



**Children affected by HIV/AIDS attending programmes
to improve psychosocial well-being:
current status and pathways to effective interventions**

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ABSTRACT

The HIV/AIDS pandemic has a substantial impact on children across the globe and particularly in sub-Saharan Africa. Across the region, there are a number of organisations and programmes providing care and support to children affected by HIV/AIDS. However, this strong programmatic focus on mitigating the impact of HIV/AIDS on children at community level has not been matched with concomitant research investment into the needs of children who attend these programmes at these organisations, their health and development, how these organisations work, and whether they are effective. This thesis attempts to address this gap through reporting the results of a systematic review and three individual analyses of data from the Child Community Care Study in South Africa and Malawi.

The systematic review reports on interventions developed to improve the psychosocial well-being of children affected by HIV/AIDS, published between January 2008 and February 2016. In the second analysis I report on developmental outcomes of children affected by HIV/AIDS attending community-based programmes and the types of services these children are receiving. In the third part I report on the mental health of caregivers of these children. In the fourth analysis I report on the relationship between different forms of violence and mental health status among the same sample over time.

The results of these studies highlight the complex needs of children affected by HIV/AIDS attending these organisations. CBOs are reaching a vulnerable group of children and their families, and are well-placed to intervene with this population. There are promising models

of interventions available, although the evidence base remains small. Caregivers should not be neglected in programming - parenting programmes provide a potential mechanism for delivering integrated interventions that address multiple risk factors for caregiver and child well-being. Mental health, particularly of caregivers, should be explicitly addressed as a part of CBO programming. However, funding for programming needs to be implemented with opportunities for training and supervision. In addition, there is a need for increased partnerships between practitioners and researchers in order to evaluate existing programmes and to design evaluation studies that suit community settings, and that can feed into the growing evidence base.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
CBO	Community-Based Organisation
CCABA	Coalition For Children Affected By AIDS
CSI	Child Status Index
HAART	Highly Active Antiretroviral Therapy
HIC	High Income Country
HIV	Human Immunodeficiency Virus
HREC	Health Research Ethics Committee
IAT	Information And Action Tool
LMIC	Low And Middle Income Country
MDG	Millennium Development Goals
NGO	Non-Governmental Organization
PEPFAR	President's Emergency Plan For Aids Relief
PMTCT	Prevention Of Mother To Child Transmission
RCT	Randomised Controlled Trial
REPSSI	Regional Psychosocial Support Initiative
SDG	Sustainable Development Goals
SIDA	Swedish International Development Cooperation Agency
UNICEF	United Nations Children's Fund

CHAPTER 1: INTRODUCTION

1.1. From child mortality to child development

In the Millennium Development Goals (MDG), the global priority for improving child health was to reduce child mortality (United Nations, 2000). More specifically, efforts were primarily directed to decreasing the under-five mortality rate, as articulated in the fourth MDG (United Nations, 2000). There was large variation between countries but, by the end of 2015, the under-five mortality rate had dropped by more than 50% (UNICEF, WHO, Bank, & United Nations Population Division, 2015). While this did not reach the original target of a two-thirds reduction, it was lauded as a great success. This achievement was largely due to increased investment into actions to improve child health (Bustreo, 2015), such as interventions to strengthen health systems (Carnell et al., 2014), and the adoption of policies centred on using community health workers to manage childhood diseases (Boschi-Pinto, Dilip, & Costello, 2017).

As the MDG period came to an end, however, there was acknowledgement of the importance of looking beyond child mortality outcomes in defining improvements in child health. The *Commission on Social Determinants of Health* was one of the first high-level initiatives to highlight child development as a foundation for lifelong health. The Commission report specifically emphasized the importance of psychosocial development, along with the motor, cognitive, and communication and language domains (Marmot et al., 2008). Further, two Lancet Series on *Early Child Development in Developing Countries* were published in 2007 and

2011, making a major contribution to advancing knowledge in the area by consolidating existing evidence on the topic. The first series focused on children under the age of five and summarised evidence on the risks that children in developing countries were facing with regard to their psychosocial, cognitive and physical development (Jolly, 2007). The second series described gaps in coverage of necessary interventions and calculated the lost economic cost of poor child development (Lake, 2011). Further, in the lead up to the finalization of the Sustainable Development Goals (SDG) (United Nations, 2015), global policy makers increasingly included child development in discussions about child health, as complementary or in extension to child mortality efforts. In 2013, the then Director-General of the World Health Organization summarized the global level activities that had taken place from 2008 onwards to develop a global action agenda for child development as a foundation for lifelong health and well-being, noting that adverse experiences during childhood resulted in poorer health and education outcomes (Chan, 2013).

This focus on developmental outcomes for lifelong health and well-being marked a watershed moment for child development as a global health priority. As a result of these and other advocacy efforts, the SDGs are the first set of global development goals to include a target relating directly to early child development (United Nations, 2015). The updated Global Strategy for Women's, Children's and Adolescent's Health 2016-2030 describes the current approach to achieving the highest attainable standard of health and well-being for children, aligned with the targets set out in the SDGs (Every Woman Every Child, 2015; Kuruvilla et al., 2016). The strategy focuses on reducing mortality, promoting development and transforming the global context in order to facilitate these activities. It spans pregnancy, childbirth, the early years

and adolescence, and focuses on optimising both physical and mental health and well-being, with a view to enhancing long-term social and economic opportunities sustained throughout the life course (Kuruvilla et al., 2016).

This global paradigm shift is particularly significant for low and middle income countries (LMIC) with high rates of poverty where child and adolescent health and development is a foremost concern, such as South Africa and Malawi, where the research reported in this thesis is located. Extreme poverty disproportionately affects the young, those from sub-Saharan African countries and people living in rural areas (World Bank, 2016). Poverty is the primary driver of poor health outcomes (Levin, 2017); research from LMICs has shown that people living in poverty are exposed to a range of threats to their health, including poor educational levels, poor nutrition, poor household living conditions, environmental toxins, and lack of access to clean water and sanitation (Braveman & Gruskin, 2003; Marmot et al., 2008). They often incur costs for seeking healthcare which may be unaffordable or even catastrophic (Saksena, Hsu, & Evans, 2014). Simultaneously, many health protective behaviours, such as exclusive breast-feeding, school attendance, and attaining and maintaining employment depend on a good level of health, which is under threat when living in poverty (Murray, 2006). Importantly for this thesis, HIV is often described as a disease of poverty – it is more common in conditions of poverty, it exacerbates the experience of people living in poverty, and poverty can limit the ability of people to cope with the disease and its impact on their lives (Mbirimtengerenji, 2007; Mufune, 2015; Whiteside, 2002).

Related to this, much has been written about the complex relationship between poverty and child development (Engle & Black, 2008; Reiss, 2013; Walker et al., 2011). Specifically, factors associated with poverty that can affect child developmental outcomes include poor caregiver mental health, caregiving relationships which may be compromised in adversity, environmental conditions at home and school, financial stress, and limits in access to services and community resources (Lipina & Evers, 2017). The types of risk factors that are prevalent in LMICs can lead to specific deficits in brain development (Walker et al., 2011). For example, continued exposure to negative environmental factors such as physical abuse, psychological abuse and neglect, caregiver mental health problems or substance use and violence can lead to changes in brain structure attributed to the experience of chronic or “toxic” stress (Shonkoff, Boyce, & McEwen, 2009; Shonkoff, Richter, van der Gaag, & Bhutta, 2012). However, little is known about the impact of how these risks interact and accumulate, and are affected by timing and duration of exposure (Lipina & Evers, 2017).

Issues such as undernutrition and disease also play a specific role. Exposure to infectious diseases such as diarrhoea, malaria and HIV is common in sub-Saharan African countries. These diseases can affect a child directly through infection, or indirectly through time away from school in the case of a child being infected, or compromised caregiving or lost income when a parent is affected. Certainly, one of the biggest threats to child development and well-being in this era is that of HIV/AIDS, the focus of this thesis. In the next section, I describe the HIV context and its relevance for child outcomes. A more detailed investigation of the direct and indirect effects of HIV on child’s health and development is included in Chapter 2.

1.2. The HIV context

Since the start of the HIV/AIDS pandemic, nearly 80 million people across the globe have been infected with HIV, with approximately half still living with the virus. Sub-Saharan Africa has been worst hit, and is home to over 70% of all people living with HIV and close to a million new infections annually (World Health Organization, 2015).

The impact of the pandemic has been felt across multiple levels in sub-Saharan Africa (Piot, Bartos, Ghys, Walker, & Schwartlander, 2001). The effect on mortality levels has been substantial, with life expectancy in a number of countries dropping dramatically in the early years of the pandemic (World Health Organization, 2004) and having an impact on the development of affected nations through a number of pathways (Dixon, McDonald, & Roberts, 2002). For example, high rates of mortality and morbidity among young adults reduced the number of skilled and unskilled workers in the labour market. Where workers were in employment, HIV has impacted upon productivity due to long periods of illness. Several southern African countries lost large portions of their health workforces in the early 2000s due to HIV infection of health workers, due to illness and death from AIDS (Marchal, Brouwere, & Kegels, 2005). In recent years, due to ongoing attention on and investment in combatting HIV, some of these losses have been recovered, with enrolment in antiretroviral programmes increasing life expectancy (Johnson et al., 2013), lowering absenteeism rates at work (Habyarimana, Mbakile, & Pop-Eleches, 2010), and increasing rates of resumption of or entry into work for HIV-infected adults (Thirumurthy, Galárraga, Larson, & Rosen, 2012).

1.2.1. HIV and children

The HIV pandemic has had a substantial impact on children. Globally, 3.3 million children are HIV infected, and more than 90% of children with the disease live in sub-Saharan Africa (UNAIDS, 2013). An estimated 14.8 million of the 16 million children who have lost one or both parents to the disease live in this region (UNAIDS, 2010), and many millions more live in families and communities who are affected.

Children are affected by HIV in different ways, partly depending on whether they are HIV-positive, were exposed to the virus during pregnancy but uninfected (known as HIV exposed), or are residing in a family where someone has HIV. HIV infection has led to increased mortality rates in children and has been linked with poor social, behavioural, physical and mental health outcomes (Sherr, Croome, Parra Castaneda, Bradshaw, & Romero, 2014; Stein et al., 2014a). HIV infection not only causes structural changes to the brain (Van Rie, Mupuala, & Dow, 2008), but children who are infected are also more likely to spend time in hospital, away from school, experience prolonged periods of ill-health, and social isolation (Sherr, Mueller, & Varrall, 2009). For children who are not necessarily infected themselves but who live with caregivers, family and community members who are HIV positive, there are a number of other serious risks to well-being, including parental death, parental illness, increased caregiving burden, and higher healthcare costs (Sherr et al., 2014). Families affected by HIV are likely to also be affected by poor mental health and substance use, and interpersonal violence, all of which has an impact on child well-being (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013).

Yet, children are often side-lined in global HIV/AIDS policy, particularly when it comes to clinical outcomes (Sherr, Cluver, Tomlinson, & Coovadia, 2015). Child HIV/AIDS clinical research has focused primarily on epidemiological trends of child infection and on the prevention of mother to child transmission. This approach has been successful in reducing child infections, but there is still a concern that improvements in HIV outcomes for infected children do not match those of adults. In fact, children are less likely to be tested for HIV than adults (Sherr et al., 2015), are less likely to be on treatment if they are infected (Newell, Grimwood, Cluver, Fatti, & Sherr, 2016), and the lack of child-friendly formulations of antiretroviral medication remains a barrier to adherence to anti-retroviral medication for this group (Schlatter, Deathe, & Vreeman, 2016). Paediatric treatments tend to have complex administration rules which change rapidly as children grow (Grimwood et al., 2012).

While children have not been a focus of clinical intervention, there are a vast number of organisations and programmes providing care and support services to mitigate the impact of the disease on children (Richter, Foster, & Sherr, 2006). As early as 1987, there were growing numbers of community-based organisations (CBOs) developing programmatic responses to meet the needs of HIV-affected children, with international organisations and government programmes lagging behind these grassroots efforts. In the late 90s, the United States Agency for International Development (USAID) published the first edition of *Children on the Brink* which kick-started formal global efforts to mitigate the impact of the pandemic on children (Richter et al., 2006). In sub-Saharan Africa, in particular, CBOs continued to flourish and, over the years, donors have increasingly adopted community-centred approaches, often funding these organisations directly. For example at present, the President's Emergency Plan For AIDS Relief

(PEPFAR) is providing care and support programmes focused on mitigating the impact of HIV/AIDS to an estimated 6 million HIV-affected children globally, largely through community programmes (PEPFAR, 2017).

However, this strong programmatic focus on mitigating the impact of HIV/AIDS on children at community-level has not been matched with concomitant research investment into what works to improve child outcomes in community settings. Community organisations tend to have limited resources for programme delivery, and reliable evidence is essential to guide training, supervision and management in these circumstances (Kim, Farmer, & Porter, 2013). Yet, there has been little in the way of routine evaluation of interventions for children affected by HIV/AIDS. A Cochrane review published in 2009 was not able to identify a single intervention to improve the psychosocial well-being of children affected by HIV and AIDS that met their criteria (King, De Silva, Stein, & Patel, 2009). Other reviews that have used modified criteria for inclusion have noted concerns about the quality and rigour of available evidence (Betancourt et al., 2013; Schenk, 2009).

There is also little evidence about parent-directed interventions in the context of HIV and their impact on child outcomes, although some examples focusing on disclosure and parental-child communication are available (Rochat, Mitchell, Stein, Mkwanazi, & Bland, 2016; Rochat Netsi, Redinger & Stein, 2017). In related but non-HIV specific fields there is emerging evidence that community-based parent-directed programmes can improve child outcomes for young children (Cooper et al., 2009; Murray, Cooper, Arteché, Stein, & Tomlinson, 2016) while

efforts are currently underway to evaluate programmes for older children (Cluver et al., 2016) but the evidence base is small.

The limited evidence that is available in this field is problematic in light of the high burden of disease and significant financial investment that the field has already received. Little is known about children who attend these programmes, their health and development trajectories, how these organisations work, and whether they are effective. Yet, policy decisions that direct programming efforts continue to be made at higher levels, often based on poor quality information from under developed and non-standardised monitoring and evaluation systems. It is thus important that researchers are able to identify who is attending these programmes, what needs they have, and what works, for whom and in what circumstances. This thesis intends to address part of this gap in knowledge.

1.3. This study

1.3.1. Research questions

This PhD forms part of a larger study (conducted by Stellenbosch University and University College London) that investigated the impact of community-based programmes for children affected by HIV/AIDS. The aim of the larger project was to generate evidence on what types of community-based care provision are associated with improvements in child health, mental health, behavioural, educational, and health outcomes. This PhD study is more specifically focused on the needs of children attending these programmes, their developmental

and mental status, their caregivers' mental health, exposure to violence, and what new evidence exists for community-based interventions to improve psychosocial well-being of children affected by HIV/AIDS.

This thesis is structured around 6 research questions:

Research question 1: What evidence exists for interventions to improve the psychosocial well-being of children affected by HIV/AIDS?

First, I report on the results of a systematic review to evaluate the overall effectiveness of interventions that aim to improve the psychosocial well-being of children affected by HIV and AIDS. The review, in Chapter 4, provides an update on the evidence since a Cochrane review was published on the subject in 2009 (King et al., 2009).

Research question 2: What are the prevalence and correlates of child developmental problems for children affected by HIV/AIDS who attend CBOs?

HIV has an impact on child development outcomes at a number of levels (Stein et al., 2014a) and its impact can limit children's ability to participate in and contribute to their communities, leaving a long-term impact on the child, their families and the societies in which they live (Hertzman, Vaghri, & Arkadas-Thibert, 2013). However, little is known about the developmental status of children affected by HIV/AIDS who attend CBOs. Improved knowledge of the developmental profiles of HIV-positive and HIV-negative children attending

these programmes for children affected by HIV/AIDS in South Africa and Malawi will provide useful information for future intervention development.

Research question 3: What are the prevalence and correlates of mental disorders in caregivers of children affected by HIV/AIDS?

Family level risk factors are important for child psychosocial outcomes. Families living in communities with high burden of HIV often have heavy care-giving responsibilities (Casale, Wild, Cluver, & Kuo, 2015). On the other hand, protective factors that promote good mental health outcomes in the context of HIV include strong family support networks and having cash savings (Kagotho & Ssewamala, 2012; Simbayi et al., 2007). Caregivers who are HIV-positive may be at risk for mental health problems, as HIV and mental health are related in a complex cyclical relationship: people with HIV are at increased risk for mental health problems, while mental health problems may place people at risk for contracting HIV (Freeman, Patel, Collins, & Bertolote, 2005). A better understanding of caregiver mental health burden, its implications for caregivers and its impact on their children will help to ensure that community-based services for children affected by HIV/AIDS can be adequately and accurately targeted to improve both child and caregiver well-being.

Research question 4: What is the prevalence of exposure to home and community violence for children affected by HIV/AIDS?

There is a complex relationship between HIV and violence. Gender-based violence is a key driver of HIV infection for women (Jewkes, Dunkle, Nduna, & Shai, 2010). In addition to gender inequality and intimate partner violence, many of the risk factors for violence against children are prevalent in families and communities affected by HIV/AIDS including alcohol use, high levels of community violence (World Health Organization, 2006), risk behaviours such as substance use (Betancourt et al., 2013), and HIV stigma (Boyes, Mason, & Cluver, 2013). As such, we would expect that children affected by HIV are also affected by exposure to violence in their homes and communities. I report on an investigation into the prevalence of exposure to violence among children affected by HIV/AIDS, who are a highly vulnerable sample who are often hard to reach and rarely included in research. Improved knowledge of their experiences will be useful to understand the burden of the problem and also provide useful information for future programming.

Research question 5: How is violence exposure in this group linked to the psychosocial well-being of children affected by HIV/AIDS?

Exposure to violence is detrimental to children's well-being and has deep and lasting consequences, including increased risk of HIV infection, misuse of substances, and engagement in violent behaviour during childhood and later in life (Chaux, Molano, & Podlesky, 2009; Dubowitz & Bennett, 2007; Fleming & Jacobsen, 2010; Huesman, 2011; Mathews &

Benevenuti, 2014; Mills et al., 2011; Mock, Peden, Hyder, Butchart, & Krug, 2008; Richter et al., 2014). Mental health sequelae of exposure to violence are commonly reported in the literature (Hillis, Mercy, & Saul, 2017; Norman et al., 2012). An improved understanding of how violence exposure has impacted this sample over time, and specifically what types of violence are linked with mental health sequelae may be useful to better understand issues about the type and duration of certain risks and their correlates for children.

Research question 6: Does service delivery differ by HIV status?

The lack of research examining community-based programmes has meant that there is little consistency in programming and a wide variety of interventions are defined by the term “psychosocial” (King et al., 2009). In addition, little is known about how organisations provide their services within their recipient groups; and how best to provide a mix of targeted and universal services in low-resource settings (Tomlinson et al., 2015). To answer this question, I report on a comparison of services received by HIV-positive and HIV-negative children, in order to provide an assessment of whether or not they are receiving different services from their CBOs and if their needs are likely to be being met by their current programming.

1.3.2. Outline of this thesis

The thesis is structured as follows:

In Chapter 2, I review the relevant literature for each of the research questions. The Chapter focuses on:

- i) definitions of important constructs for this thesis,
- ii) risks to child development outcomes posed by HIV/AIDS,
- iii) efforts to address the impact of HIV on children, highlighting the current lack of evidence in this field, and current funder priorities

In Chapter 3, I provide an overview of the overall methodology used in the Child Community Care study, on which Chapters 5, 6 and 7 are based.

In Chapters 4-7 I address the research questions proposed in this thesis in a systematic review (Chapter 4) and in separate analyses of data collected as a part of the Child Community Care study (Chapters 5-7). Each chapter will have an introductory section to contextualize the issue addressed, describe and justify the research methodology and present the results of the data analysis. In each of these chapters I will discuss the main findings from the chapter and implications of the research findings.

In Chapter 8, I discuss the findings of each of the individual chapters in relation to the research questions and discuss the overall implications of the accumulated evidence in relation to its implications for programming, capacity development and future research for children affected by HIV/AIDS.

This thesis incorporates work published in the following papers:

- i) Skeen, S., Sherr, L., Croome, N., Gandhi, N., Roberts, K., Macedo, A., & Tomlinson, M. (2017). Interventions to improve psychosocial well-being for children affected by HIV and AIDS: a systematic review. *Vulnerable Children and Youth Studies*, 12(2), 91-116.
- ii) Skeen, S., Tomlinson, M., Macedo, A., Miltz, A., Croome, N., & Sherr, L. (2014). Child development in HIV-positive and HIV-affected children in South Africa and Malawi—What role for community organisations? *Children and Youth Services Review*, 45, 90-97.
- iii) Skeen, S., Tomlinson, M., Macedo, A., Croome, N., & Sherr, L. (2014). Mental health of caregivers of children affected by HIV attending community-based programmes in South Africa and Malawi. *AIDS care*, 26(sup1), S11-S20.
- iv) Skeen, S., Macedo, A., Tomlinson, M., Hensels, I., & Sherr, L. (2016). Exposure to violence and psychological well-being over time in children affected by HIV/AIDS in South Africa and Malawi. *AIDS Care*, 28(sup1), 16-25.

CHAPTER 2: LITERATURE REVIEW

2.1. Chapter outline

In this chapter, I will provide an overview of the relevant literature for the research questions outlined in the introduction. This chapter is made up of three parts. The first part describes the definitions used in this study. The second part focuses on child development, and more specifically on the risks to child development outcomes posed by HIV/AIDS. This includes a general background to child development in LMIC, then I discuss the direct and indirect impact of HIV on the development of children from an ecological perspective, with special reference to psychosocial family and community level risk factors, including caregiver mental health and violence. In the third part of the chapter, I change focus to addressing the impact of HIV on children, including potential ways in which CBO programmes might be effective, highlighting the current lack of evidence in this field and the importance of research in this area. Finally, I provide an overview of the current policy priorities of a range of large funders and non-governmental organisations (NGO) who are invested in this area.

Where possible, throughout this chapter, evidence from sub-Saharan countries has been used. Literature for this chapter was sourced using a range of academic databases, scanning reference lists of published studies, relevant grey literature, and through consultation with academic mentors and peers.

2.2. Defining key concepts

Evidence-based interventions to address child psychosocial well-being in the context of HIV are under-developed, in part because research on this group is beset with problems relating to definition and measurement which make the available data on risks and vulnerability difficult to generalise (Mueller, Alie, Jonas, Brown, & Sherr, 2011). There are a range of terms used in this thesis which have ambiguous or contested definitions. In this section, and in the course of the review of the literature below, I will provide background and rationale for the definitions used in this study.

Foremost, there is a struggle to define who the children who are affected by HIV/AIDS actually are. Early on in the pandemic, programming efforts were solely focused on “AIDS orphans”. USAID coined this term for any child under 15, and then 18 years of age, who had lost either parent (as opposed to the traditional definition of an orphan as a child who has lost both parents) (Sherr et al., 2008). This was due to the high death rate of adults after infection, and the limited knowledge about the impact on children of the loss of one or both parents, the nature and spacing of multiple deaths, and residual family support (Richter et al., 2006). The perhaps unintended effect of this meant that much of the early research in this area tended to focus on the single causal pathway of poor development of parental death.

This approach was in contrast with child development theory (Cluver et al., 2013), which hypothesized that child development is influenced by exposure to a broad range of diverse factors at different intensities, over time (Bronfenbrenner, 1979, 1992, 2009). Child

development is a complex process or set of processes by which a child grows to maturity and adulthood (Bellman, Byrne, & Sege, 2013). It is influenced by a range of factors, at different levels, some of which even occur pre-conception, during pregnancy and throughout a child's life. There are different periods of child development. It is generally accepted that there is a period of early, middle and late childhood, followed by adolescence, but the age cut offs for these differ greatly. Child development tends to be conceptualized in terms of discrete but interlinked domains, including sensori-motor, cognitive-language, and social-emotional (or psychosocial) development (Walker et al., 2007). (More information about current models of child development and their relevance for this study is included in the following section of this review).

More recent definitions of children affected by HIV/AIDS have attempted to capture this complexity. PEPFAR currently defines an "orphan" as a child under 17 years of age who has lost either or both of their parents, but also highlights the existence of a "social orphan" whose parents are no longer providing care for their child for a number of reasons, such as illness or substance abuse (PEPFAR, 2012). Subsequently, there has been a more widespread recognition of the challenges experienced by children living with an AIDS-sick caregiver prior to their death, for which the broader term "orphans and vulnerable children" (OVC) was adopted (Sherr et al., 2008). Most recently, this term has come to capture an even more extensive group, including those who live in communities with high HIV prevalence. These children might only be affected indirectly, such as through compromised health and education services (JLICA, 2009). For the purposes of this thesis, I have used this broad definition.

Next, the term “psychosocial intervention” tends to be used as a broad catch-all phrase which can refer to a range of different types of programmes. Kaljee et al (2017: 382) define psychosocial support as addressing “physical, economic, educational, health and social needs and [building] internal and external resources to help children and their families cope with adversity”. Richter et al (2006) describe it as programming that employs a psychological, health, or social approach, or a combination of these, to improve well-being. For this thesis I have used the definition supplied by King et al (2009) who describe psychosocial programmes as promoting good mental health or preventing the development of mental health problems in children by impacting on individual level processes, or improving outcomes at a family, group or community level. They are highly heterogeneous, including psychological interventions (e.g. support groups, psychological debriefing, parenting interventions) or social interventions (e.g. cash transfer programmes, material assistance, skills building programmes) which can be delivered in a range of formats (King et al., 2009). These interventions can result in improved psychosocial outcomes, but can also affect biomedical outcomes, for example through improved treatment adherence (Grimwood et al., 2012).

The delivery of psychosocial interventions in the context of HIV/AIDS tends to fall to CBOs, which are a focus of this thesis. CBOs can be difficult to define. The term can refer to a range of civil society organizations with different methods of working, funding, and human resources (Wilson, Lavis, & Guta, 2012). The interventions that are delivered by CBOs are often complex and consist of several components, which can be difficult to describe, disentangle and measure. Methods of delivery also vary. For example, many programmes rely heavily on regular home-visiting whilst others engage children at a central location after school. For the

purpose of this thesis, a CBO is a non-profit organization that directly provides services and is based in a community where children affected by HIV/AIDS live.

2.3. Child development and well-being in the context of HIV in LMICs.

In this section I will review the background literature on child development as a global health priority, the core issues in LMIC, and the impact of HIV on child development and well-being, with particular reference to psychosocial risk factors such as parenting, caregiver mental health and exposure to violence in this context. Much of the work undertaken in child development in LMICs focuses on the early years, up until the age of 5 years of age, with less written about middle and late childhood, highlighting the need for increased research into research on middle and late childhood in LMIC. Adolescent-focused research from these settings tends to focus on specific themes such as risk behaviours and mental health problems. For the purpose of this thesis, I refer to child development in a broad sense, and include a wider range of ages in the studies on which I report. The three studies using data from the Child Community Care in Chapters 4-6 of this thesis refer to children between the ages of 4 and 13, and the systematic review refers to children from birth to 18 years of age.

2.3.1. Child development as a global health priority

Reducing the child mortality rate has long been the primary focus of global child health researchers, but child development is increasingly of interest to this group partly because of its importance for an individual's lifelong health and life trajectory. For the past 30 years evidence

from longitudinal studies has confirmed that events during pregnancy and early development have a long-term impact on health outcomes later in life, and that health status is not a product solely of genetics and lifestyle, but a more complex mix of these and other biological, social and environmental factors (Halfon, Larson, Lu, Tullis, & Russ, 2014). These include factors such as nutrition, exposure to environmental toxins, medications, diseases, and stress at specific points in development (Heindel et al., 2015; Heindel & Vandenberg, 2015).

As such, good childhood health status in combination with positive early experiences is likely to lead to good adult health (Center on the Developing Child at Harvard University, 2010). On the other hand, adults reporting a history of traumatic stress in childhood are more likely to have mental health problems, misuse substances, smoke, have cancer, respiratory problems and cardiovascular disease, fall pregnant as teens, be obese and have low rates of physical activity (Shonkoff et al., 2009). Further, benefits or disadvantages experienced as a result of experiences in childhood can flow down from one generation to the next (Shonkoff et al., 2012). Poor development can curtail educational attainment and earning potential, and affect opportunities for the next generation. At a population level, the consequences can lead to massive economic losses, such as through expenditure on healthcare (Daelmans et al., 2017). Thus, poor developmental outcomes do not only affect the child or family, but have broader implications for societies (Heckman & Masterov, 2007).

As a result of the evidence of the impact of child development throughout the life course, there is renewed focus on child development in LMICs. The updated *Global Strategy for Women's, Children's and Adolescent's Health 2016-2030* integrates child development into

efforts to improve child health through its *survive-thrive-transform* approach (Every Woman Every Child, 2015), while the SDGs are the first set of global development goals to include a target relating directly to child development (United Nations, 2015).

2.3.2. Child development in LMICs

Two Lancet Series on *Early Child Development in Developing Countries* (2007 and 2011) summarised risks to child development in LMIC, described gaps in coverage of necessary interventions and calculated the lost economic cost of investment in child development (Jolly, 2007; Lake, 2011). A third follow up series entitled *Advancing Early Childhood Development: from Science to Scale* (2016) reviewed new interventions and proposed mechanisms for scaling up services in low resource settings (Lo, Das, & Horton, 2017). Together these three series provide a comprehensive overview of the status of child development in low resource settings. In the first series it was estimated that more than 200 million children under the age of five were not reaching their potential (Grantham-McGregor et al., 2007); in 2016 this was re-estimated at 250 million (Black et al., 2016). At the heart of the issue is that factors that influence child development are common across all cultures and countries, but that children in low resource settings are exposed to a range of risk factors associated with living in poverty, such as malnutrition, disease, lack of stimulation, environmental toxins, low maternal education, maternal depression, gender inequality, and exposure to violence, that are detrimental to their development (Britto et al., 2017; Grantham-McGregor et al., 2007; Walker et al., 2007). On the other hand, the protective influence of responsive and sensitive parenting may be compromised in contexts of poverty, as the ability of parents to provide for themselves and their children is

under stress (Mejia, Calam, & Sanders, 2012). Other protective factors, such as antenatal care, skilled birth attendants, and early childhood development services are also routinely limited in availability (Britto et al., 2017).

Developmental disability in LMIC

In considering child development in LMIC, it is important to consider children with disabilities. Children with disabilities in LMICs are a group that have been left out of the children's development agenda in the past (World Health Organization & UNICEF, 2012). Developmental disorders or disabilities are conditions that present either as delays in attaining age-appropriate milestones or do not follow the usual pattern of development which are present early in childhood (such as pervasive developmental disorders or autism) (Bellman et al., 2013). They can be difficult to disentangle from child development as an area of study and could be thought of as both an outcome of and a risk factor to the child development process. As with other developmental outcomes, prevalence of developmental disability is likely to be higher in areas of poverty (Bornstein & Hendricks, 2013; Stefan & Pramila, 2009) and when risk factors such as poor maternal education and nutrition are present (Sachdeva et al., 2010). Another important consideration is that they are often accompanied by high levels of stigma, particularly in the case of intellectual disability, mental disorders and epilepsy (Maulik & Darmstadt, 2007).

Rates of developmental disability vary depending on how they are measured but numbers are estimated to be as high as 5% (Yousafzai, Lynch, & Gladstone, 2014) and by some accounts are increasing as child mortality drops (Maulik & Darmstadt, 2007). To date, research on this

group has focused on prevalence rates (Yousafzai, Rasheed, Rizvi, Armstrong, & Bhutta, 2014) but good quality data from LMICs is limited (Mung'ala-Odera et al., 2004).

2.3.2. Child development and HIV

In considering the specific impact of HIV/AIDS on children's psychosocial development and mental health, there are lessons to be learnt from the wider field of child development and the knowledge that exists about how children are affected by and adapt to challenges (Stein et al., 2014a).

Theories of child development

The HIV pandemic is extremely complicated, influencing and influenced by a range of biological, social, economic, and governmental factors. There are numerous theories of child development which have contributed to our understanding of the complex and multi-layered nature of the process of human maturation, and how risk and protective factors act to influence it, that can help us to understand the impact of HIV/AIDS on this group. In this section, I provide a brief description of three theories of child development that are currently in use, as they relate to the research questions in this thesis:

- i) Bronfenbrenner's Ecological Systems theory;
- ii) Sameroff's transactional model; and the
- iii) Biodevelopmental framework

Risks for vulnerability for children affected by HIV/AIDS can perhaps best be understood in terms of ecological systems theory, which considers a range of factors that influence the developmental trajectory of a child (Bronfenbrenner, 2009). The ecological model focuses on the quality of the child's environment, and places the child at the centre of a system of risk and protective factors, usually depicted graphically as a series of concentric circles (Bronfenbrenner, 1979), as depicted in Figure 2.1. At the centre of the system is the individual child, known as the "microsystem" referring to any individual characteristics that he or she might have, such as sex, temperament, health conditions, and genetic make-up. The next level, the "mesosystem", refers to the family setting in which the child lives, the "exosystem" to the immediate environment or community (including the school), and the "macrosystem" refers to the society at large. The relationships at each of these levels are bi-directional. For example, at the microsystem level, parenting style may affect a child, but a child's individual characteristics may also affect parenting style. For example, a child (micro level) will be affected by the (meso level) parenting style of their caregiver, but the child's individual characteristics (such as medical needs in the case of HIV infection) may also, in turn, affect that same parenting style. Finally, the "chronosystem" describes how timing of exposure plays a role in how the various levels of risk and protective factors might affect a child and allows for different factors to assume more or less importance at different stages in development (Bronfenbrenner, 1979, 1992, 2009).

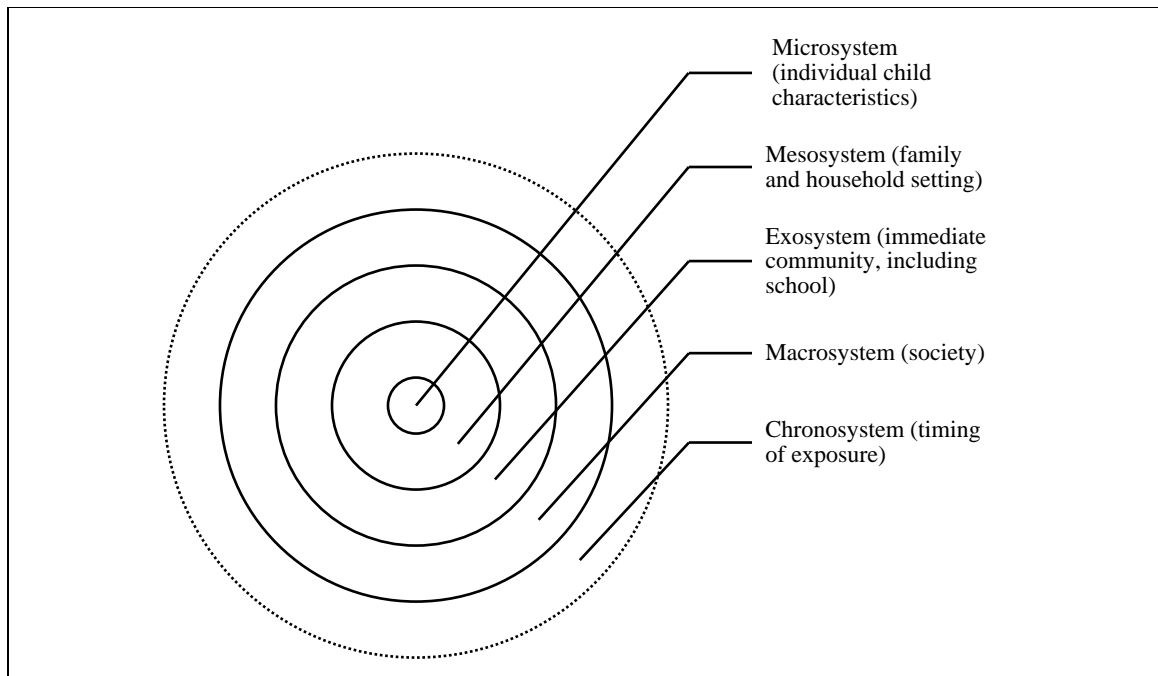


Figure 2.1.: Bronfenbrenner’s Ecological Systems Theory (adapted from Bronfenbrenner, 1979)

Similarly, the transactional model describes “proximal” and “distal” influences on child development (Sameroff, 2009). Proximal influences refer to risk and protective factors that are especially “close” to the child. For children affected by HIV/AIDS, key proximal influences are likely to be the caregiving relationships and family dynamics in their homes. Distal influences describe factors that affect the child less directly, such as community characteristics. As a child grows up they are more likely to be exposed to and affected by distal factors. A CBO might act at this more distal level or may seek to influence proximal factors, such as through direct provision of child or caregiver counselling. Again, in this model, the development of the child is not only reliant on the impact of these factors upon the child, but rather on their interaction between the child and these factors which may influence each other (Sameroff, 2009).

While both the ecological systems and transactional theories can be used to describe the nature of risk and protective factors and their influence on children, our understanding of the exact causal mechanisms of how something such as violence in the home or living in an area of extreme poverty physically impacts upon the brain and body of a child, and thus their developmental status, is still incomplete (Shonkoff et al., 2009). A biodevelopmental framework allows us to account for these biological processes which occur as a result of environmental factors. An example of this, and of particular relevance for children affected by HIV/AIDS, is the concept of “toxic stress” (Shonkoff et al., 2009). Ongoing exposure to stressful circumstances, particularly in the absence of a stable, supportive and loving caregiver, has been shown to result in frequent and enduring activation of the stress-response system. This occurs when children are exposed to risk factors such as physical abuse, psychological abuse and neglect, caregiver mental health problems or substance use and violence (Shonkoff et al., 2011). These early stressors can have a direct impact on the brain and other organ development as children grow older, and can impact physical and mental health and development (Shonkoff, 2010).

Next, I use the ecological systems theory to arrange the various risk factors that influence the developmental trajectory of a child affected by HIV/AIDS. Some of these factors, linked to HIV and relevant for psychosocial well-being and mental health specifically, are reviewed below. However, in doing so, it is important to keep in mind that in this context, as in others, exposure to risk is not experienced as a once-off phenomenon (such as death of a parent), but rather as an ongoing process of multiple and cumulative threats to development (Walker et al., 2007; Walker et al., 2011).

An ecological systems approach

Individual level factors

For the individual child, there are a number of important factors to consider. There are currently more than 19 million children (0-14y) who are infected with HIV in southern and eastern Africa (UNAIDS, 2013). Before the widespread rollout of ART, perinatally acquired HIV infection was associated with a 50% 2 year mortality rate; more recently there has been a dramatic increase in the life expectancy of HIV positive children (Lowenthal et al., 2014). In these surviving children, HIV infection is detrimental to the development of the brain, and leads to neurological changes in children (Van Rie, Harrington, Dow, & Robertson, 2007). A review found that negative effects of infection on cognitive development were identified in the majority of studies on the topic (Sherr et al., 2009). Other consequences of HIV infection during early development are apparent, such as compromised growth of the heart, lungs and other organs (Bernays, Jarrett, Kranzer, & Ferrand, 2014). This is significant for child mental health as chronic physical illness is likely to have an impact on child psychosocial development outcomes (Hysing, Elgen, Gillberg, Lie, & Lundervold, 2007; Mellins & Malee, 2013), and it has been established that children who require higher levels of care (Devries et al., 2014) may be more likely to be victims of violence from their caregivers and others (World Health Organization, 2006). Evidence on the impact of highly active antiretroviral therapy on slowing or reversing damage to the developing brain is mixed (Walker et al., 2011), with some research showing improvements after initiating treatment (Lindsey, Malee, Brouwers, & Hughes, 2007). Overall,

it is difficult to tease out the effects on the brain of infection, timing of infection, opportunistic infections, treatment, and the broader context in which many infected children live.

There is also a large group of HIV-negative children born to HIV-positive mothers who are exposed to HIV and ART in utero. HIV-exposed but uninfected children are more likely to have neurodevelopmental delays than HIV-unexposed children (Le Doare, Bland, & Newell, 2012; Sanmaneechai, Puthanakit, Louthrenoo, & Sirisanthana, 2005; Van Rie et al., 2008, Kerr, Nicholson). In terms of physical health, HIV-exposed children are more likely to be low birth weight, have lower growth and more vulnerable immune systems than unexposed children (Boivin et al 2017). In addition, a systematic review showed that HIV-exposed children had poorer psychological functioning than HIV-negative comparison groups in most studies, but noted the limitations of the available data and called for ongoing longitudinal studies to track outcomes for this group, especially given the widespread roll out of Prevention of Mother to Child Transmission (PMTCT) services (Sherr et al., 2014b).

These children are more likely to be born into households affected by HIV which are vulnerable for a range of reasons explored in the following section on Parenting and Family Factors detailed below. However, in terms of individual level influences, these children are exposed to HIV in utero and also subsequently to antiretrovirals as part of a PMTCT regimen (Filteau & Rowland-Jones 2016). In spite of concerns about the safety of PMTCT treatment (Thorne & Newell, 2007) most research has shown no negative impact of highly active antiretroviral therapy (HAART) exposure during pregnancy (Nozyce et al., 2014; Williams et al., 2016; Williams et al., 2010), but there are some exceptions. For example, Rice et al (2013)

found a higher risk of language delay in infants who had been exposed to atazanavir. This is an area where ongoing research is needed.

Parenting and family level factors

“Mesosystem” factors refer to aspects of the child’s immediate environment, such as within their household or family. For an HIV-infected child, family-related factors can have a direct impact on disease progression and subsequent health and development outcomes, as children tend to be entirely dependent on their caregivers to access and adhere to treatment regimens (Bernays et al., 2014). In addition, we also know that children affected by HIV/AIDS are more likely to be living in families facing a number of other challenges: adults are at increased risk of contracting HIV if they are from marginalized groups, engage in risky sexual behaviour and substance use, all of which are likely to impact upon the well-being of their children (Sherr, et al., 2014a). Children aged 10-17 who have lost a parent to HIV or who are living with an HIV positive caregiver are more likely to have mental health problems, experience social isolation, drop out of school, engage in transactional sex and be victims of child maltreatment than unaffected children (Cluver, 2011).

Five of the most significant family-related factors are discussed in more detail below.

Household poverty

HIV may have heavy economic consequences on affected families, through increased health expenditure, job loss or reduced productivity due to illness (Thomas, 2006). Children of parents with HIV are more likely to have poor educational outcomes (Guo, Li, & Sherr, 2012) and to drop out of school to earn money (Cluver & Operario, 2009). They may have increased caregiving responsibilities, for their sick parent or for younger children in the home. These risks are closely associated with the trajectory of adult illness, with ART treatment initiation being associated with better school attendance and short-term benefits to child nutritional status (Zivin, Thirumurthy, & Goldstein, 2009), both of which have implications for child mental health.

Caregiver death

Caregiver death can lead to changes in primary caregivers and living arrangements, and children may move to live with extended family or non-family members (Sherr, et al., 2014a). Palliative care services are typically not available and there may be little in the way of formal palliative care or psychological or financial support for children and caregivers (Harding & Higginson, 2005; Walker et al., 2011).

Parenting

Nurturing care is essential for child development (Britto et al., 2017) and having responsive and sensitive parents may buffer the impact of HIV/AIDS on a child. However, HIV-

positive caregivers have to deal with the increased burden of stigma, a lack of social support, physical illness, hospital visits, mental health issues and possible loss of earnings and economic hardship (Sherr, et al., 2014a). Infected or sick caregivers may be pre-occupied with issues relating to their status, such as relationship strain and physical health challenges, which can increase stress and affect parenting quality (Rochat et al., 2017). HIV-positive caregivers are thus less likely to engage in positive parenting practices than non-affected caregivers, may be less engaged with their children (Lachman, Cluver, Boyes, Kuo, & Casale, 2014) and may not be able to support their children to access early learning opportunities, which are important for development. Parental infection has also been linked with inconsistent parental care and abandonment of children (Floyd et al., 2007; Zabina et al., 2009). Importantly, for the two countries included in this study, in South Africa, research has highlighted the prevalence of poverty, parental depression poor social support and increased child behaviour problems in the context of HIV, all of which are in turn are likely to impact parenting behaviours (Lachman et al., 2014). In Malawi, poverty, food insecurity, and gender inequality have all been shown to affect parenting behaviours in the context of HIV (Gombachika, Sundby, Chirwa & Malata, 2014).

Caregiver mental health

HIV infection is associated with a number of negative physiological and psychological effects related to disease progression, side effects of medication, social stressors and the financial burden of being ill, all of which can have an effect on the mental health of individuals with the disease (Freeman, Nkomo, Kafaar, & Kelly, 2007; Kagotho & Ssewamala, 2012). People with

mental health problems are at greater risk for contracting HIV, and may engage in risky sex, including transactional sex or coercive sexual encounters, or may lack the cognitive skills to discuss and plan for safe sexual encounters (Collins, Holman, Freeman, & Patel, 2006).

Caregiving is also associated with risks to mental health. Caregivers of children affected by HIV/AIDS often face a number of challenges associated with their role, including parental stress, economic costs, stigma, and concern for their child's well-being (Casale et al., 2015). Yet, formal mental health care services in LMIC (and many High Income Countries (HICs)) remain inadequate and inaccessible to most people (Kohn, Saxena, Levav, & Saraceno, 2004; Lund et al., 2015).

Research on caregiver mental health in LMIC in the context of HIV/AIDS is limited but the burden of mental health problems in HIV-infected or affected adults is likely to have a significant impact on children. In the broader literature, there are a number of studies that examine the impact of parental, usually maternal, depression on child outcomes. Maternal depression has been linked with child development outcomes across a range of contexts, especially during the early years (Walker et al., 2011). Maternal depression and/or anxiety have been linked with perinatal problems, poor uptake of antenatal services, poor infant growth, inadequate infant feeding practices, limited opportunities for learning, and increased use of harsh parenting practices, amongst other risks in LMIC (Britto et al., 2017). However, little is known about variations between LMICs which are highly varied and diverse in terms of poverty level, nutrition and food security, cultures and parenting practices (Surkan, Kennedy, Hurley, & Black, 2011). At least part of the relationship between parental and child psychological functioning is likely due to shared genetic risk factors or differential susceptibility to environmental stressors,

or epigenetic changes as a result of exposure, but there is little available evidence (Stein et al., 2014b). The severity, chronicity, and timing of maternal (or parental) depressive symptoms in these settings is likely to be important. For example, in a high income setting, adolescents whose mothers had had perinatal depression and subsequent episodes of depression were more likely to present with affective disorders than those who had no depression or only one perinatal episode (Halligan, Murray, Martins, & Cooper, 2007). A similar finding about the additive effect of depression on behaviour problems has been identified in a study of young children (6 years of age) in Brazil (Matijasevich et al., 2015) and in Pakistan for a 7 year old sample (Maselko et al., 2016), but there are limited data from LMIC, or on outcomes during later childhood and adolescence. The impact of paternal mental health, particularly during the perinatal period, is of growing interest to researchers, with some evidence of a link between paternal depression and poor psychological outcomes in children (Kvalevaag et al., 2013; Pearson, Evans, Kounali, & et al., 2013) but there are few data from LMIC.

Household violence

Exposure to violence (both within the home and within the broader community, see below) is an important consideration for child development. There is limited research about violence in the context of HIV-affected families, but studies from related fields link exposure to a range of negative outcomes for children in later life, including risky sexual behaviour, HIV infection and substance use (Dubowitz & Bennett, 2007; Mills et al., 2011; Mock et al., 2008; Richter et al., 2014) and harsh physical discipline is linked with increased mental health problems (Norman et al., 2012). Families affected by HIV have higher rates of violent behaviours (Betancourt et al., 2013) and many of the family level risk factors for violence

overlap with those for HIV/AIDS, such as elevated substance use (World Health Organization, 2006) and gender-based violence (Jewkes et al., 2010). The latter is of particular concern; research shows violence against women and violence against children, often occur concurrently within a household (Guedes, Bott, Garcia-Moreno, & Colombini, 2016).

Exosystem system factors refer to the broader environment in which the child grows up and includes aspects such as extended family, school and the local community. Stigma about HIV/AIDS infection can lead to isolation and exclusion of people with the disease and their relatives, and the subsequent deterioration of social support networks (Betancourt et al., 2013). There is limited research on the impact of community violence on children affected by HIV, but other LMIC studies show that children living in violent societies are more likely to have insecure attachments to caregivers, post-traumatic stress symptoms, externalising behaviour problems, and depression (Walker et al., 2007; Walker et al., 2011).

Societal level factors

Macrosystem factors include broader structural and political factors that influence children. The HIV policy and legal frameworks of countries over the years are highly likely to have had an impact on child development outcomes. For example, there has been a shift from a short individual-centred to long-term response to HIV prevention which addresses social and structural drivers of the disease (Auerbach, Parkhurst, & Caceres, 2011), many of which overlap with factors affecting child development outcomes, such as poverty, gender inequality and lack of access to education. For children specifically, the highly political nature of HIV/AIDS has

influenced how responses for children have been formulated and implemented. For instance, early on in the pandemic, as noted above, the focus was specifically on so-called “AIDS orphans” due to the high levels of children who had lost one or both parents to the disease in the region. However, in doing so, a number of vulnerable children who were placed at risk because of the pandemic were inadvertently excluded from intervention efforts. This definition may have also unintentionally increased the stigmatization of children engaged in programming. In addition, at this macro level, HIV/AIDS has had a devastating effect on the health and education workforces of a number of sub-Saharan African countries, potentially contributing further to the vulnerability of children in high prevalence communities (JLICA, 2009).

This section has demonstrated the complexity of risks that are likely to be experienced by children affected by HIV/AIDS. In considering the impact of these risks on child development, there is need to consider the different levels of influence on child outcomes but also of their interaction with each other (Betancourt et al., 2013), as well as the accumulation of different risks over time (Stein et al., 2014a). A child's development is not the product of one outcome or circumstance, but a set of factors and experiences which may change and develop. For example, while parental death can have long-lasting impact on the mental well-being of a child (Li et al., 2008), a child's circumstances after the death of their mother or father can vary greatly. A child who now has no adult caregiver at all may have different outcomes from a child living with a surviving relative who has taken over their care, just as a double orphan may have a different experience to a single orphan (Belsey & Sherr, 2011). On the other hand, even when there has not been parental death there are other factors which may place a child at risk, such as living

with an unwell caregiver, changing caregivers in the home, lost income from adults who live in the home and further afield, high levels of stigma around the disease from community members.

2.4. Mitigating the impact of HIV on children

In the next section, I change focus to mitigating the impact of HIV on children, including potential ways in which CBO programmes might be effective, highlighting the current lack of evidence in this field. Finally, I provide an overview of the current policy priorities of a range of large funders and NGOs who are invested in this area.

2.4.1. Community-based organisations

Recent years have seen an increase in the attention and resources dedicated to mitigating the impact of HIV/AIDS on children (Akwara et al., 2010) coupled with a growing realisation of the importance of community-led initiatives to support families affected by the pandemic (Campbell & Cornish, 2012).

CBOs have been prioritized as a means of intervention delivery for a number of reasons. First of all, they are present in communities. Over the past three decades, CBOs have developed and delivered a range of programmes and services for children affected by HIV/AIDs, often ahead of the advent of formal services, or replacing them altogether (Richter et al., 2006). As a result, across sub-Saharan Africa, there are a vast number of grassroots organisations and

programmes activities providing care and support in a variety of different ways, a number of which are supported by international donors.

Secondly, there is a shortage of health workers in most low resource settings (Celletti et al., 2010) and the delivery of HIV programmes has progressively become the responsibility of community-based providers, such as community health workers (Hermann et al., 2009). In South Africa, there has been rapid expansion of an informal community-based workforce to address the HIV epidemic, providing care and support for affected families, and HIV testing and treatment, and as a result, HIV-related workers have formed the backbone of the community health worker system (Schneider, Hlophe, & van Rensburg, 2008).

Thirdly, involvement of affected communities is likely to be central to the success of HIV programming. Community level factors, such as community members and leaders, church and schools, have been identified as central to improving paediatric HIV treatment outcomes (Vreeman et al., 2009). Specifically, the beliefs of community members can influence child adherence to treatment, either positively through support and assistance with accessing care, or negatively affect it through stigma and discrimination (Vreeman et al., 2009). The failure of many programmes to successfully reduce infection rates, address stigma, and increase access to treatment has been attributed to a lack of effective community engagement (Campbell, 2003). CBOs fit well into an “AIDS Competent Community” model, which describes a system where community members actively engage in issues relating to HIV/AIDS and work together to reduce stigma, promote safe behaviour, provide support for affected families and work in partnership with CBOs and formal health and social services (Campbell & Cornish, 2012;

Campbell et al., 2013). The nature of CBO operations at grassroots level means that they are considered to be in a unique position to effect change. They are able to reach out to community members in the context of their homes (Selke et al., 2010) thereby reaching the most marginalised and isolated members of a community. They are thought of as being more sustainable (Campbell & Cornish, 2012), and able to advocate for the communities they support (Schwartländer et al., 2011). Involving CBOs is more likely to lead to the development of appropriate and acceptable policies and programmes (Wilson et al., 2012).

Finally, there is evidence of success of these types of grassroots approaches in the HIV sector. There is a large body of research showing the community health worker programmes can be successful in improving health outcomes (Kok et al., 2016). Other forms of community intervention, such as treatment buddies and support groups, have also shown promise in promoting adherence to ARVs (Wouters, Van Damme, Van Loon, van Rensburg, & Meulemans, 2009). Often by necessity, community programmes also tend to be multi-faceted and responsive to the needs of community members beyond one single outcome. For example, Grimwood et al. (2012) describe a successful community-based programme to increase retention of children in treatment that used a range of strategies, including education, support, and home visits, but note in addition to health-related activities team members also facilitated families' access to social income grants. On the other hand, other forms of community intervention, that focus more broadly on contextual issues of rights or driver of infection (such as gender inequality) are often discussed in the literature but rarely tested as individual interventions (Campbell, Nair & Maimane, 2007).

In Figure 2.2., factors which impact upon child psychosocial development are shown in an adapted version of Bronfenbrenner’s social ecological model of child development. Integrated into this diagram are potential areas where CBO programmes for children affected by HIV might have impact, as mental health promotion, prevention or even providers of basic treatment.

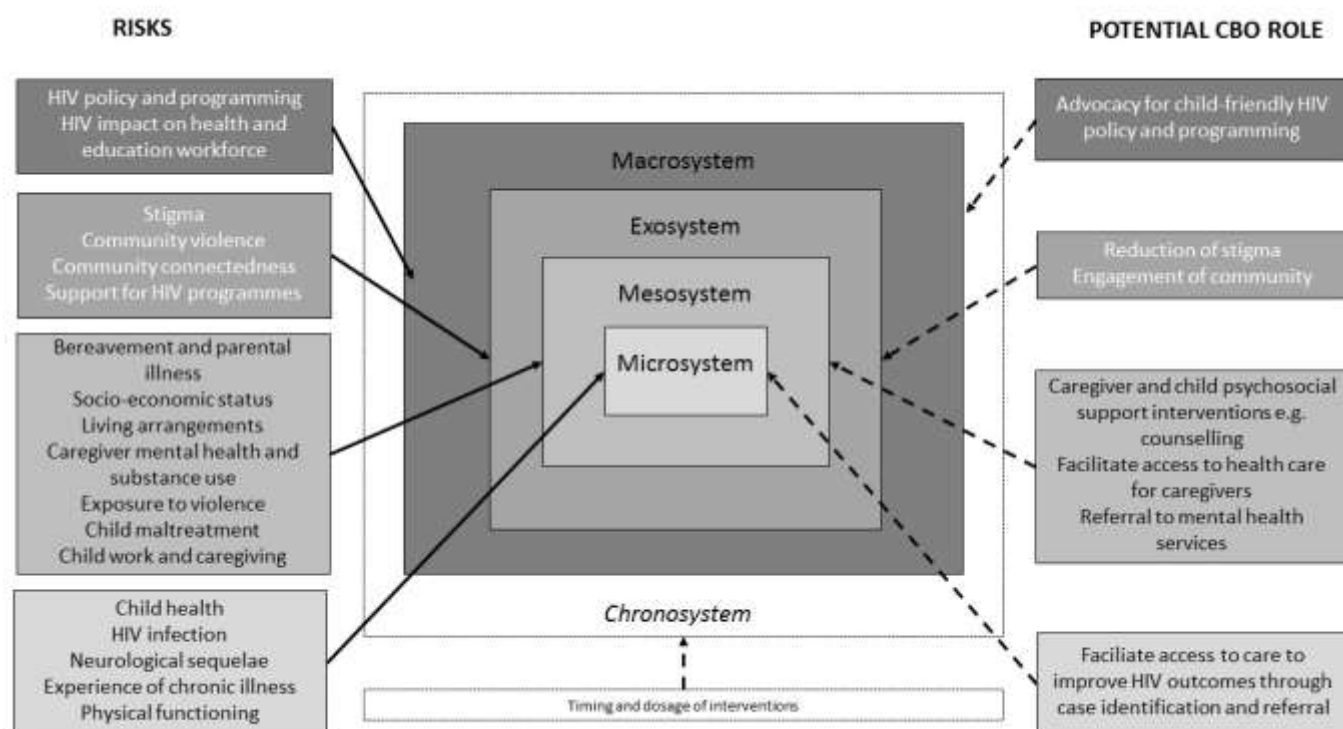


Figure 2.2.: Potential roles of CBO programming to improve mental health and psychosocial development in children affected by HIV/AIDS (adapted from Bronfenbrenner, 1979)

2.4.2. The evidence for community-based psychosocial programmes

In spite of the large numbers of CBOs, the potential for attracting funding, and positioning of their services at grassroots level, there is relatively little evidence available on what types of community-based programmes can improve health and well-being outcomes for

children affected by the pandemic. In fact, research suggests the opposite: there is little routine evaluation of community programmes, and that the information that is generated is not disseminated and taken up at a policy level.

Following the Cochrane review in 2009, which was unable to identify any study that adequately evaluated any programme for this group (King et al., 2009), a further review attempted to address the same issue focusing on community-based interventions, and using deliberately broad inclusion criteria (Schenk, 2009). In this study, any evaluation, review or assessment of a community-based programme was included if it was i) designed to support orphans and vulnerable children, ii) situated in a high HIV prevalence setting, and iii) had at least one follow up data collection point. This included interventions conducted by researchers, programme implementers or donors. In this case, 21 studies were identified for inclusion but the author noted concern about the quality and rigour of available evidence. Schenk went on to identify the urgent needs for a strategic research agenda in this field, and for donors to support capacity building in improving monitoring and evaluation of programmes at local level, and the use of evidence to inform the management of these types of programmes, including how resources should best be allocated.

Subsequently, Betancourt and colleagues (Betancourt et al., 2013) reviewed interventions that included outcomes relating to the resilience of children affected by HIV/AIDS. They found the quality of evidence available to be moderate, with most studies having satisfactory measures of mental health, but inadequate measures of resilience. Only four studies were identified which adequately evaluated an intervention to improve resilience, all of which focused on adolescents,

and three of which took place in HICs. Two of these, both of which took place in the United States, used a family-based approach (Lyon et al., 2011; Rotheram-Borus, Stein, & Lester, 2006). The authors of the review rated that the best quality evaluation had been completed on a manual-based 15 week small group programme for adolescents and their parents. Adolescents in the intervention group demonstrated better resilience outcomes, including less risky behaviours, less emotional distress and more positive future expectations than the control group (Rotheram-Borus et al., 2006). Two of the studies assessed the impact of a peer support interventions in Uganda and France (Funck-Brentano et al., 2005; Kumakech, Cantor-Graae, Maling, & Bajunirwe, 2009). In the Ugandan study, a cluster randomised controlled trial (RCT) of a school-based peer support group intervention for AIDS orphans showed a significant reduction in depression, anger and anxiety, but no improvement in self-concept (Kumakech et al., 2009). For both of these studies there were concerns about study design.

More recently, Rochat et al. (2017) describe three interventions at various stages of testing that address parenting and HIV, with the aim of improving parenting skills and the parent-child relationship. The Amagugu intervention in South Africa is a disclosure intervention aimed at HIV positive mothers with HIV-negative children. The intervention has led to increased rates of partial and full disclosure, improvements in maternal well-being, and reduced child behavioural problems (Rochat et al., 2014; Rochat et al., 2016). The Kgolo-Mmogo Project, also in South Africa, has led to reductions in children's behavioural problems through an intervention which focuses on parent-child communication (Eloff et al., 2014). The Family Strengthening Intervention, a module-based intervention directed at children, caregivers and the

broader family, has led to better family relationships, parenting quality, social support and child well-being in Rwanda (Betancourt et al., 2014a).

Cognitive and motor outcomes are not the specific focus of this review, but it is interesting to note that there are successful examples of community-based programmes to improve cognition. In the same community as the study noted above, a dialogic book sharing intervention with mothers of 14 – 16 month old children, delivered by trained and supervised lay health workers resulted in improved parental sensitivity and cognitive outcomes for children (Murray et al., 2016). An RCT in South Africa tested a home-based programme given to HIV positive caregivers to incorporate small, developmentally-focused activities into their daily routines with their children. The programme was successful in improving cognitive and motor skills over 12 months (Potterton, Stewart, Cooper, & Becker, 2010).

There are also lessons from related fields that may be relevant for psychosocial and other developmental outcomes. Non-HIV specific studies that have taken place in contexts of HIV prevalence have been successful in improving psychosocial outcomes for children. For example, in Khayelitsha, South Africa, a home visiting intervention delivered by lay health workers during pregnancy until 6 months resulted in increased rates of secure attachment in the intervention group at 18 months (Cooper et al., 2009). Other reviews of parenting programmes in low resource settings for child development found that there is good evidence for child stimulation interventions delivered at community level (Aboud & Yousafzai, 2015; Rao, Sun, Chen, & Ip, 2017), but these are non-HIV-specific.

Implications of a lack of evidence

Considering the large burden of disease of HIV/AIDS in the sub-Saharan African region in particular, the moral case for investing in research into these interventions is indisputable. In order to develop evidence-based interventions, we need to design studies that ascertain the efficacy of interventions and define causal pathways more clearly. Reliable evidence is needed to support the efficient use of limited resources for training, supervision and management (Kim et al., 2013). It is also important to ascertain whether existing programmes are creating unintended negative effects for the children and their families, for example by singling out certain children for participation, leading to stigma or isolation of the child. Finally, without evidence of what works we also do not know if there are particular groups within the target population that are not responding to community-based programming, and are particularly vulnerable.

The limited number of studies in this area has also been noted in the growing field of global mental health research, where the need for the evaluation of interventions that improve the mental health of vulnerable children has been noted. In 2007, the first Lancet Series on Global Mental Health called for the scale up of mental health services in light of the high burden of disease and large treatment gap associated with mental disorders. Specifically, the contributors placed an emphasis on the need for research to develop and evaluate interventions that can be delivered by people who do not have specialised mental health training such as community-based groups (Chisholm et al., 2007). Following this, the full results of a related priority setting activity were published, highlighting the lack of evidence generated for interventions targeting

children and adolescents (Tomlinson et al., 2009a). This paper further highlighted the need for research into the effectiveness of integrated prevention and treatment interventions delivered at community level by lay community and health workers, as well as the types of support systems that need to be in place to effectively deliver these interventions. Subsequently, the Grand Challenges in Mental Health initiative went through a similar process to identify priorities for mental health in the next decade. Amongst their top five identified challenges were the need to improve children's access to evidence-based care in LMIC, as well as the provision of community-based care that is effective and affordable (Collins et al., 2011).

2.4.3. Past and current programming priorities

Since 2008, donor funding for HIV has been falling, due to the global recession, donor fatigue, competing public health priorities, and changing foreign aid budgets (Grépin, 2012; Katz, Routh, Bitran, Hulme, & Avila, 2014). This means that the need for strategic investment into evidence-based interventions is more important than ever.

An analysis of the implementation strategies of the funders and organisations that were involved in this study shows a variety of priorities, with some areas of overlap. Some organisations provide psychosocial support directly. REPSSI has a focus on providing emotional support programmes for vulnerable children, by training community and other partners and developing and disseminating tools for use at grassroots level (REPSSI, 2017). World Vision's focus is broader, including PMTCT, supporting HIV-positive children to access care and thrive, and to eliminate children's experiences of stigma (World Vision UK, 2016). HelpAge is an organization focused on older people, but which has included children in their response to HIV

as many older people are caregivers of orphans and sick adult children. Specifically, HelpAge identifies the following as central to support affected families: boosting social networks, strengthening relationships, bereavement, involving male caregivers, dealing with abuse, encouraging self-care and home-based care programmes (HelpAge, 2011).

Others organisations provide or promote access to related HIV services. The Firelight Foundation works directly with CBOs to prevent mother to child transmission and increase access to treatment for young people with HIV (Firelight Foundation, 2017). Comic Relief's overall strategy is not in the public domain, but their focus is on reducing the stigma of HIV/AIDS by supporting local organisations that work on this issue and that support people to access treatment services (Comic Relief, 2016).

Some organisations focus more specifically on economic strengthening through cash transfer programmes. UNICEF's mandate is perhaps different from some of the INGOs and funders in that it is a part of the United Nations system and thus a multilateral agency that receives funding directly from country governments (but also from private donors). Its mandate is to work directly with host governments in countries where its offices are based. Their current approach to children affected by HIV/AIDS is strongly focused on improving economic support for households through activities such as cash transfers, which tend to be government-led initiatives, as well as increasing district-level social services to support children who are affected, and increasing access to HIV prevention and treatment programmes (UNICEF, 2017). Save the Children UK's strategic direction has changed over the past decade. In 2006, their policy document "Missing Mothers" outlined their priority target group as children who have

already been orphaned by AIDS, or living in families with a sick or dying parents, and their priority activities as i) increasing social welfare systems, ii) increasing community involvement through including CBOs or their representatives in national planning and in decisions about local service delivery, and iii) free healthcare (Save the Children UK, 2006). Recently, they have increased their focus on “cash plus” programmes, which use economic support directly or indirectly address issues affecting vulnerable children more generally (Save the Children UK, 2016). Stop AIDS Now!, recently rebranded as AIDS Fonds, focus on providing support for children and their families, linked them with community support, providing cash transfers and delivering integrated services (Stop AIDS Now!, 2017).

Finally, some are no longer active in the field. The Bernard van Leer Foundation no longer includes HIV as a focus area for its funding. However, in 2006, it was a priority area, with the strategy focused on strengthening families to care for children affected by HIV/AIDS through community-based programmes such as home visiting and income generation (Bernard van Leer Foundation, 2006). The Diana, Princess of Wales Memorial Fund has ceased to fund projects, but at the time of its closure in 2012, it funded children’s care programmes under its palliative care initiatives, including high-quality home and community-based care for people with HIV (Diana Princess of Wales Memorial Fund, 2012).

Overall, these organisations have vastly diverse approaches to tackling the challenges faced by children affected by HIV/AIDS. This may be in part due to the lack of clarity about what works and what is most cost effective to improve outcomes for children affected by HIV/AIDS.

2.5. Chapter Conclusion

The purpose of this chapter was to review the literature as they relate to the research questions outlined in the Introduction. In this chapter, I provided an overview of the core issues for the psychosocial development children affected by HIV/AIDS, the potential role of CBO programmes, the current lack of evidence in this field.

CHAPTER 3: OVERVIEW OF THE METHODOLOGY AND RESEARCH PROCEDURES OF THE CHILD COMMUNITY CARE STUDY

3.1. Chapter outline

This chapter provides a description of the study methodology and research procedures used in the Child Community Care Study, which is the data source for the analyses used in Chapters 4 – 6. It includes background information about the larger study and study partners, and my specific role in coordinating study activities. It provides an overview of the study setting, participants, and data collection procedures that were used. Specific information about the measures used in the individual analyses and data analysis is not included in this chapter, but in the relevant chapter (Chapters 5, 6, and 7). It is intended that this overview will assist the reader to contextualize the information presented in these chapters.

3.2. Study overview

This PhD study forms part of a larger multi-country study, the Child Community Care Study, which investigated the impact of community-based programmes for children affected by HIV/AIDS on child health, mental health, behavioural, educational, and health outcomes. The principal investigators of the larger project were Prof. Lorraine Sherr (University College London) and Prof. Mark Tomlinson (Stellenbosch University). It was funded by the Swedish International Development Cooperation Agency (SIDA), through a nesting grant with HelpAge and supported by the Coalition for Children Affected by HIV/AIDS (CCABA). Project partners

included Save the Children, Bernard van Leer Foundation, Firelight Foundation, World Vision, Comic Relief, REPSSI, Stop AIDS Now!, Diana Memorial Fund, and the AIDS Alliance. The study had two phases. Phase 1 took place in South Africa and Malawi, and the data from this phase is used in this thesis. Data was collected between 2012 and 2014. Phase 2 took place in Zambia, but this data is not reported here. The project had ethics approval from Stellenbosch University (HREC reference N1004112), University College London (approval reference 1478002) and the University of Cape Town (1292015). It also had approval from all funders and non-governmental partners.

3.3. Setting

The setting for the study was selected community-based programmes for children affected by HIV/AIDS in South Africa and Malawi. These two countries were selected as they both have high prevalence rates of HIV infection. In South Africa, 5,600,000 South African adults, or 17.3% of the population was living with HIV/AIDS in 2011, including 30% of pregnant women (RSA, 2012). An estimated 460 000 South African children are living with HIV and over 2 million children have lost one or both parents to HIV (UNAIDS, 2011b). Malawi has one of the highest HIV infection rates in the world with an estimated 910 000 people living with HIV in 2011, of which 170 000 were children. In addition, it is estimated that 610 000 children in the country are have lost one or both parents to the disease (UNAIDS, 2011a).

In both South Africa and Malawi, recent years have seen increased attention on HIV/AIDS. In particular, this has focused on lowering HIV infection rates and increasing access

to antiretroviral drugs. After many years of neglect the number of people on antiretroviral therapies has risen significantly in South Africa and there has been a reduction in HIV-related mortality, particularly among women (Mayosi et al., 2012), while mother-to-child transmission declined from 8.5% in 2008 to 3.5% in 2010 (RSA, 2012). Similarly, in Malawi, a renewed commitment to the fight against HIV/AIDS has led to the scale up of Malawi's national treatment programme, from only 10 000 people on treatment in 2004, to over 650 000 people in December 2014 (NAC, 2015).

3.4. Sample

The sample was children aged between 4 years and 13 years who attend community-based projects, together with their primary caregiver. The caregiver was the primary caregiver of the child, an adult whose responsibility it was to care for the child, who lived in the same household as the child for a minimum of four nights a week. Minors with caregivers other than biological caregivers were included due to high parental mortality rate for children affected by HIV/AIDS. If they were to be excluded, the sample would have been highly skewed and it is likely that the most vulnerable children would have been omitted. Participants were excluded if they were too ill to participate in the study or not able to understand the informed consent process.

The sample size was calculated to detect differences between groups attending CBOs with different features at 90% power and a 2-sided significance level of 5%. In order to detect a small difference of 0.25 of a standard deviation in the Self-Efficacy Questionnaire between two

groups, with 90% power, the sample required 674 children (337 children in each group) (Mueller et al., 2011). Due to the fact that we were recruiting a highly vulnerable sample from fragile organisations, the team aimed to over-sample by 50% to allow for drop out over time.

3.4.1. Recruitment and enrolment

As a part of the larger study, all 10 partner foundations listed previously provided the researchers with details of all community-based projects that they supported in the selected geographic areas. In order to be considered for inclusion, CBOs needed to meet the following criteria:

- i) Providing a service directly to children.
- ii) Serving children between the ages of 4 and 13 years.
- iii) seen as "research ready", i.e. that they were functioning at a sufficient level to permit the hosting of a team of data collectors over a 2-3 day period.

From this list, 580 CBO's were generated. These CBOs were arranged by province and by funder, and 28 organisations randomly selected for inclusion in the study. Of the total, 24 of the organisations were based in South Africa and 4 were based in Malawi. This ratio was based on country population size. The locations of programmes are included in Appendix 1.

Prior to a site visit being scheduled, study team members made contact with programme staff through their supporting partner foundations. At this point, extensive negotiations took place with each organisation to determine how and when a site visit could take place.

Researchers endeavoured to not to disrupt usual programming and ensure that the visit did not drain any local resources. Different organisations required different levels of support for visits, and in some cases external venues for private interviews had to be located, commonly in local schools or clinics. For each site, a Principal Investigator, the PhD student or a data collection team leader accompanied the data collectors to collect data. Data collectors maintained close contact with study management throughout data collection processes and data was monitored on a daily basis through the online console.

The data collection team consisted for 2-5 data collectors per organisation who administered pre-translated interviews in local languages (including English, isiXhosa, isiZulu and Chichewa) as required.

3.5. Research procedures and data collection methods

At each organisation, a consecutive sample of 30-40 children attending the programme was included, as well as the primary caregiver or a close family member responsible for the child, who lived with the child. In addition, data on the CBO, its management, funding, structure and services were gathered.

Community organisations provided the names of their caseload to researchers, and these were used to sample participants from each organisation. Prior to completing an interview, caregivers were taken through the informed consent process, using a translated informed consent form (see Appendix 2). Trained research staff experienced in working with vulnerable families

conducted the informed consent process. Due to low literacy levels, all consent and information forms were read aloud or together with the caregiver. All participants were told they had the right to decline to participate, and could drop out at any time and that all results would remain confidential except where participants disclosed significant harm to themselves or others, or requested help. If they consented to participate then they were interviewed by a trained, experienced interviewer in a private interview room which was arranged ahead of time.

Similarly, during the assent process for children, the data collector explained to the child, slowly and in child-friendly language, what the study was about, what they were being asked to do, the types of activities they would engage in, and also that they could stop their participation at any time. She explained that if they chose to stop, there would be no negative consequences for their decision. The data collectors were trained to adjust their level and method of communication depending on the age of the child. For example, for younger children, they would allow time for breaks and physical activities between and during tasks. While the assent form was used as a guide, the assent process was an interactive process that was supposed to engage the child before the data collection started. Once the child had indicated his/her assent the data collector continued with the research activities (see Appendix 2).

Data collection comprised face-to-face interviewer-administered interviews and direct child assessments, with data entered directly on to mobile phones. There were three different types of interviews (available in Appendix 3):

- i) organisation representative,
- ii) child; and

iii) caregiver

In all, one caregiver-child pair were engaged in answering questionnaires and other assessments for a minimum of 90 minutes and a maximum of two hours and 30 minutes. Participants were interviewed at baseline and 12 month follow up. Between baseline and follow up they attended their local CBO programme as usual and participated in the programme as they would usually have been doing, as depicted in Figure 3.1.

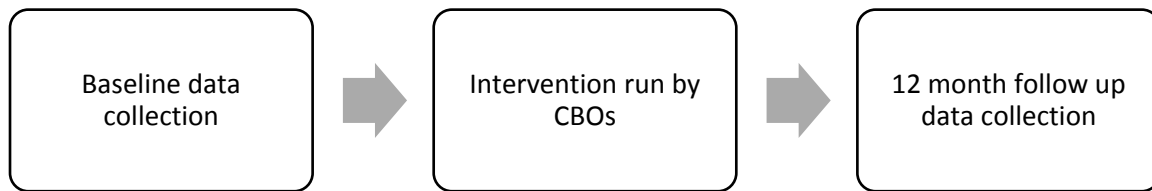


Figure 3.1.: Flow chart of data collection

All interviewers were experienced in research interviews and administration of standardised behavioural tools. They had worked on a range of other projects for Stellenbosch University and completed an additional week of didactic and practical refresher training before completing interviews. This included aspects of working with vulnerable children. Sensitive questions in the questionnaire were worded carefully, according to UNICEF guidelines (Snider & Dawes, 2006). The researchers explained questions carefully and they were on hand to answer any questions the children may have.

3.6. Measures

Data on the children were gathered using a combination of self-report from the children and reports from their caregiver. Questionnaires and information reported by both children and caregivers included a range of questions related to child’s health, education, psychosocial well-being and socio-demographic information. Standardised and validated indices were used where they were available. Parts of the questionnaire were skipped for younger children where they were not appropriate. The same measures were used as baseline and follow up.

The measures are presented in two parts.

First of all, information about the measures used in the wider study is included below in Tables 3.1. and 3.2.

Second, more information about the specific measures used in the analyses in Chapters 5, 6, and 7 is included.

All Child Community Care Study measures

Table 3.1.: Child questionnaire domains

OUTCOME	MEASURE/SOURCE
Physical growth	Age, height and weight, used to develop standardised WHO measures: Height-for Age, Weight-for-Age, Weight-for-Height
Cognitive development	Draw-A-Person Test, Digit Span test, computer-based tasks.
Living arrangements	Individual questions, adapted from CSI on Shelter
Social connection	Social connection domain
HIV status	Individual questions, relating to child, caregiver and family status

OUTCOME	MEASURE/SOURCE
Externalizing and risk behaviour	SAHA scales and Mad About Art study
Child work and responsibility	Survey of Activities of Young People
Exposure to household violence	Household Violence and Exposure to community Violence Domain
Legal protection	Child Status Index (CSI) Legal Protection
Mental health and psychosocial development	Child Depression Inventory, The Self-Efficacy Questionnaire for Children , Rosenberg Self-Esteem Questionnaire
Self Esteem	Rosenberg Self-Esteem Questionnaire
Stigma	Experience of Stigma, Discrimination and Social Exclusion Domain
Experience of trauma	Trauma Symptom Checklist for Children

Table 3.2.: Caregiver questionnaire domains

OUTCOME	MEASURE/SOURCE
Employment	Demographic and Health Survey
Relationship to child	CSI Care Domain
AIDS and illness in home	Individual questions adapted from Mad about Art study
Household structure	Individual questions developed for study
Child developmental disability	Ten Questions screening tool
Caregiver Exposure to Domestic Violence	Domestic Violence Domain
Physical child maltreatment	Use of Physical Punishment or Maltreatment in the House
Stigma	Community Maltreatment, Exploitation, Stigma and Discrimination
Caregiver mental health	Shona Symptom Questionnaire
Depression	Patient Health Questionnaire - 9
Anxiety (panic disorder)	Brief Patient Health Questionnaire
Child care	CSI Care Domain
Child social and emotional functioning	Paediatric Quality of Life Inventory: Parent Report: emotional functioning and social functioning
Internalising and externalising behaviours	Caregiver Report on Youth's Internalizing, Externalizing and Risk Behaviours Strengths and Difficulties Questionnaire (SDQ)
Child health	CSI Wellness Domain
Physical fitness	Paediatric Quality of Life Inventory: Parent Report: physical functioning
Hospital admission	Individual questions developed for study

OUTCOME	MEASURE/SOURCE
Child access to health care	CSI Health Care Services Domain
Child food security	CSI Food Security Domain
Child growth	Information and Action Tool (IAT): Nutrition and Growth Domain
Child education status	CSI Education Domain
School functioning	Paediatric Quality of Life Inventory: Parent Report: school functioning
Legal protection	CSI Legal Protection, additional individual questions developed for study
Abuse and exploitation	CSI Abuse and Exploitation domain

The programme measures were developed based on a preliminary set of qualitative interviews that were held with funder partners. Interviews were recorded and transcribed, and then coded using thematic analysis. These themes were then mapped to specific questions for both providers and recipients. Questions for recipients focused on the type of services they receive, tracking any payments or reimbursement that they are required to give for services, how often and for how long they have contact with the organisation, and their experience of community support for the organisation. Provider questions related to programme history, details about their funding, their link with government, their resources, leadership structures, training and skills development, monitoring and evaluation practices, methods of recruitment and delivery, client characteristics, and experience of community support for their programme.

Measures used in analyses in Chapters 5 – 7

Demographic information

Children reported their gender, age, and country of residence. Caregivers reported their gender, age, relationship to the child and role in child's life.

Socio-economic indicators

Children rated the condition of the home they live in, their education (school enrolment, grade), and employment of household members. Caregivers reported working status and food security. Nutritional status of the child was measured using three growth assessment indicators – stunting, wasting and underweight according to the classification of WHO Global Database on Child Growth and Malnutrition (De Onis et al., 2007).

HIV/AIDS status and other illnesses

Child HIV status was determined based on caregiver report. Caregivers were also asked about their own status and whether other members in the household had HIV. Children aged 6 to 13 years were asked if they knew their HIV status. Caregivers provided information on family illness and death.

HIV/AIDS-related stigma

Perceptions of HIV/AIDS-related stigma in the community were assessed among caregivers using a 3-item set of questions (Snider & Dawes, 2006) (e.g., Do adults in the community reject children whose parents have HIV/AIDS?). Responses were coded as yes/no. The scale had an alpha reliability of 0.72 for this study. A total mean score was calculated (range 0-3) with higher mean scores indicating greater perception of stigma.

Developmental disability

Developmental disability was assessed using the Ten Questions (TQ) (Durkin et al., 1994). Caregivers answered ten questions that screened for child developmental problems in the domains of speech, cognition, hearing, vision, motor and seizure disorders. A child was considered to have screened positive if the caregiver reported impairment on at least one of the ten questions. The TQ has been validated in LMIC countries (Durkin et al., 1994) and is currently the most widely used measure to screen for childhood disability in these settings (Gottlieb, Maenner, Cappa, & Durkin, 2009; Maulik & Darmstadt, 2007; Mung'ala-Odera et al., 2004). In South Africa it has recently been assessed as a screening instrument for developmental disability in children infected by HIV, where it was found to be sensitive to moderate to severe disabilities, but not mild sensory disabilities (Arpadi et al., 2012). The screening test has been validated for 2-9 year olds only, but used for older children as well.

Child internalising and externalising behaviour

Child emotional and behavioural functioning was assessed using a short 10 item version of the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997), describing a psychological or behavioural attribute (positive and negative) of the child over the last 6 months. Responses were coded on a 3-point scale: (2) very true, (1) somewhat true or (0) not true. Subscales were related to emotional problems (e.g., ‘Is your child often unhappy, downhearted or tearful?’), conduct problems (e.g., ‘Is your child generally obedient and usually does what adults request?’), hyperactivity-inattention (e.g., ‘Does your child think things out before acting?’), peer problems (e.g., ‘Is your child picked on or bullied by other children?’) and prosocial behaviour (e.g., ‘Is your child considerate of other people’s feelings?’). Both a total score and scores for five subscales were calculated. The total SDQ score ranged from 0 to 20 with higher values indicating greater behavioural and emotional pathology. Higher scores for individual scales indicate poorer functioning for four of the subscales (emotional, conduct, hyperactivity-inattention and peer problems) and better functioning for one of the subscales (prosocial). The SDQ has been extensively validated in both LMIC and HIC and has been used in South Africa (Cluver & Gardner, 2007).

Finally, adolescents (10-13 years) reported on their risk behaviours including substance abuse, delinquency and violence using three selected items from the Social and Health Assessment (SAHA) scales which has been used in South Africa (Mueller et al., 2011). The scale was calculated as a binary outcome of any risk behaviour vs no risk behaviour.

Child mental health

Child depressed mood was measured using the ten item Children's Depression Inventory-Short Form (Kovacs, 1992), which has been used previously in South Africa (Boyes & Cluver, 2015; Cluver et al., 2007). Trauma symptomatology was assessed with the Trauma Symptom Checklist for Children (TSCC) (Briere, 1996) a self-report measure which has been used in a middle income setting country before, but not in Sub-Saharan Africa (Li et al., 2009). Self-esteem was assessed using the child report Rosenberg Self-Esteem Scale (Rosenberg, 1965), which has been used in over 50 countries (Schmitt & Allik, 2005) including South Africa (Mueller et al., 2011).

Health-related quality of life (QOL)

This was measured using a short version of the Paediatric Quality of Life Scale (PedsQL) (Varni, Seid, & Kurtin, 2001). Caregivers completed a 15-item questionnaire on QOL in four areas of functioning in the past month: physical functioning (e.g., 'How much of a problem has your child had with walking more than one block?'), emotional functioning (e.g., 'How much of a problem has your child had with worrying about what will happen to him or her?'), social functioning (e.g., 'How much of a problem has your child had with getting along with other children?'), and school functioning (e.g., 'How much of a problem has your child had with paying attention in class?'). They rated the item severity on a 5-point Likert scale: 'never a problem' (0); 'almost never a problem' (1); 'sometimes a problem' (2); 'often a problem' (3); 'almost always a problem' (4). A total QOL score of 0-60 and two summary scores: Physical

Health Summary Score and Psychosocial Health Summary Score (emotional, social and school functioning subscales) were calculated, with greater scores indicating higher QOL. The PedsQL has been shown to have good validity and reliability in high income setting. It has however not been validated in a sub-Saharan African context.

School performance

Caregiver reports questions on school performance were adapted from Child Status Index (Nyangara, O'Donnell, Murphy, & Nyberg, 2006): (1) Does your child go to school? (Responses coded as 'Yes, regularly' versus 'No/Rarely/Sometimes'); (2) 'How do teachers report your child is doing in school?' (Responses coded as 'child does better or as well as other children' versus 'child struggles in school'); (3) 'Is the child quick to learn when introduced to new chores or things?' (Responses coded as 'Yes' versus 'No/Don't know').

Caregiver mental health

Caregiver mental health was measured using the Shona Symptom Questionnaire (SSQ) (Patel, Simunyu, Gwanzura, Lewis, & Mann, 1997) and the Patient Health Questionnaire (PHQ) (Kroenke, Spitzer, & Williams, 2001). The SSQ is a 14 item scale, with a cut-off for psychological morbidity of 8 and over. Suicidal ideation was measured using one item from the PHQ, namely "*Over the past two weeks, how often have you had thoughts that you would be better off dead, or of hurting yourself?*" Participants were asked if they had sought help from any source for mental and emotional problems during the past year.

Community support

Community-related measures were drawn from a UNICEF survey tool for orphans and vulnerable children (Snider & Dawes, 2006). These included questions for caregivers about levels of support for children affected by HIV/AIDS from the community, and caregiver exposure to violence.

Food security and nutrition

Caregivers also completed measures relating to their children, including items on food and nutrition and school functioning from the Child Status Index (Nyangara et al, 2008).

Violence

Exposure to interpersonal violence in the home was measured using scale items from a UNICEF survey tool for orphans and vulnerable children (Snider & Dawes, 2006) that enquired about children's exposure to violence in the household, both directly and as a witness. Harsh discipline practices that involved punishment or maltreatment in the household were reported by the caregiver using items adapted from the Parent-Child Conflict Tactics Scale (Straus, Hamby, Finkelhor, Moore, & Runyan, 1998) and from the International Society for the Prevention of Child Abuse and Neglect (ISPCAN) screening tools, relating to (a) use of physical violence, and (b) use of psychological violence to discipline the child. Exposure to community violence was assessed using scale items from the UNICEF survey tool (Snider & Dawes, 2006) that enquired

about child's exposure to different forms of violence within the community through witnessing and direct victimisation. For all of these outcomes (harsh physical discipline, harsh psychological discipline, domestic violence and exposure to community violence) for the analyses reported here, responses were codified as binary variables, as *any* or *none*.

3.7. Data Management

Interview data were entered directly on to mobile phones. The use of phones in data collection allowed the interviewer to input answers, by hand, directly into a database. The software allowed for simple logic to be built into the questionnaire, such as restricting the range of answers that can be inputted, or skipping irrelevant questions based on a respondent's previous responses. This can reduce the length of the administration of the questionnaire and negates the need for data entry on to the central database at a later stage (Tomlinson et al., 2009b). In particular, for young children, certain questions could be skipped depending on their age. Upon completion of the questionnaire, responses were sent directly to a study server and data were accessible on an online password-protected research portal for monitoring.

Data from all interviews were stored on computerized files at a centralized location. Data were password protected and kept in a locked office with limited access. Only research team members had access to data files.

3.8. Data analysis

Data analysis for each of the three papers in this thesis is included in the relevant chapter (Chapters 5, 6 and 7).

3.9. Role of PhD student in broader project

I was involved in this project since its inception and worked closely with the Principal Investigators to develop the research questions and hypotheses for this study. In addition, I coordinated the selection of measures for use in data collection. I was the primary contact point with all partner NGOs and funders and worked with them to create a comprehensive list of all CBOs that they were supporting. From this list I was responsible together with study partners for the random selection of organisations to take part in the study. I trained the data collection team, provided supervision on an ongoing basis, and managed all aspects of data collection (including extensive field visits) monitoring and quality control of data, including data cleaning.

Three of the chapters described in this thesis use data from the larger project (Chapters 5, 6, and 7). For Chapter 5, I conceptualised this paper under the guidance of my supervisors. I selected the measures for data collection, trained and supervised the data collectors, analysed the data together with Ms. Miltz, and wrote the first and final drafts of the paper. All other authors were involved in critically revising the manuscript and all authors approved the final draft before publication. For Chapter 6, I conceptualised this paper under the guidance of my supervisors. I selected the measures for data collection, trained and supervised the data collectors, analysed the

data under the guidance of Dr. Macedo, and wrote the first and final drafts of the paper. All other authors were involved in critically revising the manuscript and all authors approved the final draft before publication. For Chapter 7, I selected the measures for data collection, trained and supervised the data collectors, analysed the data together with Dr. Macedo, and wrote the first and final drafts of the paper. All other authors were involved in critically revising the manuscript and all authors approved the final draft before publication. The systematic review, in Chapter 4, was developed with study partners. My role was to develop the protocol for the review under the guidance of my supervisors, screen abstracts together with other authors, conduct the data extraction and write the first and final drafts of the paper. All authors reviewed and gave input into the final manuscript prior to publication.

3.10. Chapter conclusion

In this chapter I have provided a background description of the Child Community Care study, in which the PhD work is embedded, in order to provide context for the forthcoming Chapters 4 – 6 which are based on data analysed as a part of this larger project.

CHAPTER 4: INTERVENTIONS TO IMPROVE PSYCHOSOCIAL WELL-BEING FOR CHILDREN AFFECTED BY HIV AND AIDS: A SYSTEMATIC REVIEW

4.1. Chapter overview

The first research question proposed in Chapter One, was to examine what evidence exists for interventions to improve the psychosocial well-being of children affected by HIV/AIDS. The literature review (Chapter 2) provides more detail on this topic.

4.2. Background

The objective of this review was to evaluate the overall effectiveness of interventions that aim to improve the psychosocial well-being of children affected by HIV and AIDS, conducted since the original review which did not identify any adequately evaluated interventions (King et al., 2009). This included both psychological and social interventions, as well as other interventions that might have a psychosocial impact (e.g. medical interventions).

4.3. Methods

The methodology utilised standardised systematic review methodology, derived from the original review, with some minor modifications based on some of the constraints of the original systematic review, described below (King et al., 2009).

4.3.1. Criteria for considering studies for this review

Types of studies

The review allowed for inclusion of all intervention studies that carried out as RCTs, crossover trials, cluster RCTs and factorial trials. Data from non-randomised intervention studies with comparison groups were also included. Studies from both high-income countries (HIC) and LMIC were eligible for inclusion.

Types of participants

Participants included both male and female children under the age of 18 years of age, who had lost a parent to HIV/AIDS, were living with a parent with HIV and AIDS, or were vulnerable because of other social and economic factors and living in communities of high HIV and AIDS prevalence, defined as impoverished communities situated in countries or regions with high HIV rates. Reports by caregivers on young children were also eligible for inclusion.

In the King (2009) systematic review, studies were only included if 80% of the sample could be identified as orphaned or vulnerable as a result of HIV/AIDS. However, in practice, researchers may not have been able to establish causes of death or current HIV status of parents and caregivers, or may not have reported the actual percentages. This definition may have excluded studies of children living in poverty in HIV-endemic communities, and so it was not used in this updated review. Furthermore, the first review also excluded studies based on

caregiver-report outcomes. This may have led to the exclusion of studies of younger children, who may be too young to respond to interviews. Validated parent and caregiver measures are a reliable source of information about the psychosocial development of children (e.g., (Warnick, Bracken, & Kasl, 2008) and so for the purpose of this updated review, studies using caregiver report on child outcomes were included.

Types of interventions

Interventions that aim to improve the psychosocial well-being of children affected by HIV/AIDS were included, repeating the inclusion criteria included in the first review (King et al., 2009). Thus interventions were generally clustered under four types set out below:

- i) Psychological interventions, such as cognitive behavioural therapy, interpersonal psychotherapy, psychodynamic therapy, non-directive counselling, psychological debriefing and problem-solving therapy.
- ii) Psychosocial support and/or care, such as play groups, homework clubs and home-based care programmes.
- iii) Physical health interventions, including medical interventions, such as antiretroviral therapy and other pharmacological interventions
- iv) Social interventions, such as economic assistance (e.g. cash transfers, work and skills training programmes) and material assistance (e.g. provision of school materials, food baskets).

Studies that compared outcomes between groups who received an intervention and those who received usual or no care, and/or those who received a different intervention were included.

Types of outcome measures

Studies that included any outcome measure/s based on psychological or social well-being were included. These included studies that used the following outcome measures:

- i) Psychological measures to record any form of mental health status
- ii) Measures of social outcomes such as school attendance, quality of life, and/or
- iii) Adverse outcomes such as suicide or incarceration

4.3.2. Search methods for identification of studies

The updated review included relevant studies which were identified by searching for publications between January 2008 and February 2016.

Electronic searches

The methodology utilised standardised systematic review methodology and was derived from the original review, with some minor modifications from some of the constraints of the original systematic review (King et al., 2009). Searches were executed on electronic data bases. Using a combination of key terms derived exactly from the previous review, the updated

systematic search was conducted using PubMed, Medline, Embase, The Cochrane Library, PsycINFO, LILACS, Social Science Citation Index, Science Citation Index, the International Bibliography of Social Sciences, and the Web of Science.

Searching other resources

Studies were also identified in the following ways:

- iv) Searching for studies and programmatic reports found on websites of relevant organisations involved in providing services for children affected by AIDS, such as governments, non-governmental organisations, international donors and multilateral agencies.
- v) Direct contact with funding organisations within the Coalition for Children Affected by AIDS network.
- vi) Following references in papers in short-listed studies.
- vii) Hand searching through journals published in the specified time frame that had been identified as being likely to publish papers on this topic.

Search terms

Search terms were based on the King review (see Figure 4.1).

The following strategy was used to search MEDLINE and adapted for the other databases.

#1 Exp Acquired Immunodeficiency Syndrome [MeSH]

#2 Exp HIV Infections [MeSH]

#3 Exp HIV [MeSH]

#4 ("HIV* OR AIDS*")

#5 #1 OR #2 OR #3 OR #4

#6 Exp child [MeSH]

#7 "Orphan" [Text Word]

#8 ((orphan* OR "parent-less child" OR foster* OR "orphans and vulnerable children" OR "OVC")

#9 Foster Home Care [MeSH]

#10 Exp childcare

#11 Exp Orphanages [MeSH]

#12 #6 OR #7 OR #8 OR #9 OR #10 OR #11

#13 Exp Psychosocial Deprivation [MeSH]

#14 Exp Health Promotion [MeSH]

#15 Exp Social Support [MeSH]

#16 Exp Psychology, Social [MeSH]

#17 Exp Mental Health [MeSH]

#18 "psychology" [subheading]

#19 #13 OR #14 OR #15 OR #16 OR #17 OR #18

#20 Exp Social Environment [MeSH]

#21 Exp Health Behaviour [MeSH]

#22 Exp Socioeconomic [MeSH]

#23 Exp Economic [MeSH]

#24 Exp Medicine

#25 (interpersonal OR psychotherap* OR resilience OR psychosocial* OR care* OR soci* OR bereave* OR support* OR hous* OR educat* OR program* OR econ* OR work* OR behavi* OR train* OR health* OR "food" OR nutrit* OR "traditional healer" OR "drug treatment" OR "health care")

#26 #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25

#27 #5 AND #12 AND #26

Figure 4.1. Search terms from the review conducted by King et al (2009).

4.3.3. Data collection and analysis

Two reviewers (alternately SS, NC, KR and ND) independently examined the titles and abstracts of all the articles identified in the search using a short checklist of inclusion criteria. In cases of doubt, the full text article was obtained and subjected to adjudication by a senior researcher on the team (LS). From this list, the full-text versions of studies that were deemed to be potentially relevant were obtained and two reviewers independently evaluated each paper using the inclusion flow chart shown in Figure 4.2 (alternately SS, NC and NG).

Type of study				
1.	Is it randomised, including cross-over, cluster and factorial trials?	Yes ↘ Go to question 3	Unclear ✓ Go to question 2	No ↓ Go to question 2
2.	Is it a non-experimental intervention study with a comparison group? (before and after study, cohort, case control or cross-sectional observational study)	Yes ↘ Go to question 3	Unclear ✓ Exclude	No ↓ Exclude
Participants in the study				
3.	Are the participants under the age of 18 years?	Yes ↘ Go to question 5	Unclear ✓ Go to question 4	No ↓ Go to question 4
4.	Are the participants caregivers of children under the age of 18y?	Yes ↘ Go to question 5	Unclear ✓ Exclude	No ↓ Exclude
5.	Are participants either orphaned due to HIV/AIDS, or vulnerable due to HIV/AIDS (living with a family member with HIV/AIDS or in a HIV-endemic community)	Yes ↘ Go to question 6	Unclear ✓ Exclude	No ↓ Exclude
Interventions				
6.	Does the intervention aim to improve the psychosocial well-being of children affected by HIV/AIDS either as a primary or secondary aim?	Yes ↘ Go to question 7	Unclear ✓ Exclude	No ↓ Exclude

7.	Is the intervention psychological therapy, psychosocial support and/or care, medical and/or socioeconomic?	Yes ↘	Unclear ✓	No ↓
		Go to question 8		Exclude
8.	Are participants receiving the intervention compared to other children affected by HIV/AIDS who received usual care, no care or a placebo, or a different intervention?	Yes ↘	Unclear ✓	No ↓
		Go to question 9		Exclude
Outcomes				
9.	Does the study measure psychological and/or social factors measured by validated instruments or education, quality of life, socioeconomic status, school attendance, suicide or criminal behaviour using validated instruments?	Yes ↘	Unclear ✓	No ↓
		Clarify unclear points and include if relevant		
Final decision		Include	Unclear (more info)	Exclude

Figure 4.2.: Study inclusion flow chart (adapted from King et al, 2009).

Data from each of the selected studies was entered into a specially designed database, constructed to extract study details including author, date of study, design, place of study, sample characteristics (age, gender, sample size sampling procedure, participation rate), setting

(community-based, school-based, clinic-based, etc.) nature of intervention, outcomes and significant findings.

4.4. Results

4.4.1. Description of studies

The full search procedure is set out in Figure 4.3. In total, 17 studies that qualified for inclusion in this review were identified (Table 4.1). Most of these were reported in one paper only. In one case, several papers had been written on an economic intervention which took place in Uganda, with two of these reporting on psychosocial outcomes specifically. In another case, two papers reported on outcomes from a school support intervention in Kenya, one from the first follow up point of the study and the other from a subsequent follow up.

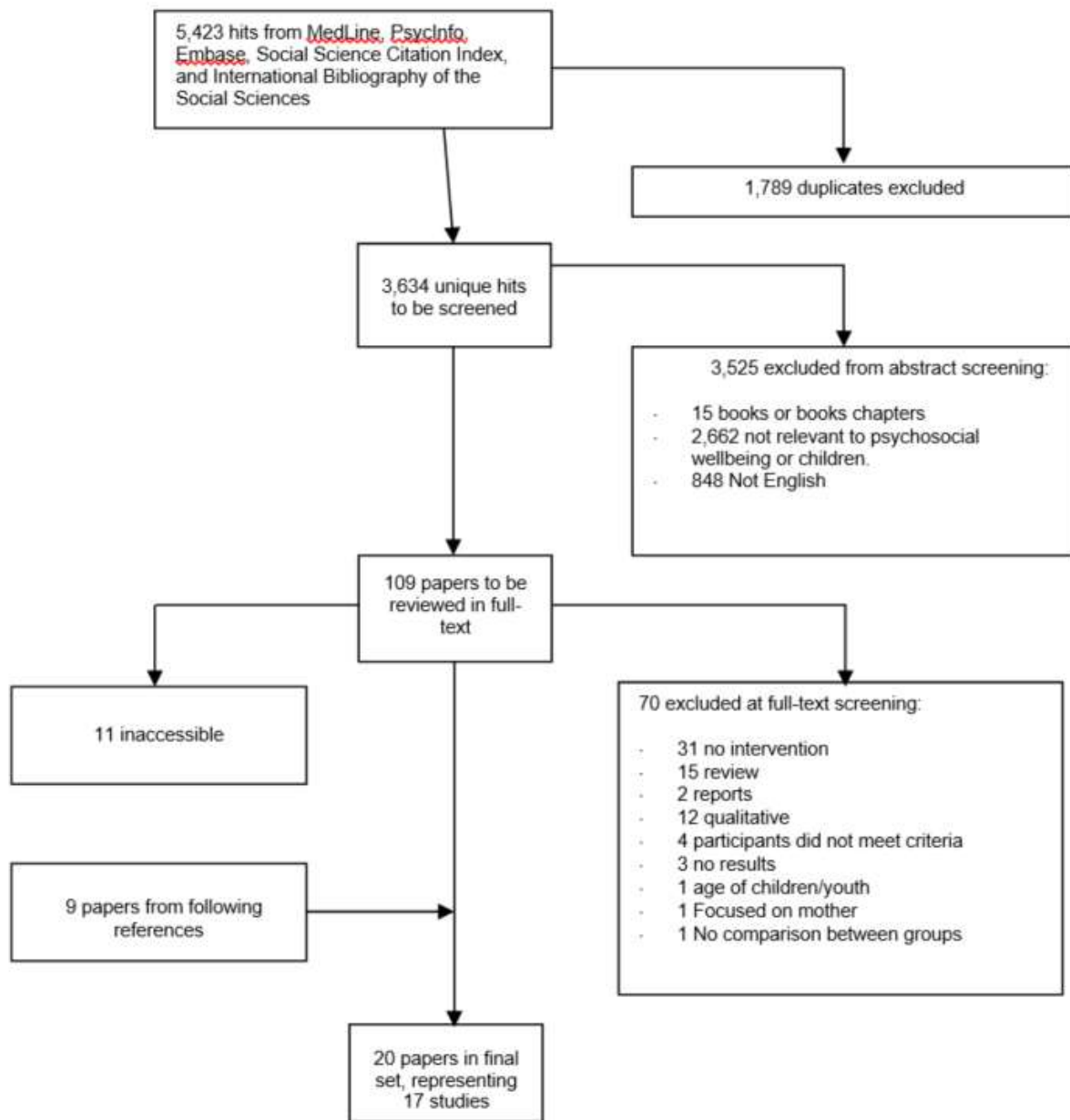


Figure 4.3.: Paper selection

Sixteen studies took place in eight LMICs, and one study took place in a high income setting. All the studies except three were conducted in southern and eastern African countries. Eleven of the studies were RCTs. Thirteen of the studies were developed specifically for research purposes and four reported on evaluations of existing and ongoing programmes.

A variety of interventions were included. Three studies reported on a psychological intervention, seven studies were of psychosocial support and/or care interventions, and six studies were of social interventions, there was one physical health intervention. Two of the interventions were focused on caregivers only, seven were child only, while seven focused on both the child and their caregiver or family (and one did not specify). The psychological and psychosocial interventions were all delivered in group-based settings. All of the social intervention studies focused on providing material support to individual children affected by HIV/AIDS, through cash transfers or school materials. The health intervention was delivered on a one-to-one basis to the child. The length of interventions varied, with some as short as 8 weeks, up to 10 months or in some cases unspecified. In addition, follow up varied from 10 weeks to 2 years.

The outcomes and outcome measures used within the studies differed considerably which prevented us from conducting a meta-analysis. Even when similar concepts were measured, different scales were utilized.

Table 4.1.: Included studies

Year	Author	Country	Study Design	Sample	Intervention	Outcomes	Results
Psychological							
2012	Rotheram-Borus et al., 2012	USA	Randomized control trial	339 mothers with HIV and 259 of their school-age children, children aged 6-20 years, mean age 15y.	Group, bi-weekly, mother and adolescent sessions, 8 weeks.	Internalising and externalising behaviours, school attendance, grades, problem behaviour	Mixed - alcohol and hard drug use reduced marijuana use increased in intervention group. No difference in internalising and externalising behaviours.
2012	Thurman, Jarabi, & Rice, 2012	Kenya	Cross-sectional post-intervention design.	766 caregivers and 1028 children aged 8 - 14 years.	Group, weekly, ongoing intervention for caregivers	Child psychosocial well-being: emotional and behavioural problems, prosocial behaviour	Higher prosocial behaviour and fewer behavioural problems.
2014	Eloff et al., 2014	South Africa	Randomised clinical trial.	HIV positive mothers and their children. 390 mother-child pairs. Children 6-10y.	Group, weekly, caregivers and children, 24 weeks in duration	Children's behaviour (internalising and externalising problems), adaptive functioning, depressive symptoms, anxiety, emotional intelligence.	Decreased externalising problems, improved communication and daily living skills, no difference for internalising behaviour and emotional intelligence, negative outcome for anxiety.

Year	Author	Country	Study Design	Sample	Intervention	Outcomes	Results
Psychosocial							
2014	Li, Liang, Ji, Wu & Xiao, 2014	China	Cluster randomized design. Interviews were administered at baseline, 3 and 6 months.	79 families in four village clusters. Participants: (1) with confirmation of an AIDS diagnosis or HIV-positive status; (2) having a seronegative family member living at home; and (3) having at least one child aged 6 to 18 years living with a PLH participant. Two age groups of children (6–12 and 13–18 years) were included in the study.	Family groups and community events.	Children's self-esteem, perceived parental care, and problem behaviour	No difference in self-esteem or problem behaviour, increased in perception of parental care

Year	Author	Country	Study Design	Sample	Intervention	Outcomes	Results
2008	Bell et al., 2008	South Africa	Randomized control trial	281 intervention and 298 control children, aged 9 to 14y. Being reared by an adult caregiver age >18 years that fulfils parenting responsibilities, enrolled in school, and indicated agreement to participate in the study via caregiver consent and child assent.	Group, caregiver and child, weekly, 10 sessions.	Anxiety, AIDS transmission knowledge, stigma, Psychological autonomy, range of parenting skills	No differences between groups in child psychosocial outcomes
2009	Kumakech et al., 2009	Uganda	Cluster randomised control trial	326 AIDS 'orphans' (lost one or both parents to HIV/AIDS) aged 10-15y	Groups, children in school, 10 weeks.	self-concept, anxiety, anger, and depression	Lower anxiety, depression and anger.
2011	Mueller, et al., 2011	South Africa	Quasi- experimental, cross-sectional post- intervention	177 intervention group and 120 control group children aged 8-18 years.	Groups, children in school, 50 or more sessions over 6 months. Focus on increasing self-esteem, self-efficacy and psychological well-being.	self-esteem, self-efficacy, child depression was, emotional-behavioural problems	No differences in depression, emotional and behavioural problems and self-esteem, but increase self-efficacy.
2012	Carlson, Brennan, & Earls, 2012	Tanzania	Cluster randomised control trial	726 children, aged 9-14y.	Group, adolescents, weekly, 28 weeks	Five aspects of self-efficacy	Improvements in deliberative self- efficacy, communicative self-efficacy and emotional control, no difference in academic efficacy or peer resistance.

Year	Author	Country	Study Design	Sample	Intervention	Outcomes	Results
2016	Sherr et al., 2016	South Africa	Longitudinal study	1848 children aged 9-13 years old from South Africa and Malawi who were either CBO attenders or had not received CBO support (control group)	Range of different community-based programmes for children affected by HIV/AIDS with different modalities of provision	Depressive symptoms, suicide ideation, post-traumatic symptoms, harsh discipline, perceived praise for child	Less suicidal ideation, depression, stigma, domestic violence, peer problems and conduct problems, and improved prosocial behaviour. No difference in perceived parental praise or post-traumatic stress symptoms.
2013	Balfour et al., 2013	South Africa	Quasi experimental design	629 participants, age range not reported	Group sport, children, eight sessions over 12 weeks.	HIV stigma, substance use.	Lower HIV stigma and drug use.
Social							
2011	Hallfors et al., 2011	Zimbabwe	Randomised control trial	329 girls in Grade 6 in 25 schools (ages range 10-16 years)	Individual material support, child and family support, duration not specified	Child perceptions of caring adults, school dropout, educational aspiration, gender equity, attitudes towards sex, sexual debut, marital status, pregnancy	Reduced school dropout, early marriage and increased school attendance, educational aspiration, and delayed sexual debut. No difference for perceptions of caring of teachers and gender equity.

Year	Author	Country	Study Design	Sample	Intervention	Outcomes	Results
2012	Cho et al, 2011 Hallfors, Cho, Mbai, Milimo, & Itindi, 2012	Kenya	Randomized control trial. 2 year follow up.	105 children, 11-14y	Ongoing programme delivered on an individual level to learners to provide material support for school supplies, as well as visits from a female community visitor, as a means to provide comprehensive support for girls to stay in school and reduce HIV risk.	School absence, perceptions of caring adults, school dropout, educational aspiration, future expectations, gender equity, attitudes towards sex	No differences between groups.
2010	Baird, Chirwa, McIntosh, & Özler, 2010	Malawi	Quasi-experimental, intervention and control group	1225 adolescent girls, 13-22 years old (mean <18)	Cash transfers paid to households over 10 months, split between caregiver and child, conditional on school attendance record, and secondary school fees paid to schools upon confirmation of enrolment.	school attendance, early marriage	Increased school enrolment, reduced early marriage, pregnancy, sexual activity, risky sexual behaviour.
2009, 2010, 2012	Ssewamala, Han, Neilands, Ismayilova, & Sperber, 2010; Ssewamala, Han, &	Uganda	Randomised control trial	2009: 267; 2010: 260, 2012: 286. Mean age 13.71.	Intervention group received usual care for orphaned children (counselling and education supplies) plus a comprehensive microfinance intervention consisting of matched savings accounts, financial management classes and an adult	Depression, self-esteem	Reduced depression, higher self-esteem

Year	Author	Country	Study Design	Sample	Intervention	Outcomes	Results
	Neilands, 2009; Ssewamala, Neilands, Waldfogel, & Ismayilova, 2012				mentor for children. Duration between 10 and 12 months.		
2013	Robertson et al., 2013	Zimbabwe	Cluster randomized control trial	5172 children aged 6-12y in 4043 households	Comparison of conditional and unconditional cash transfers delivered at household level over 12 months. UC and CC groups received same cash amounts, but CC group had to comply with various conditions, including applying for a birth certificate, vaccinations, attending parenting classes and others.	School attendance for 6-12 year olds and other non-relevant outcomes	Increased school attendance

Year	Author	Country	Study Design	Sample	Intervention	Outcomes	Results
2016	Ssewamala et al., 2016	Southern Uganda	Quasi-experimental design (schools randomised, not individuals)	317 AIDS-orphaned adolescents	An further study of the Suubi Maka intervention focused on matched savings for promoting monetary savings for educational opportunities for children, financial management workshops and family level income generating projects, and providing mentors to children (one mentorship meeting per month for the 12-month intervention period), and an additional 10 workshops about starting family-based income generating activities.	Hopelessness and self-concept	Lower levels of hopelessness, higher self-concept.
Physical health							
2008	Hernandez-Reif et al., 2008	Dominican Republic	Randomized control trial	52 HIV infected children, data for 48 children reported, 2-8y.	Bi-weekly massage sessions or group play sessions, 12 weeks.	Internalizing and externalizing problems, self-help age, social age.	Children under 6y no differences between group but positive results for internalising and self-help for children over 6y, negative for social development.

4.4.2. Sample selection

Sample selection varied, with some studies only including HIV-infected or AIDS orphaned children, and others including all children affected by HIV/AIDS. Eight of the studies were targeted specifically at children who were HIV positive or had HIV positive caregivers, whilst the others took place in communities with high HIV prevalence.

Sampling methods varied. Methods included both one-stage (individuals selected directly) and two-stage sampling (with schools or communities first selected, and then individuals selected within the cluster). At each stage, there were instances of random, systematic and convenience sampling being employed. Studies included children from the age of 2 years into early adulthood, but only one study included children of 5 or younger. The number of studies per age is included in Figure 4.4. Most studies included children between the ages of 10 and 14 years, with few studies focusing on early and middle childhood, or the mid-late teen years.

Studies that did include young children did not provide an analysis of their results based on child age. Approximately half of the studies in this review focused more or less equally on both girls and boys. Two studies included only girls, while a further three had more than 60% of girls included in their sample. No studies focused only on boys, and two studies did not report child gender at all.

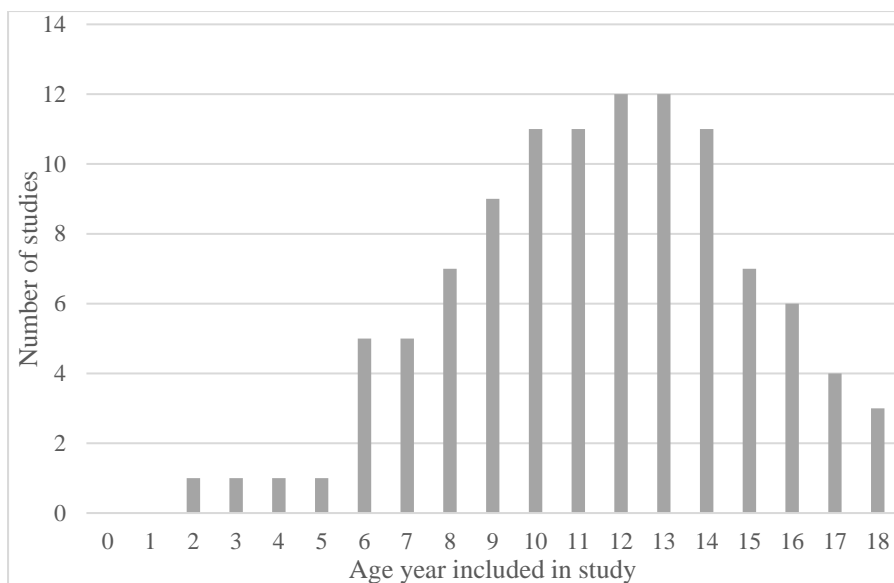


Figure 4.4.: Number of studies per age year

4.4.3. Effects of interventions

The interventions are clustered into four groups – psychological (n=3), psychosocial (n=7), social (n=6) and physical health (n=1). All three of the psychological interventions identified showed at least one positive result. Six out of seven of the psychosocial interventions, and five out of six of the social interventions also reported a positive impact, as did the physical health interventions.

Psychological interventions

All three of the psychological interventions engaged caregivers directly in their delivery. The only high-income country study was a psychological intervention targeting mothers with HIV and their children (Rotheram-Borus et al., 2012). Mothers and their children met concurrently in their own groups for some sessions, and attended joint groups at certain stages. The intervention took place twice a week over 8 weeks. For adolescents, the

intervention had some positive impact in that intervention adolescents had lower frequency of use of alcohol and hard drug users, but findings were mixed in that frequency of marijuana was significantly higher in the intervention group and there were no group differences in the reduction of internalizing and externalizing behaviours over time. In Kenya, Thurman et al. (2012) evaluated an ongoing support group programme for caregivers of orphans and vulnerable children. The intervention was delivered on a weekly basis in large caregiver groups. They found that support group members reported higher prosocial behaviour and fewer behavioural difficulties for the children under their care and no negative psychosocial impact was reported. Eloff et al. (2014) conducted an individual RCT to promote resilience of young children with HIV-positive mothers. The intervention was delivered over 24 weekly sessions, with over half of the sessions held with caregivers and children separately and the rest held together. The focus of the sessions was to improve the well-being of the mother and child, family relationships, and to provide information about HIV/AIDS. The intervention group children showed a significant improvement in externalizing behaviours, communication and daily living skills, and no difference in internalising behaviour and emotional intelligence between groups. On the other hand, children in the intervention group reported significantly higher levels of anxiety. Boys tended to gain greater benefit from the intervention than did girls.

Psychosocial interventions

Of the seven psychosocial interventions, two reported positive results, four reported mixed results, and one reported a null result. Five of the seven identified psychosocial interventions were all delivered in group-based support interventions targeted at peers.

Two family-centred psychosocial interventions were identified. Bell et al., (2008) used a family group-based intervention in South Africa, which included both caregiver and child, delivered each weekend over 10 sessions. The focus was on reducing youth HIV risk behaviours by the strengthening of family relationships, and targeting peer influences through enhancing social problem-solving and peer negotiation skills for youths. While there were differences noted between intervention and control group for AIDS transmission knowledge and stigmatizing attitudes, there was no difference between groups for psychosocial outcomes specifically. In China, an intervention delivered to family groups and at community level was made up of six sessions with adult family members, followed by joint activities with children, and three community events, with a focus on improving family's capacity to overcome the impact of living with HIV (Li et al., 2014). Mixed results were reported, with no differences in psychological measures of self-esteem or problem behaviours between groups, but improved perceived parental care at 6 months in the intervention group compared to controls.

There were four interventions directed at children or adolescents specifically. Carlson et al., (2012) report on another group-based intervention that was delivered weekly over 28 weeks, after school or on weekends, focused on increasing self- and collective efficacy through public education and community mobilization. The authors found a positive impact on different types of self-efficacy, but no difference in academic efficacy or peer resistance. Two school-based interventions were identified. Mueller et al. (2009) report on using an art-based intervention to increase self-esteem, self-efficacy and psychological well-being. The intervention was delivered during class over 6 months, meaning that the children received 50 or more sessions. Intervention children in this study also had significantly better self-efficacy than comparisons post-intervention, but similar levels of self-esteem, depression, and

behavioural problems. In Uganda, Kumakech et al. (2009) reported on a school-based group intervention delivered to groups of children only, in the form of exercise (e.g. a game or play) over a period of 10 weeks. The focus of the intervention was to reflect on the challenges of being an orphan, and to develop coping strategies to deal with these issues. Intervention children had significantly lower anxiety, depression and anger than controls, but similar levels of self-esteem. Soccer was used as an intervention tool in the WhizzKids programme, which was delivered in eight sessions over 12 weeks to large groups (Balfour et al., 2013). It aimed to change attitudes towards HIV and to improve self-efficacy to make healthy choices, including the uptake of sexual health services. Intervention participants had a significantly lower likelihood of engaging in drug and alcohol use than the comparison group and lower reported HIV stigma.

Finally, in South Africa, Sherr et al. (2016) compared outcomes for children attending community-based programmes and those who were not, drawing data from two comparable studies. The community-based programmes were specifically for children affected by HIV/AIDS but had different modalities of service provision, including income, emotional, child development, medical provision or emergency support. The authors found that children in community-based programmes were less likely to experience domestic violence, suicidal ideation, depression, stigma, peer problems and conduct problems, and more likely to display prosocial behaviour. However, there was no difference in perceived parental praise or post-traumatic stress symptoms.

Social interventions

All six of the social interventions that were eligible for the review documented material assistance programmes. Three of the studies reported positive results, two studies had mixed results and one a null result (Table 4.2). Two of the six studies focused only on girls, while a further three enrolled approximately 60% girls in their samples. No studies focused only on boys.

An economic intervention tested on two different occasions in Uganda tested the impact of the Suubi Maka intervention. In the first study, the intervention group received usual care for orphaned children (counselling and education supplies) plus a comprehensive microfinance intervention consisting of matched savings accounts, financial management classes and an adult mentor for children, over 10-12 months (Ssewamala et al., 2009; Ssewamala et al., 2012). Intervention group children had significantly better self-esteem and lower depression compared to controls at follow up. In the second study, the same intervention was delivered, in addition to ten workshops focused on starting family-based income generating activities. Children in the treatment group reported significantly lower levels of hopelessness than control children as well as significantly higher scores of self-concept (Ssewamala et al., 2016).

Similarly, a community-based conditional cash transfer intervention in Malawi to promote staying in school for girls resulted in significantly higher rates of school retention in the intervention group (Baird et al., 2010). Cash transfers were paid to households over 10 months, split between caregiver and child, conditional on school attendance record, and secondary school fees were paid to schools on behalf of families upon confirmation of

enrolment. Being involved in the programme was associated with large increases in self-reported school enrolment, as well as declines in early marriage, teenage pregnancy, sexual activity, and risky sexual behaviour. Two related interventions, in Zimbabwe and Kenya, tested the provision of material support for schooling, including fees and school supplies to provide comprehensive support for girls to stay in school and reduce HIV risk. In Zimbabwe, this was coupled with an assigned teacher from the girl's school to monitor her attendance and assist with issues relating to absenteeism. In this study, girls were significantly less likely to drop out of school, engage in early marriage, while they were more likely to attend school, have higher educational aspirations and delay sexual debut. There were no differences in their perceptions in the caring of teachers and in gender equity attitudes compared to the comparison group. In Kenya, however, where teachers were replaced with visits from a female community visitor, there was no significant intervention effect 2 years post-intervention. Finally, a Zimbabwean study comparing three groups (receiving unconditional or conditional cash transfers and control group) found that receiving cash transfers was associated with significantly better schools attendance in the conditional cash transfer group, but insignificant in the unconditional group compared with controls (Robertson et al., 2013).

Physical health intervention

The only physical health intervention section looked at the impact of a massage intervention vs. play group attendance for HIV-positive children. The authors found a positive impact of massage therapy on internalizing behaviour and self-help skills for children over six years old, but no impact on social development and no impact for younger children (Hernandez-Reif et al., 2008).

Table 4.2.: Interventions showing any positive effect

Psychological	Psychosocial	Social	Medical/physical
<ul style="list-style-type: none"> Joint mother-child groups (USA) Caregiver support groups (Kenya) Multilevel family intervention (China) Resilience-promoting intervention (South Africa) 	<ul style="list-style-type: none"> Peer support programme (Uganda) School-based art intervention (South Africa) Group-based family counselling (South Africa) Group-based health promotion and citizenship intervention (Tanzania) Educational soccer program 	<ul style="list-style-type: none"> Conditional cash transfer to keep girls in school (Malawi) Material support for schooling for girls (Zimbabwe) Economic education programme with matched savings accounts (Uganda) Conditional and unconditional cash transfers (Zimbabwe) Family-level economic strengthening intervention – (Uganda) 	<ul style="list-style-type: none"> Massage therapy (Haiti)

4.4.4. Measurement of outcomes

Outcome measures were diverse. Nine of the studies directly measured mental health problems, with a focus on depression, anxiety and behavioural problems, using validated tools. However, these studies used a variety of different instruments. The most commonly used measures were the Child Behaviour Checklist, used in three studies, and the Child Depression Inventory, used in three studies. Nine of the studies measured positive mental

health outcomes, such as self-esteem, self-efficacy, positive behaviour and feelings of social connection. Widely different measurement tools were used for these outcomes. Only the Rosenberg Self-Esteem scale was used more than once. Finally, ten of the studies measured social outcomes, including substance use and school attendance indicators.

4.4.5. Studies that were not included

A number of studies were found that were relevant to the research question but that did not meet the criteria for the review. For example, a comprehensive study which took place at six different Partners in Health sites in Haiti showed that participation in a psychosocial support group for youth affected by HIV and their caregivers led to positive mental health and social functioning outcomes for both sets of participants (Smith Fawzi et al., 2012). No comparison between sites or with different forms of the intervention was reported, and thus this study did not meet design criteria for inclusion in the review. An evaluation of a sports project for Kenyan girls compared participants who were attending the same intervention at newly established vs. long running sites and found that girls at well-established project sites had better psychosocial outcomes, however there was limited information given about any differences in the delivery of the intervention at these sites (Woodcock, Cronin, & Forde, 2012). A study from the United States showed that accessing child development services was associated with significantly higher rates of children remaining in their family homes and not having contact with child protective services (Reich & Fuger, 2012). This study focused particularly on mothers who were substance users or HIV-positive, however, only two of the 17 sites in the study focused on HIV-affected families, and HIV prevalence rates were not reported.

Other studies of intervention for children affected by HIV/AIDS were identified that focused on outcomes that were beyond the scope of this review, due to the specific focus on psychological or social outcomes. For example, two studies from the same home-based visiting programme in South Africa were located which showed that undernourished children who are recipients of a home-visiting programme are more likely to achieve healthy weights for their age than controls (le Roux et al., 2010; le Roux et al., 2011). It was also found that several studies focused purely on improving knowledge about HIV transmission and reducing risky sexual behaviour, which fell beyond the scope of the review and has been investigated separately (e.g. Medley et al. 2009). Finally, studies were found that made use of psychological intervention, but which only reported child survival outcomes. Van Wingham et al (2008) describe an intervention in Kenya which employed a range of techniques, including the provision of psycho-social support with HAART services, to significantly improve child survival rates for children under 15 who were receiving anti-retroviral treatment. Similarly, Grimwood et al. (2012) report on a community-based adherence support programme that improved retention in care of children in antiretroviral therapy services. Children in the intervention group received visits from Patient Advocates, who worked in designated geographical areas to provide psychosocial support to children's caregivers, monitored medication taking, and helped families to identify and address barriers to adherence in the home.

4.5. Discussion

In contrast to the earlier review on this topic, I identified a growing set of interventions to improve the psychosocial well-being of children affected by HIV/AIDS, most of which took place in LMICs. More specifically, the majority took place in eastern and

southern Africa where the burden of HIV is greatest. This increase in the evaluation of interventions is promising, and shows that there has been a shift towards the prioritization of generating evidence in this area.

There are lessons to be learned from the identified studies. In the final set of identified studies, most studies showed at least one significant benefit of the intervention on psychosocial outcomes, with only two showing no difference between those receiving the intervention and a control or comparison group. While it is possible that this reflects a publication bias towards positive outcome reporting, most of the studies reported mixed results. Overall, psychological changes noted for children included the reduction in internalizing and externalizing behaviours, decrease in symptoms of depression, anger, and anxiety, and higher rates of prosocial behaviour, self-help abilities and communication. Positive social outcomes that were recorded included retention in school, better school attendance, and less early marriage. There was no clear pattern in terms of type of intervention, target recipient, length of intervention, length of follow up, or intensity of delivery, but each of the four different types of intervention (psychological, psychosocial, social, and physical health) showed at least one positive benefit on child psychosocial well-being. It is also interesting to note that interventions targeting the child only, caregiver only, caregiver and child together and entire family all showed some positive impact.

However, it is important to note that the identified studies differed greatly and there are already emerging gaps in the existing database. Firstly, sampling techniques used were diverse. Some studies employed random community-based sampling techniques or random sampling of schools, and others used convenience sampling selecting participants from registers of children or adults seeking treatment for HIV. These reflect the 'real life' contexts

in which these studies took place, but may also mean that some study results have not accurately represented the study population (Suresh, Thomas, & Suresh, 2011). Inclusion criteria also varied, with eight of the studies targeted specifically at children who were HIV positive or had HIV positive caregivers. The remainder of the studies used a broader approach, and included all potentially vulnerable children within the study population. This is promising, as definitions of vulnerability shift from focusing purely on HIV child and caregiver diagnosis to looking at the broader social context which places children at risk in an era of HIV/AIDS (Sherr et al., 2008). Studies were also more likely to include girls and children aged 10-14 years. Gender issues are rarely discussed in child HIV research, for example, UNAIDS does not provide a breakdown of child data by gender until early adolescence or adulthood (UNAIDS, 2010). It is thus important that we continue to include both boys and girls in programming and research, and that we endeavour to find a balance between promoting equity for girls in these efforts, and ensuring that boys are included. Research on younger children was particularly scarce. Given the impact of HIV on early child development (ECD) outcomes, there is a need to prioritise the evaluation of these types of interventions targeted at children affected by HIV/AIDS (Chandan & Richter, 2009).

Secondly, studies showed wide variation in outcome measurement, meaning that for this review, it was difficult to compare outcomes across studies. This is partly due to the broad nature of psychosocial interventions and outcomes. Most studies focused on mental health problems, but some included positive measurement of mental well-being and other social factors. School retention was widely used as a social measure of well-being. The variety of measures used may relate to the broader problem of a lack of standardized outcome measurement tools for child-related research in LMIC, and in sub-Saharan Africa in particular (Holding et al., 2004). Globally, there are no accepted indicators or frameworks to

measure child development, partially due to concerns about training and administration of tools and cultural differences between different groups (Engle et al., 2007). A recommended set of measurements or a database of tools available for programmers and researchers to draw from would make evaluation studies more comparable.

Thirdly, study design also varied. For example, some studies had as much as two years follow up time, but in most cases follow ups were confined to immediate post-intervention assessments. This may have affected the reported results of the identified studies. For example, in Hallfors et al. (2012), the length of follow up was shown to be crucial in understanding the impact of the intervention. The material support intervention that the authors described showed a positive impact after one year, but the impact had disappeared by two years post-intervention. Similarly, the Thinking Healthy programme in Pakistan improved maternal and infant outcomes, but a longer term follow up when the children were aged 7 years showed no impact of the intervention (Maselko et al., 2015). Programmers and researchers should be encouraged to include longer-term follow ups in the designs of their studies. The Blueprints for Healthy Youth Development registry of evidence-based positive child and youth development programs (Mihalic & Elliott, 2015) requires a follow up period of at least one year beyond the end of the intervention, which is likely to be feasible for psychosocial programmes for children affected by HIV who are often operating in short funding cycles.

Surprisingly, given the community contexts of the studies in this review, 11 out of the 17 studies included were RCTs. This is a positive finding, given that RCTs are the gold standard for intervention evaluation and provide the best evidence of a programme's effectiveness (Campbell & Russo, 1999). On the other hand, only four of the studies in the

review were of existing, real-life programmes, meaning that the rest were developed specifically for research purposes only. This is likely due to the challenges of evaluating these types of community-based programmes, where study methodology often needs to fit into the reality of how programmes are delivered. As a result, it will be important to assess issues of context and implementation for these programmes before scale up of these interventions can be recommended.

This study has shown that there are effective and proven programmes to improve outcomes for children affected by HIV/AIDS. Funders and NGO partners should undertake to share these lessons learnt with their community-level partners and find ways to make these stories of success accessible to different stakeholders in these programmes. It is imperative that there are ongoing efforts to support community-based programmes in their work to improve the psychosocial well-being of their children. Funders and NGOs should continue to develop their research capacity, in partnership with researchers, to find innovative solutions to measuring their impact.

4.6. Chapter Conclusion

Efforts to improve evaluation of interventions to improve the psychosocial well-being of children affected by HIV/AIDS have resulted in a number of new studies which met the inclusion criteria for the review. However, studies are highly heterogeneous, employing different methods of implementation and evaluation, meaning that it is difficult to compare them. Existing evaluation studies should be broadly disseminated and programmers should take account of the existing evidence which shows that different types of interventions can have an impact on psychosocial outcomes, including material or financial support. Finally,

we call for increased partnerships between policy-makers, practitioners and researchers in order to design evaluation studies that are comparable and can feed into the growing evidence base.

CHAPTER 5: CHILD DEVELOPMENT IN HIV POSITIVE AND HIV AFFECTED CHILDREN IN SOUTH AFRICA AND MALAWI - WHAT ROLE FOR COMMUNITY ORGANISATIONS?

5.1. Chapter overview

This chapter seeks to answer two of the questions described in Chapter 1. The second research question proposed was to examine the prevalence and correlates of child developmental problems for children affected by HIV/AIDS who attend CBOs. The sixth research question relates to whether services to children differ by child characteristics. The Literature review (Chapter 2) provides background for this analysis, but a brief summary of the literature to contextualize this issue follows.

5.2. Background

The right of children to healthy development makes up one of the four core principles of the Convention on the Rights of the Child, yet children living in LMICs are at increased risk of poor developmental outcomes. Reasons for this include living in conditions of poverty, poor nutrition, and problems in accessing schooling and other services (Walker et al., 2011). These developmental challenges limit children's ability to participate in and contribute to their communities, leaving a long-term impact on the child, their families and the societies in which they live (Hertzman et al., 2013).

There are few studies examining specific child development outcomes in the context of HIV. The aim of this paper was to examine development outcomes of HIV-positive and

HIV-negative children living in high prevalence and low resource communities, who attend CBO programmes for children affected by HIV/AIDS in South Africa and Malawi and to examine what type of CBO provision HIV-positive and other children were receiving from the organisations that they were attending.

5.3. Methods

This study formed a part of the Child Community Care Study, and utilises cross-sectional data gathered from children attending community-based programmes, that are supported by a range of project partners. The methodology of the Child Community Care study is outlined in detail in Chapter 3.

5.3.1. Measures used in this analysis

The measures used in this analysis are detailed in Chapter 3.

5.3.2. Data analysis

After descriptive analysis, Chi-square tests and *t*-tests were used to examine associations between sample characteristics and HIV status of the child. Univariate and multivariate regression models were used to examine predictors of child psychosocial outcomes, including risk of developmental disability (assessed using TQ screen), emotional and behavioural functioning (assessed using SDQ), and health-related quality of life (measured using PedsQL). Multivariate analyses were adjusted for demographic factors (age, gender, and country), socio-economic factors (employment, housing conditions, school

attendance, food security and nutrition indicators), HIV status of child and caregiver, other illnesses, child bereavement and loss of other family members, and HIV-related stigma in the community. Analyses were carried out using SPSS 20.0 (IBM, Chicago, IL, USA).

5.4. Results

5.4.1. Sample characteristics

Initially, 996 caregiver-child pairs were approached to take part in the study. Of these, 7 caregiver-child pairs did not consent (0.7% refusal rate). In total 989 children participated with their caregivers; 834 in South Africa and 155 in Malawi. In total, 10 caregiver-child pairs were omitted from the analysis for this analysis due to missing data. There were 27 caregivers who were interviewed for more than one of their children, resulting in a final sample size of 979 children and 952 caregivers. Just over half of children (51%) were female with ages ranging from 4 to 13 years with a mean age of 8.9 years. Most children lived in a house or hut as opposed to a temporary structure (84.5%), with just over half reporting that their homes did not provide protection from bad weather. The majority of children attended school regularly (95.7%), although 28.8% of children were not in the correct class for their age. In total, 82.8% of children had caregivers who were unemployed and only 53.7% lived in a household with someone that was employed. Overall, 46.9% children lived with their birth parents, 27.8% with grandparents, 11.2% with an aunt or uncle, 6.2% with foster or adoptive parents, 3.5% with other relatives, and 4.4% with caregivers of other forms. In total, 65.4% of children had been looked after by the same caregivers since birth. Child bereavement was high, with 26.7% having lost both biological parents, 21.6% having lost only their mother, and 9.4% having lost only their father. Of the sample, 28.7%

of children had lost a close family member within the last year, 33.8% were living with someone who had HIV infection, and 22% were currently living with a sick adult. Of the total, 18.3% of children's caregivers reported being HIV-positive themselves. For children, 13.8% were HIV-positive, 54.6% were HIV-negative, 32.1% had unknown status. Children with caregivers who had never taken their child for testing, did not know their child's status or refused to answer the question were more likely to be reported as HIV-negative compared to caregivers who answered the question (35.1% versus 16.9%, $X^2(1)=23.2$, $p<0.0001$). They were less likely to be living with their biological parents (33.3% versus 53.1%, $X^2(1)=33.3$, $p<0.0001$), and were also less likely to have been with the same caregiver since birth (56.6% versus 69.4%, $X^2(1)=15.2$, $p<0.0001$). Disclosure of HIV status to children was low, with only a third of HIV-positive children ($n=43$) reporting they knew with certainty their status. In further analysis, children who were HIV-positive (13.8%, $n=135$) were compared with children who were not positive or with unknown status (86.2%, $n=844$). Table 5.1 provides a description of the sample by HIV status.

Table 5.1.: Summary of sample characteristics by HIV status of children

	HIV-positive		P value
	N (%) 'Yes' (n=135)	N (%) 'No' (n=844)	
Child mean age in years (n=978 1 value missing)	M=9.12 (SD=2.46)	M=8.94 (SD=2.91)	n.s.
Child gender			
Boy (n=476)	66 (13.9)	410 (86.1)	n.s.
Girl (n=503)	69 (13.7)	434 (86.3)	
Country			
South Africa (n=824)	95 (11.5)	729 (88.5)	<0.0001
Malawi (n=155)	40 (25.8)	115 (74.2)	
Caregiver employment			
Child with employed caregiver (n=168)	18 (10.7)	150 (89.3)	n.s.
Child with unemployed caregiver (n=811)	117 (14.4)	694 (85.6)	
Household employment			
Child in house with anyone employed (n=526)	66 (14.6)	387 (85.4)	n.s.
Child in house with no one employed (n=453)	69 (13.1)	457 (86.9)	
Type of home			
Child living in a house or flat (n=827)	116 (14.0)	711 (86.0)	n.s.
Child living in a shack (n=152)	19 (12.5)	133 (87.5)	
Child living in a comfortable home			
Yes (n=574)	78 (13.6)	496 (86.4)	n.s.
No (n=405)	57 (14.1)	348 (85.9)	
Attending school regularly			
Yes (n=902)	119 (13.2)	783 (86.8)	0.02
No (n=41)	11 (26.8)	30 (73.2)	
Child food security			
Sufficient food (n=716)	84 (11.7)	632 (88.3)	0.003
Insufficient food (n=263)	51 (19.4)	212 (80.6)	
Stunted			
Yes (n=205)	54 (26.3)	151 (73.7)	<0.0001
No (n=769)	81 (10.5)	693 (89.4)	
Wasted			
Yes (n=24)	1 (4.2%)	23 (95.8)	n.s.
No (n=950)	132 (13.9)	818 (86.1)	
Underweight			
Yes (n=33)	11 (33.3)	22 (66.7)	0.004

	HIV-positive		
	N (%) 'Yes' (n=135)	N (%) 'No' (n=844)	P value
No (n=563)	74 (13.1)	489 (86.9)	
Child with household (HH) member sick \geq 3 mths in past year			
Yes (n=215)	40 (18.6)	175 (81.4)	0.03
No (n=764)	95 (12.4)	669 (87.6)	
Child lost a close HH member in last 2 yrs			
Yes (n=281)	44 (15.7)	237 (84.3)	n.s.
No (n=698)	91 (13.0)	607 (87.0)	
Child's parent deceased			
Father (n=211)	24 (11.4)	187 (88.6)	0.02
Mother (n=92)	14 (15.2)	78 (84.8)	
Both father and mother (n=261)	50 (19.2)	211 (80.8)	
None (n=415)	47 (11.3)	368 (88.7)	

All *p* values are associated with chi-square tests and *t*-tests¹.

5.4.2. Developmental outcomes

The Ten Questions was considered in terms of the 4-9 year olds only (validated scale age range), and also for the entire group. In both instances, being HIV-positive was associated with increased risk of having disability, and more reported areas of difficulty. For the 4 - 9 year olds, 217 (43.4%) children screened positive on the TQ tool. Being HIV-positive was associated increased risk for disability compared to not having HIV (24.4%, n=53 versus 7.4%, n=21), $X^2(1)=28.2$, $p<0.0001$. More specifically, HIV-positive children were at increased risk for delay in achieving motor milestones (e.g., sitting, standing, or walking) (33.8%) compared to HIV-negative children (6.3%), $X^2(1)=51.0$, $p<0.0001$. They were also more likely to have hearing difficulties (18.8% versus 8.9%, $X^2(1)=6.8$, $p=0.02$),

¹ All *p* values are reported in this thesis, unless they are under 0.001, in which case they are denoted as <0.001 .

speech problems (20.3% versus 10.3%, $X^2(1)=6.0$, $p=0.02$), and mental difficulties (e.g., slowness) (28.4% versus 13.1%, $X^2(1)=11.2$, $p=0.01$). HIV-positive children had higher rates of difficulty: 36.5% had difficulties in one of ten development indicators compared to 25.1% in the comparison group, 20.3% had difficulties in two of ten development indicators compared to 8.5% in the other group, and 15% had difficulties in three or more of the ten development indicators compared to just 4.9% in the non-HIV-positive group. For the entire sample aged 4 to 13 years, 414 children (45.0%) screened positive to the TQ screen. Being HIV-positive was associated with an increased risk for developmental disability (21.5%, $n=95$ versus 7.4%, $n=40$, $X^2(1)=40.6$, $p<0.0001$), including a delay in achieving motor milestones (35.9% versus 11.2%, $X^2(1)=47.4$, $p<0.0001$), and also having hearing difficulties (27.8% versus 12.1%, $X^2(1)=19.9$, $p<0.0001$), walking difficulties (32.6% versus 12.9%, $X^2(1)=14.4$, $p<0.0001$), abnormal speech (22.2% versus 12.8%, $X^2(1)=6.59$, $p=0.01$), and mental difficulties (26.7% versus 11.0%, $X^2(1)=30.2$, $p<0.0001$).

Using the problems scale of the SDQ, it was found that reported rates of emotional and behavioural difficulties were low for the overall sample (SDQ, range 0-18, $M=3.01$, $SD=2.39$), but that there were statistically significant differences by HIV status, with HIV-positive children scoring higher, that is, presenting more problems ($M=3.42$, $SD=0.21$) than the other group ($M=2.94$, $SD=0.08$), $t(977)=2.17$, $p=0.03$.

5.4.3. Health-related quality of life

The PedsQL total score was high for the overall sample indicating good health-related quality of life on these four domains (range 0-60, $M=54.60$, $SD=5.88$). However, children who were HIV-positive had a lower physical health summary score (range 0-20) compared to

the other group (mean=18.67 versus mean=19.40), $t(977) = -3.04$, $p=0.003$. They also had a lower mental health summary score (range 0-40) (mean=34.25 versus mean= 35.45), $t(977) = -2.61$, $p=0.009$, and a lower educational summary score ($M=9.52$, $SD=0.27$) compared to the HIV-negative group ($M=10.36$, $SD=0.09$), $t(941) = -3.01$, $p=0.003$. Of the total sample, 940 children (96%) reported attending school. HIV-positive children attended school less regularly (8.5% versus 3.7%, $X^2(1)=6.2$, $p=0.01$). They were also more likely to be in the incorrect class for their age (50% versus 25.5%, $X^2(1)=32.9$, $p<0.0001$), to be slow learners (43.7% versus 27.5%, $X^2(1)=14.7$, $p<0.0001$), and to struggle more at school (32.3% versus 14.1%, $X^2(1)=26.6$, $p<0.0001$).

5.4.4. Factors associated with child development outcomes

Factors associated with developmental delay are shown in Table 5.2. Children living in Malawi were less likely to be at risk of developmental delay (OR: 0.29, 95% CI: 0.12-0.72, $p=0.006$) compared to those in South Africa. Of the socio-economic factors, school attendance was the only significant predictor, with children not attending school regularly being at higher risk (OR: 2.94, 95% CI: 1.09-7.97, $p=0.03$) than those attending regularly. HIV-positive children were also more likely to be at risk for developmental delay (OR: 4.55, 95% CI: 2.29-9.04, $p<0.0001$) compared to those who were not HIV-positive. Food insecurity and malnutrition were not associated with risk for developmental delay.

The analysis of predictors of risk for developmental delay among all children (4 to 13 years) was repeated to examine usefulness of the scale beyond the 9 year old age range. After adjusting for all variables, country and HIV status remained significant predictors of delay. In addition, children living in poorer housing (OR: 1.35, 95% CI: 0.89-2.02, $p=0.04$), or with

a sick family member (OR: 1.54, 95% CI: 1.09-2.17, $p=0.01$) were more likely to show delay.

Table 5.2.: Logistic regression showing factors associated with developmental delay among age eligible children and the overall sample

	^a Subsample (n=500) screening positive in TQ (n=217, 43.4%)		Overall sample (n=979) screening positive in TQ (n=441, 45.0%)	
	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Child mean age in years	1.12 (1.02-1.25)*	1.08 (0.96-1.23)	1.03 (0.99-1.08)	1.05 (1.00-1.11)
Child gender				
Girl	1.00	1.00	1.00	1.00
Boy	1.19 (0.84-1.70)	1.25 (0.83-1.86)	1.29 (1.01-1.67)*	1.27 (0.97-1.67)
Country				
South Africa	1.00	1.00	1.00	1.00
Malawi	1.01 (0.58-1.78)	0.29 (0.12- 0.72)**	0.95 (0.67-1.34)	0.51 (0.30-0.87)*
Child living in a comfortable home				
Yes	1.00	1.00	1.00	1.00
No	1.18 (0.83-1.70)	1.19 (0.78-1.82)	1.35 (1.04-1.74)*	1.35 (0.89-2.02)*
Child attending school regularly				
Yes	1.00	1.00	1.00	1.00
No	3.32 (1.35-8.17)**	2.94 (1.09-7.97)*	2.43 (1.26-4.70)**	1.92 (0.94-3.94)
HIV-positive child				
No	1.00	1.00	1.00	1.00
Yes	4.03 (2.35-6.93)***	4.55 (2.29- 9.04)***	3.42 (2.31-5.07)***	3.30 (2.12- 5.12)***
Child's caregiver HIV status				
Negative	1.00	1.00	1.00	1.00
Positive	1.94 (1.28-2.94)**	1.19 (0.71-1.98)	1.78 (1.29-2.45)***	1.29 (0.89-1.85)
Child with HH member sick ≥ 3 mths in past year				

	^a Subsample (n=500) screening positive in TQ (n=217, 43.4%)		Overall sample (n=979) screening positive in TQ (n=441, 45.0%)	
No	1.00	1.00	1.00	1.00
Yes	1.78 (1.17-2.71)**	1.57 (0.96-2.56)	1.79 (1.32-2.42)***	1.54 (1.09- 2.17)**
Child lost a close HH member in last 2 yrs				
No	1.00	1.00	1.00	1.00
Yes	1.46 (0.97-2.19)	1.22 (0.76-1.94)	1.54 (1.17-2.03)**	1.33 (0.98-0.98- 1.81)
HIV/AIDS-related stigma	1.40 (1.01-1.93)*	1.31 (0.91-1.88)	1.34 (1.04-1.72)*	1.25 (0.95-1.63)

OR: Odd ratios; CI: Confidence intervals; * Significant at p<0.05, ** Significant at p<0.01, ***Significant at p<0.0001

^a The Ten Questions Screen has been validated for children up to 9 years of age, so the subsample includes 4 to 9 year olds

The other variables – caregiver employment, household employment, type of home, food security, malnutrition and parental death were not significant for any of the outcomes.

Table 5.3 shows predictors of having emotional or behavioural developmental difficulties. Being younger was associated with having more emotional or behavioural problems ($\beta=-0.11$, $p=0.001$). Boys were also more likely to have higher scores in the emotional or behavioural problems subscale than girls (mean=3.25 versus mean=2.78), $\beta=-0.11$, $p=0.001$, and so were children living in South Africa compared to Malawi (mean=3.14 versus mean=2.30), $\beta=-0.18$, $p<0.0001$. Children living in poorer standard homes were more likely to present problems (mean=3.37 versus mean=2.75), $\beta=-0.14$, $p<0.0001$, and so were those who did not attend school regularly compare to those who did (mean=5.34 versus mean=2.90), $\beta=-0.19$, $p<0.0001$. Children who were HIV-positive were also more likely to have emotional or behavioural difficulties than those who were not (mean=3.42 versus mean=2.94), $\beta=-0.63$, $p=0.05$; and so were children living with someone sick compared to those who were not (mean=3.50 versus mean=2.87), $\beta=-0.07$, $p=0.03$. Children living in a

community where people were not concerned with the welfare of children with HIV-positive parents were also more likely to have problems, $\beta=0.08$, $p=0.01$.

5.4.5. Predictors of health related quality of life

A separate multivariate analysis (controlling for all variables shown in Table 5.3) was run to test predictors of physical health-related quality of life (QOL). Demographic factors (age, gender and country) were not associated with QOL, and neither were the employment and household variables. School attendance was a significant predictor, with children not going to school regularly having a decreased QOL (mean=18.4 versus mean=19.4), $\beta=0.08$, $p=0.02$. Food security was not associated with QOL, but being stunted was also associated with having a decreased physical health-related QOL compared to those who were not undernourished (mean=18.8 versus mean=19.4), $\beta=-0.10$, $p=0.004$. HIV-positive children were also more likely to have a reduced QOL compared to those who were not HIV-positive (mean=18.7 versus mean=19.4), $\beta=0.09$, $p=0.007$; so were those living in households where someone was sick (mean=18.9 versus mean=19.4), $\beta=0.08$, $p=0.02$ or in communities with high-levels of stigma, $\beta=-0.09$, $p=0.008$.

Factors affecting children's psychosocial health-related QOL were also examined (Table 5.3). After adjusting for all variables in the model, gender and country were found to be significant predictors. Boys were more likely to have a reduced psychosocial health-related QOL compared to girls (mean=34.9 versus mean=35.6), $\beta=0.07$, $p=0.03$; so were children from South Africa compared to Malawi (mean=34.9 versus mean=37.2), $\beta=0.32$, $p<0.0001$. Employment and household variables were not significant. Children who did not attend school regularly were also more likely to have a decreased QOL compared to children

who did (mean=31.5 versus 35.5), $\beta=0.16$, $p<0.0001$, so were children living in food insecure households compared to those who had sufficient food (mean=35.3 versus 35.4), $\beta=-0.14$, $p<0.0001$. Being HIV-positive also had a detrimental effect on psychosocial health-related QOL (mean=34.3 versus mean=35.5), $\beta=0.08$, $p=0.02$, so did family sickness (mean=33.5 versus mean=35.7), $\beta=0.12$, $p<0.0001$, and loss (mean=34.1 versus mean=35.8), $\beta=0.12$, $p<0.0001$. Stigma in the community also had a negative impact on children's QOL ($\beta=-0.14$, $p<0.0001$).

Table 5.3.: Multivariate regression analyses showing predictors of functioning outcomes, including HIV status, demographic and socio-economic factors

	SDQ emotional, conduct, hyper and peer problems		Physical health-related QOL		Psychosocial health-related QOL	
	Unstandardised ^a	Standardised	Unstandardised	Standardised	Unstandardised	Standardised
Age	-0.09	-0.11***	-0.03	-0.04	-0.04	-0.02
Gender	-0.05	-0.11***	-0.16	-0.04	0.67	0.07*
Country	-1.19	-0.18***	0.46	0.08	4.26	0.32***
Child's caregiver employment	-0.23	-0.04	-0.03	-0.01	0.44	0.03
Child's household employment	-0.07	-0.01	0.00	0.00	0.57	0.06
Child type of home	-0.28	-0.04	0.00	0.00	0.81	0.06
Comfortable home	-0.70	-0.14***	0.20	0.05	0.59	0.06
Child attending school regularly	-2.25	-0.19***	0.76	0.08*	3.82	0.16***
Child food security	0.15	0.03	0.04	0.01	-1.59	-0.14***
Stunted	0.04	0.01	-0.48	-0.10**	0.38	0.03
Wasted	0.39	0.03	-0.30	-0.02	-0.53	-0.02
Underweight	-	-	-	-	-	-
Child HIV status	-0.44	-0.63*	0.55	0.09**	1.09	0.08*
Child's caregiver HIV status	-0.10	-0.02	0.01	0.00	0.45	0.04
Child sickness in household	-0.41	-0.07*	0.40	0.08*	0.42	0.12***
Child loss in household	-0.10	-0.02	0.02	0.01	1.29	0.12***
Child's parent deceased	-0.02	0.01	0.01	0.01	-0.00	0.00
HIV/AIDS-related stigma	0.37	0.08**	-0.34	-0.09**	-1.30	-0.14***

* Significant at p<0.05, ** Significant at p<0.01, ***Significant at p<0.0001

^a 'Standardised' and 'unstandardised' refer to regression coefficients

5.4.6. Community-based programme provision and child HIV status

Finally, the types of community-based programme services the children received based on caregiver report were examined. There was no difference between South Africa and Malawi in terms of enrolment of children, the duration of contact with CBOs, and services provided. HIV-positive children tended to have been enrolled in CBO programmes for a longer period (at least a year) compared to HIV-negative children (80.7% versus 65.2%, $X^2(1)=12.8$, $p<0.0001$). More than two thirds of HIV-positive children were in contact with their CBO once a month or less often, which was significantly lower than that reported for the HIV-negative children - over a third of whom were in daily contact with their CBO, and two thirds were seen at least once a week. A greater proportion of children with HIV received medical services (37% versus 2.1%, $X^2(1)=12.8$, $p<0.0001$), psychosocial interventions (34.1% versus 24.4%, $X^2(1)=5.7$, $p=0.02$), and emotional support (26.7% versus 15.3%, $X^2(1)=10.8$, $p=0.001$) compared to the other group. However, fewer children who were HIV-positive were enrolled in play groups (38.5% versus 52.3%, $X^2(1)=8.7$, $p=0.003$), and in early childhood intervention programmes (17.8% versus 27.6%, $X^2(1)=5.8$, $p=0.02$), with a trend for these children to have worse access to educational support programmes (18.5% versus 25.7%). Access to food and nutrition, home-based care, and skills building programmes was comparable for both groups (Table 5.4).

Table 5.4. Services provided by status

Organization characteristic		HIV positive children, n=135 (%)	HIV negative children, n=844 (%)	P value
Food/nutrition service provided	Yes	72 (53.3)	385 (45.6%)	$\chi^2=0.059$, $\pi=0.809$
	No	63 (46.7)	459 (54.4%)	
Medical services provided	Yes	50 (37)	59 (7)	$\chi^2=$, $\pi < 0.001^*$
	No	85 (63)	785 (93)	
Play services provided	Yes	52 (38.5)	441 (52.2)	$\chi^2=8.760$, $\pi = 0.003^*$
	No	83 (61.5)	403 (47.8)	
ECD programme	Yes	24 (17.8)	232 (27.5)	$\chi^2=5.721$; $\Pi = 0.017^*$
	No	111 (82.2)	612 (72.5)	
Education services provided	Yes	25 (18.5)	215 (25.5)	$\chi^2=3.089$, $\pi=0.079$
	No	110 (81.5)	629 (74.5)	
Emotional support services	Yes	36 (26.7)	128 (15.2)	$\chi^2=10.931^a$, $\pi=0.001^*$
	No	99 (73.3)	716 (84.8)	
Home-based care services provided	Yes	32 (23.7)	224 (26.5)	$\chi^2=0.624^a$, $\pi=0.430$
	No	103 (76.3)	620 (73.5)	
Assistance with accessing social grants	Yes	22 (16.3)	93 (11)	$\chi^2=3.150^a$, $\pi=0.076$
	No	113 (83.7)	751 (89)	
Skills building and training services provided	Yes	14 (10.4)	82 (9.7)	$\chi^2=0.79^a$, $\pi = 0.779$
	No	121 (89.6)	762 (90.3)	

5.5. Discussion

In the study it was found that 13.5% of children attending randomly selected CBO programmes (for children living in high HIV prevalence and low resource communities) were reported to be HIV-positive. Overall, while the prevalence of developmental difficulties was high in the sample overall, they were more common among HIV-positive children. As a group, over two-thirds of children with HIV presented with developmental difficulties. However, the prevalence of developmental difficulties was also high in the non-affected group at over 40%. HIV-positive children had significantly higher rates of cumulative developmental problems across more than one domain and were more likely to have emotional difficulties. In terms of health-related quality of life, HIV-positive children had poorer physical and psychosocial outcomes. There were low rates of disclosure noted, with only a third of positive children knowing their status with certainty.

There was a clear pattern in the data showing that developmental difficulties and physical health and psychosocial-related quality of life were predicted by HIV-positive status, living in South Africa, not attending school regularly, living in poor housing conditions and in a household with a sick family member. In addition, living in communities where people were not concerned with the welfare of children with HIV-positive parents was an additional predictor for poor emotional developmental, as was being male, and younger. School attendance and caring for sick relatives have been identified as risk factors for poor child outcomes in previous research. Children affected by HIV/AIDS are more likely to leave school early and have poor educational outcomes (Cluver & Operario, 2008; Guo et al., 2012), while children with disabilities are systematically excluded from education, and are almost always less likely to both begin school and to remain in school (Filmer, 2005).

The results show that screening for developmental problems using short tools is possible in community settings in order to identify children at risk for poor developmental outcomes, and plan services accordingly. The study has also highlighted the important role of CBOs in intervening to improving child development outcomes. These results indicate that, although the two groups were attending the same CBOs, there were differences in the types of provision that they were receiving. Children who were HIV-positive tended to have been enrolled in programmes for longer, but were receiving the least input from organisations, with more than two-thirds only in contact with the CBO once a month or less. They were significantly more likely to be receiving medical care and emotional support programmes, but on the other hand, they were less likely to be accessing play groups, childhood development programmes and school support programmes. It is encouraging that there is some indication that CBOs are working to meet the specific needs of certain children,

for example, through the provision of medical care for HIV-infected children. The fact that these services are available bodes well for future programming development in this area. However, it is of particular concern, that there is limited access to educational support programmes for HIV-positive children with developmental problems. The data shows that these services were available, but that targeting and inclusion differed by HIV status. The reasons for this need to be better understood so that existing CBO provision can be enhanced and adapted. It may be that the special support needs for children with developmental difficulties are more complex, specific training on early childhood development needs to be improved, or that mixed ability provision is too difficult.

The Convention on the Rights of People with Disabilities (CRPD) states that children with disabilities or other developmental problems should be able to access services on an equal basis with other children (CRPD., 2006). To promote the inclusion of children with HIV, and to ensure that they are able to achieve their right to healthy development, there is a need to design community-based services that are sensitive to the developmental issues that are common in HIV-infected and affected children. CBOs need to work together with caregivers, schools, health services and communities to develop systems that make use of local resources to support children with developmental delay. There is an urgent need for research to inform the development of these types of community-based targeted interventions and screening programmes for children with developmental difficulties (Abubakar et al., 2008; Potterton et al., 2010). Good examples of successful community-level programmes exist, showing that providing specific services to promote child development to mitigate the impact of developmental difficulties associated with HIV is possible (Luyirika et al., 2011; Potterton et al., 2010).

5.5.1. Limitations

The data are subject to a number of limitations. Firstly, HIV status is based on caregiver report and was not verified with a biological measure. This may have led to under-reporting of child HIV status. CBOs that were included were identified as organisations for children affected by HIV/AIDS, however, and it is likely that caregivers and children felt more comfortable to speak about HIV in the context of the CBO than they would in the broader community. This study, as with others that focus on comparing outcomes between HIV-positive and HIV-negative children, is likely to have included HIV-exposed but uninfected children in the sample. Little is known about the developmental trajectory of HIV-exposed children but it is possible that this influenced the results of the study. However, it is important to note that in spite of this, HIV-positive children were still significantly more likely to present with a range of negative outcomes. Secondly, the criterion that both a child and their caregiver be interviewed may have inadvertently led to the exclusion of children living in child-headed households, but we are not aware of this having taken place; in several cases it was found that children were living with an older sibling were included in the interview process. Thirdly, the outcome measures have not all been validated in the sub-Saharan African context. There are limited appropriate and validated tools available for screening for child development outcomes in LMIC. For the purpose of this study, screening tools and questionnaires were required that could be administered by trained data collectors that were not time-consuming or too onerous for participants, who are required to provide responses to a range of tools beyond those described in this paper. Future research that focuses on this area should include more detailed neurodevelopmental assessments.

5.6. Chapter Conclusion

This analysis highlights the important role of CBOs to intervene in improving child development outcomes, but also that there is a need to develop their programming to reach children in need of developmental services. As efforts to improve community-based programming for children affected by HIV continue to grow, there is a need for an approach which is sensitive to the individual developmental needs of HIV-infected and HIV-affected children. Delivery of evidence-based services that target child development outcomes will enable HIV-infected children to meet their developmental potential and promote their participation in their communities.

CHAPTER 6: MENTAL HEALTH OF CAREGIVERS OF CHILDREN AFFECTED BY HIV ATTENDING COMMUNITY-BASED PROGRAMMES IN SOUTH AFRICA AND MALAWI

6.1. Chapter overview

This chapter explores the third research question relating to the prevalence and correlates of caregiver mental health problems in this sample. In the literature review in Chapter 2 I have described this issue in more detail. In this chapter, I provide a brief summary of the issue to contextualize the findings reported here.

6.2. Background

HIV has been linked with depression, post-traumatic stress disorder and suicidal behaviour in a range of contexts (Catalan et al., 2011; Sherr, Clucas, Harding, Sibley, & Catalan, 2011; Sherr, Nagra, et al., 2011), however there have been few studies investigating this relationship in Malawi and South Africa, where adult HIV prevalence is 10.8% and 17.9% respectively (UNAIDS, 2012). In South Africa, studies of HIV positive people accessing HIV services have shown depression rates varying from 14 to 43% (Freeman et al., 2007; Hughes, Jelsma, Maclean, Darder, & Tinise, 2004; Myer et al., 2008) and poor mental health outcomes have been found in caregivers of both children and adults with HIV (Kuo & Operario, 2011; Nyirenda, Chatterji, Rochat, Mutevedzi, & Newell, 2013). Access to mental health care in both countries is limited. The only nationally representative survey of mental health in South Africa revealed that only 28% of people with severe mental disorders had received treatment (Williams et al., 2008). In Malawi, as in many LMICs, mental health care

is delivered primarily through centralised mental hospitals making it largely inaccessible (Kauye et al., 2011).

The emerging evidence suggests that caring for children affected by HIV/AIDS in a context of poverty places caregivers at risk of developing depression and other mental health problems, and that accessing mental health services may be difficult. This is likely to have a profound impact on the well-being of caregivers and the children in their care (Casale, Wild, Cluver, & Kuo, 2014; Smith Fawzi et al., 2012).

Child caregivers of HIV-sick adults show increased depression, anxiety, and posttraumatic stress symptoms that persist over time (Cluver, Orkin, Boyes, Gardner, & Nikelo, 2012), yet there are few studies on the mental health burden of adult caregivers. There is a need for studies that examine the prevalence of mental health problems in caregivers of HIV-affected children, and the correlates of these conditions among this population (Kagotho & Ssewamala, 2012) so that services can be adequately and accurately targeted to improve both child and caregiver well-being.

The aim of this study was to examine the mental health of the primary caregivers of children affected by HIV, who attend CBO programmes in South Africa and Malawi.

6.3. Methods

This study formed a part of the Child Community Care Study, and utilises cross-sectional data gathered from children attending community-based programmes, that are

supported by a range of project partners. The methodology of the Child Community Care study is outlined in detail in Chapter 3.

6.3.1. Measures used in this analysis

The measures used in this analysis are detailed in Chapter 3.

6.3.2. Data analysis

After descriptive analyses, logistic regression models were used to test for a range of factors associated with caregivers scoring above the clinical cut-off for psychological morbidity and experiencing suicidal ideation. Potential predictors were demographics (age, gender, country of residence), socio-economic factors (employment, housing conditions), health status (HIV burden, other illnesses and loss in the household), exposure to violence at home, perceptions of stigma in the community, and child psychosocial outcomes. In multivariate analyses we explored the independent effects of all these variables. Adjusted odd ratios (OR) and 95% confidence intervals (CI) are presented, with a significance level of $p < 0.05$. Analyses were carried out using SPSS 20.0 (IBM, Chicago, IL, USA).

6.4. Results

6.4.1. Sample characteristics

Initially, 996 caregiver-child pairs were approached to take part in the study. Of these, 7 caregiver-child pairs did not consent (0.7% refusal rate). In total 989 children

participated with their caregivers; 834 in South Africa and 155 in Malawi. In total, 10 caregiver-child pairs were omitted from the analysis for this analysis due to missing data. There were 27 caregivers who were interviewed for more than one of their children, resulting in a final sample size of 979 children and 952 caregivers. Of the caregivers sampled as a part of this study, 903 (94.9%) of the caregivers were female and 797 (83.7%) lived in South Africa. HIV burden in the household was high, with 33.8% (n=322) reporting that someone in the household had HIV. Of the total, 19.4% (n=185) of caregivers reported being HIV positive themselves and 14.4% (n=137) reported living with someone else with HIV. Only 53.8% (n=512) reported that someone in the household was employed, and 27.2% (n=259) reported food insecurity. About a fifth (21.5% n=205) overall had a household member sick for more than three months in the preceding year and 273 (28.7%) had experienced a death in the household in the preceding 24 months (Table 6.1).

6.4.2. Prevalence of psychological morbidity

Levels of psychological morbidity were high, with 28% of caregivers (n=267) in the study scoring above the clinical cut-off, indicating the presence of a current mental health problem in the past week and 12.2% (n=116) reported suicidal ideation in the past 2 weeks.

Participants who scored above the clinical cut-off were more likely to be living in South Africa vs. Malawi and have HIV burden in the household. Participants with suicidal ideation were more likely to be living in households with no one employed and HIV burden in the household.

Table 6.1.: Demographic information for caregivers above and below the SSQ clinical cut-off and for those with or without suicidal ideation

	SSQ scores			Suicidal ideation		
	> cut-off (n=267)	< cut-off (n=685)	<i>P</i> value	'yes' (n=116)	'no'(n=836)	<i>P</i> value
Age (n=950)	M=43.8 (SD=14.4)	M=43.3 (SD=15.2)	n.s.	M=42.5 (SD=13.9)	M=43.6 (SD=15.1)	n.s.
Country						
South Africa (n=797)	237 (29.7)	560 (70.3)	0.008	100 (12.5)	697 (87.5)	n.s.
Malawi (n=155)	30 (19.4)	125 (80.6)		16 (10.3)	139 (89.7)	
Gender						
Male (n=49)	8 (16.3)	41 (83.7)	n.s.	4 (8.2)	45 (91.8)	n.s.
Female (n=903)	259 (28.7)	644 (71.3)		112 (12.4)	791 (87.6)	
Caregiver employed						
Yes (n=162)	39 (24.1)	123 (75.9)	n.s.	16 (9.9)	146 (90.1)	n.s.
No (n=790)	228 (28.9)	562 (71.1)		100 (12.7)	690 (87.3)	
Caregiver household employment						
Anyone employed (n=512)	130 (25.4)	382 (74.6)	n.s.	47 (9.2)	465 (90.8)	0.003
No-one employed (n=430)	137 (31.1)	303 (68.9)		69 (15.7)	371 (84.3)	
HIV burden in household						
HIV positive caregiver (n=185)	64 (34.6)	121 (65.4)	0.02	28 (15.1)	157 (84.9)	n.s.
Other HIV positive (n=137)	45 (32.8)	92 (67.2)		19 (13.9)	118 (86.1)	
No-one HIV positive (n=630)	158 (25.1)	472 (74.9)		69 (11.0)	561 (89.0)	
Caregiver household sickness						
Yes (n=205)	78 (38.0)	127 (62.0)	<0.0001	39 (19.0)	166 (81.0)	0.002
No (n=747)	189 (25.3)	558 (74.7)		77 (10.3)	670 (89.7)	

	SSQ scores			Suicidal ideation		
Caregiver loss family member						
Yes (n=273)	83 (30.4)	190 (69.6)	n.s.	45 (16.5)	228 (83.5)	0.01
No (n=679)	184 (27.1)	495 (72.9)		71 (10.5)	608 (89.5)	
Caregiver household food security						
Food secure (n=693)	191 (27.6)	502 (72.4)	n.s.	81 (11.7)	612 (88.3)	n.s.
Food insecure (n=259)	76 (29.3)	183 (70.7)		35 (13.5)	224 (86.5)	
Caregiver comfortable home						
Yes (n=558)	150 (26.9)	408 (73.1)	n.s.	59 (15.0)	501 (89.8)	0.03
No (n=394)	117 (29.7)	277 (70.3)		59 (15.0)	335 (85.0)	

Note: All *p* values are associated with chi-square tests and *t*-tests

Table 6.2.: Logistic regression models testing predictors of psychological morbidity and suicidal ideation in caregivers

	SSQ above clinical cut-off			Suicidal ideation		
	Univariate	Multivariate ^a		Univariate	Multivariate ^b	
	Unadjusted %	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted %	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
<i>All</i> (n=952)	28.0			12.2		
Age in years (for each additional year) (n=950)	M=43.8 (SD=14.4)	1.00 (0.99-1.01)	1.01 (1.00-1.02)	M=42.8 (SD=14.0)	1.00 (0.98-1.01)	1.00 (0.98-1.01)
Gender						
Female (n=903)	28.7	Reference	Reference	12.4	Reference	Reference
Male (n=49)	16.3	0.49 (0.22-1.05)	0.51 (0.23-1.12)	8.2	0.63 (0.22-1.78)	0.60 (0.20-1.76)
Country						
South Africa (n=797)	29.7	Reference	Reference	12.5	Reference	Reference
Malawi (n=155)	19.4	0.57 (0.37-0.87)**	0.30 (0.17-0.52)***	10.3	0.80 (0.46-1.40)	0.44 (0.21-0.91)*
Work status						
Working (n=162)	24.1	Reference	Reference	9.9	Reference	Reference
Not working (n=790)	28.9	1.28 (0.87-1.89)	1.01 (0.71-1.69)	12.7	1.32 (0.76-2.31)	1.07 (0.57-1.99)
Comfortable home						

	SSQ above clinical cut-off			Suicidal ideation		
	Univariate		Multivariate ^a	Univariate		Multivariate ^b
	Unadjusted %	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted %	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Yes (n=558)	26.9	Reference	Reference	10.2	Reference	Reference
No (n=394)	29.7	1.15 (0.86-1.53)	1.24 (0.92-1.68)	15.0	1.55 (1.05-2.29)*	1.55 (1.03-2.34)*
Employment in HH						
Anyone employed (n=512)	25.4	Reference	Reference	9.2	Reference	Reference
No one employed (n=430)	31.1	1.33 (1.00-1.76)*	1.57 (1.13-2.18)**	15.7	1.84 (1.24-2.73)**	2.23 (1.41-3.55)**
HIV burden in HH						
No one HIV-positive (n=630)	25.1	Reference	Reference	11.0	Reference	Reference
HIV-positive caregiver (n=185)	34.6	1.58 (1.11-2.25)**	1.42 (0.97-2.07)	15.1	1.45 (0.90-2.33)	1.20 (0.68-2.13)
Other HIV-positive (n=137)	32.8	1.46 (0.98-2.17)	1.33 (0.87-2.02)	13.9	1.31 (0.76-2.59)	1.15 (0.69-1.91)
HH sickness						
No (n=747)	25.3	Reference	Reference	10.3	Reference	Reference
Yes (n=205)	38.0	1.81 (1.31-2.51)***	1.65 (1.16-2.36)**	19.0	2.04 (1.34-3.12)**	1.68 (1.06-2.65)*
HH loss						
No (n=679)	27.1	Reference	Reference	10.5	Reference	Reference
Yes (n=273)	30.4	1.18 (0.86-1.60)	1.00 (0.72-1.39)	16.5	1.69 (1.13-2.53)**	1.48 (0.96-2.28)

	SSQ above clinical cut-off			Suicidal ideation		
	Univariate		Multivariate ^a	Univariate		Multivariate ^b
	Unadjusted %	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted %	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
HH violence						
No (n=883)	27.2	Reference	Reference	11.6	Reference	Reference
Yes (n=69)	39.1	1.72 (1.04-2.86)*	1.46 (0.85-2.50)	20.3	1.95 (1.05-3.63)*	1.69 (0.87-3.28)
Stigma (each additional point) (n=952)	M=0.25 (SD=0.66)	1.65 (1.28-2.12)***	1.60 (1.23-2.09)***	M=0.30 (SD=0.71)	1.68 (1.26-2.25)***	1.64 (1.21-2.23)**
Child food security						
Sufficient food (n=716)	27.6	Reference	Reference	11.7	Reference	Reference
Insufficient food (n=263)	29.3	1.09 (0.80-1.50)	1.82 (1.20-2.77)**	13.5	1.28 (0.77-1.81)	1.37 (0.78-2.39)
Child hunger last night						
Not hungry (n=827)	28.3	Reference	Reference	11.4	Reference	Reference
Hungry (n=125)	26.4	0.91 (0.59-1.39)	0.81 (0.51-1.28)	17.6	1.67 (1.00-2.77)*	1.43 (0.83-2.48)
Child depression (n=705)	M=1.01 (SD=1.40)	1.03 (0.92-1.14)	--	M=1.04 (SD=1.41)	1.04 (0.90-1.19)	--
Performance at school						
Better/equal (n=765)	27.1	Reference	--	10.7	Reference	--
Struggles (n=151)	32.5	1.30 (0.89-1.89)	--	20.5	2.15 (1.36-3.40)**	--

Adjusted OR: Odd ratios adjusted for all variables (except those with smaller Ns: CDI score and school performance); CI: Confidence interval.

* Significant at $p < 0.05$, ** Significant at $p < 0.01$, ***Significant at $p < 0.0001$.

Child depression was assessed using the CDI measure which has been validated for children above 7 years, thus $n = 705$.

^a $N = 950$, $X^2(14) = 63.45$, $p < 0.0001$, Nagelkerke $R^2 = 0.093$, ^b $N = 950$, $X^2(14) = 50.05$, $p < 0.0001$, Nagelkerke $R^2 = 0.098$.

As seen in Figure 6.1, being HIV positive or living with someone HIV positive was associated with poor mental health outcomes. Prevalence of psychological morbidity was higher in HIV positive caregivers (34.6%) and caregivers living with someone with HIV (32.8%), compared to caregivers living in HIV-free households (25.1%) ($X^2(2) = 8.24$, $p=0.016$). Prevalence of suicide ideation was also higher among HIV positive caregivers (15.1%) and caregivers living with someone with HIV (13.9%) compared to caregivers living in HIV-free households (11%), but this difference did not reach statistical significance.

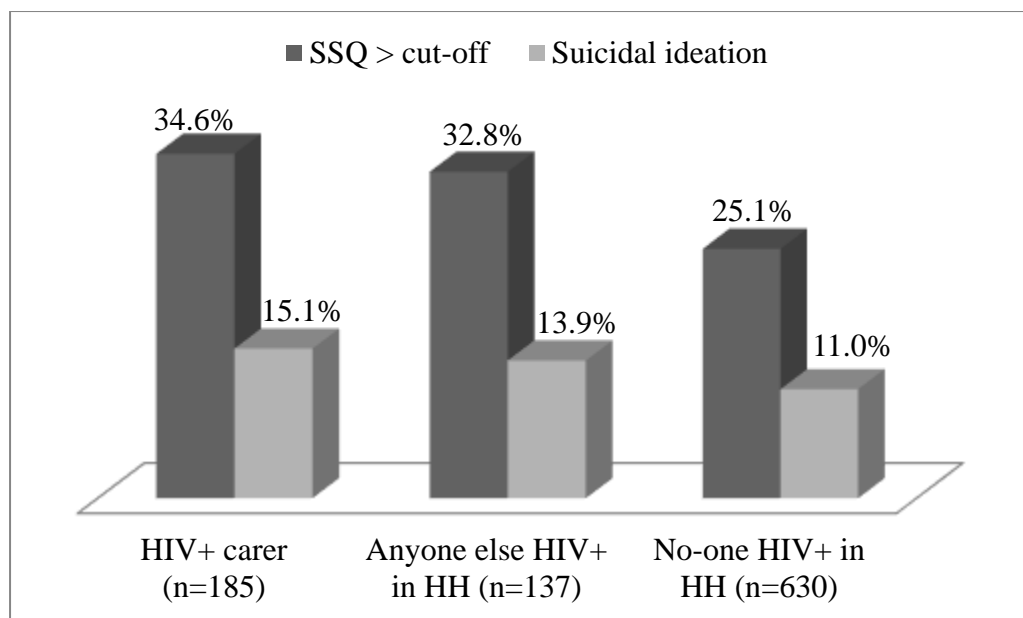


Figure 6.1: SSQ scores and suicidal ideation according to HIV status.

6.4.3. Predictors of psychological morbidity and suicidal ideation in caregivers

Logistic regression models were used to test factors associated with scoring above the clinical cut-off for psychological morbidity and having suicidal ideation (Table 6.2).

Caregivers living in Malawi were less likely to meet the threshold for psychological morbidity compared to those living in South Africa (19.4% vs. 29.7%, Adjusted OR: 0.30, 95% CI: 0.17-0.52, $p<0.0001$), and were less likely to have suicidal ideation compared to

those in South Africa (10.3% vs. 12.5%, Adjusted OR: 0.44, 95% CI: 0.41 (0.21-0.91), p=0.028). Caregivers who lived in households where no one was employed were more likely to score above the clinical cut-off (31.1% vs. 25.4%, Adjusted OR: 1.57, 95% CI: 1.13-2.18), p=0.008) and to report suicidal ideation (15.7% vs. 9.2%, Adjusted OR: 2.23, 95% CI: 1.41-3.55, p=0.001) compared to those who lived in households where someone was employed. Caregivers who lived with a sick family member were more likely to meet the threshold for psychological morbidity (38% vs. 25.3%, Adjusted OR: 1.65, 95% CI: 1.16-2.36), p<0.0001) and to report suicidal ideation (19% vs. 10.3%, Adjusted OR: 1.68, 95% CI: 1.06-2.65, p=0.027) than those who lived in households with no one sick in the past year. Caregivers reporting low perceived community support for people with HIV were more likely to have current psychological morbidity (M=0.25, SD=0.66 vs. M=0.10, SD=0.43, Adjusted OR: 1.60, 95% CI: 1.23-2.09, p<0.0001), and were also more likely to report suicidal ideation (M=0.30, SD=0.71 vs. M=0.12, SD=0.47, Adjusted OR: 1.64, 95% CI: 1.21-2.23, p=0.002). Caregivers who reported their child had insufficient food were more likely to score above the clinical cut-off for psychological morbidity compared to those who reported their child to be food secure (29.3% vs. 27.6%, Adjusted OR: 1.82, 95% CI: 1.20-2.77, p=0.005). Caregivers living in poor housing conditions were more likely to report suicidal ideation compared to those living in dry and comfortable houses (15% vs. 10.2%, Adjusted OR: 1.55, 95% CI: 1.03-2.34, p=0.036).

Table 6.3.: Association between caregivers' psychological morbidity and care seeking

	Sought mental health care (n=342)	Did not seek mental health care (n=610)
SSQ above cut-off (n=267)	159 (59.6%)	108 (40.4%)
SSQ below cut-off (n=685)	183 (26.7%)	502 (73.3%)
Suicidal ideation (n=116)	79 (68.1%)	37 (31.9%)
No suicidal ideation (n=836)	263 (31.5%)	573 (68.5%)

6.4.4. Help-seeking

Approximately one third of all participants (35.9%) had sought help for mental or emotional distress in the past year. Nearly two-thirds (59.6%) of participants above the SSQ cut-off, and 68.1% of participants with suicidal ideation had sought care. On the other hand, 26.8% of participants who did not reach the threshold for psychological morbidity reported having sought help (Table 6.3).

6.5. Discussion

In this study, it was found that mental health problems and suicidal ideation were common in caregivers of children affected by HIV/AIDS in different community settings across two Southern African countries. Most studies of adult mental health in the context of HIV/AIDS have taken place in clinic settings and have looked specifically at the links between HIV infection or disease progression and mental health outcomes. However, these data show that people in families affected by HIV are exposed to a range of other risks for poor mental health, besides their own HIV status. These cluster of factors include unemployment, hunger, violence, household illness and stigma. In this study, caregiver status was not associated with psychological morbidity. Rather, higher rates of mental health problems were found both in people living with a sick family member. The findings suggest that in this sample HIV status itself is secondary to other associated factors. Socio-economic factors play a key role in affecting caregiver mental health, which is compounded by the burden of care-giving for sick family members, and the existence of community level HIV stigma. The study feeds into a growing body of research on the prevalence and risk factors for poor mental health in Southern Africa. Previous studies have also found that caregiving is

associated with elevated mental health problems in both young and adult caregivers (Casale et al., 2014; Kuo & Operario, 2011; Kuo, Reddy, Operario, Cluver, & Stein, 2013).

Caregivers in Malawi were less likely to score above clinical cut-off for mental disorders than those in South Africa. South Africa may have higher rates of mental health problems than many other African countries, but the reasons for this are uncertain (Herman et al., 2009). South Africa has a traumatic history, with high levels of abuse perpetuated by the apartheid government on a national scale. There is ongoing poverty, inequality and elevated levels of unemployment in the country, all of which have mental health effects (Lund et al., 2010). Substance use is common, with extremely high levels of misuse of alcohol (Scott-Sheldon et al., 2012) and rising use of methamphetamine (Plüddemann, Flisher, McKetin, Parry, & Lombard, 2010), but this was not tracked in the study.

In this community-based study there are relatively low rates of reported help-seeking for mental health problems. This appears to suggest that while caregivers are in contact with CBOs, they are not identifying them as potential sources of support and care for mental health problems, and CBOs may not be detecting and recognising the burden of mental health problems among the caregivers of children that they serve. The World Mental Health surveys found that up to 85% of people with serious mental disorders and 87% of people with suicidal ideation in LMIC were not seeking or receiving mental health care of any kind (Bruffaerts et al., 2011; Demyttenaere et al., 2004). This has been attributed to stigma, poor mental health knowledge (Gulliver, Griffiths, & Christensen, 2010) and a lack of mental health professionals and availability of services in LMIC settings. Poor recognition of depression in community health settings is of particular concern in LMIC (Saxena, Thornicroft, Knapp, & Whiteford, 2007), and as a result the integration of screening for

mental disorders into primary health care is a global mental health priority (Collins et al., 2011).

Mental health is increasingly being recognised as a global public health priority and WHO's recent *Mental Health Action Plan 2013-2020* recommends a number of actions to address the existing treatment gap, including capacitating non-specialised health professionals to provide mental health services, especially at primary care level (World Health Organisation, 2013). International efforts to improve health outcomes require targeted focus on addressing health inequities, or risk leaving behind the most vulnerable groups (Victora et al., 2003). Engaging CBOs in the provision of mental health care and support services for families is central to promoting equity in mental health.

6.5.1. Limitations

This study was conducted within CBOs, and the sample was thus not necessarily representative of the broader communities in which the study took place. It is possible that there are higher rates of poor mental health in this group compared with the community at large, as vulnerable caregivers may have sought extra help from CBOs, or been selected by CBOs to engage in their programmes. The data is cross sectional and causal inferences cannot therefore be drawn. Longitudinal data will be collected as part of the ongoing study. HIV status is confined to self-report and was not confirmed with laboratory testing. Underreporting due to lack of testing as well as stigma may be an issue. Despite these limitations, the robust sample provides useful information for future programme planning and policy.

6.6. Chapter Conclusion

The study adds to the literature on mental health outcomes in adult caregivers of children affected by HIV/AIDS in communities across southern Africa. The predictors of poor mental health are linked household illness, socio-economic outcomes, caregiving and lack of community support. This provides important evidence for inclusion of CBO projects into broader efforts to improve population mental health.

CHAPTER 7: EXPOSURE TO VIOLENCE AND PSYCHOLOGICAL WELL-BEING OVER TIME IN CHILDREN AFFECTED BY HIV/AIDS IN SOUTH AFRICA AND MALAWI

7.1. Chapter overview

This chapter explores the fourth and fifth research questions relating to prevalence of exposure to home and community violence, and how violence exposure is linked to the psychosocial well-being of children in this sample. In addition to the literature reviews on this topic in Chapter 2, I provide a brief summary of the issue to contextualize this analysis in the Background section.

7.2. Background

There is little research on community-based programming to prevent violence in LMIC (World Health Organization, 2014), particularly for vulnerable children such as those affected by HIV. In Sub-Saharan Africa, efforts to prevent or address violence against children are hampered by this lack of evidence. In South Africa, rates of interpersonal violence are high (Seedat, Van Niekerk, Jewkes, Suffla, & Ratele, 2009), and physical abuse of children is common (Richter & Dawes, 2008). The national under-5 homicide rate is more than double that of other LMIC (Norman, Matzopoulos, Groenewald, & Bradshaw, 2007) and several times higher than high income settings (UNICEF, 2014). The picture in Malawi is more mixed. The child homicide rate in Malawi is one of the lowest in the region, yet at least 21% of girls report that they have experienced physical violence (UNICEF, 2014) and violence against girls has been identified as a key barrier to attending and performing well in

school (Bisika, Ntata, & Konyani, 2009). In both Malawi and South Africa there are high rates of gender-based intimate partner violence (Abrahams, Jewkes, Laubscher, & Hoffman, 2006; Rico, Fenn, Abramsky, & Watts, 2011). It is likely that children in these countries are also witnesses to violence in their homes and communities - in South Africa 45% of children have witnessed their mother being beaten (Seedat et al., 2009).

In addition, there is little research available investigating the relationship between violence exposure and other mental health outcomes of children in Sub-Saharan Africa. Most of the research investigating the relationship between exposure to violence and child mental health outcomes in Sub-Saharan Africa is focused on post-traumatic stress disorder in adolescents, with studies showing a positive relationship between the number of traumatic events and the severity of PTSD and depression (Suliman et al., 2009). Young children affected by HIV/AIDS are a vulnerable population, yet many of them are hard to reach and rarely included in research, meaning we know little about their exposure to violence and its impact.

The aim of this study was to assess the rates of child exposure to violence, the relationship with mental health status, and the mental health outcomes over time of children affected by HIV aged 4-13 years attending community-based programmes.

7.3. Methods

This study formed a part of the Child Community Care Study, and utilises longitudinal data gathered from children attending community-based programmes, that are

supported by a range of project partners. The methodology of the Child Community Care study is outlined in detail in Chapter 3.

7.3.1. Measures used in this analysis

The measures used in this analysis are detailed in Chapter 3.

7.3.2. Data analysis

After descriptive analysis, *t*-tests and chi-square tests were used to examine associations between exposure to violence and child functioning and mental health. Next, multivariate regression models were used to examine associations with child mental health (depressive and trauma symptoms, self-esteem), emotional and behavioural functioning, and risk behaviours. Follow-up data was analysed using repeated measures analysis of variance (ANOVA) for continuous outcome variables and multiple logistic regression controlled for baseline for binary outcome variables. Multivariate analyses were adjusted for demographic factors (age, gender, country) and child HIV status. Analyses were carried out using SPSS 20.0 (IBM Corp., 2012).

7.4. Results

7.4.1. Sample characteristics

The sample is described in more detail in Chapter 5 and 6. At baseline, nearly half of the children had been exposed to interpersonal violence between adults in the home, and

42.5% exposed to violence in their community. Harsh discipline practices were common with 47.8% of caregivers reporting striking a child with an implement, or on the head or face and 45.4% of caregivers engaging in harsh psychological punishment. Figure 7.1 compares HIV-positive children, HIV affected children (HIV-negative but living in a household with someone who was HIV-positive) and unaffected children. Exposure to violence varied significantly by group with higher rates in the HIV affected group and lower rates in the unaffected group. Older children (10-13y, n=469) were asked about their engagement in risk behaviours, and over a third (34.8%) reported that they had beaten up someone (33.0%), been drunk or high (4.7%) or had been arrested (0.4%).

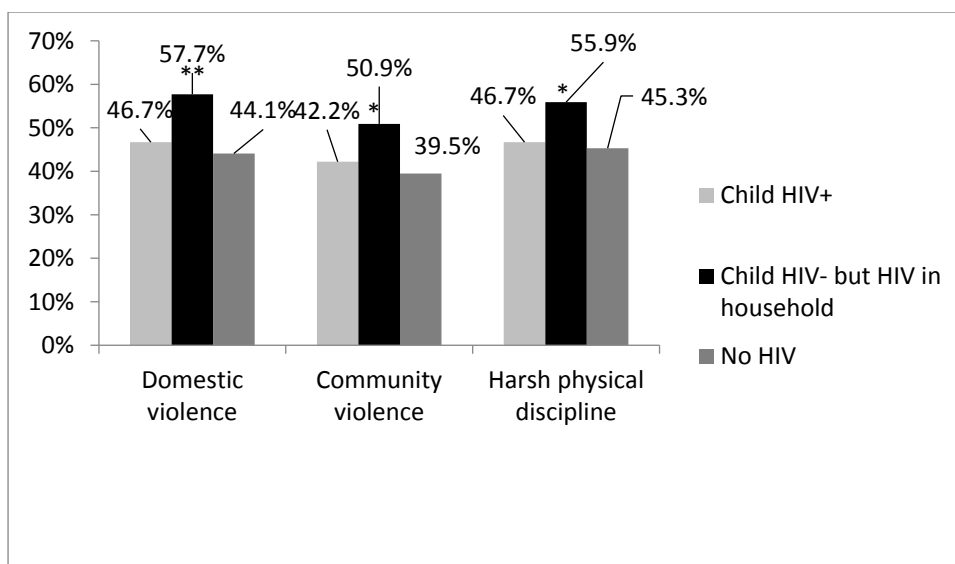


Figure 7.1: Rates of domestic and community violence and harsh physical discipline as a function of child HIV burden.

** $p < .01$.

Chi-square difference test was performed for all three types of violence * $p < .05$,

At follow up, 854 children were re-enrolled in the study. Children lost to follow-up were more often from South Africa (92.9%) than those who were followed up (82.7%; $\chi^2(1)=10.42, p=0.001$). They also more often lived in a shack (25.3% vs 13.8%; $\chi^2(1)=12.61,$

p<0.001), and consequently less often lived in a comfortable home (50.7% versus 60.0%; $\chi^2(1)=4.47$, p=0.035). However, children lost to follow-up were more often food secure (80.1% versus 71.8%; $\chi^2(1)=4.65$, p=0.031). Children who were lost to follow-up and children who were followed up did not differ significantly on any of the violence measures at baseline, nor on mental health measures or any other demographic variables.

Table 7.1.: Associations between exposure to violence and child functioning and mental health

	Depressive symptoms M (SD)	p	Trauma symptoms M (SD)	P	Self Esteem M (SD)	p	Internalising problems M (SD)	P	Externalising problems M (SD)	P	Int & Ext problems M (SD)	p
Domestic violence												
Any (n=462)	1.22 (1.76)	≤0001	4.69 (3.58)	≤0001	20.46 (2.59)	≤0001	2.02 (1.66)	.002	1.31 (1.43)	≤0001	3.33 (2.55)	≤0001
None (n=510)	0.69 (0.96)		3.41 (2.92)		21.50 (3.08)		1.71 (1.43)		0.99 (1.22)		2.70 (2.17)	
Community violence												
Any (n=413)	1.05 (1.61)	n.s.	4.68 (3.66)	≤0001	20.86 (2.88)	n.s.	2.01 (1.61)	.01	1.27 (1.48)	.02	3.28 (2.56)	.003
None (n=559)	0.86 (1.23)		3.42 (2.84)		21.11 (2.84)		1.75 (1.51)		1.06 (1.21)		2.82 (2.23)	
Harsh physical discipline												
Any (n=473)	1.00 (1.41)	n.s.	4.12 (3.14)	n.s.	20.42 (2.55)	≤0001	2.21 (1.64)	≤0001	1.55 (1.40)	≤0001	3.75 (2.45)	≤0001
None (n=516)	0.90 (1.45)		3.93 (3.46)		21.51 (3.04)		1.52 (1.39)		0.79 (1.16)		2.31 (2.09)	
Harsh psychological discipline												
Any (n=449)	1.01 (1.48)	n.s.	4.29 (3.50)	n.s.	20.71 (2.73)	.009	2.16 (1.67)	≤0001	1.37 (1.40)	≤0001	3.53 (2.48)	≤0001
None (n=540)	0.89 (1.38)		3.80 (3.14)		21.22 (2.95)		1.59 (1.40)		0.97 (1.25)		2.56 (2.21)	

p value associated with independent t-tests

7.4.2. Violence exposure and mental health outcomes at baseline

Table 7.1 shows associations between various types of violence exposure and child mental health outcomes. Interpersonal violence in the home was significantly associated with higher depression symptom score, higher trauma symptom score, higher behavioural and emotional problems and lowered self-esteem. Community violence was not associated with depression scores, but was associated with higher trauma scores, and behavioural and emotional problems. Both harsh physical and psychological discipline measures were associated with lower self-esteem and higher behavioural and emotional problems. Table 7.2 sets out the associations between exposure to violence and problematic risk behaviours, all of which were significant.

Table 7.2.: Associations between exposure to violence and risk behaviour among 10-13 yr olds

	Delinquency		X ² (df), p value
	Any (n=163)	None (n=306)	
Domestic violence			
Any (n=462)	98 (60.1%)	121 (39.7%)	17.84 (1), ≤0.0001
None (n=510)	65 (39.9%)	184 (60.3%)	
Community violence			
Any (n=413)	103 (63.2%)	126 (41.3%)	20.35 (1), ≤0.0001
None (n=559)	60 (36.8%)	179 (58.7%)	
Harsh physical discipline			
Any (n=473)	93 (57.1%)	131 (42.8%)	8.65 (1), 0.004
None (n=516)	70 (42.9%)	175 (57.2%)	
Harsh psychological discipline			
Any (n=449)	90 (55.2%)	130 (42.5%)	6.92 (1), 0.009
None (n=540)	73 (44.8%)	176 (57.5%)	

Given the significant associations, the next step was to explore associations with child mental health and behaviour. Table 7.3 shows linear regression models of the range of child mental health and behaviour outcomes. After controlling for demographic factors (country, age, gender, and HIV status), exposure to interpersonal violence in the home was found to be the only predictor of depressive symptoms ($\beta=0.17$, $p<0.001$). Trauma symptoms were higher for children in Malawi ($\beta=0.23$, $p<0.001$), for girls ($\beta=0.08$, $p=0.03$), and for children exposed to home violence ($\beta=0.17$, $p<0.001$) and community violence ($\beta=0.16$, $p<0.001$). Self-esteem was higher for older children ($\beta=0.12$, $p<0.001$), and for children in South Africa ($\beta=0.87$, $p=0.02$), and was negatively associated with exposure to domestic violence ($\beta=-0.17$, $p<0.001$) and harsh physical discipline practices ($\beta=-0.18$, $p<0.001$). Internalizing and externalizing behavioural problems were found to be greater in younger children ($\beta=-0.14$, $p<0.001$), and for those who were HIV positive ($\beta=0.08$, $p=0.008$). Exposure to violence in the home or in the community was positively associated with greater internalizing and externalizing behavioural problems, as was exposure to harsh discipline practices. Boys were more likely to engage in externalizing behaviours than girls ($\beta=0.12$, $p<0.001$). Externalizing behaviours were also greater in South Africa ($\beta=0.12$, $p=0.001$), and for children exposed to domestic violence ($\beta=0.06$, $p=0.04$).

Table 7.3.: Linear regression models showing predictors of child outcomes

	Depressive symptoms		Trauma symptoms		Self Esteem		Internalising problems		Externalising problems		Int & Ext problems	
	B	β	B	β	B	β	B	β	B	B	B	β
South Africa	-.24	-.07	-1.9***	-.23***	.65*	.87*	-.22	-.05	.41**	.11**	.19	.03
Age	-.03	-.04	-.007	-.003	.14**	.12**	-.04*	-.08*	-.08***	-.17***	-.12***	-.14***
Male	-.05	-.02	-.55*	-.08*	-.11	-.02	.02	.006	.31***	.12***	.33*	.07*
HIV positive	-.002	.01	-.21	-.02	-.04	-.14	.55***	.12***	.007***	.002***	.55**	.08**
Domestic violence	.49***	.17***	1.1***	.17***	-.94***	-.17***	.13	.04	.17*	.06*	.30*	.07*
Community violence	.10	.03	1.0***	.16***	-.04	-.007	.18	.06	.15	.05	.32*	.07*
Harsh physical discipline	.06	.02	.39	.06	-1.0***	-.18***	.58***	.19***	.55***	.21***	1.1***	.24***
Harsh psychological discipline	.06	.02	.39	.06	-.17	-.03	.41***	.13***	.18*	.07*	.58***	.12***
R ²	.038***		.11***		.08***		.09***		.15***		.15***	
F (df)	3.52 (8, 708)***		10.2 (8, 639)***		8.96 (8, 827)***		12.2 (8, 959)***		21.3 (8, 969)***		20.8 (8, 959)***	

B - Unstandardised coefficient, β - Standardised coefficient

* Significant at $p < 0.05$, ** Significant at $p < 0.01$, ***Significant at $p < 0.0001$.

A multivariate logistic regression model was run to test factors associated with risk behaviours among older children (10 years or above, n=469) (Table 7.4). Country and exposure to home and community violence were found to be significant independently associated with delinquent behaviour. Children living in South Africa were three times more likely to engage in any type of delinquency than those in Malawi (39.4% vs. 17.3%, Adjusted OR: 3.03, 95% CI: 1.63-5.66, p<0.0001). Children exposed to any type of domestic violence were also more likely to engage in delinquent behaviour (44.7% vs. 26.1%, Adjusted OR: 1.89, 95% CI: 1.23-2.85, p=0.002), so were those exposed to community violence (45% vs. 25.1%, Adjusted OR: 2.39, 95% CI: 1.57-3.62, p<0.0001). Age, gender, HIV status and exposure to harsh discipline practices were not significantly associated with delinquent behaviour.

Table 7.4.: Logistic regression model showing predictors of risk behaviour

	Any risk behaviour (n=163)		
	Univariate	Multivariate	
	Unadjusted %	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
<i>All</i> (n=469)	34.8%		
Country			
Malawi (n=98)	17.3%	Reference	Reference
South Africa (n=371)	39.4%	3.09 (1.76-5.43)***	3.03 (1.63-5.66)***
Age (n=469)	M=11.4 (SD=0.99)	1.00 (0.83-1.21)	1.09 (0.89-1.34)
Gender			
Girl (n=240)	31.2%	Reference	Reference
Boy (n=229)	38.4%	1.37 (0.94-2.01)	1.23 (0.81-1.86)
HIV status			
HIV-negative(n=409)	35.7%	Reference	Reference

Any risk behaviour (n=163)			
	Univariate	Multivariate	
	Unadjusted %	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
HIV-positive (n=60)	28.3%	0.71 (0.39-1.29)	0.62 (0.32-1.18)
Domestic Violence			
None (n=249)	26.1%	Reference	Reference
Any (n=219)	44.7%	2.29 (1.56-3.38)***	1.89 (1.25-2.85)**
Community Violence			
None (n=239)	25.1%	Reference	Reference
Any (n=229)	45.0%	2.44 (1.65-3.61)***	2.39 (1.57-3.62)***
Harsh physical discipline			
None (n=245)	28.6%	Reference	Reference
Any (n=224)	41.5%	1.78 (1.21-2.61)**	0.73 (1.81)
Harsh psychological discipline			
None (n=249)	29.3%	Reference	Reference
Any (n=220)	40.9%	1.67 (1.14-2.45)**	1.23 (0.80-1.90)

* Significant at p<0.05, ** Significant at p<0.01, ***Significant at p<0.0001.

7.4.3. Mental health outcomes at 15 month follow-up

At follow-up, changes in mental health outcomes over time and the relationship with violence exposure were investigated. Repeated measures (Figure 7.2 and Table 7.5), controlling for the covariates country, gender, age and HIV status, showed that there was a significantly larger decrease in depressive symptoms from baseline to follow-up in those children who were exposed to domestic violence at baseline ($F(1, 815)=5.08, p=0.024$). Trauma symptoms were stable over time for the children who were exposed to community violence at baseline, while they increased for those who were not ($F(1, 828)=6.47, p=0.011$). Children experiencing harsh physical discipline at baseline had a significantly larger increase

in self-esteem ($F(1, 701)=4.73, p=0.030$) and a decrease in internalising behaviour where the non-exposed group experienced a slight increase ($F(1, 821)=7.86, p=0.005$). Lastly, these children also had a decrease in externalising behaviour where the non-exposed group experienced an increase ($F(1, 821)=8.58, p=0.003$), an effect which was also found for exposure to domestic violence ($F(1, 821)=7.62, p=0.006$).

Table 7.5.: Repeated measures ANOVAs showing effects of domestic violence, community violence, harsh physical and harsh psychological discipline on change over time of several psychosocial child outcomes

	Depressive symptoms		Trauma symptoms		Self Esteem		Internalising problems		Externalising problems		Int & Ext problems	
	F	p	F	p	F	p	F	p	F	P	F	p
Country	0.33	.57	28.93	<.001	5.93	.015	5.90	.015	22.47	<.001	0.91	.34
Age	9.64	.002	0.031	.86	1.83	.18	0.59	.44	0.32	.57	0.046	.83
Gender	0.25	.62	0.003	.96	0.34	.56	0.95	.33	0.089	.77	0.70	.40
HIV status	0.085	.77	4.41	.036	4.05	.045	4.11	.043	0.13	.72	1.43	.23
Domestic violence	5.08	.024	2.89	.090	0.71	.40	0.12	.73	7.62	.006	3.13	.077
Community violence	0.65	.42	6.47	.011	0.29	.59	0.14	.71	0.94	.33	0.63	.43
Harsh physical discipline	0.001	.98	1.09	.30	4.73	.030	7.86	.005	8.58	.003	12.60	<.001
Harsh psychological discipline	1.99	.16	0.26	.61	0.051	.82	0.013	.91	0.26	.61	0.042	.84

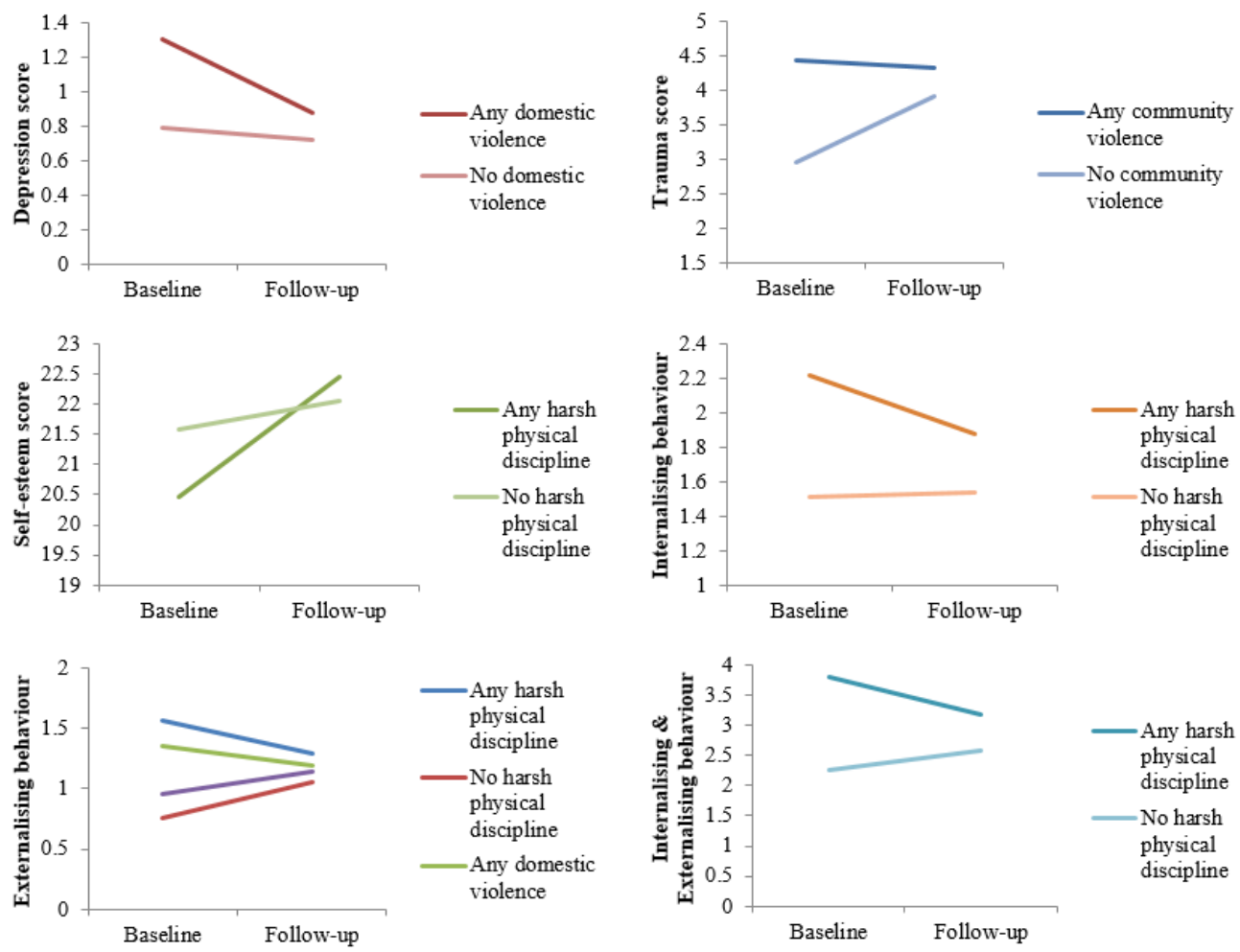


Figure 7.2. Change of child mental health measures over time according to exposure to domestic and community violence and harsh physical discipline.

All differences between exposure and non-exposure to these three types of violence are significant ($p < .05$).

7.5. Discussion

There are few studies from Sub-Saharan countries that have examined the relationship between violence exposure and child mental health outcomes over time, and fewer still exploring very vulnerable populations of children affected by HIV. This study compared exposure to home and community violence and harsh discipline practices with a range of child mental health outcomes over a 15 month period. There were high rates of violence exposure, that children living with someone who was HIV-positive were most affected, and that there are a range of negative mental health outcomes and problematic externalizing behaviours associated with this exposure to violence.

The high levels of domestic violence are commonly seen in South Africa at least, and may be linked to the fact that the sample was drawn from community organisations that serve children affected by HIV/AIDS, who are living in families in which risk for children may be particularly acute. In this study, violence exposure was more prevalent when someone else (other than the child) was HIV-positive. This could refer to other adult(s) in the household, which may have had ramifications on the social and economic make-up of the household. Previous studies have found high levels of negative behaviours, including violence, in households where a family member is HIV positive, and its impact on children (Betancourt et al., 2013). There was also considerable exposure to community violence which was not associated with depressed mood, but with trauma symptoms and behavioural difficulties. Harsh physical violence was associated with low self-esteem and both harsh physical violence and psychological violence was associated with emotional and behavioural problems. Violence between adults in the home was the only independent factor associated with depressive symptoms, and also predicted poorer outcomes across other domains of

mental health, including trauma symptoms, low self-esteem, and emotional and behavioural problems. This echoes findings from another recent South African school-based study in which home-based violence was the most significant risk factor for both internalizing and externalizing mental health problems in 12 to 15 year olds in an area of high community violence in Cape Town (du Plessis, Kaminer, Hardy, & Benjamin, 2015).

In the findings, older children were more likely to have higher self-esteem scores and lower reported emotional and behavioural problems. This pattern has been noted in previous research, with a decrease in the severity of behavioural problems rated by parents in studies in HICs (Niclasen et al., 2012). In line with previous findings, boys were also more likely to present with externalizing behaviour problems (Crijnen, Achenbach, & Verhulst, 2014). There were also country differences in these data. Unsurprisingly, given South Africa's turbulent political past and high levels of inequality (Seedat et al., 2009), violence exposure was higher among South African children, and related risk behaviours were three times more common. However, higher trauma symptoms in children from Malawi were noted. The reasons for these country differences are uncertain and it is difficult to draw conclusions about cross-country differences in the context of limited research about the relationship between violence exposure and mental health in Sub-Saharan African countries. However, a previous cross-country study, based in Kenyan and South African schools, also noted differences in trauma exposure and resultant trauma-related symptoms. In that study, the researchers found higher rates of exposure to violence among Kenyan adolescents, but significantly higher rates of post-traumatic stress disorder in their South African counterparts (Seedat et al., 2004). The authors suggest that these results may be due to cultural differences in the way in which trauma is understood and experienced, or due to trauma-related factors

that were not measured as a part of the study, such as the severity and timing of traumatic events. Both of these are potential reasons for this finding in the current study.

Over time, there was a decrease in symptoms of depressed mood, internalising and externalising behaviours, and an increase in self-esteem score for children experiencing different types of violence exposure at baseline. This may have been due to ongoing participation in the community-based programme, and that participation in the programme may mitigate the mental health risks experienced by these children over time. This is in spite of the fact that most CBOs do not have a direct focus on violence prevention, but rather a more generalist focus of provision of different forms of psychosocial support, nutrition and basic health services in the context of HIV. CBOs are particularly well-placed to work directly with families about issues relating to violence and that there is potential to develop community-based programming that focuses on violence prevention.

Limitations

The design of this study is subject to some limitations. First, it is a cross-sectional study, and thus it is not possible to attribute causality of child mental health outcomes to exposure to different types of violence. In addition, while efforts were made to ensure systematic sampling of participants for enrolment in the study, participants were recruited on a consecutive basis from CBOs and thus generalizability of the findings may be limited beyond this population. There is no comparison group in this study and all participants were in receipt of a community-based programme. Finally, violence exposure measures were based on child and caregiver-report. Previous studies from high-income settings have indicated that reporting of corporal punishment may vary according to informant.

7.6. Chapter Conclusion

Many risk factors for violence against children are particularly prevalent in HIV/AIDS affected families and communities. Violence in the home is associated with a range of negative mental health outcomes for children. It is possible that participation in community-based programmes mitigates the impact of violence exposure over time. CBOs who are working to improve psychosocial outcomes for vulnerable children affected by HIV/AIDS should integrate violence prevention programming into their work.

CHAPTER 8: DISCUSSION

The previous chapters (Chapters 4-7) addressed each of the research questions and discussed implications for the findings reported in that chapter. Chapters 4 reported on a review of interventions for children affected by HIV/AIDS while Chapter 5-7 reported on results of the Child Community Care study. In this chapter, I will review the main findings of the four chapters, and present the broader implications of the four. This chapter has three parts: firstly I provide an overview of the findings, with specific reference to answering the research questions in this study, the country differences reported and the study limitations. Secondly I reflect on the results of these different investigations as a whole; and finally I make four recommendations based on the implications of the findings for programme development in this area.

8.1. Overview of findings

8.1.1. Addressing the research questions

In the introduction, I outlined six separate research questions to be answered in this thesis.

- i) What evidence exists for interventions to improve psychosocial well-being of children affected by HIV/AIDS?
- ii) What are the prevalence and correlates of child developmental problems for children affected by HIV/AIDS who attend CBOs?

- iii) What are the prevalence and correlates of mental disorders in caregivers of children affected by HIV/AIDS?
- iv) What is the prevalence of exposure to home and community violence for children affected by HIV/AIDS?
- v) How is violence exposure in this group linked to the psychosocial well-being of children affected by HIV/AIDS?
- vi) Does service delivery differ by HIV status?

These were answered in detail in Chapters 4 – 7. In this section, I will summarise how the results presented answered each of these questions with related findings from this research.

Finding 1: There is a small but growing evidence base.

In contrast to the earlier review on this topic, the review in Chapter 4 identified a growing set of interventions to improve the psychosocial well-being of children affected by HIV/AIDS, which had primarily taken in place in eastern and southern Africa, where the burden of HIV is greatest. This revealed a gradual shift towards the prioritization of evaluating these interventions, which is promising. The interventions described differed greatly, however. Firstly, sampling strategies were varied. Had we used the King criterion of only including studies where 80% of the sample could explicitly be identified as orphaned or vulnerable as a result of HIV/AIDS, we would only have identified six studies (King et al., 2009). Secondly, there was no clear pattern of effects in terms of type of intervention, target recipient, length of intervention, length of follow up, or intensity of delivery. Thirdly, study design, outcome measurement and follow up time also varied. Interestingly, each of the four

different types of intervention (psychological, psychosocial, social, and physical health) showed at least one positive benefit on child psychosocial well-being, while interventions targeting the child only, caregiver only, caregiver and child together and entire family each showed some positive impact. Positive changes were noted across a range of psychological outcomes, including internalizing and externalizing behaviours, depression, anger, and anxiety, and higher rates of prosocial behaviour, self-help abilities and communication. Positive social outcomes that were recorded included retention in school, better school attendance, and less early marriage.

Overall, while the increase in research investment was a welcome finding of the review, it was noted that only four of the identified studies were of existing, real-life community-based programmes - the rest were developed specifically for research purposes. While it is important to test an intervention under controlled circumstances before scaling it up, it is likely that there are significant lost opportunities for evaluation in existing programmes. This is likely due at least partly to the challenges of evaluating these types of community-based programmes, where commonly used study methodologies might not fit well with the reality of how programmes are delivered.

Finding 2: There are high rates of developmental delay in children affected by HIV/AIDS attending CBO programmes.

In this sample, the prevalence of developmental difficulties was high, with over 40% of children screening positive in at least one domain. This is comparable to a new global estimate which stated that 43% of children under five years of age living in LMICs are at risk

of suboptimal development due to exposure to stunting or living in extreme poverty (Lu, Black, & Richter, 2016).

Finding 3: Child development outcomes are associated with HIV status and other family factors.

Developmental difficulties, physical health and psychosocial-related quality of life were all predicted by HIV status. Other independent predictors of these outcomes included irregular school attendance, poor housing conditions, living in a household with a sick family member, and living in South Africa. These findings appear to corroborate those from previous research on this issue; specifically that HIV status independently predicts poor developmental outcomes in children, even in the face of other challenges (Laughton, Cornell, Boivin, & Van Rie, 2013; Sherr et al., 2009b; Van Rie et al., 2007). The other factors associated with poor development in this study are also consistent with the literature: both school attendance and caring for sick relatives have been linked with poor child outcomes in previous research. Children affected by HIV/AIDS have been shown to be more likely to leave school early and have poor educational outcomes (Cluver & Operario, 2008; Guo, Li, & Sherr, 2012). It is not clear which risk precedes which in this case. Children who are developmentally delayed may be more likely to leave school prematurely: in South Africa, failing to keep up with school work is a primary determinant of dropout controlling for a range of other factors (Branson, Hofmeyr, & Lam, 2013). On the other hand, dropout is likely to affect long-term development. Caring for HIV-sick family members is also commonly reported for children affected by HIV, and is associated with a range of persisting negative outcomes in children (Cluver et al., 2013). Some evidence suggests that this is of

particular concern for girls, who are more likely to be taken out of school to care for sick family members (Cluver & Operario, 2009), but this was not evident in our data.

Finding 4: There is a high burden of mental health problems in caregivers of children affected by HIV/AIDS.

The mental health burden among caregivers was high, with 28% of caregivers scoring above the clinical cut-off for current psychological morbidity and 12.2% reporting recent suicidal ideation. Help-seeking rates were low, with only (59.6%) of participants with psychological morbidity having sought some kind of informal or formal care, even though they were actively in contact with the CBO.

There are limited epidemiological data on the prevalence of mental health problems in Malawi and South Africa. In Malawi, previous studies have investigated depression rates in women with young infants (30.4%) (Stewart et al., 2010), pregnant women recruited in an antenatal clinic (21.1%) (Stewart, Umar, Tomenson, & Creed, 2014), and people attending an outpatient department (30.3%) (Udedi, 2014). A study of adolescents reported a depression rate of 18.9% and a suicidal ideation rate of 7.1% (Kim et al., 2014). However, none of these studies was related to HIV, and none of these populations is directly comparable to the sample described in this study.

In South Africa, there has been one nationally representative epidemiological mental health study, the South African Stress and Health Study (SASH) which found a 12 month prevalence of 4.9% of major depressive disorder and of any mental disorder of 16.5% (Williams et al., 2008). Depression prevalence was higher among women and those with a

low level of education (Tomlinson, Grimsrud, Stein, Williams, & Myer, 2009). This prevalence varies greatly from what was found in this study. A study in the rural Eastern Cape Province detected a current depression rate of 21.1% among women and 13.6% among men (Nduna, Jewkes, Dunkle, Shai, & Colman, 2010). HIV-related studies have noted a prevalence of depression symptoms of 14% in ARV clinic attenders (Myer et al., 2008) and 25.4% in new treatment initiators respectively (Pappin, Wouters, & Booysen, 2012). A similar community study of caregivers of children affected by HIV reported rates of clinically significant depression symptoms of 30.3% (Kuo & Operario, 2011), similar to the finding reported here.

In terms of help-seeking, as noted earlier, the SASH study data showed that only a quarter of respondents with a mental health problems had received treatment in the past 12 months from any provider (Seedat et al., 2008). There is no help-seeking data available from Malawi, but extremely poor detection rates of depression have been noted in health settings (Udedi, 2014). This highlights another concern: in most LMICs hard hit by the epidemic, mental health services are under-developed and not meeting the needs of those who need them. In South Africa, there is large variation in the availability and quality of mental health care (Lund, Kleintjes, Kakuma, & Flisher, 2010) and in Malawi mental health care is delivered primarily through centralised mental hospitals making it largely inaccessible (Kauye et al., 2011).

Finding 5: Caregiver mental health problems are associated with socio-economic factors, caregiving burden and lack of community support.

Poor caregiver mental health was associated with socio-economic factors (household unemployment, food insecurity, country of residence), caregiving (living with a sick family member) and perceived lack of support from the community.

The relationship between household unemployment and food insecurity in our data is line with previous studies. There has been a wealth of research showing that poverty and mental health are linked in a bi-directional manner: those living in poverty are more likely to develop mental health problems as a result of the numerous risks to which they are exposed, while having a mental illness can also lead to economic vulnerability (Lund et al., 2011). On the other hand, however, we did not find a direct independent relationship between caregiver HIV status and mental health as has been noted in other research. This finding is likely to be due to the high levels of vulnerability of this sample and the fact that even in the absence of the caregiver being directly infected, there were high numbers of caregivers (one third) who were living in the same household as someone with HIV, an important risk factor in itself in this study. Factors associated with high mental health burden have included aspects of caregiving, although in other research these have been found to be caregiving for AIDS-orphaned children (Kuo & Operario, 2011; Kuo et al., 2013), which was not specifically reported on here. Lack of social support for caregivers of AIDS-affected children has also previously been identified as an important factor (Casale et al., 2013).

Finding 6: There are high levels of violence exposure in this sample

There were high levels of exposure to interpersonal violence in this sample, with nearly half of the children exposed to violence between adults at home, and 42.5% exposed to violence in their community. Harsh physical and psychological discipline techniques were also reported at similar rates. Given that the sample is a population of children affected by HIV/AIDS, these results were in line with other research. Previous studies have found elevated levels of negative risk factors, including violence, in households where someone is HIV positive (Betancourt et al., 2013).

Finding 7: Child mental health problems in this sample are linked with exposure to violence.

In these data, there is a clear link between exposure to different type of violence and poor mental health outcomes in children. Interpersonal violence in the home predicted child depression, trauma symptoms, lower self-esteem, and internalising and externalising behavioural problems, while exposure to community violence predicted trauma symptoms and behavioural problems. Harsh physical discipline predicted lower self-esteem and behavioural problems for children. There has been little research on child abuse and exposure to violence in sub-Saharan Africa (Centre for Justice and Crime Prevention, 2016). Existing research tends to focus on adolescents (Kaminer, Grimsrud, Myer, Stein, & Williams, 2008; Seedat et al., 2004). Engaging in risk behaviours was also associated with exposure to home and community violence. This is also commonly reported in the literature from high income settings (Dubowitz & Bennett, 2007; Mills et al., 2011; Mock et al., 2008; L. Richter et al., 2014).

Finding 8: There are differences in programme delivery reported by HIV status

There was a fair degree of variation in services received by children. HIV+ children tended to have been enrolled in CBO programmes for a longer period compared to HIV- children, but had significantly lower levels of contact with these organisations. It is possible that HIV+ children had been enrolled in programmes for longer based on the fact that programmes may have used HIV status as a criterion for entry in the past. It is likely that entry to programmes is increasingly not limited to orphans or HIV+ children only.

Secondly, services that were received by children differed in terms of HIV status. HIV+ children were more likely to be receiving medical services, and psychological interventions, but less likely to be enrolled in early childhood intervention programmes and educational support programmes. This suggests that, to some extent at least, CBOs are already engaging in a level of targeting of services. This is a promising finding as it suggests that organisations are able to tailor services for children who have particularly complex needs. However, given the evidence from this and other studies that HIV-positive children have poor developmental outcomes (Sherr et al., 2009a), it appears that organisations may not be sufficiently focusing on stimulation and educational support programmes for infected children.

8.1.2. Country differences

There was no difference between South Africa and Malawi in terms of enrolment of children, the duration of contact with CBOs, and services provided. However, there were country differences noted in terms of outcomes for both children and caregivers. South African children and their caregivers appeared to be worse off than their Malawian counterparts. For a start, South African caregivers were more likely to report mental health problems and suicidal ideation, and South African children were more likely to present with developmental delays, be exposed to violence and engage in risk behaviours. On the other hand, trauma symptoms were higher in children from Malawi than in South Africa.

The cultural contexts of South Africa and Malawi are very different. Malawi is a small but heterogeneous country, with English and Chichewa dominating as spoken languages. South Africa is much larger, also multi-ethnic society, with eleven national languages and many race groups, as well as many migrants from other African countries. South Africa is wealthier than Malawi with a GDP per capita of USD5691.7 compared to Malawi's USD381.4 (World Bank, 2016). However, there are extremely high levels of inequality in South Africa compared to Malawi, with Gini indices of 63.4 and 46.1 respectively (World Bank, 2017). In terms of HIV, infection rates vary widely in South Africa with an overall average of 19.2%; in Malawi, prevalence is lower at 9.1%. South Africa had delayed roll-out of antiretroviral therapy but now has one of the largest programme in the world. In spite of this, coverage of antiretroviral therapy is better in Malawi at 61% vs South Africa's 48% (UNAIDS, 2017).

Overall, while differences in the two countries are clear, the explanation for these country differences are uncertain, particularly in the context of limited research about mental health and developmental outcomes in the sub-Saharan African countries. In terms of caregiver mental health, previous research has suggested that South Africa may have higher rates of mental health problems than many other African countries (Herman et al., 2009). South Africa has a traumatic recent history. Substance use is common, with extremely high levels of misuse of alcohol (Scott-Sheldon et al., 2012), cannabis, non-medical use of medications (Saban, Flisher, Grimsrud, Morojele, London et al., 2014) and rising use of methamphetamine (Plüddemann et al., 2010).

There are high rates of violence and injury (Seedat et al., 2009). Of note, intimate partner violence has been associated with depression, PTSD, binge drinking and suicidal thoughts and attempts in women in the country (Jewkes, 2013). In terms of the trauma finding, contradictory relationships such as this one has been found before. As noted in the relevant chapter, a previous cross-country study in Kenya and South Africa noted the same relationship in terms of trauma exposure, with higher rates of exposure to violence among Kenyan adolescents, but higher rates of PTSD in a South African comparison group (Seedat et al., 2004). In this study, as in that one, the lack of measures of repeated trauma and nature and severity of trauma, may have contributed to this finding. One possible explanation for the finding about the different rates of developmental delay is linked to treatment coverage. In South Africa, the estimated coverage of children receiving antiretroviral therapy is 68%, compared to Malawi's 55% (UNICEF, 2016). This may mean that infected children in South Africa are more likely to survive, and present with developmental problems. However, more information is needed before this can be ascertained.

Finally, the lack of standardized tools available is likely to be another consideration. The outcomes measures used in this study have not all been validated or used in both countries. For the purpose of this study, we required screening tools and questionnaires that could be administered by trained non-professional data collectors in a range of community environments. The tools needed to be relatively easy to administer and not too onerous for participants, who are required to provide responses to a range of tools beyond those described in this thesis. It is possible that there were differences in terms of the two countries in terms of responses to the tools that were used. However, at all times, tools were selected based on their use and validation in these two countries or in other countries that were judged to be as similar as possible. There are limited appropriate and validated tools available for assessing and screening for child development outcomes in LMIC in general (Sabanathan, Wills, & Gladstone, 2015) meaning that selection of tools was difficult. Until such time as tools are developed using appropriate universal stimuli, validated in-country, and used on an ongoing basis to track child well-being, it will be difficult to judge what kinds of measurement issues persist in the measurement of child development in LMIC.

8.1.3. Limitations

In addition to the lack of standardized tools available for tracking child outcomes discussed above, there are there are other limitations to this study which should be noted. First of all, the sample for this study was drawn entirely from community-based programmes for children affected by HIV/AIDS, and was not a community-based sample. This was required in order to fulfil the aims of the overall project of investigating outcomes within a programmatic context. This does mean, however, that the population might not be representative of all children affected by HIV/AIDS. It is likely that particularly needy

caregivers are more likely to seek out community services for support, or that CBOs actively seek out vulnerable families with which to work, or that CBOs end up receiving a high number of complex cases from their communities because of a lack of local services.

Secondly, from a methodological perspective, the data reported in this study are largely cross-sectional data at one time point and thus causal inferences cannot be drawn. It is useful however, from an epidemiological perspective in order to improve our understanding of the various risk factors linked to the outcomes that were explored in this study. In Chapter 8, we have included data from a one year follow up which allowed us to detect changes in the sample over time. Other findings from the larger Child Community Cohort study which report on longitudinal data have been published elsewhere (Hensels et al., 2016; Sherr, Skeen, Hensels, Tomlinson, & Macedo, 2016; S Skeen, Macedo, Tomlinson, Hensels, & Sherr, 2016).

There is no direct comparison group in this study who received no intervention at all. Given the context of where the study was conducted, in a number of small CBOs, it was not possible to use a design with a comparison group. In this case, programme roll-out was already underway and it was not ethical to randomise new participants in these programmes as they are often the only source of support for a community (Rossi, Lipsey, & Freeman, 2004). The purpose of the overall study is to examine differences in programme outcomes, but this will be reported elsewhere.

Thirdly, HIV status was confined to self-report and was not confirmed with laboratory testing. Of note for this study, the CBOs that were included were identified as organisations for children affected by HIV/AIDS; and it is likely that caregivers and children felt more

comfortable to speak about HIV in the context of the CBO than they would in the broader community. In addition, in order to maximize data quality, data collectors were well trained to administer tools in a standardized way, ask all questions in a sensitive manner, and to ensure confidentiality at all times. All team members underwent regular supervision, and there was ongoing quality control of all data.

Finally, it was part of our study criteria that all children who were interviewed were included in the study along with their caregiver. Part of the ethical requirements of the study were that this person was an adult over the age of 18y. This may have led to the exclusion of children living in child-headed households. Data from South Africa has shown that child-headed households are rare (0.47% of households) and that the majority are made up of adolescents over 15 years of age (Meintjes, Hall, Marera, & Boule, 2010) meaning that this was unlikely.

8.1.4. Reflections on combined findings of this thesis

The Child Community Care study, of which this PhD forms a part, is the first study to describe child outcomes for children affected by HIV/AIDS who are attending community-based programmes to improve psychosocial well-being. Most studies of this group have sampled children from clinic populations, or from single schools or organisations. Often, caregivers are not included in study design. By including a wide variety of outcomes, at all levels, we have been able to trace relationships between different types of risk, where there is limited research data available.

In the results reported in Chapters 4 – 6 we get an overall picture of a group of children who are exposed to high levels of intertwining risks, including extreme poverty, elevated developmental problems, a high rate of caregiver mental health problems, who are exposed to violence both at home and in their communities. This, in combination with either their own HIV infection, that of their caregiver, or other adults in their homes and communities, means that this continues to be an extremely vulnerable group that requires ongoing attention from funders, even as rates of child infections fall.

In the data reported in this thesis, caregivers were at risk of poor health and psychosocial outcomes, and factors relating to caregivers and parenting were associated with developmental disability, child mental health and child exposure to violence. In framing recommendations for programming for this group, I have considered the potential role of CBOs to address the different levels of risk discussed in the introduction, with a specific focus on caregivers and their role in these interacting and transacting components. Caregivers, “proximal” to the child, have high levels of influence on his or her development (Sameroff, 2009). In the violence literature it has been suggested that parenting is a protective factor or buffer against the risk of violence exposure (Spano, Vazsonyi, & Bolland, 2009). Similarly, previous research supports the notion that parenting promotes resiliency in children affected by HIV/AIDS (Kaljee et al., 2016). While causal inferences cannot be drawn from these cross-sectional data, this relationship between caregiving and child outcomes appears to be highly relevant for this sample.

Our results show that CBOs are reaching vulnerable children and their families. Based on the findings from the organisation sample and the systematic review, we can conclude that CBOs certainly remain a viable option for delivering interventions. CBOs were

found to be delivering a wide range of interventions, while the review showed that it is feasible to deliver interventions effectively in community settings. However, the studies reported here also expose gaps in service delivery for this group, and suggest potential mechanisms for delivering successful interventions in future work. Recommendations for the development and delivery of programmes that target these areas are included in the next section.

8.2. Recommendations for programming

In the next section I discuss four recommendations for programme development for CBOs that have emerged from this work:

- i. to target caregivers in CBO interventions, through integrated parenting-based programmes that address a range of risk factors including violence prevention;
- ii. to explicitly include mental health as a programme priority for this group;
- iii. to build capacity of CBOs through providing ongoing training, supervision, support; and
- iv. to develop partnerships between researchers and CBOs.

8.2.1. Target caregivers through integrated caregiver-inclusive programming

My first recommendation is to develop integrated caregiver-inclusive programming for families affected by HIV/AIDS.

The results of this study have highlighted the complexity of needs that children affected by HIV and their caregivers and families experience. In spite of this, it appears that

a number of programmes still operate without caregiver involvement. The systematic review in Chapter 4 revealed a number of interventions that were delivered in the absence of the caregiver's participation at any level.

One potential avenue is through the adoption or integration of parenting programmes as an intervention delivery method, as standalone activities or as add-ons to existing programming. A parenting programme is an intervention designed to improve parenting skills and the functioning of families, to the benefit of children and their parents (Kane, Wood, & Barlow, 2007). These types of interventions provide a promising model of intervention delivery for CBOs to utilize in their service delivery. The evidence base from LMICs is small, but parenting interventions have been used to improve diverse outcomes for children in a wide range of contexts, through changing parenting practices. There are existing models which are deliverable by trained and supported lay community health workers that have been tested in South Africa, Rwanda, and Bangladesh, among other settings (Aboud, Singla, Nahil, & Borisova, 2013; Betancourt et al., 2014a; Cluver et al., 2016; Cooper et al., 2009; Vally, Murray, Tomlinson, & Cooper, 2015). There is evidence (from HIV or closely related studies in LMIC) that they can improve parent-child relationships (Li et al., 2014; Murray et al., 2016; Cooper et al., 2009), cognitive and motor development (Potterton et al., 2010), child psychosocial well-being (Rochat et al., 2017) and reduce child abuse (Cluver et al., 2016). There is also evidence that they can benefit maternal mood. In South Africa, the Thula Sana home visiting intervention led to an improvement in maternal mood shortly after the intervention ended (Cooper et al., 2009) which appears to have been sustained at 13 years post-intervention (Tomlinson, 2017). In HIC, there are a number of examples of the benefit of parenting programmes to maternal mental health

(Barlow, Coren, & Stewart-Brown, 2003; Barlow, Smailagic, Huband, Roloff, & Bennett, 2014).

Programmes to improve child psychosocial and other development outcomes are most likely to be successful if they address multiple risks at the same time, and do not have a narrow focus on single factor outcomes (Yousafzai et al., 2014). CBOs are a good vehicle for the delivery of integrated parenting interventions focusing on a number of different risk factors, as they tend to offer broad interventions and focus on multiple issues simultaneously. Current funding priorities for CBO funders have been outlined in Chapter 2 and include the provision of cash transfers and cash plus care type interventions. In the systematic review reported in Chapter 4, there were a number of interventions which included cash or material support components, delivered at community level, that were successful in improving a range of child and adolescent psychosocial outcomes (Baird et al., 2010; Hallfors et al., 2011; Ssewamala et al., 2016; Ssewamala et al., 2012). Other research has shown the benefit integrated cash plus care on HIV-risk behaviour in adolescents (Cluver, Orkin, Boyes, & Sherr, 2014). For the most part, these payments were made to caregivers (when not paid directly to schools for fees, for example). This type of engagement with caregivers may provide a good contact point for the provision of services directly to the caregiver and lay a foundation for ongoing and regular contact with them.

8.2.2. Explicitly include mental health as a programming priority

My second recommendation is to specifically and explicitly include mental health in programming efforts, in particular for caregiver mental health.

The results reported in this study, and particularly in Chapter 5, have shown that there is a heavy burden of mental health problems in this group, particularly with regard to caregivers of children affected by HIV/AIDS. This study has shown that CBOs are already engaging with people in need of mental health support and providing various forms of care for children and their families. However, mental health does not have clear and explicit focus as a priority area for programming which is evidenced by its omission the past and current lists of priority areas for study partners outlined in Chapter 2 and the low rates of help-seeking for mental health in this group (even though they are in contact with community-based psychosocial services). Part of the reason for this lack of recognition of mental health as an area of concern is likely to be linked to the fact that mental health continues to be seen as a standalone and specialized area for intervention in many contexts, and not necessarily recognized as a consequence of poverty and other negative social circumstances at a policy level (Plagerson, 2015).

In developing interventions which address mental health concerns there are lessons to be learned from the field of global mental health, which seeks to improve mental health and to promote equity in accessing mental health care, with special relevance to LMIC (Patel & Prince, 2010). To date, a large body of work in this field has focused on closing the treatment gap for mental health problems in LMIC. WHO's Mental Health Action Plan 2013–2020 recommends a number of actions to address this, including capacitating non-specialised health professionals to provide mental health services, especially at the primary care level (World Health Organization, 2013). This approach is likely to be the most effective and sustainable strategy to increase the accessibility of mental health care globally (Patel et al., 2011).

There is a great deal of evidence from low-resource settings on the effectiveness and acceptability across contexts of task-shifting (the use of non-specialist workers) to provide mental health services (Murray, Dorsey, & Haroz, 2014). The authors of a Cochrane review on the topic concluded that non-specialist health workers (specifically general doctors, nurses, social workers, and community health workers) could improve mental health outcomes for adults with depression, anxiety and post-traumatic stress disorder, including for mothers with perinatal depression during the perinatal period (Van Ginneken et al., 2013). In a similar, more recent review of psychological treatments delivered by generalist health workers for the same three conditions in LMIC, authors concluded that there was evidence of medium to strong effects of these types of programmes (Singla et al., 2017).

While non-specialist programmes are successful in improving mental health outcomes, the interventions that have been developed are targeted at non-specialist doctors, nurses and community health workers who are aligned to government services for the most part. Based on the results presented in this thesis, I would argue that efforts to increase equity in mental health care and to meet the needs of vulnerable groups need to extend beyond the formal health sector only. This will require engaging more effectively with non-governmental programmes and more specifically with community-based groups. This is supported by members of the global mental health community who suggest that the delivery of interventions could be expanded to include a range of community members, including volunteers and peers (Patel et al., 2011).

Task-shifting

Many task shifting approaches to mental health care make use of structured, manualized interventions, prescribe numbers of sessions of treatment, are based on set diagnostic categories and do not address treatment of co-morbid conditions, and have limited flexibility to change focus depending on client needs (Murray et al., 2014a). Implementation of these types of mental health interventions thus requires extensive training across a range of different treatment protocols for different disorders, and when to implement each type (Farchione & Bullis, 2014).

A common elements approach

There is increasing interest in and evidence for transdiagnostic interventions, which may be more suitable for these contexts (Weisz, Chorpita, Palinkas, et al., 2012). This type of approach has been developed based on the notion that different evidence-based mental health interventions rely on the same set of skills or practices, across different diagnostic categories (Bolton et al., 2014). It entails teaching health workers these different elements, with the use of decision rules and guidelines, which can then be sequenced and combined depending on client needs (Murray & Jordans, 2016). There are a number of benefits to this approach which are relevant for the community setting, including flexibility of delivery, and the fact that facilitators only need to be taught one approach to mental health interventions which can be adapted to different problems (Brown, de Graaff, Annan, & Betancourt, 2017). This reduces the required resources needed to teach skills across a range of different diagnoses, rather than focusing on different problems separately (Murray et al., 2014a).

There is evidence to support the use of common elements interventions for both adults and children. The Common Elements Treatment Approach (CETA) developed by Murray and colleagues (Murray et al., 2014a) was used to address depression and posttraumatic stress in Burmese adult refugees with trauma history in Thailand and found a large effect on both outcomes (Bolton et al., 2014). Murray et al. (2014a) report on positive findings of a pilot of the intervention in Iraq for adult survivors of torture or systematic violence. Work for children using this approach has identified core elements for improving well-being such as psychoeducation for the child and caregiver, building insight into problems, building relationships with significant others (including caregivers) among other components (Brown et al., 2017). Evidence from HIC has shown that this approach can improve mental health outcomes for children and youth (Chorpita, Taylor, Francis, Moffitt, & Austin, 2004; Weisz et al., 2012). Previous studies using this approach in LMICs include an intervention with youth with complex mental health needs in Sierra Leone which used this approach resulted in improved emotional regulation, prosocial behaviour, social support, school enrolment and attendance and behaviour (Betancourt et al., 2014b).

Using a flexible common elements approach is likely to especially be useful for CBOs, such as those sampled in this study, to target specific high-risk children and families within their client base. Targeting of interventions to the most vulnerable in this way can reduce inequities in the provision of health care (Malqvist, Yuan, Trygg, Selling, & Thomsen, 2013). We have seen that within this sample, there are specific sub-groups with more complex needs who may need additional specific support, such as children with HIV infection, those exposed to domestic violence, and those with developmental disabilities, and their caregivers.

8.2.3. Invest in building capacity in programmes

My third recommendation is that funding CBOs should be coupled with ongoing capacity development for programmes and programme implementers.

Community-based programmes require resources in order to establish, maintain and strengthen their programming (Lehmann & Sanders, 2007). In order to build upon CBO activities, such as parenting and mental health interventions as recommended above, there is a need for significant investment into the programmes that are providing these services to children and their families affected by HIV/AIDS. Combining programme funding with resources capacity development will require additional or earmarked resources from funders.

Previous research on community health worker interventions in LMIC has shown that there are different factors that are important to ensure the success of these types of programmes. These include community involvement, political or institutional support, potential for career development and remuneration, linkages to the broader health system, flexibility of programming, and training, and supervision and support (Celletti et al., 2010; Scott & Shanker, 2010). In this section, I focus particularly the role of funders in supporting efforts to improve training and supervision in these programmes.

Training and supervision

CBOs should be encouraged and supported to link to existing training programmes. There are some training models developed specifically for these types of organisations that have been successful in improving skills in psychosocial support and care. For example,

study partner REPSSI has been running an eighteen month distance-learning course in Community-Based Work with Children and Youth in ten countries in Africa over several years. The course aims to professionalise care for vulnerable children and youth by training community workers working in the field, and has had success in a range of settings (Chakanyuka, Vilakati, & Ferreira-Meyers, 2015; Kakowa, 2016). Another example is the Diploma Programme on Psychosocial Care, Support and Protection which is a 15 month long-distance learning programme focused on upskilling educators to improve psychosocial support within schools. An RCT of this programme in Zambia showed that there was a positive impact on both facilitators and their clients (Kaljee et al., 2016).

However, in addition to linking to external training programmes, funders and large NGO partners should include access to training, supervision and ongoing support as a part of their commitments to CBOs. These include initial training, as well as ongoing training and supervision opportunities.

Initial training programmes are of critical importance to establishing new community programmes or integrating new aspects of caregiving into existing modalities (Celletti et al., 2010). They should be considered as a foundation or first step for skills building, with an aim of providing the basic knowledge and skills required for implementing new content (Murray et al., 2011). However, an initial once-off training is not likely to be sufficient to benefit programme implementers or their clients on an ongoing basis. Previous research has shown that once-off training approaches may increase knowledge in the short term (Murray et al., 2011), but that this will not be sustained over time (Hermann et al., 2009).

Training should rather be seen as an ongoing activity that requires ongoing support. Using supervision as a strategy to improve community worker performance may work well in CBO settings. Supervision activities tend to consist of a local senior worker, familiar with the programme, who provides feedback and coaching to the community worker with the aim of supporting them to implement the programme with fidelity (Murray et al., 2011). They have been identified as a key ingredient for success in a review of successful community worker interventions (Patel et al., 2011). Yet, they are often not planned for or funded in the inception phase of new interventions, to the detriment of programme roll-out (Celletti et al., 2010). One promising option that might work well at scale in settings with limited resources is peer supervision which has been used effectively in mental health interventions in LMIC (Brown et al., 2017). Community health workers can be trained to review and provide feedback on the performance of their peers in the delivery of psychosocial interventions (Singla et al., 2014). The ‘ENhancing Assessment of Common Therapeutic factors’ (ENACT) rating scale has been developed specifically for this purpose for common elements treatment programmes.

8.2.4. Develop partnerships between researchers and community-based organisations

My fourth recommendation is that funders should invest in the development of partnerships between researchers and CBOs, specifically through directing funding towards joint evaluation projects, with the dual aim of evaluating intervention outcomes and documenting the processes of intervention delivery.

This recommendation ties in with recent calls in global health for an increased focus on research into the delivery of health care interventions to improve health outcomes in

LMIC in order to maximise programmatic resources (Kim et al., 2013). As noted in Chapter 4, there are few working programmes that are being systematically evaluated and disseminated to stakeholders working in this field. While the growth in research in this area is a welcome development, the limited numbers of tested real-life CBO interventions means that funders are likely to be having to make decisions about scaling up interventions based on limited information.

There are good examples of collaboration where strong study designs can be integrated into existing programming without compromising intervention delivery. One example is the *Philani Maternal, Child Health and Nutrition Project*, a non-governmental organization that provides home visits through its Mentor Mother programme to pregnant women, new mothers and their infants. They have been engaged in a collaborative project with researchers over several years to assess the impact of their intervention, using a cluster RCT (Rotheram-Borus et al., 2011; Rotheram-Borus et al., 2014).

However, there are a number of challenges inherent in evaluating the outcomes of CBO programmes, such as the small size of many of these organisations, the lack of local research capacity, the conflict of interest inherent in programme evaluation for funding purposes, high cost and the logistical difficulties of conducting research in vulnerable communities (King et al., 2009). CBO programmes tend to have developed in response to community needs, with blurred lines of provision with other community services and groups. The interventions that are delivered by CBOs are often complex and consist of several components, which can be difficult to disentangle. Psychosocial programmes for children affected by HIV/AIDS are highly varied and methods of delivery also vary. Research activities often need to take place in settings with limited trained personnel, high staff

turnover, lack of resources such as private interview rooms and transport for participants, among other challenges (Murray, Tol, & Jordans, 2014). Building partnerships with communities is likely to take time, as is developing research capacity in CBOs (Baydala, Ruttan, & Starkes, 2015).

It is also likely that collecting additional specific information on child psychosocial well-being and associated risks is likely to lead to the identification of particularly vulnerable children from within organisation's services. In the development stages of new research activities with organisations, careful consideration will need to be given to ethical concerns arising from such partnerships. This will entail developing plans for referral and follow up for severe acute and chronic cases together with organisations and other local resources (Betancourt et al., 2016).

In recognition of the challenges noted above, and of the complicated nature of evaluating child well-being outcomes, there is a need for new research methodologies which take these complex intervention types, settings and delivery modes into account (Landsverk, Brown, Reutz, Palinkas, & Horwitz, 2011). This requires the development of studies that are designed to fit into real-world settings (Hohmann & Shear, 2002), and take account of a range of factors in designing their studies, including feasibility, generalisability of the study setting, and acceptability of the intervention. In addition to these practical concerns, however, study design should also be dictated by particular research needs in the area of study (Petticrew & Roberts, 2003), so that the evidence that is generated can be applied in the context in which it is going to be used (Rychetnik, Frommer, Hawe, & Shiell, 2002).

For example, it is often not possible to use an RCT design in assessing community programmes for children affected by HIV/AIDS. RCTs are often understood to be the gold standard of programme evaluation, in that they can provide the strongest evidence for a programme's effectiveness (Campbell & Russo, 1999; Shadish, Cook, & Campbell, 2002). However, they are not suitable for use in all research contexts. They are well-known to be time-intensive and expensive (Rossi et al., 2004). This can make them difficult to complete in resource constrained contexts, or where there is an urgent need for information regarding an intervention's effectiveness. Often, as is the case of the present study, programme roll-out has already occurred. It may not be ethical to randomise new participants into existing programmes as they are often the only source of support for a community (Rossi et al., 2004).

Although using other methodologies, such as quasi-experimental evaluations, may yield more biased estimates of programme effects than RCTs, arguably because of the pressing need for evidence on the effectiveness of these community programmes for children in the sub-Saharan context, they may be better suited to generating the initial research on this than RCTs. In this way programme evaluations may contribute to the development of a preliminary evidence base, which is later substantiated by RCTs for those programmes which have shown at least some suggestion to be effective – thereby preventing resources from being wasted on expensive trials for programmes which were unlikely to show any effects.

Promoting partnerships between CBOs and researchers will allow for systematic tracking of data from intervention programmes. But, it is important that research partnerships do not only focus on outcomes, but also on the processes of delivering interventions. In order to improve the implementation of new interventions across different settings, there is a need to record and measure the processes that are undertaken to deliver them. Yet, often

implementation-related information is restricted to case studies and anecdotal evidence (Proctor et al., 2009). Measuring implementation outcomes has a number of benefits. First of all, it is critical to understanding if the intervention was implemented as planned, how the implementation took place, and if the intervention worked (or didn't work) because of contextual factors as opposed to intervention-related factors (Proctor et al., 2011). Secondly, the information gathered can be used for programming purposes, such as to identify the minimum required resources for aspects such as training and supervision for successful interventions (Murray et al., 2014b) and for improving the quality of interventions (Powell, Proctor, & Glass, 2014). Finally, an understanding of implementation processes is important for scaling up interventions to be used at a broader level (Betancourt & Chambers, 2016).

There are a number of technical support areas where funders could provide valuable assistance to CBOs, such as assistance with mapping interventions, strengthening monitoring and evaluation frameworks, advising on indicators and tools for tracking change over time that are quick and easy to administer and providing training in data collection and management. Funders could also support work to develop a core set of indicators to track programme performance and outcomes, across their suite of funded programmes, or different funders could work together to promote the use of a core set of indicators across the field. On the other hand, it is imperative that CBOs are seen as equal partners in these relationships. Community involvement and participation is a prerequisite for successful community interventions (Lehmann & Sanders, 2007; Scott & Shanker, 2010) and without the support and involvement of local community partners, recommendations from research may not be readily taken up. Partnerships between CBOs and researchers would require engagement of both partners from conception of joint projects and through each phase in the process (Israel, Schulz, Parker, & Becker, 1998). Understanding how interventions for children can be

introduced and carried out successfully in real-life settings requires the meaningful involvement and contribution of those who will be the implementers (Parsons et al., 2013).

It is through ongoing investment in developing these partnerships that we will be able to develop new intervention strategies that are evidence-based, acceptable, appropriate and feasible for delivery in CBO settings.

CONCLUSION

The findings from this study feed into a growing knowledge base on developing interventions to support the millions of children affected by HIV who are in need of care and support programmes, particularly in sub-Saharan Africa. CBOs are well-placed to intervene with vulnerable and hard to reach children and families and there are promising models of interventions available, although the evidence is still limited. These data provide us with a number of potential pathways to improve CBO programming to meet the needs of these children. Caregivers should not be neglected in programming, and parenting programmes provide a potential mechanism for delivering integrated interventions that address multiple risk factors for caregiver and child well-being. Mental health, particularly of caregivers, should be explicitly addressed as a part of CBO programming. However, support for programming in these areas needs to be implemented with training and supervision from the agencies that fund these organisations. In addition, there is a need for increased partnerships between practitioners and researchers in order to evaluate existing programmes and to design evaluation studies that meet community needs, are feasible in community settings, and provide lessons for future intervention development and delivery.

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Appendix 2: Consent forms

Carer consent form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM: CARER
--

You are being invited to take part in a research project. Please take some time to read the information on this form, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you clearly understand what this research is about and how you could be involved. Also, whether you choose to be involved in this study or not is completely up to you. No one is forcing you to take part. If you say no, this will not affect you negatively in any way whatsoever. You are also free to change your mind at any point, even if you do agree to take part in the beginning.

This study has been approved by the Committee for Human Research at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki (2013), South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

This study will be conducted at the local community-based organisation (CBO) where your child is being seen. A lot of children from a lot of different CBOs will be included in the study. The information from the study will be examined by researchers in South Africa and in the United Kingdom. The Swedish International Development Cooperation Agency (SIDA) is paying for the study.

What are we trying to do?

This is a study which aims to find out more about how children who attend CBOs are doing at home and at school, about their relationships with others, and how the homes and communities in which they live have an impact on their lives. The answers will help the CBO know how to improve the service that they give.

How will we do this study?

The assessment includes asking for information about social factors (such as about the households that they live in), child development and school performance of the children. Once we have done the assessment with all the participating families we will be able to learn about child development in this community.

What will the assessment involve?

- Children will be interviewed by the research staff using questions which tell us a little bit about how they function in the social world, at school and at home.

- Their carers will be interviewed about their own lives, and how they function in the social world, at home and at work.
- The community organisation will be interviewed about what kind of services they provide for children.
- All of the answers will be entered into a mobile phone which will send the information as a message to our storage computer.

Why have you been invited to participate?

Your child is presently involved with a community-based organisation and we would like to help the organization know how to improve the service that they give.

What will we be asking you to do?

We will ask you to attend the research centre at a time convenient to you, so that we may interview you and your child. The whole assessment should take no more than a couple of hours of your time at the most.

Will you benefit from taking part in this research?

The research will not benefit you or your family directly, but the CBO may benefit from the findings.

Are there any risks involved in your taking part in this research?

This study involves speaking to you and your child. Most children enjoy taking part and the research is conducted in a child friendly, non-threatening manner. A few carers or children might

become upset, however, this is unlikely. No harm will come to you or your child through taking part in the tasks which form the study.

If you do not agree to take part, what alternatives do you have?

You do not have to take part in this project and, if you decide not to, this will not affect you or your child at all.

Who will have access to your information?

All data will be stored anonymously and your and your child's name will be kept in a secret record held by members of the research team. The only time we might share a child's name with others is if we find that the child is the victim of abuse. If this study is published in a journal, all the families involved and names of individuals will remain anonymous.

Study monitors, may need to look at all study records at some point, but nobody will be able to identify you personally. The results of the study might become public, but your information will remain confidential.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study.

Is there any thing else that you should know or do?

- You can contact Prof. Mark Tomlinson at 021- 808 3446 (office) if you have any further queries or encounter any problems.

- You can contact the Health Research Ethics Committee (HREC2) at 021-938 9207 if you have any questions or concerns about your rights and welfare as study participants.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant. By signing below, I agree to take part in the study.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signature of participant: _____ **on (date):** _____.

Declaration by investigator

I (*name*): _____ declare that:

- I explained the information in this document to: _____
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

Signed at (*place*): _____ on (*date*): _____

Signature of investigator: _____

Child assent form

PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM: CHILD

What is RESEARCH?

Research is something we do to find new knowledge about the way things (and people) work.

We use research projects or studies to help us find out more about keeping people healthy and free from disease or illness.

What is this research project all about?

This is a study which aims to find out more about how children act at home and at school, and about how they play with and talk to people and the things around them.

Why have I been invited to take part in this research project?

We have asked you to be involved in this study because you have been spending time at a community-based organisation _____(name organisation).

Who is doing the research?

Two professors called Lorraine Sherr and Mark Tomlinson are in charge of the study. They are doing the study because they are interested in learning about young people. Mark is from Stellenbosch University.

What will happen to me in this study?

We would like to do an interview with you which means that we would like to spend some time with you asking you certain things about yourself. The things we are interested in are about how things are for you at school. We want to know how you get on with other people in your class and with your friends at home. We also want to know how you are doing at school. We also have some questions about your thoughts and feelings. In total we think the interview should take about one hour.

Can anything bad happen to me?

Although most children enjoy the interview, it is possible that some of the questions might make you feel upset. If you are feeling upset you must tell your parents or carer.

Can anything good happen to me?

The research will not benefit you or your family personally, but the information we collect might help to make sure that we have enough information about children your age to help other children who have problems in the future.

Will anyone know I am in the study?

Nobody can find out what you said. We are not going to write your name on your interview record so no one will be able to link your answers to you. Everything you tell us will be kept secret, and the only people who will see your answers are members of the research team, the people who pay for the study, or people from Stellenbosch University. When we have gathered

everybody's answers, we will write a report about what everyone has told us. We will not use your name in the report. We cannot do that because your name will not be on the questionnaire.

Who can I talk to about the study?

- If you have any questions about the study or you have any problems with the study, you are welcome to phone the man who is in charge of the study, who is called Mark, at 021-808 3446 (office) if you have any further queries or encounter any problems.

What if I do not want to do this?

We would very much like you to complete the questionnaire. However, just because your parent / mother / father / carer etc has given us permission to talk to you, does not mean you have to do it. It is not a problem if you don't want to. All you have to do is tell me. Also, even if you agree to fill in the questionnaire, you can decide to stop at any time if you want to. Just tell me if you want to do this.

Do you understand this research study and are you willing to take part in it?

 YES NO

Has the researcher answered all your questions?

 YES NO

Do you understand that you can pull out of the study at any time?

YES

NO

Name of Child: _____

Date: _____

Declaration by investigator

I (*name*): _____ declare that:

- I explained the information in this document to: _____
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

Signed at (*place*): _____ on (*date*): _____

Signature of investigator: _____

Appendix 3: Questionnaires

Carer questionnaire

Section 1. Information about yourself

1.1 Study ID

Study ID:

Expects a valid GS1 identifier (required)

1.2 Organisation

Organisation:

Expects a single line text response (required)

1.3 Date

Date:

Expects a date response (required)

1.4 Contact details

Please can you tell me your phone number, as well as a second number that we can contact you on.

Expects a single line text response (required)

1.5 Introduction

Below we will ask some questions about yourself and your relation to the child you care for as well as about the child. Please take your time to answer the questions correctly!

1.6 My name

My name (please include both first name and surname):

Expects a single line text response (required)

1.7 My age

My age.

Expects a numeric response (required)

1.8 My gender

My gender.

Expects a single option response (required)

Male [1]

Female [2]

1.9 Work

Do you work? If you do, how often?

Expects a single option response (required)

- No [1]
- Yes, everyday [2]
- Yes, sometimes [3]

Branches

If response Equals 'No [1]' then skip to *Childs name (2.1)*

1.10 Payment

Are you paid for your work?

Expects a single option response (required)

- Yes [1]
 - No [2]
-

Section 2. The household I live in and my relationship to the child I care for

2.1 Child's name

Name of child I care for:

Expects a single line text response (required)

2.2 Child Age

How old is q76494 ?

Expects a numeric response (required)

Constraints

Response must be Greater Than or Equal '0' AND

Response must be Less Than or Equal '18'

2.3 Role in child's life

I am this child's:

Expects a single option response (required)

- Parent [1]
- Guardian [2]
- Caregiver [3]
- Other [4]

Prerequisites

Skip when Role in child's life (2.3) Not Equal 'Other [4]'

2.4 Role in child's life - Other

Please specify:

Expects a single line text response (required)

2.5 Relation to child

Please indicate how you relate to the child. The child I care for is my:

Expects a single option response (required)

- Son/daughter [1]
- Foster/adopted child [2]
- Grand-daughter/grandson [3]
- Niece/nephew [4]
- Other relative [5]
- Other [6]

Prerequisites

Skip when Relation to child (2.5) Not Equal 'Other [6]'

2.6 Relation to child - Other

Please specify:

Expects a single line text response (required)

2.7 Cared for child - how long

How long have you cared for this child?

Expects a single option response (required)

Since birth [1]

Other [2]

Prerequisites

Skip when *Cared for child - how long (2.7)* Not Equal 'Other [2]'

2.8 Cared for child - how long - Other

Please specify:

Expects a single line text response (required)

2.9 Care as long as needed

Are you planning to care for this child as long as needed?

Expects a single option response (required)

Yes [1]

No [2]

Maybe [3]

2.10 Loss of family

Has this child lost a close family member in the last year?

Expects a single option response (required)

Yes [1]

No [2]

Branches

If response Equals 'No [2]' then skip to *HIV in household (2.14)*

2.11 Loss of family - how many

How many?

Expects a numeric response (required)

2.12 Loss of family - relation

Were any of these:

Expects multiple selected options (required)

Father [1]

Mother [2]

Carer [3]

Sibling [4]

Other [5]

Prerequisites

Skip when *Loss of family - relation (2.12)* Excludes 'Other [5]'

2.13 Loss of family - relation - Other

Please specify:

Expects a single line text response (required)

2.14 HIV in household

Does anyone in the child's household have AIDS?

Expects a single option response (required)

Yes [1]

No [2]

Branches

If response Equals 'No [2]' then skip to *Family sickness (2.18)*

2.15 HIV in household - how many

How many?

Expects a numeric response (required)

2.16 HIV in household - relation

Were any of these:

Expects multiple selected options (required)

Father [1]

Mother [2]

Carer [3]

Sibling [4]

Other [5]

Prerequisites

Skip when *HIV in household - relation (2.16)* Excludes 'Other [5]'

2.17 HIV in household - Other

Please specify:

Expects a single line text response (required)

2.18 Family sickness

Has a close family member of this child been sick for three months or more during the past 12 months?

Expects a single option response (required)

Yes [1]

No [2]

Branches

If response Equals 'No [2]' then skip to *Natural mother (2.22)*

2.19 Family sickness - how many

How many?

Expects a numeric response (required)

2.20 Family sickness - relation

Were any of these:

Expects multiple selected options (required)

- Father [1]
- Mother [2]
- Carer [3]
- Sibling [4]
- Other [5]

Prerequisites

Skip when *Family sickness - relation (2.20)* Excludes 'Other [5]'

2.21 Family sickness - Other

Please specify:

Expects a single line text response (required)

2.22 Natural mother

Is the child's natural mother alive?

Expects a single option response (required)

- Yes [1]
- No [2]
- Don't know [3]

2.23 Natural father

Is the child's natural father alive?

Expects a single option response (required)

- Yes [1]
- No [2]
- Don't know [3]

2.24 Same household

Do you live in the same household as the child?

Expects a single option response (required)

- Yes [1]
- No [2]

2.25 Other children in household

How many other children under 18 years of age live in the child's household?

Expects a numeric response (required)

Constraints

Response must be *Greater Than or Equal '0'*

Branches

If response Equals '0' then skip to *Number of adults (2.31)*

2.26 Son daughter in household

How many of the other children in the household are your biological sons/daughters?

Expects a numeric response (required)

Constraints

Response must be *Less Than or Equal* '___{76517}__' AND

Response must be *Greater Than or Equal* '0'

2.27 Foster/adopted child in household

How many of the other children in the household are foster/adopted children?

Expects a numeric response (required)

Constraints

Response must be *Less Than or Equal* '___{76517}__' AND

Response must be *Greater Than or Equal* '0'

2.28 Granddaughters/grandsons in household

How many of the other children in the household are granddaughters/grandsons?

Expects a numeric response (required)

Constraints

Response must be *Less Than or Equal* '___{76517}__' AND

Response must be *Greater Than or Equal* '0'

2.29 Nieces/nephews in household

How many of the other children in the household are nieces/nephews?

Expects a numeric response (required)

Constraints

Response must be *Greater Than or Equal* '0' AND

Response must be *Less Than or Equal* '___{76517}__'

2.30 Other relative in household

How many of the other children in the household are other relatives?

Expects a numeric response (required)

Constraints

Response must be *Greater Than or Equal* '0' AND

Response must be *Less Than or Equal* '___{76517}__'

2.31 Number of adults

How many adults live in the child's household?

Expects a numeric response (required)

Constraints

Response must be *Greater Than or Equal* '0'

2.32 Sitting Standing Walking

Compared with other children, did q76494 have any serious delay in sitting, standing, or walking?

Expects a single option response (required)

- Yes [1]
 - No [2]
 - I don't know as I was not the child's carer at that time. [3]
-

2.33 Difficulty Seeing

Compared with other children does q76494 have difficulty seeing, either in the daytime or at night?

Expects a single option response (required)

- Yes [1]
 - No [2]
-

2.34 Difficulty Hearing

Does q76494 appear to have difficulty hearing?

Expects a single option response (required)

- Yes [1]
 - No [2]
-

2.35 Understanding

When you tell q76494 to do something, does he/she seem to understand what you are saying?

Expects a single option response (required)

- Yes [1]
 - No [2]
-

2.36 Difficulty Walking

Does q76494 have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?

Expects a single option response (required)

- Yes [1]
 - No [2]
-

2.37 Fits

Does q76494 sometimes have fits, become rigid, or lose consciousness?

Expects a single option response (required)

- Yes [1]
 - No [2]
-

2.38 Learning

Does q76494 learn to do things like other children his/her age?

Expects a single option response (required)

- Yes [1]
 - No [2]
-

2.39 Speaking

Does q76494 speak at all (can he/she make himself/herself understood in words; can he/she say any recognisable words)?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites

Skip when *Child Age (2.2) Less Than '3'*

2.40 Speech Different

Is q76494 s speech in any way different from normal?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites

Skip when *Child Age (2.2) Greater Than '2'*

2.41 Name Object

Can q76494 name at least one object (animal, toy, cup, spoon)?

Expects a single option response (required)

Yes [1]

No [2]

2.42 Mental Difficulty

Compared with other children of his/her age, does q76494 appear in any way mentally backward, dull, or slow?

Expects a single option response (required)

Yes [1]

No [2]

2.43 Violence over the past year

Over the past year, has anyone in the household kicked, bitten, slapped, hit with a fist, threatened with a weapon (knife, stick or gun), or thrown something that could hurt another adult who lives in your household?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites

Skip when *Violence over the past year (2.43) Equals 'No [2]'*

2.44 Violence over the past year - Yes

How often does this happen?

Expects a single option response (required)

Weekly [1]

Monthly [2]

Less often [3]

2.45 Discipline in the child's household

In the past year, how often have you or another adult in the household used any of the following methods of discipline with any child in the child's household? DATA COLLECTOR: these questions below refer to any child in the household.

2.46 Discipline in the child's household - sticks

Used a stick, belt, hairbrush or other hard item to discipline the child?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

2.47 Discipline in the child's household - slapped

Slapped, punched or hit the child on his/her head or face?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

2.48 Discipline in the child's household - send away

Said you would send him/her away or kick him/her out of the house?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

2.49 Discipline in the child's household - threaten with ghosts

Threaten to invoke ghosts or evil spirits, or harmful people against the child?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

2.50 Discipline in the child's household - withhold meals

Withheld a meal to punish him or her?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

2.51 Discipline in the child's household - call names

Called him or her dumb, lazy or other names like that?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

2.52 Discipline in the child's household - explain wrong deeds

Explained to the child something they did was wrong?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

2.53 Discipline in the child's household - took away privileges

Took away privileges or stopped him/her from going out with friends, or stopped other activities like playing sport to teach him/her a lesson?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

2.54 Children whose parents have HIV/AIDS

How does this community feel about children whose parents have HIV/AIDS?

Expects multiple selected options (required)

- Adults in this community are generally concerned for the welfare of these children and help them as much as they can [1]
 - The community rejects these children [2]
 - These children are more likely to be hurt (maltreated or taken advantage of) than helped by people in this community [3]
-

2.55 Community talking about HIV

Does this community talk about HIV and acknowledge it as an issue?

Expects a single option response (required)

- No [1]
 - Yes [2]
-

Section 3. About yourself

3.1 How you felt in the last week

The next questions ask you to think about how you felt in the LAST WEEK.

3.2 Thinking about many things

Did you have times in which you were thinking deeply or thinking about many things?

Expects a single option response (required)

Yes [1]

No [2]

3.3 Failure to concentrate

Did you find yourself sometimes failing to concentrate?

Expects a single option response (required)

Yes [1]

No [2]

3.4 Lost temper

In the last week did you lose your temper or get annoyed over trivial matters?

Expects a single option response (required)

Yes [1]

No [2]

3.5 Nightmares

Did you have nightmares or bad dreams?

Expects a single option response (required)

Yes [1]

No [2]

3.6 Seeing or hear things

Did you sometimes see or hear things which others could not see or hear?

Expects a single option response (required)

Yes [1]

No [2]

3.7 Stomach ache

In the last week was your stomach aching?

Expects a single option response (required)

Yes [1]

No [2]

3.8 Trivial things

Were you frightened by trivial things?

Expects a single option response (required)

Yes [1]

No [2]

3.9 Fail to sleep

Did you sometimes fail to sleep or lose sleep?

Expects a single option response (required)

Yes [1]

No [2]

3.10 Wanted to cry

In the last week were there moments when you felt life was so tough that you cried or wanted to cry?

Expects a single option response (required)

Yes [1]

No [2]

3.11 Tired

Did you feel run down (tired)?

Expects a single option response (required)

Yes [1]

No [2]

3.12 Suicide

In the last week did you at times feel like committing suicide?

Expects a single option response (required)

Yes [1]

No [2]

3.13 Unhappy

Were you generally unhappy with things you were doing each day?

Expects a single option response (required)

Yes [1]

No [2]

3.14 Work lagging behind

Was your work lagging behind?

Expects a single option response (required)

Yes [1]

No [2]

3.15 Problems in deciding

Did you feel you had problems in deciding what to do?

Expects a single option response (required)

Yes [1]

No [2]

3.16 Problems over the last 2 weeks

The next set of questions will ask you how often over the last TWO WEEKS, you have been bothered by any of the following problems:

3.17 Depression - Little interest

Little interest or pleasure in doing things.

Expects a single option response (required)

Not at all [1]

Several days [2]

More than half the days [3]

Nearly every day [4]

3.18 Depression - Feeling down

How often in the last two weeks were you feeling down, depressed, or hopeless.

Expects a single option response (required)

Not at all [1]

Several days [2]

More than half the days [3]

Nearly every day [4]

3.19 Depression - Trouble falling asleep

Trouble falling or staying asleep, or sleeping too much.

Expects a single option response (required)

Not at all [1]

Several days [2]

More than half the days [3]

Nearly every day [4]

3.20 Depression - Feeling tired

How often in the last two weeks did you feel tired or have little energy.

Expects a single option response (required)

Not at all [1]

Several days [2]

More than half the days [3]

Nearly every day [4]

3.21 Depression - Poor appetite

Poor appetite or overeating.

Expects a single option response (required)

- Not at all [1]
 - Several days [2]
 - More than half the days [3]
 - Nearly every day [4]
-

3.22 Depression - Feeling bad about yourself

Feeling bad about yourself - or that you are a failure or have let yourself or your family down.

Expects a single option response (required)

- Not at all [1]
 - Several days [2]
 - More than half the days [3]
 - Nearly every day [4]
-

3.23 Depression - Trouble concentrating on things

How often in the last two weeks did you have trouble concentrating on things, such as reading the newspaper or watching television.

Expects a single option response (required)

- Not at all [1]
 - Several days [2]
 - More than half the days [3]
 - Nearly every day [4]
-

3.24 Depression - Moving or speaking slowly

Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual.

Expects a single option response (required)

- Not at all [1]
 - Several days [2]
 - More than half the days [3]
 - Nearly every day [4]
-

3.25 Depression - Thoughts of death

How often in the last two weeks did you have thoughts that you would be better off dead or of hurting yourself in some way.

Expects a single option response (required)

- Not at all [1]
 - Several days [2]
 - More than half the days [3]
 - Nearly every day [4]
-

3.26 Anxiety - Anxiety attack

In the last 4 weeks, have you had an anxiety attack - suddenly feeling fear or panic?

Expects a single option response (required)

Yes [1]

No [2]

Branches

If response Equals 'No [2]' then skip to *Difficult times (3.32)*

3.27 Anxiety - Recurrence

Has this ever happened before?

Expects a single option response (required)

Yes [1]

No [2]

3.28 Anxiety - Out of the blue

Do some of these attacks come suddenly out of the blue - that is, in situations where you dont expect to be nervous or uncomfortable?

Expects a single option response (required)

Yes [1]

No [2]

3.29 Anxiety - Attacks bother you

Do these attacks bother you a lot or are you worried about having another attack?

Expects a single option response (required)

Yes [1]

No [2]

3.30 Anxiety - Last anxiety attack

During your last bad anxiety attack, did you have symptoms like shortness of breath, sweating, your heart racing or pounding, dizziness or faintness, tingling or numbness, or nausea or upset stomach?

Expects a single option response (required)

Yes [1]

No [2]

3.31 Difficulties caused by problems

How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Expects a single option response (required)

Not difficult at all [1]

Somewhat difficult [2]

Very difficult [3]

Extremely difficult [4]

3.32 Difficult times

When the times are very difficult, people can feel very sad or unhappy. They can also feel that life is a struggle that is too big for them, or they can feel spiritually or emotionally troubled. When things are difficult they can also feel pain in their bodies, get headaches or stomach aches. When this happens, many people with children feel they need to be strong for the children.

3.33 In the past year

In the past year have you felt like this:

Expects a single option response (required)

- Every week [1]
 - At least once a month [2]
 - Only sometimes [3]
 - Not at all [4]
-

3.34 In the last year - Emotionally troubled

In the last year, have you felt so spiritually or emotionally troubled that you felt you needed to consult a healer (spiritual healer, faith healer or traditional healer), counsellor or health worker (clinic nurse or doctor?).

Expects a single option response (required)

- Yes [1]
 - No [2]
-

Section 4. About the child I care for I

4.1 Child you care for

In this section we will ask you what you think about how the child you care for does at school, his or her health and happiness. First we will talk about the child's feelings.

4.2 Consistent care

Does your child have at least one adult (over 18) who provides consistent care, attention, and support? Please select the most appropriate option:

Expects a single option response (required)

- This child has a primary adult caregiver who is involved in his/her life and who protects and nurtures him/her [1]
 - This child has an adult who provides care but who is limited by illness, age, or seems indifferent to this child [2]
 - This child has no consistent adult in his/her life that provides love, attention and support [3]
 - This child is completely without the care of an adult and must fend for him or herself or lives in a child-headed household [4]
-

4.3 Problems your child has had

In the past ONE month how much of a problem has your child had with:

4.4 Feeling afraid or scared

In the past ONE month how much of a problem has your child had with feeling afraid or scared.

Expects a single option response (required)

- Never [1]
 - Almost Never [2]
 - Sometimes [3]
 - Often [4]
 - Almost Always [5]
-

4.5 Feeling sad or blue

In the past ONE month how much of a problem has your child had with feeling sad or blue.

Expects a single option response (required)

- Never [1]
 - Almost Never [2]
 - Sometimes [3]
 - Often [4]
 - Almost Always [5]
-

4.6 Feeling angry

How much of a problem has your child had with feeling angry.

Expects a single option response (required)

- Never [1]
 - Almost Never [2]
 - Sometimes [3]
 - Often [4]
 - Almost Always [5]
-

4.7 Worrying about him or her

How much of a problem has your child had with worrying about what will happen to him or her.

Expects a single option response (required)

- Never [1]
 - Almost Never [2]
 - Sometimes [3]
 - Often [4]
 - Almost Always [5]
-

4.8 Getting along with others

How much of a problem has your child had with getting along with other children.

Expects a single option response (required)

- Never [1]
 - Almost Never [2]
 - Sometimes [3]
 - Often [4]
 - Almost Always [5]
-

4.9 Other kids not wanting friendship

How much of a problem has your child had with other kids not wanting to be his or her friend.

Expects a single option response (required)

- Never [1]
 - Almost Never [2]
 - Sometimes [3]
 - Often [4]
 - Almost Always [5]
-

4.10 Getting teased

How much of a problem has your child had with getting teased by other children.

Expects a single option response (required)

- Never [1]
 - Almost Never [2]
 - Sometimes [3]
 - Often [4]
 - Almost Always [5]
-

4.11 Child troubled

In the last year, has the child been so mentally, spiritually or emotionally troubled that you felt you needed to take them to a healer (spiritual healer, faith healer or traditional healer), counsellor or health worker (clinic nurse or doctor)?

Expects a single option response (required)

- Yes [1]
 - No [2]
-

4.12 Child often complain

Does your child often complain of headaches, stomach aches or sickness?

Expects a single option response (required)

- Certainly true [1]
 - Somewhat true [2]
 - Not true [3]
-

4.13 Child often unhappy

Is your child often unhappy, downhearted or tearful?

Expects a single option response (required)

- Certainly true [1]
 - Somewhat true [2]
 - Not true [3]
-

4.14 Child Nervous or Clingy

Is your child often nervous or clingy in new situations and easily loses confidence?

Expects a single option response (required)

- Certainly true [1]
 - Somewhat true [2]
 - Not true [3]
-

4.15 Child Obedient

Is your child generally obedient and usually does what adults request?

Expects a single option response (required)

- Certainly true [1]
 - Somewhat true [2]
 - Not true [3]
-

4.16 Child often fight

Does your child often fight with other children and bully them?

Expects a single option response (required)

- Certainly true [1]
 - Somewhat true [2]
 - Not true [3]
-

4.17 Child steal

Does your child steal from home school or elsewhere?

Expects a single option response (required)

- Certainly true [1]
 - Somewhat true [2]
 - Not true [3]
-

4.18 At Least one Good Friend

Does your child have at least one good friend?

Expects a single option response (required)

- Certainly true [1]
 - Somewhat true [2]
 - Not true [3]
-

4.19 Child picked on

Is your child picked on or bullied by other children?

Expects a single option response (required)

- Certainly true [1]
 - Somewhat true [2]
 - Not true [3]
-

4.20 Think before Acting

Does your child think things out before acting?

Expects a single option response (required)

- Certainly true [1]
 - Somewhat true [2]
 - Not true [3]
-

4.21 Child considerate

Is your child considerate of other people's feelings - for example, is helpful if someone is hurt, upset or feeling ill?

Expects a single option response (required)

- Certainly true [1]
 - Somewhat true [2]
 - Not true [3]
-

4.22 Childs health

Now we will talk about the child's health. Is your child physically healthy?

Expects a single option response (required)

- In the past month, this child has been healthy and active, with no fever, diarrhoea or other illnesses [1]
 - In the past month, this child was ill and less active for a few days (1 to 3 days) but he/she participated in some activities [2]
 - In the past month, this child was often (more than 3 days) too ill for school, work or play [3]
 - In the past month, this child has been ill most of the time (chronically ill) [4]
-

4.23 Childs HIV status

Do you know if the child is:

Expects a single option response (required)

- HIV positive [1]
 - HIV negative [2]
 - HIV untested [3]
 - Don't know [4]
 - Don't wish to discuss [5]
-

4.24 Problems child has had

In the past ONE month how much of a problem has your child had with:

4.25 Walking more than one block

In the past ONE month how much of a problem has your child had with: walking more than one block (in other words, from one street corner to another).

Expects a single option response (required)

- Never [1]
 - Almost Never [2]
 - Sometimes [3]
 - Often [4]
 - Almost Always [5]
-

4.26 Running

In the past ONE month how much of a problem has your child had with: running.

Expects a single option response (required)

- Never [1]
 - Almost Never [2]
 - Sometimes [3]
 - Often [4]
 - Almost Always [5]
-

4.27 Participating in sports

In the past ONE month how much of a problem has your child had with: participating in sports activity or exercise.

Expects a single option response (required)

- Never [1]
 - Almost Never [2]
 - Sometimes [3]
 - Often [4]
 - Almost Always [5]
-

4.28 Lifting something heavy

How much of a problem has your child had with lifting something heavy.

Expects a single option response (required)

- Never [1]
 - Almost Never [2]
 - Sometimes [3]
 - Often [4]
 - Almost Always [5]
-

4.29 Doing chores

How much of a problem has your child had with doing chores around the house or picking up his or her toys.

Expects a single option response (required)

- Never [1]
 - Almost Never [2]
 - Sometimes [3]
 - Often [4]
 - Almost Always [5]
-

4.30 Hospital/clinic admission

Has this child been admitted to a clinic, nursing home or hospital during the past year for a period of 24 hours or more?

Expects a single option response (required)

- Yes [1]
 - No [2]
-

Prerequisites

Skip when *Hospital/clinic admission (4.30)* Equals 'No [2]'

4.31 Hospital/clinic admission - Number

How many times has this child been admitted?

Expects a numeric response (required)

Constraints

Response must be *Greater Than or Equal '1'*

Repeat this section for value of *Hospital/clinic admission - Number (4.31)*

Section 5. Hospital admission

Prerequisites

Skip when *Hospital/clinic admission (4.30)* Equals 'No [2]'

5.1 Hospital/clinic admission - Age

For admission #REPEAT IDX, what was the child's age at the time of admission?

Expects a numeric response (required)

Prerequisites

Skip when *Hospital/clinic admission (4.30)* Equals 'No [2]'

5.2 Hospital/clinic admission - Duration

What was the duration of the child's admission (number of days)?

Expects a numeric response (required)

Prerequisites

Skip when *Hospital/clinic admission (4.30)* Equals 'No [2]'

5.3 Hospital/clinic admission - Reason

What was the reason for the child being admitted?

Expects a single line text response (required)

Section 6. About the child I care for II

6.1 Can child access health care

Can your child access health care services, including medical treatment when ill and preventive care?

Expects a single option response (required)

- This child has received all or almost all necessary health care treatments when ill and preventive care [1]
- This child received medical treatment when ill, but some health care services (e.g. immunisations) are not received [2]
- This child only sometimes or inconsistently received needed health care services (treatment or preventative) [3]
- This child rarely or never receives the necessary health care services [4]

6.2 Bed net

Does your child have a bed net?

Expects a single option response (required)

- Yes [1]
- No [2]

6.3 Immunisation

Has your child been immunised?

Expects a single option response (required)

- Yes [1]
- No [2]

6.4 If the child is ill

If the child is ill does he/she see a nurse, doctor or any health professional?

Expects a single option response (required)

- Yes [1]
- No [2]

Branches

If response Equals 'Yes [1]' then skip to *Needs medicine (6.7)*

6.5 If the child is ill - No

Please select reason for this:

Expects multiple selected options (required)

- The doctor is too far away [1]
- The doctor is too expensive [2]
- Other [3]

Branches

If response Excludes 'Other [3]' then skip to *Needs medicine (6.7)*

6.6 If the child is ill - No - Other

Please specify:

Expects a single line text response (required)

6.7 Needs medicine

When the child needs medicine can he or she get it?

Expects a single option response (required)

Yes [1]

No [2]

6.8 Food and nutrition - sufficient food

Now we will talk about the child's food and nutrition. Does your child have sufficient food to eat at all times of the year?

Expects a single option response (required)

This child is well fed and eats regularly [1]

This child has enough to eat some of the time, depending on season or food supply [2]

This child frequently has less food to eat than needed, complains of hunger [3]

This child rarely has food to eat and goes to bed hungry most nights [4]

6.9 Food and nutrition - Size

Is this child smaller than average?

Expects a single option response (required)

Yes [1]

No [2]

6.10 Food and nutrition - Looks thin

Does this child look very thin?

Expects a single option response (required)

Yes [1]

No [2]

6.11 Child Age Starting at School

How old was the child when he or she first started school?

Expects a numeric response (required)

6.12 Performance at school - Enrollment

Now we will talk about the child's performance at school. Is your child enrolled in school, preschool or creche?

Expects a single option response (required)

Yes [1]

No [2]

Branches

If response Equals 'No [2]' then skip to *Other child responsibilities (6.24)*

Prerequisites

Skip when *Performance at school - Enrollment (6.12)* Equals 'No [2]'

6.13 Performance at school - Correct class

Is your child in the correct class for his or her age?

Expects a single option response (required)

Yes, or above [1]

No [2]

Prerequisites

Skip when *Performance at school - Enrollment (6.12)* Equals 'No [2]'

6.14 Performance at school - Attendance

Does your child go to school?

Expects a single option response (required)

- No [1]
- Yes, regularly [2]
- Yes, sometimes [3]
- Not a lot [4]

6.15 Number School Days Child Missed

How many days of school has the child missed in the past two weeks?

Expects a numeric response (required)

Prerequisites

Skip when *Performance at school - Enrollment (6.12)* Equals 'No [2]'

6.16 Performance at school

How do teachers report your child is doing in school?

Expects a single option response (required)

- He or she does better than most children [1]
- He or she does as well as most children [2]
- He or she struggles in school [3]

6.17 Problems child has had - Performance at school

In the past ONE month how much of a problem has your child had with:

6.18 Problems child has had - Paying attention

In the past ONE month how much of a problem has your child had with paying attention in class.

Expects a single option response (required)

- Never [1]
- Almost Never [2]
- Sometimes [3]
- Often [4]
- Almost Always [5]

6.19 Problems child has had - Forgetting

In the past ONE month how much of a problem has your child had with forgetting things.

Expects a single option response (required)

- Never [1]
- Almost Never [2]
- Sometimes [3]
- Often [4]
- Almost Always [5]

6.20 Problems child has had - Keeping up

In the past ONE month how much of a problem has your child had with keeping up with school activities or work.

Expects a single option response (required)

- Never [1]
- Almost Never [2]
- Sometimes [3]
- Often [4]
- Almost Always [5]

6.21 Performance at school - Quick learner

Is the child quick to learn when introduced to new chores or things?

Expects a single option response (required)

- Yes [1]
- No [2]
- Somewhat [3]
- Don't know [4]

6.22 Performance at school - Uniform

Who pays school fees, buys uniforms and school materials?

Expects multiple selected options (required)

- My household [1]
- Relatives [2]
- A charity [3]
- Other [4]

Prerequisites

Skip when *Performance at school - Uniform (6.22)* Excludes 'Other [4]'

6.23 Performance at school - Uniform - Other

Please specify:

Expects a single line text response (required)

6.24 Other child responsibilities

Now we will talk about other child responsibilities and my child's circumstances. Does this child have access to legal protective services as needed? If no response, For example, an NGO that helps with legal services.

Expects a single option response (required)

- No [1]
- Yes, fully [2]
- Yes, partially [3]
- Not sure [4]

6.25 Abuse and exploitation - Safe

Now we will talk about abuse and exploitation. Is this child safe from any abuse, neglect or exploitation?

Expects a single option response (required)

- No [1]
- Yes, fully [2]
- Yes, partially [3]
- Not sure [4]

Branches

If response Equals 'Yes, fully [2]' then skip to *Abuse and exploitation - Work (6.31)*

6.26 Child Most Unsafe Place

In terms of abuse and exploitation, where is the child most unsafe?

Expects a single option response (required)

- Home [1]
- School [2]
- At this programme [3]
- Other family or friends houses [4]
- Other [5]

Prerequisites

Skip when *Child Most Unsafe Place (6.26)* Not Equal 'Other [5]'

6.27 Child Most Unsafe Place Other

Please specify:

Expects a single line text response (required)

6.28 Child Most Safe Place

Where is the child most safe?

Expects a single option response (required)

- Home [1]
- School [2]
- At this programme [3]
- Other family or friends houses [4]
- Other [5]

Prerequisites

Skip when *Child Most Safe Place (6.28)* Not Equal 'Other [5]'

6.29 Child Most Safe Place Other

Please specify:

Expects a single line text response (required)

6.30 Child Unsafe Rating

Please give a rating of how often you think the child is unsafe?

Expects a single option response (required)

- Never [1]
 - Almost never [2]
 - Sometimes [3]
 - Often [4]
 - Almost always [5]
-

6.31 Abuse and exploitation - Work

Does your child work?

Expects a single option response (required)

- No [1]
 - Yes [2]
-

Prerequisites

Skip when *Abuse and exploitation - Work (6.31)* Equals 'No [1]'

6.32 Abuse and exploitation - Work - Outside

My child works outside of the household.

Expects a single option response (required)

- Yes [1]
 - No [2]
-

Prerequisites

Skip when *Abuse and exploitation - Work (6.31)* Equals 'No [1]' OR
Skip when *Abuse and exploitation - Work - Outside (6.32)* Equals 'No [2]'

6.33 Abuse and exploitation - Work - Payed

Does he or she get paid for it?

Expects a single option response (required)

- Yes [1]
 - No [2]
-

6.34 Birth certificate

Does this child have a birth certificate?

Expects a single option response (required)

- No [1]
 - Yes [2]
 - Don't know [3]
-

6.35 Immunisation certificate

Does this child have an immunisation certificate?

Expects a single option response (required)

- No [1]
 - Yes [2]
 - Don't know [3]
-

Section 7. Organisation that your child attends

7.1 Childs organisation

Lastly, we will talk about the organisation or programme that your child attends.

7.2 Organisation Visits

How long has this child been coming to this organisation?

Expects a single option response (required)

- Less than 1 month [1]
 - 1 month to a year [2]
 - More than a year [3]
-

7.3 Childs organisation - Frequency

How often does your child have contact with the organisation?

Expects a single option response (required)

- Every day [1]
 - 2-3 times a week [2]
 - Once a week [3]
 - Every two weeks [4]
 - Every month [5]
 - Never [6]
 - Other [7]
-

Prerequisites

Skip when *Childs organisation - Frequency (7.3)* Not Equal 'Other [7]'

7.4 Childs organisation - Frequency - Other

Please specify:

Expects a single line text response (required)

7.5 Childs organisation - Your contact

How often do you have contact with the organisation?

Expects a single option response (required)

- Every day [1]
 - 2-3 times a week [2]
 - Once a week [3]
 - Every two weeks [4]
 - Every month [5]
 - Never [6]
 - Other [7]
-

Prerequisites

Skip when *Childs organisation - Your contact (7.5)* Not Equal 'Other [7]'

7.6 Childs organisation - Your contact - Other

Please specify:

Expects a single line text response (required)

7.7 Services received

What kind of services do you or your child receive from the organisation?

Expects multiple selected options (required)

- Food/nutrition (feeding or food parcels) [1]
- Medical provision (ARV/treatment for children living with HIV) [2]
- Play supervision [3]
- Psychosocial interventions such as counselling or parenting workshops [4]
- Early child development services [5]
- School (education, fees, uniforms) [6]
- Emotional support [7]
- Home based care [8]
- Emergency (emergency care) [9]
- Assistance with accessing social grants [10]
- Skills building and training [11]
- Direct income support [12]
- Referral to health or social services [13]
- Clothes and/or blankets [14]

7.8 Childs organisation - Travel

Does it cost money for you or your child to travel to the organization?

Expects a single option response (required)

- No [1]
- Yes [2]

Prerequisites

Skip when *Childs organisation - Travel (7.8)* Equals 'No [1]'

7.9 Childs organisation - Travel - Yes - Cost

How much per month (in Rands)?

Expects a decimal response (required)

7.10 Childs organisation - Missed work

Do you ever lose money due to missing work to go to the organisation?

Expects a single option response (required)

- No [1]
- Yes [2]

Prerequisites

Skip when *Childs organisation - Missed work (7.10)* Equals 'No [1]'

7.11 Childs organisation - Missed work - Cost

How much per month (in Rands)?

Expects a decimal response (required)

7.12 Childs organisation - Reimbursement

Do you support or reimburse the organisation in any way?

Expects multiple selected options (required)

- Assistance with programme activities [1]
- Use of your house or property for activities [2]
- Payment [3]
- Other [4]
- No, I don't support or reimburse the organisation in any way [5]

Prerequisites

Skip when Childs organisation - Reimbursement (7.12) Excludes 'Other [4]'

7.13 Childs organisation - Reimbursement - Other

Please specify:

Expects a single line text response (required)

7.14 Local community

Does your local community:

7.15 Local community - Support

Support the group?

Expects a single option response (required)

- Yes [1]
- No [2]
- I don't know [3]
- Some community members support the group and others do not [4]

7.16 Local community - Difficult

Make things difficult for the group?

Expects a single option response (required)

- Yes [1]
- No [2]
- I don't know [3]

7.17 Local community - Contribute

Contribute (food, volunteers, premises) to the group?

Expects a single option response (required)

- Yes [1]
- No [2]
- I don't know [3]

7.18 Local community - Raise money

Raise money for the group?

Expects a single option response (required)

- Yes [1]
- No [2]
- I don't know [3]

Section 8. End

8.1 Require Referral

Does this participant require referral to the organisation or other services?

Expects a single option response (required)

Yes [1]

No [2]

8.2 End

You've reached the end of the questionnaire. Please press BACK to review the responses, or press NEXT to submit the questionnaire.

Child questionnaire

Section 1. Background Information

1.1 Study ID

Study ID:

Expects a valid GS1 identifier (required)

1.2 Organisation

Organisation:

Expects a single line text response (required)

1.3 Date

Date:

Expects a date response (required)

Section 2. Who I Am

2.1 Child Name

Child's name is (please include both the name and surname):

Expects a single line text response (required)

2.2 Instruction 1

DATA COLLECTOR: please ensure that the carer is in the room until after q74484's birthday has been captured.

2.3 Child Gender

Are you a:

Expects a single option response (required)

Boy [1]

Girl [2]

2.4 Child Schooling

Are you enrolled in school

Expects a single option response (required)

No [1]

Yes [2]

Branches

If response Equals 'No [1]' then skip to *Child Age (2.6)*

2.5 Grade

What grade are you in now?

Expects a numeric response (required)

2.6 Child Age

Please enter q74484's age:

Expects a numeric response (required)

Constraints

Response must be Greater Than or Equal '0' AND

Response must be Less Than or Equal '21'

2.7 Child Birthdate Known

Is q74484's date of birth known?

Expects a single option response (required)

Yes [1]

No [2]

Branches

If response Equals 'No [2]' then skip to *Child Height (2.9)*

2.8 Birthday

When is your birthday?

Expects a date response (required)

2.9 Child Height

Child's height in centimeters:

Expects a decimal response (required)

2.10 Child Weight

Child's weight in kilograms:

Expects a decimal response (required)

2.11 Drawing Instruction 1

Make sure the child has completed the drawing tests before moving on to the next section.

2.12 Digit Span Instruction 1

For the digit span test, remember the following: 1. Make sure that you have the child's complete attention 2. Remove all toys or distracting articles from the table 3. The digits should be read out at a rate of one a second. 4. Do not group the digits in any rhythmic fashion

2.13 Digit Span Instruction 2

Start by saying: Let's see how well you can say numbers. Say 4. (Wait for the child's response), Now say 8. Start with item 1 and say: I am going to say some numbers. Listen carefully and repeat them after me

2.14 Incorrect Answers

Numeric

This field is not displayed on the handset, Value: 0

2.15 Digit Span - Series 1-1

1 - 4

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Correct Set - 2-1 (2.18)*

2.16 Digit Span - Series 2-1

6 - 3

Expects a single option response (required)

Right [1]

Wrong [0]

Prerequisites

Skip when *Digit Span - Series 2-1 (2.16)* Equals 'Right [1]'

2.17 Incorrect Set - 2-1

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) , Sum of (q8296) ,1)`

Prerequisites

Skip when *Digit Span - Series 2-1 (2.16)* Equals 'Wrong [0]'

2.18 Correct Set - 2-1

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) ,0)`

2.19 Digit Span - Series 1-2

2 - 8 - 5

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Correct Set - 2-2 (2.22)*

2.20 Digit Span - Series 2-2

1 - 7 - 4

Expects a single option response (required)

Right [1]

Wrong [0]

Prerequisites

Skip when *Digit Span - Series 2-2 (2.20)* Equals 'Right [1]'

2.21 Incorrect Set - 2-2

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) , Sum of (q8296) ,1)`

Prerequisites

Skip when *Digit Span - Series 2-2 (2.20)* Equals 'Wrong [0]'

2.22 Correct Set - 2-2

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) ,0)`

Prerequisites

Skip when *Incorrect Answers (2.14)* Greater Than '1'

2.23 Digit Span - Series 1-3

4 - 5 - 1 - 8

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Correct Set - 2-3 (2.26)*

Prerequisites

Skip when *Incorrect Answers (2.14) Greater Than '1'*

2.24 Digit Span - Series 2-3

2 - 6 - 4 - 1

Expects a single option response (required)

Right [1]

Wrong [0]

Prerequisites

Skip when *Digit Span - Series 2-3 (2.24) Equals 'Right [1]'* OR
Skip when *Incorrect Answers (2.14) Greater Than '1'*

2.25 Incorrect Set - 2-3

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) , Sum of (q8296) ,1))`

Prerequisites

Skip when *Digit Span - Series 2-3 (2.24) Equals 'Wrong [0]'* OR
Skip when *Incorrect Answers (2.14) Greater Than '1'*

2.26 Correct Set - 2-3

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) ,0)`

Prerequisites

Skip when *Incorrect Answers (2.14) Greater Than '1'*

2.27 Digit Span - Series 1-4

6 - 9 - 2 - 8 - 3

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Correct Set - 2-4 (2.30)*

Prerequisites

Skip when *Incorrect Answers (2.14) Greater Than '1'*

2.28 Digit Span - Series 2-4

7 - 2 - 9 - 6 - 5

Expects a single option response (required)

Right [1]

Wrong [0]

Prerequisites

Skip when *Digit Span - Series 2-4 (2.28) Equals 'Right [1]'* OR
Skip when *Incorrect Answers (2.14) Greater Than '1'*

2.29 Incorrect Set - 2-4

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) , Sum of (q8296) ,1))`

Prerequisites

Skip when *Digit Span - Series 2-4 (2.28)* Equals 'Wrong [0]' OR
Skip when *Incorrect Answers (2.14)* Greater Than '1'

2.30 Correct Set - 2-4

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) ,0)`

Prerequisites

Skip when *Incorrect Answers (2.14)* Greater Than '1'

2.31 Digit Span - Series 1-5

3-8-4-7-1-9

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Correct Set - 2-5 (2.34)*

Prerequisites

Skip when *Incorrect Answers (2.14)* Greater Than '1'

2.32 Digit Span - Series 2-5

5-2-7-8-1-6

Expects a single option response (required)

Right [1]

Wrong [0]

Prerequisites

Skip when *Digit Span - Series 2-5 (2.32)* Equals 'Right [1]' OR
Skip when *Incorrect Answers (2.14)* Greater Than '1'

2.33 Incorrect Set - 2-5

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) , Sum of (q8296) ,1)`

Prerequisites

Skip when *Digit Span - Series 2-5 (2.32)* Equals 'Wrong [0]' OR
Skip when *Incorrect Answers (2.14)* Greater Than '1'

2.34 Correct Set - 2-5

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) ,0)`

Prerequisites

Skip when *Incorrect Answers (2.14)* Greater Than '1'

2.35 Digit Span - Series 1-6

3-6-7-8-2-4-9

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Correct Set - 2-6 (2.38)*

Prerequisites

Skip when *Incorrect Answers (2.14) Greater Than '1'*

2.36 Digit Span - Series 2-6

9 - 3 - 2 - 6 - 4 - 7 - 5

Expects a single option response (required)

Right [1]

Wrong [0]

Prerequisites

Skip when *Digit Span - Series 2-6 (2.36) Equals 'Right [1]'* OR
Skip when *Incorrect Answers (2.14) Greater Than '1'*

2.37 Incorrect Set - 2-6

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) , Sum of (q8296) , 1)`

Prerequisites

Skip when *Digit Span - Series 2-6 (2.36) Equals 'Wrong [0]'* OR
Skip when *Incorrect Answers (2.14) Greater Than '1'*

2.38 Correct Set - 2-6

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) , 0)`

Prerequisites

Skip when *Incorrect Answers (2.14) Greater Than '1'*

2.39 Digit Span - Series 1-7

8 - 5 - 6 - 2 - 7 - 9 - 5 - 3

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Digit Span - Series 1-8 (2.42)*

Prerequisites

Skip when *Incorrect Answers (2.14) Greater Than '1'*

2.40 Digit Span - Series 2-7

2 - 5 - 3 - 8 - 6 - 7 - 3 - 9

Expects a single option response (required)

Right [1]

Wrong [0]

Prerequisites

Skip when *Digit Span - Series 2-7 (2.40) Equals 'Right [1]'* OR
Skip when *Incorrect Answers (2.14) Greater Than '1'*

2.41 Incorrect Set - 2-7

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers (2.14) , Sum of (q8296) , 1)`

Prerequisites

Skip when *Incorrect Answers (2.14)* Greater Than '1'

2.42 Digit Span - Series 1-8

6-4-8-5-1-3-2-9-7

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Child Home (2.81)*

Prerequisites

Skip when *Incorrect Answers (2.14)* Greater Than '1'

2.43 Digit Span - Series 2-8

4-6-5-7-2-3-8-9-1

Expects a single option response (required)

Right [1]

Wrong [0]

2.44 Correct Set

Numeric

This field is not displayed on the handset, Value: Set(*Incorrect Answers (2.14)* ,0)

Prerequisites

Skip when *Child Age (2.6)* Greater Than '5'

2.45 Child Under 6

You have indicated that q74484 is 5 or younger. As such, the next section will be skipped. If this is incorrect, please go back and update the child's age.

Expects a single option response (required)

Correct [1]

Incorrect [2]

Branches

If response Equals 'Correct [1]' then skip to *Child Home (2.81)*

If response Equals 'Incorrect [2]' then skip to *Child Age (2.6)*

2.46 Reverse Digit Span Instruction 1

Now I am going to say some more numbers which you must repeat after me. This time I want you to begin with the last number that I say and repeat them backwards.

2.47 Reverse Digit Span Instruction 2

For example, if I say 2 - 5, you would say 5 - 2. Do you understand?

Expects a single option response (required)

Yes [1]

No [2]

2.48 Reverse Digit Span Instruction 3

What do you say if I say 2 - 5?

Expects a single option response (required)

Correct [1]

Wrong [2]

Prerequisites

Skip when *Reverse Digit Span Instruction 3 (2.48)* Equals 'Correct [1]'

2.49 Reverse Digit Span Instruction 4

No, you would say 5 - 2. I said 2 - 5. To say it backwards you would say 5 - 2. Lets try some more.

2.50 Reverse Digit Span Instruction 5

If I say 3 - 7 - 5, what should you say?

Expects a single option response (required)

Correct [1]

Wrong [2]

2.51 Reverse Digit Span Instruction 6

Pause for the testee to respond. If the testee responds correctly (5 - 7 - 3) say . That is correct.

Prerequisites

Skip when *Reverse Digit Span Instruction 5 (2.50)* Equals 'Correct [1]'

2.52 Reverse Digit Span Instruction 7

No, you should say 5 - 7 - 3. I said 3 - 7 - 5, so to say it backwards, you should say 5 - 7 - 3.

Prerequisites

Skip when *Reverse Digit Span Instruction 5 (2.50)* Equals 'Correct [1]'

2.53 Reverse Digit Span Instruction 8

Now try these numbers. Remember, you must say them backwards. 1 - 9 - 4

Expects a single option response (required)

Correct [1]

Wrong [2]

2.54 Incorrect Answers 2

Numeric

This field is not displayed on the handset, Value: 0

2.55 Reverse Digit Span - Series 1-1

3 - 1

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Reverse Digit Span - Series 1-2 (2.59)*

2.56 Reverse Digit Span - Series 2-1

5 - 3

Expects a single option response (required)

Right [2]

Wrong [0]

Prerequisites

Skip when *Reverse Digit Span - Series 2-1 (2.56)* Equals 'Right [2]'

2.57 Reversed Incorrect Set - 2-1

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers 2 (2.54) , Sum of (q10506) ,1)`

Prerequisites

Skip when *Reverse Digit Span - Series 2-1 (2.56)* Equals 'Wrong [0]'

2.58 Reversed Correct Set - 2-1

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers 2 (2.54) ,0)`

2.59 Reverse Digit Span - Series 1-2

2 - 7 - 5

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Reverse Digit Span - Series 1-3 (2.63)*

2.60 Reverse Digit Span - Series 2-2

4 - 9 - 2

Expects a single option response (required)

Right [2]

Wrong [0]

Prerequisites

Skip when *Reverse Digit Span - Series 2-2 (2.60)* Equals 'Right [2]'

2.61 Reverse Incorrect Set - 2-2

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers 2 (2.54) , Sum of (q10506) ,1)`

Prerequisites

Skip when *Reverse Digit Span - Series 2-2 (2.60)* Equals 'Wrong [0]'

2.62 Reversed Correct Set - 2-2

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers 2 (2.54) ,0)`

Prerequisites
Skip when *Incorrect Answers 2 (2.54) Greater Than '1'*

2.63 Reverse Digit Span - Series 1-3

9 - 2 - 8 - 2

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Reverse Digit Span - Series 1-4 (2.67)*

Prerequisites
Skip when *Incorrect Answers 2 (2.54) Greater Than '1'*

2.64 Reverse Digit Span - Series 2-3

7 - 3 - 4 - 8

Expects a single option response (required)

Right [2]

Wrong [0]

Prerequisites
Skip when *Reverse Digit Span - Series 2-3 (2.64) Equals 'Right [2]'* OR
Skip when *Incorrect Answers 2 (2.54) Greater Than '1'*

2.65 Reversed Incorrect Set - 2-3

Numeric

This field is not displayed on the handset. Value: `Set(Incorrect Answers 2 (2.54) , Sum of (q10506) , 1)`

Prerequisites
Skip when *Reverse Digit Span - Series 2-3 (2.64) Equals 'Wrong [0]'* OR
Skip when *Incorrect Answers 2 (2.54) Greater Than '1'*

2.66 Reversed Correct Set - 2-3

Numeric

This field is not displayed on the handset. Value: `Set(Incorrect Answers 2 (2.54) , 0)`

Prerequisites
Skip when *Incorrect Answers 2 (2.54) Greater Than '1'*

2.67 Reverse Digit Span - Series 1-4

3 - 5 - 2 - 6 - 7

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Reverse Digit Span - Series 1-5 (2.71)*

Prerequisites
Skip when *Incorrect Answers 2 (2.54) Greater Than '1'*

2.68 Reverse Digit Span - Series 2-4

8 - 3 - 4 - 6 - 2

Expects a single option response (required)

Right [2]

Wrong [0]

Prerequisites

Skip when *Reverse Digit Span - Series 2-4 (2.68)* Equals 'Right [2]' OR
Skip when *Incorrect Answers 2 (2.54)* Greater Than '1'

2.69 Reversed Incorrect Set - 2-4

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers 2 (2.54) , Sum of (q10506) ,1)`

Prerequisites

Skip when *Reverse Digit Span - Series 2-4 (2.68)* Equals 'Wrong [0]' OR
Skip when *Incorrect Answers 2 (2.54)* Greater Than '1'

2.70 Reversed Correct Set - 2-4

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers 2 (2.54) ,0)`

Prerequisites

Skip when *Incorrect Answers 2 (2.54)* Greater Than '1'

2.71 Reverse Digit Span - Series 1-5

8-2-9-4-7-5

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Reverse Digit Span - Series 1-6 (2.75)*

Prerequisites

Skip when *Incorrect Answers 2 (2.54)* Greater Than '1'

2.72 Reverse Digit Span - Series 2-5

3-1-9-6-8-4

Expects a single option response (required)

Right [2]

Wrong [0]

Prerequisites

Skip when *Reverse Digit Span - Series 2-5 (2.72)* Equals 'Right [2]' OR
Skip when *Incorrect Answers 2 (2.54)* Greater Than '1'

2.73 Reversed Incorrect Set - 2-5

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers 2 (2.54) , Sum of (q10506) ,1)`

Prerequisites

Skip when *Reverse Digit Span - Series 2-5 (2.72)* Equals 'Wrong [0]' OR
Skip when *Incorrect Answers 2 (2.54)* Greater Than '1'

2.74 Reversed Correct Set - 2-5

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers 2 (2.54) ,0)`

Prerequisites

Skip when *Incorrect Answers 2 (2.54) Greater Than '1'*

2.75 Reverse Digit Span - Series 1-6

6-3-8-9-1-4-7

Expects a single option response (required)

Right [2]

Wrong [0]

Branches

If response Equals 'Right [2]' then skip to *Reverse Digit Span - Series 1-7 (2.79)*

Prerequisites

Skip when *Incorrect Answers 2 (2.54) Greater Than '1'*

2.76 Reverse Digit Span - Series 2-6

6-1-3-7-5-2-8

Expects a single option response (required)

Right [2]

Wrong [0]

Prerequisites

Skip when *Reverse Digit Span - Series 2-6 (2.76) Equals 'Right [2]'* OR
Skip when *Incorrect Answers 2 (2.54) Greater Than '1'*

2.77 Reversed Incorrect Set - 2-6

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers 2 (2.54) , Sum of (q10506) , 1)`

Prerequisites

Skip when *Reverse Digit Span - Series 2-6 (2.76) Equals 'Wrong [0]'* OR
Skip when *Incorrect Answers 2 (2.54) Greater Than '1'*

2.78 Reversed Correct Set - 2-6

Numeric

This field is not displayed on the handset, Value: `Set(Incorrect Answers 2 (2.54) , 0)`

Prerequisites

Skip when *Incorrect Answers 2 (2.54) Greater Than '1'*

2.79 Reverse Digit Span - Series 1-7

4-6-1-5-9-2-7-8

Expects a single option response (required)

Right [2]

Wrong [0]

Prerequisites

Skip when *Reverse Digit Span - Series 1-7 (2.79) Equals 'Right [2]'* OR
Skip when *Incorrect Answers 2 (2.54) Greater Than '1'*

2.80 Reverse Digit Span - Series 2-7

4-6-1-5-9-2-7-8

Expects a single option response (required)

Right [1]

Wrong [0]

2.81 Child Home

Which of the following best describe where you live?

Expects a single option response (required)

- Living in a house or flat [1]
- Living in a shack [2]
- Living on the street [3]

Prerequisites

Skip when *Child Age (2.6)* Less Than '6'

2.82 Number People Living With Child

Count all the people that in your house, including yourself.

Expects a numeric response (required)

Prerequisites

Skip when *Child Age (2.6)* Less Than '6'

2.83 Look After Younger Kids

Do you help look after younger kids in your home?

Expects a single option response (required)

- No [1]
- Yes [2]

Prerequisites

Skip when *Child Age (2.6)* Less Than '6'

2.84 Looked After Unwell People

Have you ever helped to look after unwell people in your home?

Expects a single option response (required)

- No [1]
- Yes [2]

2.85 Sleep in Your Own Bed

Do you sleep in your own bed? (adapted from CSI: Domain Shelter)

Expects a single option response (required)

- No [1]
- Yes [2]

2.86 Home Has Comfortable Temperature

Is your home dry and has a comfortable temperature?(adapted from CSI: Domain Shelter)

Expects a single option response (required)

- No [1]
- Yes [2]

2.87 Anyone Lives With You Has a Job

Does anyone who lives with you have a job?

Expects a single option response (required)

- No [1]
- Yes [2]

2.88 Feel You Belong With People You Live With

Do you feel that you belong with the people that you live with (i.e., does it feel like home)?

Expects a single option response (required)

- Yes [1]
- Somewhat [2]
- Not at all [3]

2.89 Praised When Have Done Something Well

Does someone at home praise you when you do something well?

Expects a single option response (required)

- Often [1]
- Rarely [2]
- Never [3]

2.90 Get Same Necessities as Other Children

Do you get the same food/clothes/school fees/ school equipment as other children you live with?

Expects a single option response (required)

- I get more [1]
- I get less [2]
- The same [3]
- I am an only child [4]

2.91 Treatment Compared to Other Children

How are you treated compared to other children you live with?

Expects a single option response (required)

- Better [1]
- Worse [2]
- The same [3]
- I am an only child [4]

Prerequisites

Skip when *Child Age (2.6) Less Than '6'*

2.92 Troubled Such That Needed to Consult

Have you been so mentally, emotionally or spiritually troubled you needed to consult a healer/health worker in the last year (for example, sad or worried)?

Expects a single option response (required)

- No [1]
- Yes [2]

2.93 Moved Home to Live With Different People

Have you moved home to live with different people in the last year?

Expects a single option response (required)

- No [1]
- Yes [2]

Branches

If response Equals 'No [1]' then skip to *Instruction Someone You Can Depend On (2.96)*

2.94 Compare Two Places You Lived In

What is it like compared to where you used to live?

Expects a single option response (required)

- Better [1]
- Worse [2]
- The same [3]

2.95 Compare Two Places You Lived In Reason

Please tell us why:

Expects a single line text response (required)

Prerequisites

Skip when *Child Age (2.6) Less Than '6'*

2.96 Instruction Someone You Can Depend On

Do you have someone in your life you can depend on, in the following things:

Prerequisites

Skip when *Child Age (2.6) Less Than '6'*

2.97 Advice and Guidance

Someone you can depend on for advice and guidance?

Expects a single option response (required)

- Yes [1]
- No [2]

Prerequisites

Skip when *Child Age (2.6) Less Than '6'*

2.98 Comfort When Sad or Sick

Someone you can depend on to comfort you when you feel sad or sick?

Expects a single option response (required)

- Yes [1]
- No [2]

Prerequisites

Skip when *Child Age (2.6) Less Than '6'*

2.99 Go With When Needing Help

Someone you can depend on to go with you to the clinic, schools or social service agency if you need help?

Expects a single option response (required)

- Yes [1]
- No [2]

Prerequisites

Skip when *Child Age (2.6) Less Than '6'*

2.100 Tell When Something Fun or Exciting Happened

Someone you can depend on to tell him/her when something fun or exciting happened ? (CSI, domain care)

Expects a single option response (required)

- Yes [1]
- No [2]

Section 3. Health and Food

3.1 Went to Bed Hungry Last Night

Did you go to bed hungry last night?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites

Skip when *Child Age (2.6) Less Than '6'*

3.2 Instruction HIV AIDS

HIV and AIDS is something that lots of kids in South Africa have come across. We would like to know if you have been affected by it and how you feel about it. Please remember that everything you say is confidential and to answer only what you are comfortable with.

Prerequisites

Skip when *Child Age (2.6) Less Than '6'*

3.3 Have HIV or AIDS

Do you have HIV or AIDS?

Expects a single option response (required)

Yes I'm sure [1]

Yes I think so but I'm not sure [2]

No I don't think so [3]

I don't want to answer [4]

I don't know [5]

Prerequisites

Skip when *Child Age (2.6) Less Than '6'*

3.4 Anyone Got or Have HIV or AIDS

Has anyone in your family or in your home got HIV or AIDS

Expects a single option response (required)

No [1]

Yes [2]

I don't know [3]

Branches

If response Equals 'No [1]' then skip to *Parent Died (3.6)*

If response Equals 'I don't know [3]' then skip to *Parent Died (3.6)*

Prerequisites

Skip when *Child Age (2.6) Less Than '6'*

3.5 Number People with HIV or AIDS at Home

If yes, how many people have AIDS?

Expects a numeric response (required)

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

3.6 Parent Died

Has your mother or father died?

Expects a single option response (required)

- No [1]
 - Yes, my mother [2]
 - Yes, my father [3]
 - Yes, both [4]
 - I don't know [5]
-

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

3.7 Anyone Died in Last Two Years

Has anyone else in your family or home died recently?

Expects a single option response (required)

- Yes [1]
- No [2]

Branches

If response Equals 'No [2]' then skip to *Instruction Things I do (5.1)*

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

3.8 Number Died in Last Two Years

How many?

Expects a numeric response (required)

Constraints

Response must be *Greater Than or Equal '0'*

Repeat this section for value of *Number Died in Last Two Years (3.8)*

Section 4. Names for those who died

Prerequisites

Skip when *Anyone Died in Last Two Years (3.7)* Equals 'No [2]' OR
Skip when *Child Age (2.6)* Less Than '6'

4.1 Deceased Name

Referring to deceased number #REPEAT IDX, what was your relationship to the person who died?

Expects a single line text response (required)

Section 5. Health and Food 2

5.1 Instruction Things I do

Now we are going to talk about things you do. In the past 6 months, how many times have you done the following?

5.2 Chosen to a Team or Group

How many times have you been chosen to be in a team or a group? For example, at soccer, church or another activity.

Expects a single option response (required)

- 0 [0]
 - 1 [1]
 - 2 [2]
 - 3 - 4 [3]
 - 5 + [4]
-

5.3 Been Drunk or High

How many times have you been drunk or high from using alcoholic beverages or using drugs (marijuana, etc)?

Expects a single option response (required)

- 0 [0]
 - 1 [1]
 - 2 [2]
 - 3 - 4 [3]
 - 5 + [4]
-

5.4 Rewarded for Doing Good School or Group Work

How many times have you been rewarded for doing good school or group work?

Expects a single option response (required)

- 0 [0]
 - 1 [1]
 - 2 [2]
 - 3 - 4 [3]
 - 5 + [4]
-

5.5 Arrested by Police

How many times have you been arrested by the police for your behavior?

Expects a single option response (required)

- 0 [0]
 - 1 [1]
 - 2 [2]
 - 3 - 4 [3]
 - 5 + [4]
-

5.6 Made New Friends

How many times have you made new friends?

Expects a single option response (required)

- 0 [0]
 - 1 [1]
 - 2 [2]
 - 3 - 4 [3]
 - 5 + [4]
-

5.7 Threatened or Beaten Someone up

How many times have you threatened someone or beaten up somebody?

Expects a single option response (required)

- 0 [0]
 - 1 [1]
 - 2 [2]
 - 3 - 4 [3]
 - 5 + [4]
-

5.8 Helped Somebody

How many times have you helped somebody?

Expects a single option response (required)

- 0 [0]
 - 1 [1]
 - 2 [2]
 - 3 - 4 [3]
 - 5 + [4]
-

Prerequisites

Skip when *Child Age (2.6)* Less Than '6'

5.9 Missed School to Attend Household Duties

In the past year, did you ever have to stay out of school to attend to household duties? (fetching water/wood, tending animals, working on the land, caring for younger children or sick adults, or getting money) to support the household?

Expects a single option response (required)

- Yes [1]
 - No [2]
-

Prerequisites

Skip when *Missed School to Attend Household Duties (5.9)* Not Equal 'Yes [1]'

5.10 How Often Missed School

How often does this happen?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less Often [3]
 - Never [4]
-

5.11 Instruction Stuff thats Been Good and Difficult

Now we are going to talk about stuff that's been good and difficult for me. Sometimes kids experience things that might be difficult as well as good things. We would like to know whether these things have happened to you too. DATA COLLECTORS, please ensure that carers are not present for this part of the interview.

5.12 Adult or Guardian Looking After You

Do you have an adult or guardian in your home who looks after you?

Expects a single option response (required)

Yes [1]

No [2]

Branches

If response Equals 'No [2]' then skip to *Fear Losing Properties (5.22)*

5.13 How Often Adults Shout at Each Other

How often do adults in your home shout at each other?

Expects a single option response (required)

Weekly [1]

Monthly [2]

Less often [3]

Never [4]

5.14 How Often Adults Been Kind to Each Other

How often do adults in your home kind to each other?

Expects a single option response (required)

Weekly [1]

Monthly [2]

Less often [3]

Never [4]

5.15 How Often Adults Hit Each Other

How often do adults in your home hit each other?

Expects a single option response (required)

Weekly [1]

Monthly [2]

Less often [3]

Never [4]

5.16 How Often Adults Fight

How often do adults in your home slap, punch or hit you on your head or face?

Expects a single option response (required)

Weekly [1]

Monthly [2]

Less often [3]

Never [4]

5.17 How often adult beats child

How often do adults in your home beat you with a shoe, wet towel or pinch you in any part of your body?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

5.18 How Often Adults Hug Kiss and Praise You

How often do adults in your home hug, kiss and praise you?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

5.19 How Often Have You Been Attacked

How often have you been attacked outside your home?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

5.20 How Often Have You Seen Someone Stabbed Beaten or Shot

How often have you seen someone stabbed, beaten or shot?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

5.21 How Often Have You Been Given Treats

How often have you been given treats at your home?

Expects a single option response (required)

- Weekly [1]
 - Monthly [2]
 - Less often [3]
 - Never [4]
-

5.22 Fear Losing Properties

Do you fear losing your or your familys properties or possessions?

Expects a single option response (required)

- Almost always [1]
 - Sometimes [2]
 - Never [3]
-

Section 6. How I Feel

6.1 Instruction DC

IF you want to, you can use the feelings track printed card for the next 9 questions.

6.2 Instruction Feeling Tracks

Now we are going to talk about how you have been feeling in the last TWO WEEKS.

6.3 Friends

In the following list pick the one that you have been feeling the most in the last 2 weeks?

Expects a single option response (required)

- I have plenty of friends [1]
 - I have some friends but I wish I had more [2]
 - I don't have any friends [3]
-

6.4 Sadness

In the following list pick the one that you have been feeling the most in the last 2 weeks?

Expects a single option response (required)

- I am sad once in a while [1]
 - I am sad many times [2]
 - I am sad all the time [3]
-

6.5 Myself

In the following list pick the one that you have been feeling the most in the last 2 weeks?

Expects a single option response (required)

- I hate myself [1]
 - I do not like myself [2]
 - I like myself [3]
-

6.6 Killing Myself

In the following list pick the one that you have been feeling the most in the last 2 weeks?

Expects a single option response (required)

- I do not think about killing myself [1]
 - I think about killing myself but I would not do it [2]
 - I want to kill myself [3]
-

6.7 Love

In the following list pick the one that you have been feeling the most in the last 2 weeks?

Expects a single option response (required)

- Nobody really loves me [1]
 - I'm not sure if anybody loves me [2]
 - I'm sure that somebody loves me [3]
-

6.8 Bothering

In the following list pick the one that you have been feeling the most in the last 2 weeks?

Expects a single option response (required)

- Things bother me all the time [1]
 - Things bother me many times [2]
 - Things bother me once in a while [3]
-

6.9 Alone

In the following list, pick the one you have been feeling most in the last 2 weeks?

Expects a single option response (required)

- I do not feel alone [1]
 - I feel alone many times [2]
 - I feel alone all the time. [3]
-

6.10 Work Out for Me

In the following list pick the one that you have been feeling the most in the last 2 weeks?

Expects a single option response (required)

- Nothing will ever work out for me [1]
 - I'm not sure if things will work out for me [2]
 - Things will work out for me ok [3]
-

6.11 How I do Things

In the following list pick the one that you have been feeling the most in the last 2 weeks?

Expects a single option response (required)

- I do most things ok [1]
 - I do many things wrong [2]
 - I do everything wrong [3]
-

6.12 Crying

In the following list pick the one that you have been feeling the most in the last 2 weeks?

Expects a single option response (required)

- I feel like crying every day [1]
 - I feel like crying many days [2]
 - I feel like crying once in a while [3]
-

Prerequisites

Skip when *Child Age (2.6)* Less Than '6'

6.13 Instruction Statements

Here is a list of things to do with your feelings about yourself. Please select how much you agree with what the statement says. DATA COLLECTORS:
Please use the smiley faces card for the next 10 questions if needed

Prerequisites
Skip when *Child Age (2.6) Less Than '6'*

6.14 Satisfied With Myself

On the whole, I am satisfied with myself. On the whole I feel okay about myself.

Expects a single option response (required)

- Agree a lot [1]
 - Agree [2]
 - Disagree [3]
 - Disagree a lot [4]
-

Prerequisites
Skip when *Child Age (2.6) Less Than '6'*

6.15 Think I am No Good

At times, I think I am no good at all.

Expects a single option response (required)

- Agree a lot [1]
 - Agree [2]
 - Disagree [3]
 - Disagree a lot [4]
-

Prerequisites
Skip when *Child Age (2.6) Less Than '6'*

6.16 Have a Number of Good Qualities

I feel that I have a number of good qualities.

Expects a single option response (required)

- Agree a lot [1]
 - Agree [2]
 - Disagree [3]
 - Disagree a lot [4]
-

Prerequisites
Skip when *Child Age (2.6) Less Than '6'*

6.17 Able to Do Things

I am able to do things as well as most other people.

Expects a single option response (required)

- Agree a lot [1]
 - Agree [2]
 - Disagree [3]
 - Disagree a lot [4]
-

Prerequisites
Skip when *Child Age (2.6) Less Than '6'*

6.18 Not Much to Be Proud of

I feel I do not have much to be proud of.

Expects a single option response (required)

- Agree a lot [1]
 - Agree [2]
 - Disagree [3]
 - Disagree a lot [4]
-

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.19 Feel Useless at Times

I certainly feel useless at times.

Expects a single option response (required)

- Agree a lot [1]
 - Agree [2]
 - Disagree [3]
 - Disagree a lot [4]
-

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.20 Person of Worth

I feel that I'm a person of worth, at least on an equal plane with others.

Expects a single option response (required)

- Agree a lot [1]
 - Agree [2]
 - Disagree [3]
 - Disagree a lot [4]
-

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.21 Respect for Myself

I wish I could have more respect for myself.

Expects a single option response (required)

- Agree a lot [1]
 - Agree [2]
 - Disagree [3]
 - Disagree a lot [4]
-

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.22 Feel That I am a Failure

All in all, I am inclined to feel that I am a failure.

Expects a single option response (required)

- Agree a lot [1]
 - Agree [2]
 - Disagree [3]
 - Disagree a lot [4]
-

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.23 Take Positive Attitude Towards Myself

I take a positive attitude toward myself.

Expects a single option response (required)

- Agree a lot [1]
 - Agree [2]
 - Disagree [3]
 - Disagree a lot [4]
-

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.24 Feel Proud of Your Community

You feel proud of your community?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.25 No One Cares About You in Your Community

You feel that no one cares about you in this community?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.26 Feel You Have Lots of Friends in Your Community

Do you feel that you have lots of good friends in your community?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.27 Feel You are Isolated in Your Community

Do you feel that you are isolated from others in this community?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.28 Feel That People will Hurt You than Help you in Your Community

Do you feel that people in this community would rather hurt you than help you?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.29 Feel That There are People Who Like to Help You

Do you feel that there are lots of people nearby who like to help you?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.30 Feel That People Speak Badly About You

Do you feel that people speak badly about you or your family?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.31 Feel That People Make Fun of Your Situation

Do you feel that people make fun of your situation?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.32 Feel That You Fit Well in Your Community

Do you feel that you fit in well to your community?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites
Skip when *Child Age (2.6)* Less Than '6'

6.33 Feel That Caregivers Have AIDS

Do you feel that you have AIDS or your caregivers have AIDS?

Expects a single option response (required)

Yes [1]

No [2]

6.34 Bad Dreams or Nightmares

I have bad dreams or nightmares.

Expects a single option response (required)

Never [1]

Sometimes [2]

Lots of times [3]

Almost all of the time [4]

6.35 Scary Ideas or Pictures in My Head

I have scary ideas or pictures just pop into my head.

Expects a single option response (required)

Never [1]

Sometimes [2]

Lots of times [3]

Almost all of the time [4]

6.36 Remember Things That Happened That I dont Like

I remember things that happened that I didn't like.

Expects a single option response (required)

- Never [1]
 - Sometimes [2]
 - Lots of times [3]
 - Almost all of the time [4]
-

6.37 Going Away in My Mind

I am going away in my mind trying not to think.

Expects a single option response (required)

- Never [1]
 - Sometimes [2]
 - Lots of times [3]
 - Almost all of the time [4]
-

6.38 Remember Scary Things

I remember scary things.

Expects a single option response (required)

- Never [1]
 - Sometimes [2]
 - Lots of times [3]
 - Almost all of the time [4]
-

6.39 Feel Scared of Men

I feel scared of men.

Expects a single option response (required)

- Never [1]
 - Sometimes [2]
 - Lots of times [3]
 - Almost all of the time [4]
-

6.40 Feel Scared of Women

I feel scared of women.

Expects a single option response (required)

- Never [1]
 - Sometimes [2]
 - Lots of times [3]
 - Almost all of the time [4]
-

6.41 Cant Stop Thinking About Something Bad That Happened

I can't stop thinking about something bad that happened to me.

Expects a single option response (required)

- Never [1]
 - Sometimes [2]
 - Lots of times [3]
 - Almost all of the time [4]
-

6.42 Remember Things I Dont Want to Remember

I remember things I don't want to remember.

Expects a single option response (required)

- Never [1]
 - Sometimes [2]
 - Lots of times [3]
 - Almost all of the time [4]
-

6.43 Wish Bad Things Never Happened

I wish bad things had never happened.

Expects a single option response (required)

- Never [1]
 - Sometimes [2]
 - Lots of times [3]
 - Almost all of the time [4]
-

Section 7. End

7.1 Require Referral

Does this participant require referral to the organisation or other services?

Expects a single option response (required)

Yes [1]

No [2]

7.2 End Instruction

You have reached the end of this questionnaire. Please press BACK to review your responses or press NEXT to submit the questionnaire.

Section 1. Introduction

1.1 Introduction Instruction

We would like to ask you about facts about the organisation that you are working for, the children you see and the premises you work in.

1.2 Organisation Name

What is the name of the organisation you work for?

Expects a single line text response (required)

1.3 Name

What is your name?

Expects a single line text response (required)

1.4 Role

What is your role in the organisation?

Expects a single line text response (required)

1.5 Date

Date:

Expects a date response (required)

Section 2. Organisation Characteristics

2.1 Organisation Start Date

When did your organisation start?

Expects a date response (required)

2.2 Who set up the organisation

Who set up the organisation?

Expects a single option response (required)

- People from the community had the idea and set it up [1]
- An external organisation brought the idea and set up the organisation [2]

2.3 Programme Inspiration

Was your programme:

Expects a single option response (required)

- Locally inspired [1]
- Internationally inspired [2]

2.4 Programme Delivery

Is your programme:

Expects a single option response (required)

- Delivered by a local organisation [1]
- Delivered by an international organisation [2]

2.5 Organisation Funder

This organisation is funded by:

Expects a single option response (required)

- One funder only [1]
- Multiple funders [2]

2.6 Funders

Please tick the boxes of all the kind of funders that apply:

Expects multiple selected options (required)

- Community raised funds [1]
- National government [2]
- National charities [3]
- International charities [4]
- National commercial organisations [5]
- International commercial organisations [6]

2.7 Organisation Annual Budget

What is the overall annual budget of your organisation?

Expects a decimal response (required)

2.8 Programme Term

Is your programme:

Expects a single option response (required)

- Long term or permanent [1]
- Short term [2]
- Fixed term [3]

Prerequisites

Skip when *Programme Term (2.8)* Not Equal 'Fixed term [3]'

2.9 Programme Term Length

How long is it running for?

Expects a numeric response (required)

Constraints

Response must be Greater Than or Equal '0'

2.10 Link to Government

What is the nature of your link with government provision?

Expects a single option response (required)

- There is no link [1]
- The organisation has government support to deliver the programme [2]
- The organisation has links with the government and policy makers to influence policy [3]
- Other [4]

Prerequisites

Skip when *Link to Government (2.10)* Not Equal 'Other [4]'

2.11 Link to Government Other

Please specify:

Expects a single line text response (required)

2.12 Office and Work Space

Please indicate what space you have for office space and to work with the children:

Expects a single option response (required)

- Small (room and garden) [1]
- Medium (few rooms and garden) [2]
- Large (entire building and garden) [3]
- Other premises [4]

Prerequisites

Skip when *Office and Work Space (2.12)* Not Equal 'Other premises [4]'

2.13 Office and Work Space Other

Please specify:

Expects a single line text response (required)

2.14 Working Hours

What are the working hours of the organisation?

Expects a single option response (required)

- Normal working hours / full day [1]
- Half days [2]
- Weekends only [3]
- Other (e.g. school holidays only) [4]

Prerequisites

Skip when *Working Hours (2.14)* Not Equal 'Other (e.g. school holidays only) [4]'

2.15 Working Hours Other

Please specify:

Expects a single line text response (required)

2.16 Leadership

Is there leadership of your organisation?

Expects a single option response (required)

- Male [1]
- Female [2]
- Both male and female [3]

2.17 Youth Leaders

Are there youth leaders in your organisation?

Expects a single option response (required)

- Yes [1]
- No [2]

2.18 Organisation Lead

Is your organisation led by:

Expects a single option response (required)

- One individual [1]
- A team of leaders [2]

2.19 Advisory Committee

Does your organisation have an advisory committee?

Expects a single option response (required)

- Yes [1]
- No [2]

2.20 Length of Term

How long has the current leader of your organisation been in this position? Specify in years

Expects a numeric response (required)

2.21 Rotating Leadership

Do you have rotating leadership?

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites

Skip when *Rotating Leadership (2.21)* Not Equal 'Yes [1]'

2.22 Length of Rotation

How long is the leadership term?

Expects a numeric response (required)

2.23 Location

Your organisation is located:

Expects a single option response (required)

In a big city [1]

In a small town [2]

In a village [3]

In the country [4]

2.24 Number Paid Staff

What is the number of paid staff that currently work this organisation?

Expects a numeric response (required)

2.25 Number Volunteers

How many volunteers currently work for this organisation?

Expects a numeric response (required)

2.26 Instruction Staff Qualification

How many of your paid staff or volunteers have following:

2.27 Tertiary Degree

A tertiary degree (please enter 999 for I don't know):

Expects a numeric response (required)

2.28 Certificate

A certificate (please enter 999 for I don't know):

Expects a numeric response (required)

2.29 Finished High School

Finished high school (please enter 999 for I don't know):

Expects a numeric response (required)

2.30 Some High School

Some high school (please enter 999 for I don't know):

Expects a numeric response (required)

2.31 Finished Primary School

Finished primary school (please enter 999 for I don't know):

Expects a numeric response (required)

2.32 Instruction Staff Needs

Do your staff and volunteers have the following:

2.33 Training Updates

Training updates?

Expects a single option response (required)

Yes [1]

No [2]

2.34 Supervision Sessions

Supervision sessions?

Expects a single option response (required)

Yes [1]

No [2]

2.35 Library/Material Access

Library/Material access?

Expects a single option response (required)

Yes [1]

No [2]

2.36 Internet Access

Internet access?

Expects a single option response (required)

Yes [1]

No [2]

2.37 Staff Meetings

Staff meetings?

Expects a single option response (required)

Yes [1]

No [2]

2.38 Staff Follow Written Program and Protocols

Do your staff and volunteers follow written program protocols and procedures?

Expects a single option response (required)

Yes [1]

No [2]

2.39 Instruction Research

Do you do any of the following to track your performance:

2.40 Monitor Progress

Monitor/evaluate your progress?

Expects a single option response (required)

Yes [1]

No [2]

2.41 Report to Funders

Report to funders?

Expects a single option response (required)

Yes [1]

No [2]

2.42 Keep Audit of Children

Keep audit of all children?

Expects a single option response (required)

Yes [1]

No [2]

2.43 Keep Notes and Records

Keep notes and records?

Expects a single option response (required)

Yes [1]

No [2]

2.44 Involvement in Other Research

Have involvement in any other research?

Expects a single option response (required)

Yes [1]

No [2]

2.45 Organisation Based on Theory or Inspiration Ideas

Is your organisation based on Theory, or specific inspirational ideas?

Expects a single option response (required)

Yes [1]

No [2]

Branches

If response Equals 'No [2]' then skip to *Main Issue Trying to Address (2.49)*

2.46 Deep Need To Help Children

Is your programme based on a deep need to help children?

Expects a single option response (required)

Yes [1]

No [2]

2.47 Urgent Crisis

Is your programme based on an urgent crisis?

Expects a single option response (required)

Yes [1]

No [2]

2.48 Pre-planned Programme

Is your programme based on a pre-planned programme?

Expects a single option response (required)

Yes [1]

No [2]

2.49 Main Issue Trying to Address

What is the main issue that your organisation is trying to address?

Expects a single option response (required)

Mental health and/or wellness [1]

Poverty [2]

Food security [3]

Human rights [4]

Education and skills [5]

General health care [6]

Early childhood development [7]

Other [8]

Prerequisites

Skip when *Main Issue Trying to Address (2.49)* Not Equal 'Other [8]'

2.50 Main Issue Other

Please specify:

Expects a single line text response (required)

2.51 Primary Programme Recipients

Who are your services primarily aimed at/who is the direct recipient of your programme?

Expects multiple selected options (required)

- Children affected by HIV [1]
- Vulnerable children, including those affected by HIV [2]
- Carers of children affected by HIV [3]
- Families affected by HIV [4]
- Communities affected by HIV [5]
- Other [6]

Prerequisites

Skip when *Primary Programme Recipients (2.51)* Excludes 'Other [6]'

2.52 Primary Programme Recipients Other

Please specify:

Expects a single line text response (required)

2.53 Services Provided Directly

What services do you provide directly?

Expects multiple selected options (required)

- Food/Nutrition (feeding or food parcels) [1]
- Medical provision (Read/ARV/treatment for children living with HIV) [2]
- Play supervision [3]
- Psychosocial interventions [4]
- Early child development services [5]
- School (Education, fees, uniforms) [6]
- Emotional support [7]
- Home based care [8]
- Emergency (emergency care) [9]
- Assistance with accessing social grants [10]
- Skills building and training [11]
- Direct income support [12]
- Other [13]

Prerequisites

Skip when *Services Provided Directly (2.53)* Excludes 'Other [13]'

2.54 Services Provided Directly Other

Please specify:

Expects a single line text response (required)

2.55 Services you Assist People to Access

What services do you assist people to access e.g. through referral?

Expects multiple selected options (required)

- Food/ Nutrition (feeding or food parcels) [1]
- Medical provision (Read/ARV/treatment for children living with HIV) [2]
- Play supervision [3]
- Psychosocial interventions [4]
- Early child development services [5]
- School (Education, fees, uniforms) [6]
- Emotional support [7]
- Home based care [8]
- Emergency (emergency care) [9]
- Assistance with accessing social grants [10]
- Skills building and training [11]
- Direct income support [12]
- Other [13]

Prerequisites

Skip when *Services you Assist People to Access (2.55)* Excludes 'Other [13]'

2.56 Services you Assist People to Access Other

Please specify:

Expects a single line text response (required)

2.57 School Fees

Do most children in your programme pay school fees?

Expects a single option response (required)

- Yes [1]
- No [2]

2.58 School Provision

Does your organisation assist with any form of school provision?

Expects a single option response (required)

- Yes, this organisation assists with fees [1]
- Yes, this organisation supports learners to access schooling [2]
- No [3]

2.59 Community Support your Group

Does the local community support your group?

Expects a single option response (required)

- Yes [1]
- No [2]

2.60 Community Make Things Difficult for Your Group

Does the local community make things difficult for your group?

Expects a single option response (required)

Yes [1]

No [2]

2.61 Community Contribute

Does the local community contribute (food, volunteers, premises) to your group?

Expects a single option response (required)

Yes [1]

No [2]

2.62 Community Raise Money for Your Work

Does the local community raise money for your work?

Expects a single option response (required)

Yes [1]

No [2]

2.63 Work with Government Services

Do you work with other government services in your area?

Expects a single option response (required)

Yes [1]

No [2]

2.64 Work With Other Community-based Organisation

Do you work with other community-based organisations in your area?

Expects a single option response (required)

Yes [1]

No [2]

Section 3. Clients Characteristics

3.1 Number Children Registered by Your Organisation

How many children are currently registered by your organisation in total?

Expects a numeric response (required)

3.2 Instruction Input

Do you provide input for any of the following age groups?

3.3 Toddler

Toddler (2 and under)

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites

Skip when *Toddler (3.3)* Not Equal 'Yes [1]'

3.4 Number Toddlers

How many?

Expects a numeric response (required)

3.5 Preschool

Preschool (age 3 - 5)

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites

Skip when *Preschool (3.5)* Not Equal 'Yes [1]'

3.6 Number Preschool

How many?

Expects a numeric response (required)

3.7 Primary school

Primary school (6 - 12)

Expects a single option response (required)

Yes [1]

No [2]

Prerequisites

Skip when *Primary school (3.7)* Not Equal 'Yes [1]'

3.8 Number Primary school

How many?

Expects a numeric response (required)

3.9 Adolescents

Adolescents (13 - 18)

Expects a single option response (required)

- Yes [1]
 No [2]

Prerequisites

Skip when *Adolescents (3.9)* Not Equal 'Yes [1]'

3.10 Number Adolescents

How many?

Expects a numeric response (required)

3.11 Where do Children Come From

Where do the children you see come from?

Expects a single option response (required)

- The local village/town/city [1]
 From the local village/town/city and neighbouring villages/towns/cities [2]
 From all over the country [3]

3.12 How Contact Between Organisation and Children Established

How is contact between your organization and the children who you work with established?

Expects multiple selected options (required)

- Children/families come directly to the organization [1]
 We go out and seek those who need help [2]
 Someone refers the child/family to the organization [3]

Prerequisites

Skip when *How Contact Between Organisation and Children Established (3.12)* Excludes 'Someone refers the child/family to the organization [3]'

3.13 Where Referrals Received From

When referrals are received, they are made from: [Fieldworker tick as many as appropriate]

Expects multiple selected options (required)

- Health facilities such as clinics or hospitals [1]
 Schools [2]
 Other [3]

Prerequisites

Skip when *Where Referrals Received From (3.13)* Excludes 'Other [3]'

3.14 Where Referrals Received From Other

Please specify:

Expects a single line text response (required)

3.15 Organisation Services Demand

What is the demand for your organizations' services?

Expects a single option response (required)

- There are more children than we can help and we have a waiting list [1]
- We are full but have no children on the waiting list [2]
- We have capacity left and could therefore take in more children [3]

3.16 Frequency Seeing Each Child

How frequently do you see each child?

Expects a single option response (required)

- Every day [1]
- 2-3 times a week [2]
- Once a week [3]
- Every two weeks [4]
- Every month [5]
- Other [6]

Prerequisites

Skip when *Frequency Seeing Each Child (3.16)* Not Equal 'Other [6]'

3.17 Frequency Seeing Each Child Other

Please specify:

Expects a single line text response (required)

3.18 Visit Duration

How long is each visit?

Expects a single option response (required)

- 1 hour or less [1]
- 2-3 hours [2]
- 4-5 hours [3]
- All day [4]
- All day and night [5]
- Other [6]

Prerequisites

Skip when *Visit Duration (3.18)* Not Equal 'Other [6]'

3.19 Visit Duration Other

Please specify:

Expects a single line text response (required)

3.20 Where You See Children

Where do you see the children?

Expects multiple selected options (required)

- At home [1]
- At the organisation's premises [2]
- At school [3]
- Other [4]

Prerequisites
Skip when *Where You See Children (3.20)* Excludes 'Other [4]'

3.21 Where You See Children Other

Please specify:

Expects a single line text response (required)

3.22 How Often is Contact With Main Carer

How often are you in contact with the main carer/carers of each child?

Expects a single option response (required)

- Every day [1]
- 2-3 times a week [2]
- Once a week [3]
- Every two weeks [4]
- Every month [5]
- Never [6]
- Other [7]

Prerequisites
Skip when *How Often is Contact With Main Carer (3.22)* Not Equal 'Other [7]'

3.23 How Often is Contact With Main Carer Other

Please specify:

Expects a single line text response (required)

3.24 Discuss Child Progress With Carer

When you see the carer, do you discuss the child's progress with him or her?

Expects a single option response (required)

- Always [1]
- Sometimes [2]
- Never [3]

3.25 Any Other Types of Input

Do you provide other types of input to the carer?

Expects a single option response (required)

- Yes [1]
- No [2]

3.26 Other Type of Input Provided to Carer

Then which of the following do you provide?

Expects multiple selected options (required)

- Health education and information [1]
- Health services [2]
- Parenting skills training [3]
- Assistance with accessing social grants [4]
- Skills building and training [5]
- Referral to health or social services [6]
- Other [7]

Prerequisites

Skip when *Other Type of Input Provided to Carer (3.26)* Excludes 'Other [7]'

3.27 Other Type of Input Provided to Carer Other

Please specify:

Expects a single line text response (required)

Section 4. End

4.1 End Instruction

You have reached the end of this questionnaire. Please press **BACK** to review your responses or press **NEXT** to submit the questionnaire.
