTS

Details of the organisation (if appropriate):

1. What services does this organisation offer to children and adolescents?
2. Who refers the children to your organisation?
3. Does this organisation work with any children living with HIV?

Context specific difficulties and stressors

4. What are the main problems and challenges that the children that you work with face?
5. In your opinion what specific problems do HIV-positive children face?

Psychosocial wellbeing

6. How do you know if a child is not doing well?

(*Probe: emotional signs and symptoms, behavioural signs and symptoms, cognitive signs and symptoms, somatic signs and symptoms and also conduct and rule-breaking.)*

7. What kinds of things help children and adolescents to cope better?
    - Probe for age range of 12-18, social and environmental conditions
    - Probe aspects of social support are important for kids- emotional, to have fun, practical support, validation, information and who is most likely to provide that kind of support.

- Also note what services are children likely to access? Psychologist, social worker, school counsellor, other counsellor – is there any other service that children might access?

8. What kinds of things make it difficult for children to cope or recover after difficult situations?

MEDICAL INFORMANTS (working with children and adolescents living with HIV)

1. Who refers the children to you?
2. Details of the children/adolescents seen at your Medical centre/practice
    - Number of children seen per week or month,
    - Age groups of children seen etc.

Disclosure

3. What procedures do you follow to disclose a child/adolescent´s HIV status? At what age? Who is present?
4. What reactions have you observed when a child/adolescent is disclosed their status?
    - Probe for emotional signs and symptoms, behavioural signs and symptoms, cognitive, somatic signs and symptoms ALSO for conduct and rule breaking
5. In your experience what does help children cope after learning about their status. Probe for aspects of social support.

Adherence to medication

6. What do you see as the main problems that children have with medication adherence/main barriers to medication adherence?

Health status of the patient

7. What health related factors could impact the wellbeing of a child? Illnesses, hospitalizations, Stage of illness?

Closing question

Can you recommend any other persons which we could interview about the topics we discussed today?

Appendix 3.4 Signs and symptoms of mental distress (Findings from group discussions and key informant interviews)

Internalising symptoms

Group 1 (High School)	**Group 2 (Community centre, primary school children)**	**Group 3 (Primary School)**	**Group 4 (Community centre, high school children)**	**Key informant interviews (experienced by ALHIV)**
Depressive depressed, moody (“gets upset quickly”), feeling down or sad, wants to be left alone, does not eat- no appetite, feels insecure, cries a lot, feel very sensitive especially when criticised, the person can try to kill him or herself, you can cry inside/keep it inside/can´t get it out lonely, always negative sleep a lot, sleep too little suicide “Does not feel free in life” Negative thoughts (“Think that parents do not care about him” “thinking they are not good enough”) *Anxiety* you talk a lot/keep busy sleep too little, “stresses over some things”	*Depressive* Moody, sad, all of a sudden becomes quiet, isolates self Low self-esteem, maybe the person used to be proud Suicide thoughts, Not taking part in any activities anymore (“ Like not playing sports an more withdraws from the group”), Sleeps a lot *Anxiety* No concentration because of worries, Might stay away from school, afraid to be seen in public	*Depressive* Child wants to be alone all the time The person does not want to talk a lot The person feels ashamed, as if he did something wrong and people will find out (guilt) Sadness Mood swings: “it means your mood can change from time to time, you can be rude to others” *Anxiety* The person will feel shy	*Depressive* Sad, Unhappy, Always crying Moody: “they child is rude, shout at you when you ask to borrow their pencil” “you can just snap at your friends” Silence- just keep quiet because he has no energy (from lack of food) Person is just not in the mood Suicide Feels like no-one cares *Anxiety* Scared, Fearful	*Depressive* Less spontaneous with friends More withdrawn. Unhappy. Depressed, quiet and withdrawn, Suicidal Feelings of hopelessness. *Anxiety* Afraid (of taking so many pills) Fear (losing their friends or boy/girlfriends if they disclose) Fear (kids will discriminate against them at school and in the community)

Externalising symptoms

Group 1 (High School)	**Group 2 (Community centre, primary school children)**	**Group 3 (Primary School)**	**Group 4 (Community centre, high school children)**	**Key informant interviews (experienced by ALHIV)**
Conduct/aggressive Bossy, controlling, Aggressive Bully other kids, drug abuse, “alcohol abuse, smoking or other social evils,” running away from home” Does wrong or bad things to anger parents, “Selling stuff from the house (stealing)” *ADHD like* hyperactivity- you talk a lot/ keep busy	*Conduct/aggressive* Stays away from home for a days Disrespectful towards parents, Stay out late Easily provoked Person may become violent *ADHD like* No concentration	*Conduct/aggressive* Laziness- does not want to do anything (e.g. at school does n’t want to listen) Bullying kids who have what you don’t have/ or kids who are weaker than you Children misbehave: don’t listen to teachers, don’t do their homework, interrupt the teacher all the time disturb the class, break the HOUSE Rules at home, Back chat, curse or swear at the teacher, Delinquent behaviour because of peer influence: Vandalism (breaking windows, vandalising bathrooms and toilets, graffiti), dating guys older than	*Conduct/aggressive* Aggressive Rude to parents Run away from home Can change because of peer pressure they can rob, sell their bodies, skip classes, smoke, take drugs or alcohol, crime, rape, don’t do their homework *ADHD like* Lack of concentration “the child is worrying about food, can’t concentrate on his school work”	*Conduct/aggressive* Anger and aggression, Blaming others for problems Acting out (e.g. purposely have unprotected sex) Aggression towards parents Drinking, picking fights on the street, they sort of become careless. *ADHD like* (none mentioned)

		you, stealing *ADHD like* Lack of concentration: the child's grades begin to drop		

Other signs and symptoms

Group 1 (High School)	**Group 2 (Community centre, primary school children)**	**Group 3 (Primary School)**	**Group 4 (Community centre, high school children)**	**Key informant interviews (experienced by ALHIV)**
Feelings of jealousy towards other people who have the things you want or that you don´t have like if you lost your parents, Very sensitive especially when criticised		Jealousy and envy		Pressure on school work, school performance can go down
Definition of "depression" feel as if no future, no hope, alone, a part of you gone, you feel like you are no use to people, stressed, suicidal feelings *Definition of "anxiety"* Phobia- you afraid of something, you feel nervous, heart beats fast, restless, jittery	*Definition of "depression"* Always alone, loses concentration, always crying, never interested to do things *Definition of "anxiety"* Person is happy, wants to do things	*Definition of "depression*" Person feel miserable, always sad, wants to be alone all the time, the person does not want to do anything, you always have stress, you have stress when you don't want it *Definition of "anxiety"* The urge to do something addictive	*Definitions of depression and anxiety:* not asked due to time limitations.	

Appendix 3.5 Findings: Categories of social support

	High school group	Community Centre group
Emotional	"Tell them about your problems" "talk your problems with other people who are experiencing the same difficulty" "Seek assistance from relatives, that are caring and understanding" Tell people closest to Emotional and physical support like a hug, Comforting the person I would talk to my cousin who also shares his emotions Talk to someone close Bond more with the family, Confide Speak to someone that can help him or her emotionally Emotional and physical support like a hug. Tell a close friend and ask for advice Open up her heart to a friend/tell a close friend and let out all the pain Understand here situation "Someone to talk to parents and explain to them to make them understand"	Speak to the person, encourage her, Boost their self esteem, Talk to someone you trust- like a teacher, someone that will understand the situation Talk to my close friends and at least get it off my chest, go to a counsellor at school, she will help me to be strong and study, she would get a plan to help me out. Make them feel loved, talk to the teenager Support them tell them its not the end of the world, someone to motivate him because he will be sad Need counselling, parents must support and encourage them Physical abuse by parents: get counselling, and emotional support
Recreational Fun	Take you mind of the situation and enjoy a positive conversation; Travel more	Keeping busy with games, playing soccer and many more things, try to be with friends Avoid talking about it all the time, keep busy with fun activities Try something that will reduce the stress
Practical/material	"material help, e.g. clothes and food" Food and shelter and clothing Someone to stay with you Ask for financial help Stay at a friend or family members house Move to another town	Emotional abuse from parents: someone to speak to the abuser. Poverty: money, free education, soup kitchen, donations of clothes and school uniforms, "constant check –up because it does not help when a child is given counselling but the results are only short hand and they would feel the same way as they did",
Advice or knowledge	"Seek assistance from relatives, that are caring and understanding" Advice on what to do and not to do Friends for help and advice	Talk to the counselling teacher, she would get a plan and help me out Give advice
Positive feedback/validation	Show love and affection towards her Parents love	Boost their self esteem, Moral support and lots of encouragement Someone to motivate him because he will be sad Parents must support and encourage them that they are capable of passing the next exam
Other	"Medication" Finish school and find a job (i.e. become independent) I would move to another environment just to be stress free	Constant check –up because it does not help when a child is given counselling but the results are only short hand and they would feel the same way as they did" "I would pray to God to help me out" Pray to God, Try something that will reduce the stress

Appendix 3.6. Examples of participant comments for SDQ

SDQ item	**Comments from pilot interviews and group discussions.**	**Suggestions from children´s reference group**	**Final standardised parallel explanation**
I get very angry and often lose my temper	Children did not understand “lose my temper”. For example, one participant in a pilot interview (pilot 3) thought that “lose my temper” meant “I just need to be quiet” Some children were not be familiar with the word “often”	“I lose control of myself a lot, I get too angry” (they did not like the phrase “over” angry). Participants also suggested adding examples like: “I want to fight, swear, damage things, shout, and talk bad language.”	I get very angry and I lose control of myself a lot. I lose control of myself many times.
I am constantly fidgeting or squirming	In the group discussions and pilot interviews most participants did not understand the words: “constantly” “fidgeting” “squirming” (Pilot 4, 5 and 7)	“I am moving around in my chair.” “I can’t keep my hands and feet still”	I cannot keep still. I cannot keep my hands and feet still.
I am often unhappy, down-hearted or tearful	“often” was not understood the term(Pilot 4); One participant found unhappy difficult: “is it like when you are angry: like when you see someone who is just lying there and they don’t have anything you feel sad” (Pilot 5)	The children preferred sad to unhappy, but did not like “I feel sad in my heart” They also found tearful difficult and preferred crying. They suggested: “I am sad many times” “I cry a lot” They felt “depressed” would be too difficult.	I am sad many times. I cry a lot.
Other children or young people pick on me or bully me	“Pick on me” was not understood by one group and one pilot interviewee. Participants thought it might be to be picked to be on a sports team. All children understood the meaning of “bully”.	Participants provided many examples of being bullied: “They mock me” “They beat me” “They say bad words to me, bad language, they tell stories about me”; “Bother me” was interpreted it as “to disturb me, like when I am studying.”	Other children or young people bully me

Appendix 4: Forms and questionnaires for pilot study: quantitative procedures

3.1 Principal information sheet
3.2 Caregiver/adolescent consent and information forms (English, Afrikaans and Oshiwambo)
3.2 Quantitative pilot study: questionnaire

University of Complutense of Madrid

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Shelene Gentz (Clinical Psychologist)

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05 April 2013

INFORMATION SHEET

Project title: **The mental wellbeing of adolescents in Namibia**

The Principal
Name of School
P.O. Box XXXX
Katutura

Dear (Name of Principal)

My name is Shelene Gentz, a Namibian clinical psychologist and researcher with the University of Madrid. We are conducting a research study on the wellbeing of teenagers in Namibia. This study has been approved by the Ministry of Education in Namibia (date: 25 March 2013) as well as the University of Madrid (UCM). Your school ______________________has been randomly selected to participate in the study.

What is the project about? The research is about the emotional well-being of children in Namibia. We want to know more about how young people feel and act when they are not well. About 150 young people from different schools will take part.

What will be the procedure to take part in this study? We would like to invite two classes from your school to take part. We will work closely with the school so that this research takes place in a manner so that teaching and learning will be disrupted as minimally as possible. We will ask you to provide us with a list of all grade 6 and 7 classes in your school. From this list the researcher will randomly select three classes to participate. It is important that this selection is done by the researcher so that all classes have equal chance of being selected. This is important so that we do not to bias the selection process. Once the selection has occurred, we will send out consent forms to the parents of learners in the selected classes. Consent forms will be available in English, Oshiwambo and Afrikaans. If parents agree, the learners will be invited to complete a questionnaire. In the questionnaire we ask youth about their lives; their feelings and behaviour. This will happen during school time and will take about 30-40 minutes. Young people can choose if they want to take part.

Some learners will also be invited to take part in a group discussion which will happen in a few months time.

Will the learners's involvement in this study be kept confidential? Everything we are told will be treated as private. To protect the identity of learners, we will not write the name of any child in any talk or report about this study. The information will be stored in a safe place and only the lead researcher, Shelene Gentz, will be able to see it. However, if we learn in the study that any child is at risk of possible harm, we will try to help them. We may refer the child to the life skills teacher or, if it becomes necessary, we may put the child in contact with an appropriate service or organisation. We will first talk to the child about this. This is in accordance with the law and the directive of the Ministry of Education.

What are the risks of this project? Some learners may not feel comfortable with certain questions. If a learner does not feel comfortable with a question, she or he may choose not to answer. An assistant will be present if a learner needs to talk about anything in the questionnaire. We will also tell your learners about places where they can go if they need further help.

How will this study help? This study will help us to know more about how children and teenagers cope with problems. This study will help us to develop tools that can be used in Namibia to identify learners with emotional and behavioural problems. We will share this information with organisations that work with children and the government of Namibia, including the Ministry of Education so that others may learn from our project.

What if I have any questions about the study? The main person for this study is Shelene Gentz. If you have any questions about the project, you can contact me by telephone: 0813033171 or email: shelenegentz@yahoo.co.uk. I will be very happy to talk to you and explain the project further.

Please let us know if the learners in your school can participate in this study.

Thank you,

Shelene Gentz (Clinical psychologist and Researcher)

This research has been approved by the University of Complutense Research and Ethics committee

CAREGIVER CONSENT FORM

Dear Parent/Guardian

We would like to invite your teenager to take part in research project by Shelene Gentz and the University of Madrid (UCM). This form will explain the project. You can then decide if you want your child to take part. The study is approved by the Ministry of Education in Namibia (*date of approval*) and by your school (*name of school*).

What is the project about? The project is about the well-being of children in Namibia. We want to know more about the feelings of young people. We want to find out what are the signs of poor mental health in young people. Young people from different grades will be asked to fill out a form.

What will happen if I give my permission? If you agree, your child will fill out a form. In the form, we ask youth about their lives; their feelings and any symptoms they may have. This will happen at school and during school time. This will take about 30-40 minutes. Young people can choose if they want to take part or not. Your child can also stop at any time. Your child will not receive any money for taking part in this study. Some children will take part in a group discussion. It is up to you to decide if you want your child to take part. If you choose not to agree, your child will continue as normal at the school.

Will my child's involvement in this study be kept private?

Everything we are told will be treated as <u>private</u>. We will not write the name of your child in any talk or report about this study. The information from your child will be stored in a safe place. Only the researcher will be able to see it. But, if we learn in the study that your child is at risk of possible harm, we will put your child in contact with appropriate Social Services. We will talk to your child about this. This is in accordance with the law.

What are the risks or dangers of this project? There are no physical risks to take part in this study. Some children may not feel comfortable with certain questions. If you child does not feel comfortable with a question, she or he may choose not to answer. A helper will be present if your child needs to talk about anything in the questionnaire. We will also tell your child about places where they can go if they need further support.

How will this study help? This study will help us to know more about how youth cope with problems. We will learn how to help young people who have problems. We will share this information with organisations that work with children and the government of Namibia. This is so that people may learn from our project. This can help us to develop programmes for children. Names of participants will not be given.

What if I have any questions about the study? The main researcher for this study is Shelene Gentz. If you have any questions or worries about the project, you can contact me by telephone: 0813033171 or email: shelenegentz@yahoo.co.uk. I will be very happy to explain further to you.

<u>What should I do?</u>

Please fill in the slip below and let us know whether you agree. Your child can return this slip to the class teacher by (*insert dated)*.

Thank you,

Shelene Gentz (Researcher)

This research has been approved by the University of Complutense Research and Ethics committee

✂ --

I have read the above information, or it has been read to me. I have had the chance to ask questions about it. My questions have been answered to my liking. I consent freely for my child to participate in this study

Name of Child....................................... Child’s grade..............

Can the child I care for take part in this study? YES ☐ NO ☐

Name of parent/guardian..

Signature...Date............................

Complutense University of Madrid, Faculty of Psychology
Shelene Gentz (Psychologist) 0813033171

OUER KONSENTVORM

Project: Die welvaart van kinders in Namibia

Liewe Ouer/Voog

Ons wil graag u kind nooi om aan 'n navorsings projek van Shelene Gentz, met die Universiteit van Madrid (UCM) deel te neem. Die vorm verduidelik die projek. U kan besluit of u kind kan deelneem. Die projek is goedgekeur deur die skool en die Minesterie van Onderwys in Namibie.

Wat behels die projek? Die studie gaan oor die welvaart van die Namibiese kind. Ons wil gaag hiermee uitvind hoe jong mense voel en optree as hulle nie gelukkig is nie. Ongeveer 100 tieners van verskillende grade gaan aan die projek deelneem.

Wat gaan gebeur as ek toestemming gee? Met u toestemming, gaan u kind 'n vorm voltooi. In die vorm moet hulle lewens beskryf, hulle gevoelens en gedrag. Dit sal omtrent 30 - 40 minute vat om die vorm te voltooi en sal gedurende skooltyd plaasvind. Tieners kan self besluit of hulle wil deel wees van die projek, en u kind kan enige tyd besluit as hy/sy nie meer verder wil deelneem nie. Van die kinders gaan ook aan groepsbesprekings deelneem. As u verkies dat u kind nie mag deelneem nie, gaan u kind 'n normale skooldag het. U besluit of u kind mag deelneem of nie.

Sal my kind se betrokkenheid aan hierdie projek privaat wees? Alles wat ons vertel word, sal as privaat hanteer word. Ons sal nie melding maak van u kind se naam nie en u kind se besonderhede sal in 'n veilige plek bewaar word. slegs die navorsers sal die besonderhede sien. As ons agter kom dat u kind moontlik 'n risiko loop om skade te ly, sal u kind gehelp word. As dit nodig is sal ons u kind in kontak bring met die bes moontlike dienste of 'n organisasie wat hom/haar kan help. Ons sal dit eers met u kind bespreek. Dit is in lyn met die wet.

Wat is die gevolge van die projek? Sommige leerlinge sal nie gemaklik voel met sekere vrae nie. As u kind nie gemaklik voel met 'n vraag nie, het hy/sy die keuse om dit nie te beantwoord nie. Daar sal iemand byderhand wees as u kind enige vrae het oor die vorm. U kind sal ook in kennis gestel word waar hy/sy verdere hulp kan kry.

Hoe gaan hierdie projek kinders help? Die studie gaan ons help om meer uit te vind hoe kinders en tieners probleme hanteer. Ons gaan uitvind hoe ons die kinders en tieners te kan help met hulle probleme. Die inligting gaan ons met ander organisasies wat werk met kinders en die Namibiese regering deel. Ons wil graag he ander mense moet iets leer uit die projek, dit kan ons help om programme te ontwikkel om die kinders te help.

As u enige vrae het oor die projek? Die persoon verantwoordelik vir die projek is Mej Shelene Gentz, en u kan my enige tyd kontak. My selfoonnommer is 0913033171 en my eposadres is shelenegents@yahoo.co.uk.

Wat moet ek nou doen? U moet die onderstaande vorm voltooi en se of u daarmee saamstem of nie. U kind moet die vorm terugbring en by sy/haar klasonderwyser(es) inhandig voor of op .... 2013.

By voorbaat dank.

Shelene Gentz (Navorser)

Die navorsing is goedgekeur deur die Universiteit van Toegeeflikheid Navorsing en Etiek Komitee.

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OMGEE KONSENTVORM

Ek het die brief gelees, of iemand het dit aan my voorgelees. Ek verstaan die vorm. Ek gee my toestemming dat my kind aan die projek mag deelneem.

Naam van kind: .... Graad: ....

Ouderdom: ....

Kan u kind deelneem aan die projek: JA ☐ NEE ☐

Naam en van, van ouer/voog: ....

Handtekening van ouer/voog: .... Datum: ....

Complutense University of Madrid, Psychology Department
Shelene Gentz (Psychologist/Researcher), 0814319735/0813033171

CAREGIVER CONSENT FORM

Kuye Omukulunhu Wokanona

Otwa hala oku kushiiva opo u kufe ombinga momapekaapeko oo Shelene Gentz taningi oku diilila koUnivesiti ya Madrid, koSpain. Ofoloma ei otai fatulula opoloyeka ei. Opo ne konima oto dulu oku tokola ngeenge owa hala oku kufa ombinga momapekaapeko aa. Opoloyeka ei oya kolekwa ko Ministili yelongo moNamibia osho yo kofikola yeni:

Opoloyeka ei otai popi kombinga yashike? Opoloyeka ei oili kombinga youkalinawa wounona moNamibia. Otwa hala okushiiva kutya ounona ohava kala ve udite ngahelipi nohave lihumbata ngahelipi ngeenge ve heudite nawa. Konyala ounona efele limwe otava hoololwa meengudu dilili opo vakufe ombinga momapekaapeko aa.

Otapa kaningwa shike ngeenge onda yandje epitikilo (opo okanona kange kakufe ombinga) Ngeenge owa yandje epitikilo, okanona koye otaka yadeke ofoloma. Ohatu pula ounona kombinga yeenghalamwenyo davo, omaliudo avo nomikalo davo. Eshi otashi kaningwa pefimbo leetundi dofikola. Otashi kakwata oule wominute omilongonhatu (30) ile nomilongonhe (40) lwaapo. Ounona otava dulu okuhololwa opo vakufe ombinga ngeenge oveshi hala. Okanona koye otaka dulu oku tya inaka hala pefimbo keshe eli ke udite kutya inaka hala vali okupekaapekwa. Ongo omukulunhu, ove oto dulu oku yandja epitikilo opo okanona koye ka kufe ombinga. Ngeenge ino hala okanona koye ka kufe ombinga, okanona koye otaka ka twikila neetundi dako dofikola ngaashi shito no itaka kwatelwamo mopoloyeka ei.

Ekufombinga lokanona kange momapekaapeko aa otashi kala oshiholekwa? Keshe eshi hatu ka lombwelwa kokanona koye otashi kala oshiholekwa. Itatu kashanga Edina lokanona koye moshipopiwa shasha momapekaapeko aa. Oufemba wokanona ita u popiwa ile uholowe moishangomwa yomapekaapeko aa. Omupekaapeki oye ashike tashiva edina lokanona ashike iteli holola moilopotwa yaye ei taka shanga. Ngeenge otwa mono kutya okanona koye okeli moshiponga shasha, ohatu kendabala noku kwafela. Ngeenge osha pumbiwa, ohatu ka tula mekwatafano no makwafelo aa kapumbwa ile nehangano eli tali dulu oku ka kwafela. Omanga inatu shininga, ohatu popi nokanona koye. Ohatu shiningi melandulafano leemango.

Omaupyakadi elipi enasha nopoloyeka ei? Ounona vamwe otava dulu oku kala inava manguluka noku pulwa omapulo amwe. Ngeenge okanona koye kake udite nawa noku pulwa omapulo amwe, otaka dulu oku kala inake a nyamukula. Otapa kakala omukwafeli taka kala nokukwafela ngeenge okanona okapumbwa oku popya sha shinasha naasho shili mofooloma. Osho yoo ohatu kalombwela okanona koye kombinga yeenhele apa taka dulu okuya ngeenge oka pumbwa omakwafelo awedwapo.

Omapekaapeko aa otaa kwafele ngahelipi? Omapekaapeko aa otae tu kwafele opo tuushive omukalo oo ounona novangundjuka hava longifa opo vakandulepo omikundu davo. Ohatu ke lilonga kombinga yokukwafela ounona ava vena omaudjuu. Ohatu ka yandja ouyelele ou komahangano aa haalongo nounona osho yoo kepangelo laNamibia. Otashi ningwa nee opo ovanhu ve lihonge kopoloyeka yetu. Eshi otashi tu kwafele meepologalama de yambukepo lounona.

Ohandi ningi ngahelipi ngeenge ondina epulo lasha kopinga yopoloyeka ei? Omukulunhu wopoloyeka ei oye Shelene Gentz. Ngeenge ouna omapulo enasha nopoloyeka ei, oto dulu oku mu dengela kongodi ei: 0814319735/0813033171 ile u mu tumine oemail ku: shelenegentz@yahoo.co.uk. Nehafo linene ote ku kwafele.

Owa pumbwa ku ninga shike

Alikana yadeka ofooloma ei ya landula ndele totu lombwele kutya owa koleka ile ino koleka ekufombinga lokanona koye mopoloyeka ei. Okanona koye otaka dulu oku alulila ofolooma ei komulongi wako momafiku _**11 or 12 July 2013**.

Tangi Unene

Shelene Gentz (Omupekaapeki)

Omapekaapeki aa omakolekwa kokomitii yomapekaapeko oUnivesiti

Ondalesha ombapila ei, ile onde i leshelwa. Ondi udite ko kombinga yofooloma ei. Onda itavela opo okanona kange ka kufe ombinga momapekaapeko aa

Edina lokanona... Ondodo/ongudu yokanona...........

Eedula dokanona.........................

Okanakoye Okwakwasike: Okamhati(boy) ☐ Okakadona ilo (girl) ☐

Okanona otaka dulu oku kufa ombinga momapekaapeko aa? Eheno ☐ Ahawe ☐

Edina lomukulunhu wokanona ....

Eshaino..Efiku..........................

Complutense University of Complutense of Madrid

Faculty of Psychology

Campus de Somosaguas
S/n 28223 Pozuelo de Alarcón
Spain
Tel: +34 913 94 29 54
Email: infor@psi.ucm.es

Information Sheet for Teens

We want to invite you to take part in a study. This paper tells you about the study. You can decide if you want to take part. Ask the researcher if you do not understand something or if you have questions. Thank you for reading this.

What is the project about? This project is about teenagers and their feelings about their lives. It will help us to know more about young people so we can plan how to help young people and their families better. We want to know more about how teenagers in Namibia act and feel. We will invite about 150 teenagers from age 12 to age 18 to take part.

What would I have to do? If you decide to take part, you will first sign a consent form (on the next page), and then we will take about 30 minutes to answer some questions on a form. Each person will fill out their form alone. Nobody in your school will know your answers. We will not tell your teacher or principal what you tell us.

Do I have to take part? You can decide if you want to take part. If you do not want to, you will go on as normal at your school. You will not get in any trouble if you do not want to take part. If you decide to take part, you are still free to stop at any time. You do not have to give a reason.

What if the questions upset me? You can stop at any time, and you do not have to give a reason. You can also contact me or the research team at any time after we finish, and say that you want your answers about some questions to be taken out. If you want to talk to someone about anything that has come up from this, you can tell one of the researchers.

Why should I take part in this study? This study will help us to know more about what can help young people in Namibia.

What if I have a complaint? If there is anything to do with this project which you are not happy with, you can contact Shelene Gentz.

Will what I say be kept private/secret? We will not tell anyone anything you tell us about yourself. Any information we report will have your name and address removed so that you cannot be recognised from it. But if we find out that you have serious difficulties we will try to help. The researcher will explain to you some options for further help. If there is a safety issue, we may contact a welfare organisation for you. All this will be talked over with you first.

Contact for further information: Shelene Gentz (0813033171)

Thank you for reading this sheet. If you feel comfortable with everything, you can fill in the form on the next page.

University of Complutense of Madrid

Faculty of Psychology

Campus de Somosaguas
S/n 28223 Pozuelo de Alarcón
Spain
Tel: +34 913 94 29 54
Email: infor@psi.ucm.es

Consent Form

Name of Researcher: Shelene Gentz

Study: The wellbeing of adolescents in Namibia

DO I WANT TO TAKE PART?

Please tick the box

	yes	no
1. I have read and understand the information sheet for this study and have had the chance to ask questions	☐	☐
2. I understand that I have chosen to take part and that I am free to stop at any time.	☐	☐
3. I agree that the answers I give can be used, without giving my name, in the presentation of the research. I agree to take part in the study	☐	☐

....	....	....
Name of participant	Signature	Date
....	....	....
Name of Researcher	Signature	Date

TALKING TO TEENS IN NAMIBIA

Whatever you say is confidential. This means we will not report your real name.

This is not a test. There are no right or wrong answers! We want to find out more about young people in Namibia.
Thank you for taking the time to help.

If you have a question or there is a word you do not understand, just put up your hand and ask me
You will see many boxes like this one ☐
You can choose the answer you want by marking in the box like this. ☒
Let' s do this example together: Can you tell me what day it is today?

Mark in the box

Monday ☐
Tuesday ☐
Wednesday ☐
Thursday ☐
Friday ☐

Are you ready to start? ☐ Yes, I am ready!

Section 1: Could you tell us….

Name of your School:

1. Your grade? ________________
2. Your date of birth? day______ month _____________year _________
3. How old are you? I am______ years
4. What language do you speak at home most of the time? __________________________
5. Where do you live (Write the name of the suburb like Eros, Grysblok, Wanaheda, Goreangab, Academia)? ____
6. Are you a boy or a girl: (Please mark one)

   ☐ Boy

   ☐ Girl

7. Which culture are you (please mark one)?

☐ Owambo	☐ Kavango	☐ Herero	☐ Damara
☐ Nama	☐ White	☐ Coloured	☐ Caprivian
☐ San	☐ Another culture, tell us which:		

8. Do you have a <u>parent, guardian or caregiver</u> staying with you?

   ☐ Yes

   ☐ No

9. Tell us if your caregiver is your: (Please mark one)

☐ biological mother	☐ biological father	☐ aunt or uncle
☐ grandma or grandpa	☐ Sister or brother	☐ stepparent
☐ Family friend	☐ neighbour	☐ foster parent
☐ I stay alone	☐ Careworker or housemother	
☐ Another person: Tell us Who?		

10. a)How old is this person__________ b) Is this person a man or woman__________

11. Is your biological mother still alive? Yes ☐ No ☐
    If she is no longer alive, when did she pass away (year)___________

12. Is your biological father still alive? Yes ☐ No ☐
    If he is no longer alive, when did he pass away (year)____________

Section 2: In this section we will ask you some questions about your home and the people you live with

13. Please mark ☒ the one which is most like your home

☐ A house made of brick or concrete

☐ A block of flats or a flat in someone's yard, made of brick or concrete.

☐ A shack or on its own plot

☐ A shack or in someone´s yard

☐ Other. Tell us what kind:...

(For example: another kind of house or if you are living on the street)

14. Do you live in children's home or orphanage (for example like Hope village or SOS)?

☐ Yes

☐ No

15. How many people live with you in your house (the place you are staying) including yourself?

Adults: ______ Children (under 18years):_______

16. In your household, how many rooms are used for sleeping?

__________ (Do not count bathrooms, toilets)

17. In your house you get water from (please mark one) :

☐ A tap <u>inside</u> or outside your house (<u>still in your yard</u>)

☐ We share a tap close to your house <u>(not in your yard)</u>

☐ A river, stream, or a Dam

☐ Other (what kind)...

18. Does <u>anyone</u> in your household have a job?

☐ Yes. If yes, please tell us who (list all the people for example: mother, father, brother etc.) ____

☐ No

19. Do you have any of these things in your home:

		Yes	No
A	A radio	☐	☐
B	A television	☐	☐
C	A fridge	☐	☐
D	A telephone/ cell phone	☐	☐
E	Stove (using gas or electricity)	☐	☐
F	A car	☐	☐
G	A bicycle	☐	☐
H	Electricity	☐	☐

20. Did you eat breakfast this morning before you came to school?

☐ Yes. Skip to 21

☐ No. Go to question 20.b .

20. b.Tell us why you did not have breakfast

☐ There was no food in the house.
☐ I did not want food. I was not hungry
☐ Another reason. Tell us...
. ...

Sometimes kids don’t have enough food in their home:

21. Think about the last 7days and tell us how many days you did not have enough food.

☐ None ☐ 1 ☐ 2 - 3 ☐ 4 or more

22. In the last 7 days how many days did you go to bed hungry?

☐ None ☐ 1 ☐ 2 - 3 ☐ 4 or more

Children´s Strengths and Difficulties questionnaire

	Not True	Somewhat True	Certainly True
I try to be nice to other people. I care about their feelings	☐	☐	☐
I am restless; I cannot stay still for long	☐	☐	☐
I get a lot of headaches, stomach-aches or sickness	☐	☐	☐
I usually share with others (food, games, pens etc.)	☐	☐	☐
I get very angry and often lose my temper	☐	☐	☐
I am usually on my own. I generally play alone or keep to myself	☐	☐	☐
I usually do as I am told	☐	☐	☐
I worry a lot	☐	☐	☐
I am helpful if someone is hurt, upset or feeling ill	☐	☐	☐
I am constantly fidgeting or squirming	☐	☐	☐
I have one good friend or more	☐	☐	☐
I fight a lot. I can make other people do what I want	☐	☐	☐
I am often unhappy, down-hearted or tearful	☐	☐	☐
Other people my age generally like me	☐	☐	☐
I am easily distracted; I find it difficult to concentrate	☐	☐	☐
I am nervous in new situations. I easily lose confidence	☐	☐	☐
I am kind to younger children	☐	☐	☐
I am often accused of lying or cheating	☐	☐	☐
Other children or young people pick on me or bully me	☐	☐	☐
I often volunteer to help others (parents, teachers, children)	☐	☐	☐
I think before I do things	☐	☐	☐
I take things that are not mine from home, school or elsewhere	☐	☐	☐
I get on better with adults than with people my own age	☐	☐	☐
I have many fears; I am easily scared	☐	☐	☐
I finish the work I am doing my attention is good	☐	☐	☐

Overall, do you think that you have difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

NO	Yes minor difficulties	Yes definite difficulties	Yes severe difficulties
☐	☐	☐	☐

<u>If you have answered "Yes"</u>, please answer the following questions about these difficulties:

1. **How long have these difficulties been present**

Less than a month	1-5 months	6-12 months	Over a year
☐	☐	☐	☐

2. **Do these difficulties upset or distress you?**

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

3. **Do these difficulties interfere with your everyday life in the following areas?**

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	☐	☐	☐	☐
FRIENDSHIPS	☐	☐	☐	☐
CLASSROOM LEARNING	☐	☐	☐	☐
LEISURE ACTIVITIES	☐	☐	☐	☐

4. **Do the difficulties make it harder for those around you (family, friends, teachers, etc?)**

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

In this section we are interested in finding out about where teenagers get support.

23. **About how many good friends do you have?** (A good friend is someone close to you that you could share your problems with. Do not include brothers and sisters)

☐	☐	☐	☐
None	1	2 - 3	4 or more

24. Do you have someone in your life you can go to for advice and guidance?

☐ Yes. **Please tell us who**: ___________________________________

☐ No

25. Where can teenagers go if they need some help with a personal problem (such as a girlfriend/boyfriend problems or family stress)? Tell us which places (do not include family or friends):...

....

☐ I don't know any places.

26. Have you ever been to any of these places (In Question 25)?

☐ Yes: Tell us which place:...

☐ No

27. Would you feel okay discussing a problem with your life-skills teacher?

☐ Yes

If yes, can you tell us why?

....

....

.

☐ No

If no, can you tell us why

....

....

....

This is the last page Thank you for taking the time to help!!

We would like to know what it was like for you to be in this study. Read each question and then mark "yes", "no" or "maybe".

	YES	MAYBE (in the middle)	NO
It was my choice to take part in this study.	☐	☐	☐
Being in this study made me feel good about myself	☐	☐	☐
The things I said will stay private (the researcher will not report my real name)	☐	☐	☐
Being in this study made me feel upset or sad	☐	☐	☐
I feel good about helping other people by being in this study	☐	☐	☐

You can help us make the questionnaire better.

If you found any questions difficult go back and put a circle around that question number.

If there were any difficult words: please go back and underline any words that you did not understand.

Can you tell us why you found these questions difficult (Turn over if you need more space):

....

....

....

....

Do you think some questions might be upsetting to young people? Tell us which questions and also why you think this?

....

....

....

....

Appendix 5: Main study forms and questionnaires

5.1 Caregiver consent forms (school and hospital): English, Afrikaans and Oshiwambo

5.3 Adolescent consent form (school and hospital)

5.4 Final study questionnaire

5.5 Supportive questionnaire aids

5.6 SDQ standardised explanations

Complutense University of Madrid, Psychology Department
Shelene Gentz (Researcher in psychology), 0814319735/ 0813033171

CAREGIVER CONSENT FORM

Project title: the wellbeing of teenagers in Namibia

Dear Parent/ Guardian

We would like to invite your child to take part in a research project conducted by Shelene Gentz and the University of Madrid (UCM). This form explains the project. You can then decide if you want your child to take part. This study is approved by the Ministry of Health in Namibia and your hospital/ the Ministry of Education in Namibia and your school.

What is this project about? The project is about the well-being of children in Namibia. We want to know more about how young people feel and act when they are not well. About 100 teenagers from the hospital will take part. We will ask youth about their everyday lives; their feelings and their relationships. We would like to find out about the problems young people have. We also ask what helps young people to cope with their problems.

What will happen if I give my permission? You can decide if you want your child to take part. If you agree, your child will fill out a form, with the help of an interviewer. This will take about one hour. Your child can choose if she/he wants to take part. Your child can stop the interview at any time. Young people will not receive any payment for taking part in this study. If it is needed, we will pay their travel cost. We will also give them a snack. If you choose not to give permission, you and your child will still receive the same services. *If you agree, your child's doctor will provide some details about your child's health. At a later date, we will invite young people to a group meeting to tell them about the findings. We will not give one on one feedback to children or parents*[10]

Will my child's participation be kept and private? Everything we are told will be treated as <u>private</u>. We will not write the name of your child in any report or presentation about this study. Your child´s details will be stored in a safe place. Only the researcher will be able to see it. But, if we learn in the study that your child is at risk of possible harm, we will try to help them. If necessary we will put your child in contact with the appropriate Social Services. We will talk to your child about this. This is in accordance with the law.

---

[10] HIV group only

What are the risks of this research? Some children may not feel comfortable with certain questions. If your child does not feel okay with a question, she or he may choose not to answer. A helper will be present if your child needs to talk about anything in the form. We will also tell your child about places where they can go if they need further help.

How will this study be of benefit? This study will help us to know more about how children cope with problems. We will learn what can help young people with their problems. We will share this with organisations that work with children, with the doctors and the government of Namibia. This can help us to develop programmes for young people.

What if I have any questions about the study? The main person for this study is Shelene Gentz. If you have any questions, you can contact me by telephone: 0814319735 or 0813033171. I will be very happy to talk to you.

What should I do? Please fill in the slip below and let us know if your child can take part. Please contact the Shelene Gentz at 0814319735/0813033171 after you sign the slip. You may also return this slip to your doctor as soon as possible.

Thank you,

Shelene Gentz (Researcher)

This research has been approved by the University of Madrid´s Research and Ethics committee

✂ --

I have read the above paper, or it has been read to me. I understand the form. I agree that my child can take part in this study.

Name of Child.. Child’s grade..............

Child’s Age.. Date of birth:..........................

Can the child you care for take part in this study? YES ☐ NO ☐

Name of parent/guardian... Contact number:...............................

Signature.. Date............................

Complutense University of Madrid, Faculty of Psychology
Shelene Gentz (Researcher in psychology and child wellbeing) 0814319735/ 0813033171

OUER KONSENTVORM

Project: Die gesondheid en welsyn van kinders in Namibia

Liewe Ouer/ Voog[11]

Ons wil u kind nooi om aan 'n projek deel te neem. Die projek word van Shelene Gentz, en die Universiteit van Madrid (UCM) aan gebied. Die vorm vertel waaroor die project gaan. U kan besluit of u kind kan deelneem. Die projek is goedgekeur deur die hospitaal en die Ministerie van Gesondheid in Namibie/ u kind se skool en die Ministerie van Onderwys in Namibie.

Waroor gaan die projek?

Die projek gaan oor die gesondheid en welsyn van kinders in Namibia. Ons wil meer weet van hoe jong mense voel en optree as hulle nie gelukkig is nie. Ongeveer 100 tieners by die hospitaal gaan aan die projek deelneem. Ons gaan die tieners vra oor hulle daaglikse lewe, hulle gevoelens en verhoudings. Ons wil graag probeeer uitvind wat se probleme kinders het. Ons gaan ook uitvind hoe kinders hulle problem hanteer.

Wat gebeur as ek toestemming gee?

As u saamstem, gaan u kind ‘n vorm voltooi, met die hulp van ‘n ondervraer. Dit sal omtrent ‘n uur lank wees. U kind kan besluit of hy/sy wil deel wees hiervan. U kind kan enige tyd besluit as hy/sy nie meer verder wil deelneem nie. Kinders gaan nie enige betaling ontvang nie. As dit nodig is, sal ons die kind se reisgeld betaal. U kind sal ook ´n ligte maaltyd kry. As u besluit om nie u toestemming te gee nie, gaan u en u kind steeds dieselfde behandeling kry. As u, u toestemming gee, gee u ook toestemming dat u kind se dokter inligting beskikbaar gaan stel oor u kind se gesondheid[12]. Met die verloop van tyd, gaan ons die kinders na ‘n groepsbespreking nooi om hulle in te lig oor die bevindings (uitslag) van die projek. Ons gaan nie individuele terugvoering aan die ouers en kinders gee nie.

Sal my kind se betrokkenheid privaat wees?

Alles wat ons vertel word, sal as privaat hanteer word. U kind se naam sal nie gebruik word en u kind se besonderhede sal in 'n veilige plek bewaar word. Slegs die navorsers sal die besonderhede sien. As ons agter kom dat u kind moontlik risiko loop of in gevaar is, sal ons u kind help. As dit moontlik is sal ons u

---

[11] Afrikaans version
[12] HIV group only

kind in kontak bring met die beste Maatskaplike dienste wat hom/haar kan help. Ons gaan eers met u kind gesels, voordat ons hom/haar verwys. Dit is in lyn met die wet.

Wat is die gevolge van die projek?

Dit kan wees dat sommige tieners ongemaklik voel met sekere vrae. As ´n kind nie gemaklik voel met 'n vraag nie, het hy/sy die keuse om dit nie te beantwoord nie. Daar sal iemand byderhand wees as u kind enige vrae het oor die vorm. U kind sal ook in kennis gestel word waar hy/sy verdere hulp kan kry.

Hoe gaan u kind baat vind by hierdie projek? Die studie gaan ons help om meer uit te vind hoe kinders en tieners probleme hanteer. Ons gaan uitvind hoe ons die kinders en tieners te kan help met hulle probleme. Die inligting gaan ons met ander organisasies wat werk met kinders, dokters en die Namibiese regering deel. Ons wil graag he ander mense moet iets leer uit die projek. Die projek kan ons help om programme te ontwikkel om die kinders te help.

Wat as ek vrae het oor die projek? Die persoon verantwoordelik vir die projek is Mej . Shelene Gentz, en u kan my enige tyd kontak met vrae oor die studie. My selfoonnommer is 0814319735/ 0813033171.

Wat moet ek nou doen? U moet die onderstaande vorm voltooi en sê of u toestemming gee. U kan Mej Shelene Gentz kontak na die vorm voltooi is. U ka nook die form aand u doctor oorhandig so gou as moontlik.

KONSENTVORM

Ek het die brief gelees, of iemand het dit aan my voorgelees. Ek verstaan die vorm.

Naam van kind: .... Graad: ....

Ouderdom: ....

Kan u kind deelneem aan die projek: JA ☐ NEE ☐

Naam en van, van ouer/voog: ....

Handtekening van ouer/voog: .... Datum: ....

Complutense University of Madrid, Psychology Department
Shelene Gentz (Researcher in psychology and children´s wellbeing), 0814319735/ 0813033171

CAREGIVER CONSENT FORM

Oshipalanyole shoPoloyeka: Onghalonawa younona moNamibia

Kuye Omukulunhu Wokanona[13]

Otwa hala oku shiiva okanona koye opo ka kufe ombinga momapekaapeko oo Shelene Gentz taningi oku diilila koUnivesiti ya Madrid (University of Madrid), koSpain. Ofoloma ei otai fatulula opoloyeka ei. Oto dulu oku tokola ngeenge owa hala okanona koye ka kufe ombinga momapekaapeko aa. Opoloyeka ei oya kolekwa ko Ministili youndjolowele moNamibia osho yo koshipangelo sheni/ ko Ministili yelongo moNamibia osho yo kofikola yeni.

Opoloyeka ei oili kombinga yashike? Opoloyeka ei oili kombinga youkalinawa wounona moNamibia. Otwa hala okushiiva kutya ounona ohava kala ve udite ngahelipi nohave lihumbata ngahelipi ngeenge ve heudite nawa. Konyala ounona efele limwe (100) otava hoololwa opo vakufe ombinga momapekaapeko aa. Ohatu ka pula nee ounona ava kombinga yeenghalamwenyo davo, omaliudo avo osho yoo omakwatafano ile omaupambele avo. Otwa hala oku shiiva kombinga yomaudjuu oo ounona vena. Osho yoo ohatu kapula kutya oshike hashi vakwafele noku kandulapo omaudjuu aa.

Otapa kaningwa shike ngeenge onda yandje epitikilo (opo okanona kange kakufe ombinga)?

Ngeenge nee owa pitike okanona koye kakufe ombinga, otaka yadeke ofoloma nekwafo lomupekaapeki. Eshi otashi kakwata oule wovili imwe lwaapo. Ounona otava dulu okuholola vakufe ombinga ile vaha kufe ombinga. Okanona koye otaka dulu oku stopa pefimbo keshe eli ke udite kutya inaka hala vali okupekaapekwa. Ounona itava kafutwa nande nande opo vakufe ombinga momapekapeko aa. Ngeenge osha pumbiwa, ohatu kafuta eelefa davo, osho yoo ohatu kevapa oikulya. Ngeenge ove nokanona koye inamu hala oku kufa ombinga, natango otamu ka futilwa olefa notamu kapewa oikulya. Ngeenge oweshi koleke, ndokotola wokanona koye oteke tu pa ouyelele shinasha noukalinawa wokanona koye. Komafiku okomesho ohatu ka shiiva ongudu younona ava vaongale opo tuvalombwele kombinga yoidjemo yomapekapeko aa. Itatu ka yandja oidjemo koumwe noumwe.

Ekufombinga lokanona kange momapekaapeko aa otashi kala oshiholekwa? Keshe eshi hatu ka lombwelwa kokanona koye otashi kala <u>oshiholekwa</u>. Itatu kashanga Edina lokanona koye moshipopiwa ile

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[13] Oshiwambo version

moshishangomwa shasha shomapekaapeko aa. Oufemba wokanona ita ka popiwa wo itau ka hololwa. Omupekaapeki oye ashike tashiva edina lokanona koye opo eka kwafele ngeenge oke li moshiponga shasha. Ngeenge osha pumbiwa, ohatu ka tula okanona koyeye mekwatafano no makwafelo aa kapumbwa.

Omaupyakadi elipi enasha nopoloyeka ei? Ounona vamwe otava dulu oku kala inava manguluka noku pulwa omapulo amwe. Ngeenge okanona koye kake udite nawa noku pulwa omapulo amwe, otaka dulu oku kala inake a nyamukula. Otapa kakala omukwafeli taka kala nokukwafela ngeenge okanona okapumbwa oku popya sha shinasha naasho shili mofooloma. Osho yoo ohatu kalombwela okanona koye kombinga yeenhele apa taka dulu okuya ngeenge oka pumbwa omakwafelo awedwapo.

Omapekaapeko aa otaa kwafele ngahelipi? Omapekaapeko aa ota e tu kwafele opo tuushive nghee ounona hava kandulapo omikundu davo. Ohatu ke lilonga kombinga yaashi tashi dulu oku kwafela ounona ava vena omaudjuu. Ohatu ka yandja ouyelele ou komahangano aa haalongo nounona osho yoo keendokotola nokepangelo laNamibia. Eshi otashi tu kwafele opo tu totepo eepologalama de yambukepo lounona.

Ohandi ningi ngahelipi ngeenge ondina epulo lasha kopinga yopoloyeka ei? Omukulunhu wopoloyeka ei oye Shelene Gentz. Ngeenge ouna omapulo enasha nopoloyeka ei, oto dulu oku mu dengela kongodi ei: 0814319735/ 0813033171 ile u mu tumine oemail ku: shelenegentz@yahoo.co.uk. Nehafo linene ote ku kwafele.

Owa pumbwa ku ninga shike Alikana yadeka ofooloma ei ya landula ndele totu lombwele kutya owa koleka ile ino koleka ekufombinga lokanona koye mopoloyeka ei. Oto dulu oku alulila ofolooma ei komundokotola ngee we iha deke.

Tangi Unene
Shelene Gentz (Omupekaapeki)

Omapekaapeki aa omakolekwa kokomitii yomapekaapeko oUnivesiti

----

Ondalesha ombapila ei, ile onde i leshelwa. Ondi udite ko kombinga yofoolomba ei. Onda itavela opo okanona kange ka kufe ombinga momapekaapeko aa

Edina lokanona..................................... Ondodo/ongudu yokanona....................

Eedula dokanona................................... Efiku iye Valo:....................................

Okanona otaka dulu oku kufa ombinga momapekaapeko aa? Eheno ☐ Ahawe ☐

Edina lomukunhu wokanona ....

Eshaino..Efiku...........................

Information Sheet for Teens

This project is about teenagers in Namibia. This form tells you about the project so that you can decide if you want to take part. Ask me if there is anything you do not understand.

What is the project about? We are doing this project to learn about young people and their feelings and about their lives. We want to know about the difficulties young people have. We also ask your ideas about what can help young people.

Do I have to take part? You can decide if you want to take part. You will not get in any trouble if you do not want to take part.

What would I have to do? If you want to take part, you will first sign this form. I will then ask you some questions about your life and the different people in your life. This will take about 45 minutes. There would be nothing extra for you to do.

What if the questions upset me? If there is a question you do not feel okay with you do not have to answer. You may also stop the study at any time. You don´t have to give a reason. If you want to talk to someone about anything that has come up, you can tell me.

Will what I say be kept private? Anything you tell me about yourself will be kept private. Any information about you will have your name changed so that no-one will know that you were part of the project. But, if during this study, I learn that you are having serious problems, we will try to help you. If so, I will explain to you some options for further help. If we are worried about your safety, we may contact a welfare organisation for you. I will first talk to you about this.

Why should I take part in this project? This project will help us to know more about what can help young people in Namibia. This project will help organisations plan so they can help young people and their families better.

What if I have a complaint? If there is anything to do with this project that you are unhappy with, you can contact Shelene Gentz (0813033171). Thank you for reading this sheet. If you feel comfortable with everything, you can fill in the box below:

I agree to take part in the above study: **Yes** ☐ **No** ☐

....	....	....
Name of participant	**Signature**	**Date**

INTRODUCTION*: Instructions to Interviewers*

Make sure you have the signed parent consent form before beginning the interview. After introducing yourself give participant the Adolescent assent form to read. After they have read the form tell them that you want to ask them some question about the form**:**

1. What is the study about?
    - ADD: "You will only need to do the interview today and that's it. There will be nothing more for you to do."
2. What will happen if you decide that you do not want to take part in the study?
3. Will what we talk about be kept private?
    - Use this opportunity to reinforce situations where privacy may be broken
    - "for example if I find out you are being abused or if you are in any danger, or if you are in danger of hurting yourself or someone else"
4. Do you have any questions before you sign the form?

IF YOU ARE SATISFIED THAT THE PARTICIPANT UNDERSTANDS THE CONDITIONS OF THE STUDY THEN THEY CAN SIGN THE ASSENT FORMS.

"This interview has to do with your life and your feelings about different things in your lives. I will ask question about your home and also about different people in your life. We will also ask questions about your strengths and difficulties. Sometimes I will ask you questions and I will fill in your answers and other times I will ask you to complete the forms. As we go along feel free to ask any questions. Remember, this is not a test. There are no right or wrong answers! Thank you for taking the time to help."

TALKING TO TEENS IN NAMIBIA

Name of interviewer: ....

Place of interview: Paediatric clinic: ☐ School: ☐

Date of interview: ..../......./2013 (dd/mm/year)

Start time: ....

End time: ....

Code: ....

SECTION ONE: Background Information

In this first section we will ask you some of your background information and also about the place that you stay.

1. How old are you today? ______ (years)
2. Gender (*Mark w/out asking):* ☐ Male ☐ Female
3. What language do you speak at home most of the time (please mark one)?

☐ Oshiwambo	☐ Otjiherero	☐ Afrikaans	☐ Nama/ Damara
☐ English	☐ Nyemba	☐ Silozi	☐ Rukwangali
☐ Portuguese	☐ Another language, tell us which:		

4. Where do you stay?

☐ Okuryangava	☐ Hakana	☐ Goreangab	☐ Wanaheda
☐ Katutura[14]:		☐ Windhoek Nrt	☐ Otjomuise
☐ Khomasdal	☐ Rocky Crest	☐ Windhoek Ws	☐ Dorado
☐ Academia	☐ Another suburb, tell us which:...		

5. Which culture are you (please mark one)?

☐ Owambo	☐ Kavango	☐ Herero	☐ Damara
☐ Nama	☐ White	☐ Coloured	☐ Caprivian
☐ San	☐ Mixed cultures	☐ Another (which):	

6. Who stays with you in your house? (Mark all that apply)

☐ Biological mother	☐ Biological father	☐ Aunt(s):........
☐ Uncle(s).......	☐ Grandfather	☐ Grandmother
☐ Sisters[15]:	☐ Brothers[16]:	☐ Stepmother
☐ Stepfather	☐ Cousins	☐ Foster parent
☐ Family friend	☐ Housemother	☐ I stay alone
☐ Another person. Who else..		

---

[14] Specify: Gemeende, Donkerhoek, Okahandja Park, Havana etc.
[15] If there is more than one sister specify how many
[16] If there is more than one brother specify how many

7. How many people stay with you in your house (including yourself)?

Adults_____ Children (under 18 years) _____

8. Who is your main caregiver main caregiver[17]/ parent or guardian? (CIRCLE C/G in Q6)

9. Is your biological mother still alive? ☐Yes ☐ No

If she is no longer alive, how old were you when she passed away?_________

10. Is your biological father still alive? ☐Yes ☐ No

If he is no longer alive, how old were you when he passed away? ___________

11. IF EITHER PARENT IS ALIVE, BUT NOT LIVING WITH THEM, ASK WHERE THAT PARENT IS:

Biological father_____________________ Biological mother: ________________________

Please answer the following questions about your school.

12. What is the name of your school: ________________________________

13. What is your grade? ___.

If participant is not going to school ask: Up to which grade did you complete?

Highest Grade completed_____ When did you last go to school (year)? _________

14. Have you ever repeated a grade in school?

☐ Yes. Which Grade(s) did you repeat: _________

☐ No

---

[17] "Your caregiver is the person that stays with you and is mainly responsible for you."

SECTION 2: Information about your home

"This section is about your home and the people who stay with you"

15. Here are some pictures of some homes in Namibia. Which one is most like your home?

☐ A house made of brick or concrete

☐ A block of flats or a flat in someone's yard, made of brick or concrete.

☐ A shack or on its own plot or in someone´s yard

☐ Other. Tell us what kind: ....

(For example: another kind of house or if you are living on the street)

16. [18]Do you stay in an *orphanage*[19]? ☐ Yes ☐ No

17. Do you have any of these things in your home:

		Yes	No
A	A radio	☐	☐
B	A television	☐	☐
C	A fridge	☐	☐
D	Stove (using gas or electricity)	☐	☐
E	A car	☐	☐
F	Electricity	☐	☐
G	A desk or table to study at or do your homework	☐	☐
H	Books of your very own (do not count school books[20]	☐	☐
I	Enough clothes to keep you warm and dry	☐	☐

18. Did you eat breakfast this morning before you went to school?

☐ Yes. Skip to 19

☐ No. Go to question 18.b .

18. b. Tell us why you did not have breakfast

☐ There was no food in the house.

☐ I did not want food. I was not hungry

☐ Another reason: Tell us..

---

[18] If you are able to deduce whether pp stays in an orphanage or not then do not ask

[19] Orphanage definition: "A place where orphans stay together, like Hope Village or SOS"

[20] If you are not sure ask pp what kind of books. Do not include magazines, unless educational, or pamphlets.

19. Sometimes kids don’t have enough food in their home. Think about the last 7days and tell me how many days you did not have enough food.

☐ None ☐ 1 ☐ 2 - 3 ☐ 4 or more

“Now I will ask what the people in your house do.”

20. Does anyone in your household have a job?

☐ Yes. IF YES, COMPLETE QUESTION 21

☐ No. No-one in my house works. CONTINUE TO SECTION 3

☐ Participant stays in children´s home. Question not applicable. CONTINUE TO SECTION 3

21. Tell me about your (insert caregivers) jobs[21]? Does your (insert caregivers) have a job? Is it:

- a **regular job** (like everyday**),**
- **a part-time job** (some days each week, or only a few hours every day) or
- **a sometimes job** (like just on a building project or at special times during the year)”

1. Caregiver 1: ______________________ (Father, Mother, Aunt, Grandmother etc.)

Job type:
☐ Regular
☐ Part-time
☐ Sometimes
☐ No Job

1. Caregiver 2[22]: _______________ (Father, Mother, Aunt, Grandmother)

Job type:
☐ Regular
☐ Part-time
☐ Sometimes
☐ No Job

---

[21] COMPLETE FOR THE MAIN CAREGIVERS. IF ONLY ONE CAREGIVER WORKS THEN CHOOSE THE NEXT WORKING ADULT (CHOOSE THE BEST JOB). IF NONE OF THE CAREGIVERS ARE IN REGULAR EMPLOYMENT INCLUDE ANY OTHER PERSON WHO MAY BE IN REGULAR (FULL-TIME EMPLOYMENT). INCLUDE ONLY PEOPLE CURRENTLY LIVING IN THE HOUSEHOLD

Section 3: Your health

This section is about your health

22. How many times in the past month did you visit the doctor or hospital/clinic?

(Please mark one (X))

NO visits to the doctor in the last month	☐
I visited the doctor 1 to 2 times in the past month	☐
More than 2 times in the last month	☐

23. SKIP THIS QUESTION

24. Have you had Tuberculosis (TB)?	YES ☐	NO ☐	I Don´t Know ☐
a) Was it in the last year or 12 months	YES ☐	NO ☐	

25. In the past 6 months/ in this year, how many days have you been absent from school?

Number of days missed:.............. (IF NO (0) DAYS SKIP QUESTION 26)

26. **In the past 6 months/ in this year, were you absent because you were sick?**

Yes ☐ No ☐

If yes: Number of days missed due to illness............

Please describe the illness you had? ....

....

If there are other days that were missed not due to illness ask what were the reasons for missing? ....

....

Section 4: SDQ AND IMPACT SUPPLEMENT:

I will now ask you to fill out the next section. It is about children´s strengths and difficulties.

GO TO PRACTICE EXAMPLE.

Children´s Strengths and Difficulties questionnaire

	Not True	Somewhat True	Certainly True
I try to be nice to other people. I care about their feelings	☐	☐	☐
I am restless; I cannot stay still for long	☐	☐	☐
I get a lot of headaches, stomach-aches or sickness	☐	☐	☐
I usually share with others (food, games, pens etc.)	☐	☐	☐
I get very angry and often lose my temper	☐	☐	☐
I am usually on my own. I generally play alone or keep to myself	☐	☐	☐
I usually do as I am told	☐	☐	☐
I worry a lot	☐	☐	☐
I am helpful if someone is hurt, upset or feeling ill	☐	☐	☐
I am constantly fidgeting or squirming	☐	☐	☐
I have one good friend or more	☐	☐	☐
I fight a lot. I can make other people do what I want	☐	☐	☐
	Not True	Somewhat True	Certainly True
I am often unhappy, down-hearted or tearful	☐	☐	☐
Other people my age generally like me	☐	☐	☐
I am easily distracted; I find it difficult to concentrate	☐	☐	☐
I am nervous in new situations. I easily lose confidence	☐	☐	☐
I am kind to younger children	☐	☐	☐
I am often accused of lying or cheating	☐	☐	☐
Other children or young people pick on me or bully me	☐	☐	☐
I often volunteer to help others (parents, teachers, children)	☐	☐	☐
I think before I do things	☐	☐	☐
I take things that are not mine from home, school or elsewhere	☐	☐	☐
I get on better with adults than with people my own age	☐	☐	☐
I have many fears; I am easily scared	☐	☐	☐
I finish the work I am doing my attention is good	☐	☐	☐

Overall, do you think that you have difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

NO	Yes minor difficulties	Yes definite difficulties	Yes severe difficulties
☐	☐	☐	☐

If you have answered “Yes”, please answer the following questions about these difficulties:

5. How long have these difficulties been present

Less than a month	1-5 months	6-12 months	Over a year
☐	☐	☐	☐

6. Do these difficulties upset or distress you?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

7. Do these difficulties interfere with your everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	☐	☐	☐	☐
FRIENDSHIPS	☐	☐	☐	☐
CLASSROOM LEARNING	☐	☐	☐	☐
LEISURE ACTIVITIES	☐	☐	☐	☐

8. Do the difficulties make it harder for those around you (family, friends, teachers, etc?)

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

Section 5: ACTIVITIES AND SOCIAL SUPPORT

“We still have a few questions before we finish. Are you okay to continue? Do you wish to take a small break? Do you have any questions before we continue?”

We are also interested to find out about the activities that teenagers do with other young people.

24. Do you:

		YES	NO
a)	play sports like netball or soccer or another sports	☐	☐
b)	belong to singing group or choir, a dance or drama group or an after school debating club (UNDERLINE THE OPTION)	☐	☐
c)	belong to a church youth group or another youth group[23]	☐	☐
d)	have any other activity with young people (describe): ………………………………………………………………………	☐	☐

“I will ask about the help you get from different people in your life. I will ask about the help you get from your (insert caregiver) and I will also ask about the help you get from your friends. I will read some sentences and then tell me if it is “not at all true” “sort of” (USE VISUAL CARDS TO ILLUSTRATE)

25. a) Main caregiver: __________________ (E.g. mother, aunt, father etc.).

	Not at all	Sort of	Very
My ______[24] is always willing to help me in **practical ways like when I need taxi money or other things, like toiletries or things for school.**	☐	☐	☐
My ______ gives me advice and helps me figure things out when I have a problem	☐	☐	☐
My _______ **understands me and listens to m**e when I have a personal problem, or a secret to discuss	☐	☐	☐
I **have fun** with my _______	☐	☐	☐

---

[23] Do not include the teen club

[24] Insert main identified caregiver

b) About how many close friends[25] do you have? ____________.

Then next question are about these close friends or best friends.

	Not at all	Sort of	Very
My close friend(s) is always willing to help me in **practical ways like when I need taxi money or other things, like for school or a place to stay.**	☐	☐	☐
My close friend(s) **gives me advice** and helps me figure things out when I have a problem	☐	☐	☐
My close friend (s) **understands me and listens to m**e when I have a personal problem, or a secret to discuss	☐	☐	☐
I **have fun** with my close friend (s)	☐	☐	☐

c) Who else is helpful in your life? ____

This could be a family member, teacher, doctor or even the pastor at your church.[26]

	Not at all	Sort of	Very
My ……………. is always willing to help me in **practical ways like when I need taxi money or other things, like for school or a place to stay.**	☐	☐	☐
My ………….. **gives me advice** and helps me figure things out when I have a problem	☐	☐	☐
My …………… **understands me and listens to m**e when I have a personal problem, or a secret to discuss	☐	☐	☐
I **have fun** with …………………..	☐	☐	☐

27. How happy are you with the help you receive from <u>the people I stay with</u>[27]

Not at all ☐ Only a little ☐ Quite a lot ☐ A great deal ☐

28. How happy are you with the help you receive from your <u>friends</u>

Not at all ☐ Only a little ☐ Quite a lot ☐ A great deal ☐

---

[25] A CLOSE FRIEND IS LIKE A BEST FRIEND, SOMEONE YOU CAN SHARE YOU PROBLEMS WITH.

[26] IF MORE THAN ONE PERSON IS CHOSEN ASK THE PARTICIPANT TO SELECT THE MOST HELPFUL PERSON. IF THE PARTICIPANT CANNOT THINK OF ANYONE, SKIP TO THE NEXT QUESTION AND WRITE “NO-ONE”.

[27] USE VISUAL RESPONSE CARDS

29. Sometimes when a teenager has problem they may talk to a person who is not a friend or a family member**.** Have you ever been to a social worker or a counselor or a life-skills teacher or another person when you needed help with a personal problem:

☐ No. ☐ Yes. Tell us who:

Psychologist ☐	Social worker ☐	Life-skills teacher ☐	Counsellor ☐
☐ Another person, tell us which...			

If YES: Where did you see them? ………………………………..

When? ☐ 1-6 months ago[28]

☐ More than 6 months ago[29]

Section 6: Negative family processes:

In this section I am going to ask you some more questions about your home life. I will use the case of two young people like yourself. Immanuel and Maria are two teenagers living in Windhoek...

30. Immanuel's family have lots of arguments. Sometimes adults shout at each other and sometimes there is fighting. This last week, how many days were there arguments with adults shouting in your home[30]? IF NO DAYS SKIP TO QUESTION 33.

☐ None ☐ 1 ☐ 2 - 3 ☐ 4 or more

31. Did you feel bad, upset, scared, sad or mixed up the worst time when this happened?

☐ Yes ☐ No ☐ Pass

32. Can you tell me what these arguments were mainly about?

....………………………………………………

………………………………………………………………...

33. In this last week, how many days were there arguments with adults hitting each other in your home? (INCLUDE PUNCHING, KICKING OR SLAPPING) IF NO DAYS SKIP QUESTION 34

☐ None ☐ 1 ☐ 2 - 3 ☐ 4 or more

34. "Did you feel bad, upset, scared, sad or mixed up the worst time when this happened?

☐ Yes ☐ No ☐ Pass

---

[28] this year

[29] Before this year

[30] Only mark if it is adults shouting at one another

HIV Group Only

Section 7: About me and my illness

In this section we will ask some more questions about your health.[31]

SCREENING QUESTIONS[32]:

Why have you come to the hospital? What is your reason for your visit here?[33]

………

Have you heard about the teen club?

☐ Yes ☐ No (IF NO, GO TO QUESTION 39)

Why do kids come to the teen club?

....

35. Have you ever attended a meeting at the teen club? ☐ Yes ☐ No

36. When was the first time you came to the Teen club (month/year): …………….......

37. How often do you attend the sessions? I attend:

	Tick (√)
Only attended one session	
I attend only some sessions	
I attend most/all sessions	

38. Would you recommend the teen club to children in your situation?

☐ Yes. Why...

☐ No. Why not? ....
....

39. Do you go to any other support group[34]?

☐ Yes. Can you tell us where do you go? ....

☐ No

---

[31] *THE* FOLLOWING QUESTIONS ARE ASKED TO THE HIV GROUP ONLY. THIS SHOULD BE HANDLED AS A DISCUSSION. IF PARTICIPANTS NEED TO ELABORATE ON CERTAIN ISSUES DO NOT STOP THEM. *PAY ATTENTION TO THE WORDS THAT CHILDREN USE WHEN THEY TALK ABOUT THEIR ILLNESS FOR EXAMPLE "BAD GUY" OR "VIRUS" FOR HIV AND USE THESE WORDS.*

[32] ONLY ASK IF YOU ARE UNSURE ABOUT WHETHER PARTICIPANT HAS BEEN DISCLOSED THEIR STATUS.

[33] PROBE REASONS FOR TAKING MEDICATIONS, NAME OF ILLNESS

[34] MARK ONLY IF IT IS AN HIV-RELATED SUPPORT GROUP E.G. POSITIVE VIBES, NAPPA, FAMILY HOPE SERVICES

DO NOT CONTINUE THIS PART IF YOU ARE NOT SURE ABOUT WHETHER THE PARTICIPANT HAS BEEN DISCLOSED THEIR STATUS.

This last section of the interview will be about your (INSERT[35]). First we will talk about the time when you found out about (INSERT). We will also talk about your medicine. Remember that this information is private and will not be shared with anyone. If there is a question that you want to skip then just say "pass". Are you ready to continue?

40. How old were you when you found out about (INSERT)?...................

41. Who told you?

☐ Family: specify (mother, sister, aunt): ....
☐ Friend
☐ Provider (specify: nurse, doctor, treatment supporter etc.)..........................

42. Who else was there when you were told?

☐ Family: specify (mother, sister, aunt): ....
☐ Friend
☐ Provider (specify: nurse, treatment supporter etc.)..........................
☐ No-one

"Now we will talk about your visits to the clinic and about your pills. Think about the past 6 months"

43. Is there anyone that motivates or encourages you to come to your clinic appointments?

☐ YES ☐ NO
↓

If YES, who motivates or encourages you?
☐ Family: specify (mother, sister, aunt): ....
☐ Friend
☐ Provider (specify: nurse, treatment supporter, housemother[36] etc.)..........................

In what way do they encourage you?..

44. Does anyone come with you to your clinic appointments?

☐ YES ☐ Sometimes ☐ NO, I come alone
↓ ↓

If YES or sometimes, who comes with you?
☐ Family: specify (mother, sister, aunt): ....
☐ Friend
☐ Provider (specify: nurse, treatment supporter, housemother etc.)..........................

---

[35] STAY AS CLOSE AS POSSIBLE TO TERM USED BY THE PP: "BEING POSITIVE/ THE VIRUS/ HIV/ THE BAD GUYS"
[36] IF STAYING IN AN ORPHANAGE: THIS IS THE PERSON WHO CARES FOR THEM

“Now I will ask you some questions about the pills you take every day. Remember that this information is private, so I will not tell anybody about your answers, not even the doctors here at the hospital. Sometimes, for different reasons, young people may forget to take their pills or their medicine.”

45. How many times in the last seven days have you forgotten to take your pills? ...... IF NO (0) DAYS SKIP TO QUESTION 48

46. Was it in the morning or evening? ☐ morning ☐ evening

47. What was your main reason for this forgetting…………………………………………………........... ....

48. Is there anything you do that helps you to remember to take your medication? ....

49. Does anyone help you to remember to take your medication?

☐ YES ☐ NO

If YES, who helps you to remember?

☐ Family: specify (mother, sister, aunt): ....
☐ Friend
☐ Provider (specify: nurse, treatment supporter, housemother etc.)...........................

50. How does this person help you remember? (PROBE: What do they say or do to help you?)

....

51. How many people have you told about (INSERT)[37]?

☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

52. Who have you told?

☐ Friends. How many?............	☐ No-one
☐ Mother	☐ Father
☐ Sister or brother	☐ Neighbour
☐ Other (specify)..	

IF PARTICIPANT HAS TOLD FRIEND(S) →GO TO QUESTION 53.

IF PARTICIPANT HAS NOT TOLD FRIEND(S) →GO TO QUESTION 54

---

[37] DO NOT COUNT IF PERSON WAS PRESENT AT FIRST DISCLOSURE OF IF SOMEONE ELSE TOLD THEM

53. How did your friend(s) react when you told them? ....

....

I will now read some statements just tell me “yes” if it´s true or “no” if it is not true

	YES	NO
They accepted me	☐	☐
They told someone else	☐	☐
They gossiped or laughed at me	☐	☐
They motivate me to keep healthy and strong	☐	☐
They stopped talking or playing with me	☐	☐
I was treated differently at school	☐	☐
They helped me with my treatment plan. Like remembering my pills or coming to the hospital with me	☐	☐
They worry about me.	☐	☐

54. If you have not told your close friends, can you imagine they would react if you tell them? ....

....

I am going to read some statements, and just tell me “yes” if you agree, “maybe” if you are not sure, and “no” if you don´t agree.

	YES	MAYBE	NO
They would accept me	☐	☐	☐
They would tell someone else	☐	☐	☐
They will gossip or laugh at me	☐	☐	☐
They will motivate me to keep healthy and strong	☐	☐	☐
They will not want to talk to me or play with me	☐	☐	☐
I will treat me differently at school	☐	☐	☐
They will help me with my treatment plan. Like remembering my pills or coming to the hospital with me	☐	☐	☐
They would be worried about me. They would care about my health	☐	☐	☐

55. How many friends do you have that also have (INSERT)?

☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

Whatever you tell will be kept <u>private</u>

Section 8: My personal experiences with my illness

Please tick if you strongly disagree, disagree, agree or strongly agree with the statement:

	(Very False) ***I strongly disagree***	**(False)** ***I disagree***	***(True)*** ***I Agree***	***(Very True)*** ***I strongly agree***
1. I feel that I am not as good a person as others because I have HIV	☐	☐	☐	☐
2. Having HIV makes me feel unclean	☐	☐	☐	☐
3. Most people think that a person with HIV is disgusting	☐	☐	☐	☐
4. Having HIV makes me feel that I am a bad person	☐	☐	☐	☐
5. Most people with HIV are rejected when others find out)	☐	☐	☐	☐
6. I am very careful who I tell that I have HIV	☐	☐	☐	☐

Questions 7-10 assume that you have told another person that you have HIV, or that other people know. Maybe this is not true for you. If this is not true in your life just imagine yourself in that situation. Then answer the question based on how you think you would feel or how you think others would react to you.

	(Very False) ***I strongly disagree***	**(False)** ***I disagree***	***(True)*** ***I Agree***	***(Very True)*** ***I strongly agree***
7. I have been hurt by how people reacted to learning I have HIV	☐	☐	☐	☐
8. I worry that people who know I have HIV will tell others	☐	☐	☐	☐
9. I have stopped socializing with some people because of their reactions of my having HIV	☐	☐	☐	☐
10. I have lost friends by telling them I have HIV.	☐	☐	☐	☐

Section 9: Young people´s opinion Worksheet

We will now do the last section of the questionnaire! In this section we ask your opinion about young people, about what makes them happy. We also want to know if you have any advice to give young people in difficult situations and also how other people like teachers, doctors or the government can help young people in difficult situations.

61. Please tell me about some of the things that young people in your situation might feel really good or happy or important about.

Young people might feel good or happy or important about .

....

....

....

....

....

....

62. Do you have any advice for young people in your situation? What helps you cope when you are in a difficult situation?

....

....

....

....

.

63. What can teachers, doctors or the government of Namibia do to help children and families in a difficult situation? (please turn over if you need more space)

....

....

....

....

....

Section 11: Debriefing and wrap up

64. PLEASE GO BACK TO THE SDQ AND TAKE NOTE OF THE PARTICIPANTS RESPONSE TO ANY OF THE FOLLOWING QUESTIONS**:**

"I worry a lot"***/*** "I get very angry and often lose my temper"/ "I am often unhappy, downhearted or tearful"/ "Other people my age pick on me or bully me". If participants' answers indicate distress (score of 2) follow this up in the final question. (e.g. "You said that you worry a lot, I wonder if you could tell me about this"

....

....

....

....

....

....

.

65. Before we finish I would like to know how you felt during the interview. How did you like or not like the interview?[38] Which part did you like the most? Which part did you like the least? (Do NOT ask this question if the participant was clearly disturbed during the interview)

....

....

....

....

....

This completes the interview. Thank you very much for taking part!

---

[38] If participant does not have anything to say you can also ask: which part did you like the most? Which part did you find the most difficult?

Interviewer reflection form

1. How did the interview go (atmosphere, cooperation, language difficulties, etc.)?

....

. ...

2. How in your opinion did the participant feel during this interview (please make special note if there were any signs of distress, or if the participant made any comments about how s/he felt)?

....

. ...

How did you feel during this interview? What were the main issues that stuck in your mind for this interview?

....

....

3. In your opinion, what is this participants´ main presenting problem? You may pick more than one. Please elaborate in the space below.

☐ Economic issues ☐ General Peer problems ☐ Family problems (e.g. conflict)

☐ Mental health (e.g. depression, anxiety, concentration etc.) ☐ Academic problems

☐ HIV-related peer problems ☐ Adherence problems

☐ Acceptance of HIV status ☐ No problems

☐ Another : ....

Please elaborate:.. ....
....

4. Which referral agencies were specifically recommended to the participant?

☐ Teen club	☐ Peace centre	☐ Lifeskills teacher	☐ Social worker
☐ Lifeline/Childline		☐ Follow up debriefing session	
☐ The referral list was given. No follow up was needed.			

Other:...

5. How did the participant respond to the offer of follow-up? ....

....

Participant Code:................ HOSPITAL GROUP:☐ SCHOOL GROUP: ☐

SDQ supplementary material: Practice example and visual aids

The next part is about children´s Strengths and Difficulties. We are going to read some questions together. Think about yourself and say if it´s “Not true” “Sometimes true” or “Certainly true”. Some words might be difficult. If there is a difficult word, please tell me which word so that I can explain it to you. Let´s do one example together:

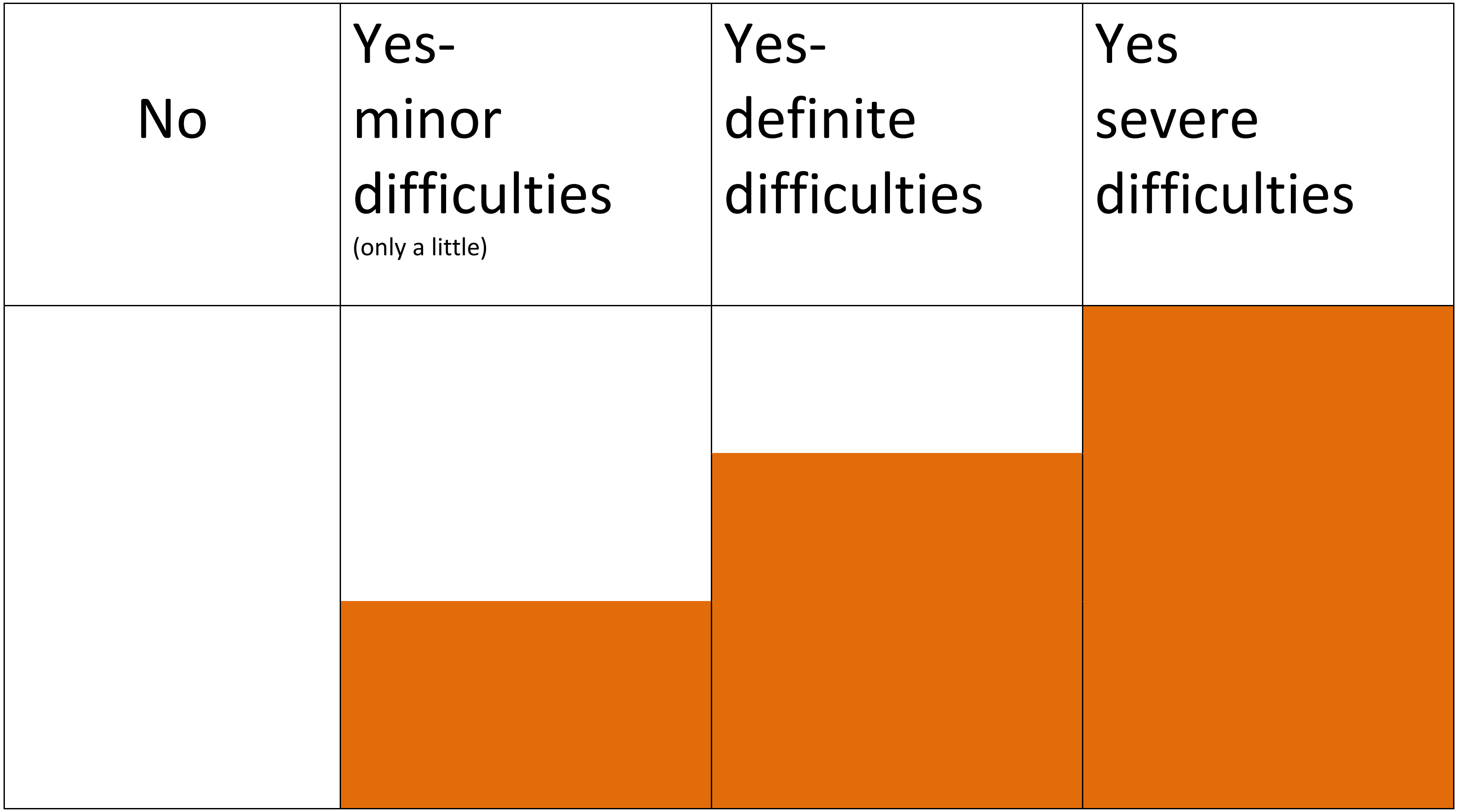
“I like sweets”

Think about yourself. Do you like sweets?

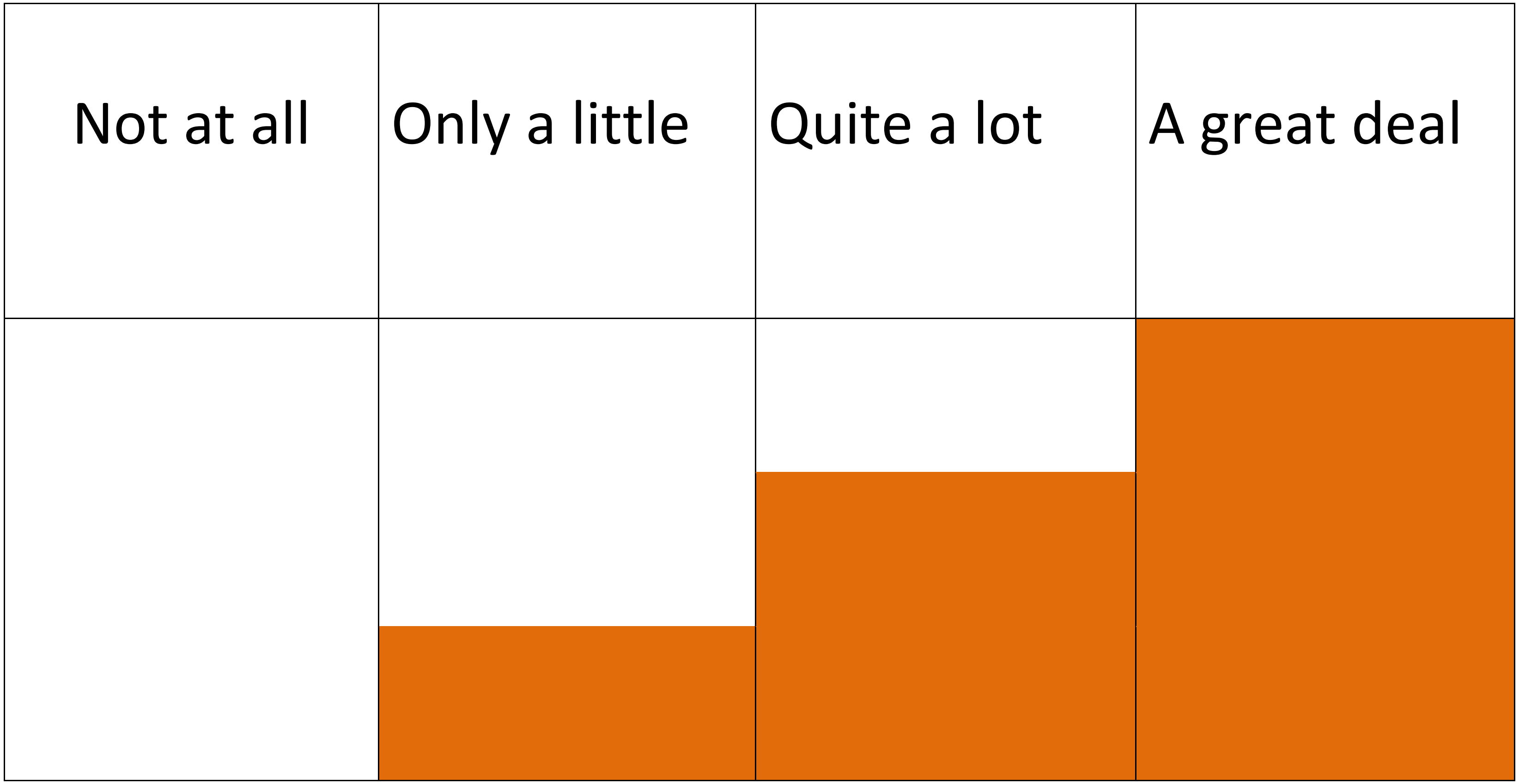
- If you do not like sweets then you would mark “No” or “Not true”
- If you sometimes like sweets then you would mark “Somewhat true”
- If you like sweets then you would mark “Yes” or “Certainly true”

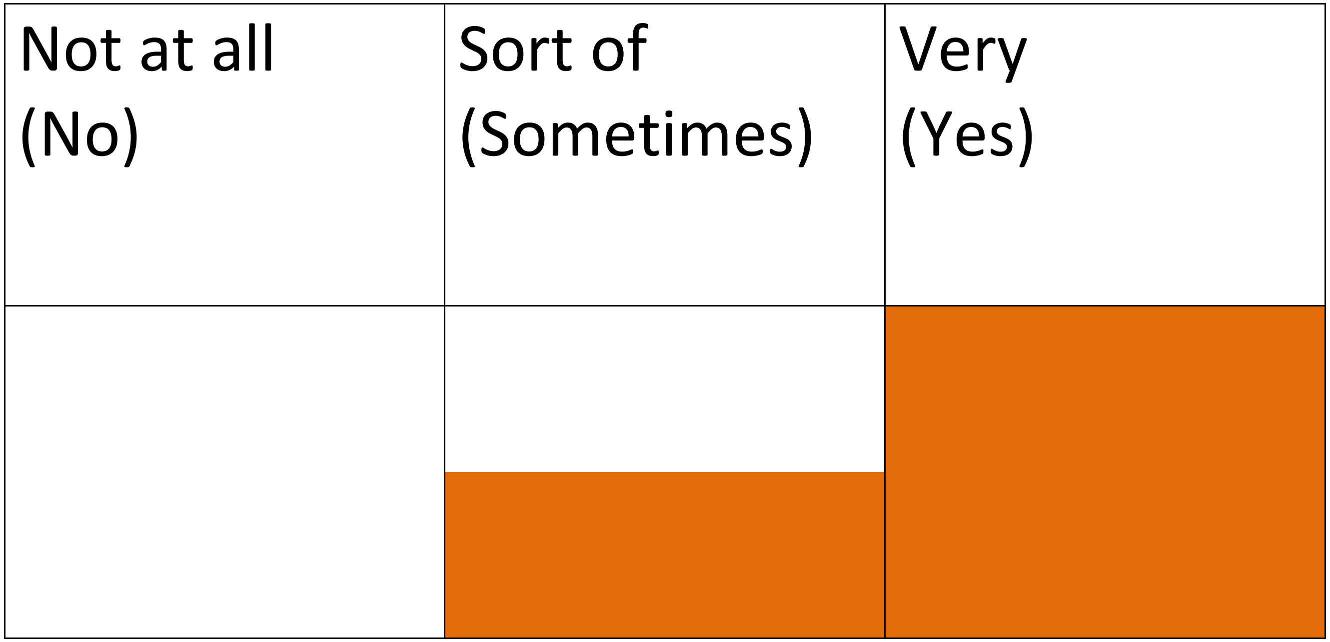
Not true or No	Somewhat True (This is like Sometimes or In the middle)	Certainly true or Yes
☐	☐	☐

Impairment supplement support (I)



Impairment supplement support II





Not at all (No)	Sort of (Sometimes)	Very (Yes)

Berger stigma scale support supplement

This section asks about your feelings about____[39] and about how other people treat people with ____. There are no right or wrong answers. I will read some sentences and I will ask you to tell me whether you agree or no with the sentence. If you agree very much, you can tell me that you strongly agree and if you disagree very much you can tell me strongly disagree. Let´s do this example together.

“I like maths.”

Now tell me if you

- “agree”, “strongly agree”
- or if you “disagree” or “strongly disagree”

I **strongly** disagree ☐	I disagree ☐	I agree ☐	I **strongly** agree ☐

---

[39] INSERT WORD AS USED BY PARTICIPANT

APPENDIX 5.6 SDQ Standardised Explanations

SDQ question	It means...
I try to be nice to other people. I care about their feelings	"I try to be nice to other people. I don´t want them to feel bad." (REPEAT RESPONSE CATEGORIES: IS THIS NOT TRUE, SOMETIMES TRUE OR CERTAINLY TRUE FOR YOU)
I am restless; I cannot stay still for long	I cannot relax. I cannot sit still even for a (short) while. (REPEAT: IS THIS NOT TRUE, SOMETIMES TRUE OR CERTAINLY TRUE FOR YOU)
I get a lot of headaches, stomach-aches or sickness	I get a lot of pains in the head, pains in the stomach, and I get sick a lot of times. (IS THIS NOT TRUE, SOMETIMES TRUE OR CERTAINLY TRUE FOR YOU)
I usually share with others (food, games, pens etc.)	(IS THIS NOT TRUE, SOMETIMES TRUE OR CERTAINLY TRUE FOR YOU)
I get very angry and often lose my temper	I get very angry and I lose control of myself a lot. I lose control of myself many times
I am usually on my own. I generally play alone or keep to myself	I stay alone a lot. I play alone or keep to myself most days.
I usually do as I am told	
I worry a lot	I have lots of worries.
I am helpful if someone is hurt, upset or feeling ill	I help if someone is hurt, feeling bad or feeling sick.
I am constantly fidgeting or squirming	I cannot keep still. I cannot keep my hands and feet still.
I have one good friend or more	
I fight a lot. I can make other people do what I want	
I am often unhappy, down-hearted or tearful	I am sad many times. I cry a lot.
Other people my age generally like me	Other people my age normally like me

	It means.....
I am easily distracted; I find it difficult to concentrate	I find it hard to pay attention in class or in other places.
I am nervous in new situations. I easily lose confidence	I feel shy or nervous in new places. I do not believe in myself.
I am kind to younger children	
I am often accused of lying or cheating	Many times, other people say that I lie or cheat
Other children or young people pick on me or bully me	Other children or young people bully me
I often volunteer to help others (parents, teachers, children)	I offer to help others like parents, teachers or other children.
I think before I do things	
I take things that are not mine from home, school or elsewhere	"I steal things that are not mine from home, school or other places"
I get on better with adults than with people my own age	FOR EVERYONE: I want to be with adults. I don´t want to be with people my age. ADD THIS ONE FOR OLDER KIDS: I prefer to be with adults more than with people my own age.
I have many fears; I am easily scared	I am afraid of a lot of things. I get scared easily.
I finish the work I am doing my attention is good	I can finish my work, like school work. I pay attention.

Appendix 6: Resources for participants

6.1 List of resources for further help

We always give children who take part in our project a list of numbers for places they may need. You may never use them, but it useful to have them handy!!

The following places offer counselling to teens that have difficulties in their lives. The counselling is free of charge.

LIFELINE/ CHILDLINE Telephone counselling service:
They can call you back on your cell phone.
Telephone: 061- 232221
Free number: 116
45 Bismarck Street, Windhoek

Philipi Trust:
They can talk to you on the telephone or make an appointment for you to come into the office.
Tel: 061- 259291
Cell: 0814261795 (Tabitha)
Address: 7693 Ara Street, Dorado Park

PEACE Centre:
26 Rhino Street
Telephone: 061-371550
They can call you back on your cell-phone

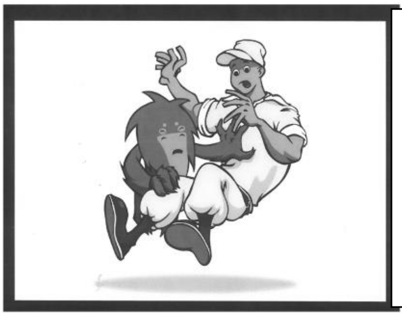
If you want to join the support group for teenagers: Speak to Dr Rukato

Remember, you can also speak to your Lifeskills teacher.

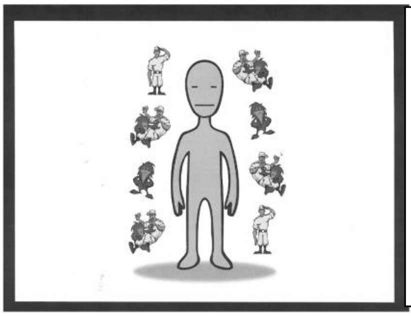
If you need to speak about anything in the questionnaire or help to put you into contact with these places you can contact us:
0814319735
OR
0813033171 (Shelene)

Appendix 6.2 Illustration from "Why I take my medicines" booklet: Chapter two

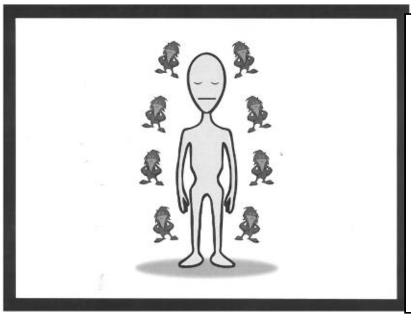
The initial chapters talk about the importance of taking medicine to keep the “body soldiers”, the terms used for CD4 cells, strong and to keep the “bad guys” asleep. The terms HIV and CD4 cells are not used until chapter five of the book. This final chapter is only introduced once the child is deemed ready, usually after 10 years of age.



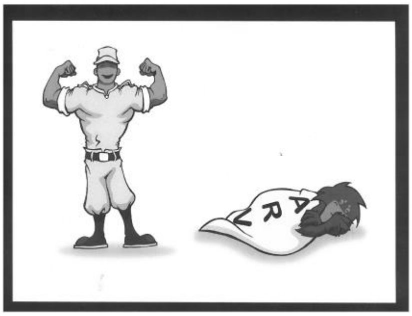
There is a “bad guy” who makes us sick by attacking our body soldiers. When the soldiers are weak and there are fewer soldiers, we get sick more easily



The bad guys are attacking the body soldiers. The child has only a few healthy soldiers left.



Now there are no body soldiers. There are only bad guys.



But there is good news. The medicines you take are called “ARVs”. ARVs help keep the bad guy sleeping under his blanket. Now he cannot hurt the body soldiers and you can have many strong body soldiers again

Appendix 7: Statistical supplementary tables

- 7.1 Estimations for sample size for a general linear model with 6 predictors
- 7.2 Binary logistic regression supplementary tables
- 7.3 Non-significant results
  - Table 7.3.1 Demographic factors and mental health outcomes for HIV group
  - Table 7.3.2 HIV-specific variables and mental health outcomes for HIV group

Appendix 7.1 Estimations for sample size for a general linear model with 6 predictors

Parameters	
Effect size f^2	0.15
α err prob	0.05
Power (1-β err prob)	0.8
Number of predictors	6
Output: Critical F	2.1999
Output: Total sample size	98

Appendix 7.2 Binary logistic regression support tables

1. Total difficulties

Cases with residuals ±2.58 were excluded as the predictive power of the baseline model without these improved from 92.4% to 95.6%.

Block 0: 95.4% of correct classifications

Block one: Hosmer and Lemeshow: $\chi^2 = 5.696$; p = .576: % of correct classifications: 95.4%

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	.015	2	.992
	Block	.015	2	.992
	Model	.015	2	.992

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	89.293[a]	.000	.000

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1[a]	Age	.016	.168	.009	1	.926	1.016
	Gender(1)	-.048	.621	.006	1	.939	.953
	Constant	-3.239	2.484	1.700	1	.192	.039

a. Variable(s) entered on step 1: Age, Gender.

Block two: Hosmer and Lemeshow: $\chi^2 = 3.059$; p = .931; % of correct classifications: 95.8%

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	49.558	5	.000
	Block	49.558	5	.000
	Model	49.574	7	.000

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	39.735[a]	.187	.601

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
Step 1[a]	Age	-.150	.217	.478	1	.489	.861	.563	1.317
	Gender(1)	.677	.905	.560	1	.454	1.969	.334	11.610
	HIVGroup(1)	1.416	1.065	1.768	1	.184	4.121	.511	33.228
	Orphan vs NonOrphan(1)	1.958	.984	3.963	1	.047	7.088	1.031	48.745
	Food security: Breakfast(1)	2.670	1.098	5.915	1	.015	14.438	1.679	124.148
	Child centred assets	-1.548	.616	6.308	1	.012	.213	.064	.712
	Social support	-.391	.132	8.827	1	.003	.676	.522	.875
	Constant	4.044	4.236	.911	1	.340	57.038		

a. Variable(s) entered on step 1: HIVGroup, Orphan/NonOrphan, Food security: Breakfast, Child centred assets, Social Support.

2. Emotional problems

Cases with residuals ±2.58 were excluded as the predictive power of the baseline model without these improved from 79.2% to 81.9%

Block zero: % of correct classifications 81.5%

Block one: Hosmer and Lemeshow: $\chi^2 = 3.401$; p = .907; % of correct classifications: 81.5%

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	10.933	2	.004
	Block	10.933	2	.004
	Model	10.933	2	.004

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	221.941[a]	.044	.071

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
Step 1[a]	Age	-.061	.097	.395	1	.530	.941	.779	1.137
	Gender(1)	-1.154	.375	9.455	1	.002	.315	.151	.658
	Constant	-.185	1.400	.018	1	.895	.831		

a. Variable(s) entered on step 1: Age, Gender.

Block two

Hosmer and Lemeshow: $\chi^2 = 4.438$; p = .816; % of correct classifications: 81.9%

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	25.014	5	.000
	Block	25.014	5	.000
	Model	25.047	7	.000

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	196.927[a]	.138	.223

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
Step 1[a]	Age	-.007	.106	.004	1	.951	.993	.807	1.224
	Gender(1)	-1.106	.398	7.716	1	.005	.331	.152	.722
	HIVGroup(1)	.153	.404	.143	1	.706	1.165	.528	2.571
	Orphan vs NonOrphan(1)	.196	.408	.231	1	.631	1.217	.546	2.709
	Food security: Breakfast(1)	.347	.517	.451	1	.502	1.415	.514	3.894
	Child centred assets	-.853	.202	17.889	1	.000	.426	.287	.633
	Social support	.086	.052	2.706	1	.100	1.090	.984	1.207
	Constant	-1.426	1.848	.596	1	.440	.240		

a. Variable(s) entered on step 1: HIVGroup, Orphan/NonOrphan, Food security: Breakfast, Child centred assets, Social Support.

3. Peer problems

Cases with residuals ±2.58 were excluded as the predictive power of the baseline model without these improved from 93.3% to 97.0%. Reference categories (0) for the dummy coding were: male, non-orphan, had breakfast, comparison group/non-HIV

Block zero: % of correct classifications 96.1%

Block one: % of correct classifications: 96.1%, Hosmer and Lemeshow: χ^2 = 10.173; p = .179

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	.237	2	.888
	Block	.237	2	.888
	Model	.237	2	.888

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	75.822a	.001	.004

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
Step 1a	v7_Age	-.003	.181	.000	1	.985	.997	.699	1.422
	v8_Gender(1)	-.331	.684	.234	1	.629	.718	.188	2.747
	Constant	-2.996	2.643	1.284	1	.257	.050		

a. Variable(s) entered on step 1: Age, Gender.

Block two: % of correct classifications: 97.0%; Hosmer and Lemeshow: $\chi^2 = 0.577$; p = 1.0

Omnibus Tests of Model Coefficients

	Chi-square	df	Sig.
Step	37.357	5	.000
Block	37.357	5	.000

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	38.465[a]	.150	.535

Model	37.593	7	.000

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
Step 1[a]	Age	-.262	.227	1.339	1	.247	.769	.493	1.200
	Gender(1)	-.846	.966	.767	1	.381	.429	.065	2.849
	HIV Group (1)	.374	.998	.141	1	.708	1.454	.205	10.285
	Orphan vs non-Orphan	2.463	1.120	4.833	1	.028	11.741	1.306	105.530
	Food security: Breakfast(1)	.755	1.069	.498	1	.480	2.127	.262	17.299
	Child centred assets	-.993	.556	3.196	1	.074	.370	.125	1.100
	Social Support	-.450	.132	11.547	1	.001	.638	.492	.827
	Constant	7.556	4.575	2.727	1	.099	1911.847		

a. Variable(s) entered on step 1: HIVGroup, Orphan/NonOrphan, Food security: Breakfast, Child centred assets, Social Support.

4. Conduct problems

Cases with residuals ±2.58 were excluded as the predictive power of the baseline model without these improved from from 90.0% to 93.8%

Block zero: % of correct classifications 93.8%

Block one

Hosmer and Lemeshow: $\chi^2 = 2.629$; p = .995

% of correct classifications: 93.8%

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	7.888	2	.019
	Block	7.888	2	.019
	Model	7.888	2	.019

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	104.461[a]	.032	.086

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
Step 1a	Age	.356	.141	6.330	1	.012	1.427	1.082	1.883
	Gender(1)	.662	.552	1.439	1	.230	1.939	.657	5.722
	Constant	-8.374	2.234	14.048	1	.000	.000		

a. Variable(s) entered on step 1: Age, Gender.

Block two

Hosmer and Lemeshow: $\chi^2 = 2.476$; $p = .963$; % of correct classifications: 93.8%

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	42.118	5	.000
	Block	42.118	5	.000
	Model	50.007	7	.000

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	62.342[a]	.187	.503

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
Step 1[a]	Age	.430	.183	5.547	1	.019	1.537	1.075	2.199
	Gender(1)	1.159	.723	2.573	1	.109	3.187	.773	13.138
	HIVGroup(1)	.867	.740	1.371	1	.242	2.379	.558	10.145
	Orphan vs NonOrphan(1)	.903	.738	1.497	1	.221	2.466	.581	10.473
	Food security: Breakfast(1)	.051	.793	.004	1	.949	1.052	.222	4.976
	Child centred assets	-2.003	.508	15.571	1	.000	.135	.050	.365
	Social support	-.163	.074	4.795	1	.029	.850	.735	.983
	Constant	-5.423	3.142	2.978	1	.084	.004		

a. Variable(s) entered on step 1: HIVGroup, Orphan/NonOrphan, Food security: Breakfast, Child centred assets, Social Support.

APPENDIX 7.3: Non-significant results

Table 7.2.1: Associations between demographic factors and mental health outcomes for HIV group (n = 99)

	Total difficulties	**p**	**Emotional difficulties**	**p**	**Peer problems**	**p**	**Hyperactivity**	**p**	**Conduct problems**	**p**	**Prosocial scale**	**p**	**Total Impact**	**p**
Age	.091	ns	.017	ns	-.033	ns	.164	ns	.117	ns	.007	ns	.180	ns
Orphan status														
non-orphan														
orphan	12.02 (6.28)	ns	4.41 (2.66)	ns	2.68 (2.08)	ns	2.83 (1.62)	ns	2.08 (1.83)	ns	8.19 (1.66)	ns	1.00 (1.53)	ns
	13.16 (5.61)		4.87 (2.36)		2.81 (1.99)		2.98 (2.26)		2.50 (1.93)		8.29 (1.75)		1.34 (2.06)	
Age of first parental loss	-.176	ns	-.237	ns	-.193	ns	.006	ns	-.121	ns	.036	ns	-.122	ns
Lives with biological parent														
No	13.52 (5.84)	ns	4.98 (2.54)	ns	2.83(2.12)	ns	3.33 (2.30)	ns	2.38 (2.12)	ns	8.19 (1.80)	ns	1.40 (2.16)	ns
Yes	12.16 (5.86)		4.50 (2.42)		2.70 (1.95)		2.63 (1.78)		2.70 (1.95)		8.30 (1.66)		1.07 (1.65)	

*denotes significance at the .05 level

Table 7.2.2 Associations between HIV-specific variables and mental health outcomes for HIV group (n=99)

	Total difficulties	**p**	**Emotional difficulties**	**p**	**Peer problems**	**p**	**Hyperactivity**	**p**	**Conduct problems**	**p**	**Prosocial scale**	**p**	**Total Impact**	**p**
CD4 count	-.102[a]	ns	-.010	ns	.015	ns	-.145	ns	-.152	ns	0.216	ns	-.092	ns
Time on ART	.039[a]	ns	.082	ns	.033	ns	-0.76	ns	-049	ns	-.131	ns	-.038	ns
Viral load														
suppressed <50	12.58 (6.20)		4.46 (2.45)		2.80 (2.21)		3.00 (2.13)		2.32 (1.90)		7.98 (1.71)		1.31 (2.03)	
Low-moderate	12.88 (5.34)	ns	4.96 (2.27)	ns	2.56 (1.71)	ns	2.60 (1.87)	ns	2.75 (2.13)	ns	8.44 (1.85)	ns	1.20 (1.91)	ns
High (>10000)	10.80 (4.09)		3.80 (2.18)		2.60 (1.82)		2.60 (1.67)		1.80 (1.48)		9.20 (1.10)		1.00 (1.41)	
Age: disclosure	-.017	ns	.042	ns	-.011	ns	-.041	ns	-.052	ns	-.008	ns	.016	ns
Time since disclosure	.067	ns	-.045	ns	-.031	ns	.155	ns	.136	ns	.002	ns	.127	ns
Attends teen group														
no	12.72 (5.56)	ns	4.57 (2.56)	ns	2.81 (1.73)	ns	3.21 (2.31)	ns	2.12 (1.78)	ns	8.32 (1.67)	ns	1.36 (1.94)	ns
yes	12.61 (6.12)		4.78 (2.41)		2.61 (2.15)		2.67 (1.75)		2.55 (2.00)		8.28 (1.77)		1.10 (1.85)	
Close friends with HIV														
no	13.22 (6.34)	ns	4.68 (2.63)	ns	2.93 (2.11)	ns	3.31 (2.35)	ns	2.26 (2.03)	ns	8.31 (1.66)	ns	1.17 (1.91)	ns
1 or more	12.40 (5.22)		4.72 (2.37)		2.63 (1.95)		2.64 (1.74)		2.40 (1.82)		8.21 (1.76)		1.25 (1.87)	

[a] Pearson correlation coefficient