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Social Support for Young Carers An Analysis of the Available Social Support for Children Caring for AIDS-Sick and Other-Sick Caregivers in Emoyeni, South Africa.

Flannery McArdle
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Social Support for Young Carers

An Analysis of the Available Social Support for Children Caring
for AIDS-sick and Other-sick Caregivers
In Emoyeni, South Africa.

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November 28, 2011

SIT Community Health

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ABSTRACT

The dual epidemics of HIV/AIDS and non-communicable diseases in South Africa are the principal drivers of the worsening orphan epidemic in South Africa. As orphanhood is often far from a singular event but rather one preceded by months or even years of the parent or guardian's declining health, many children will become the primary caregivers for a sick or dying adult. This study explores the lives of the young carers, specifically, the social support available for these children and how the support available for children caring for AIDS-sick caregivers may differ from that available for children caring for an adult critically ill from other causes. The study is based on a sample of four young carers located during four weeks of participant observation with the Holy Cross AIDS Hospice located in Emoyeni, South Africa. During this time, the researcher observed and conducted interviews with home-based care workers, young carers and members of the community working with these children. A similarly minimal level of social support was found in Emoyeni and the surrounding communities for both children caring for AIDS-sick caregivers and those caring for other-sick caregivers. However, AIDS-related stigma did have a negative effect on the level of community support provided, suggesting that there is a greater need for interventional support for children caring for AIDS-unwell caregivers than for those caring for other-unwell caregivers.

I. INTRODUCTION

1.1 SOCIO-HISTORICAL CONTEXT

South Africa currently makes up over 17 percent of the global burden of HIV/AIDS with 5.7 million people infected (Global Health Council 2010). According to the 2010 South African Health Review, there is a 25.7 percent HIV prevalence among 15-49 year olds in KwaZulu Natal making it the most affected province in a country with a national prevalence of 19 percent for the same age group (Health Systems Trust 2010, p. 257). Young women of childbearing age have proven to be one of the primary victims of this disease with an HIV prevalence of 39.5 percent among antenatal clinic attendees in KwaZulu Natal (AVERT, 2010). As many of these women have already had or will soon have children, a large number of children will find themselves living with an AIDS-sick caregiver.

According to the Global Health Council, the South African HIV epidemic is stabilizing, though a second epidemic is looming in South Africa. Non-communicable diseases (NCD'S) are on the rise and in 2000 thirty-seven percent of all deaths in South Africa were due to non-communicable diseases (Department of Health, 2011). Despite the negative effects HIV/AIDS has had on life expectancy in South Africa, the country is going through a demographic transition, creating an hour-glass population structure, whereby the age groups at both ends are greater than those in the middle of the population, ultimately leading to a greater population of people older than 60 years (Mayosi 2009). South Africa's overall ageing index, defined as the "number of people aged 65 and over per 100 youths," increased from 11 in 2001 to 16 in 2010 but "is nearly 70 in some population groups" (Health Systems Trust 2010, p. 219). The rise of NCD risk factors such as tobacco use, unhealthy diet, insufficient physical activity and harmful

use of alcohol have led to a rise of non-communicable diseases including diabetes, hypertension, cancer, and heart disease. As a result of the large number of parents falling victim to HIV/AIDS, many grandparents are left to care for their grandchildren. With the rise of non-communicable diseases, which primarily affect people over the age of forty-five (Stephen Knight, Lecture, 10/3/2011), children may find themselves caring for a chronically ill or dying grandparent, often after the death of one or both of their parents.

With the burden of disease in South Africa as great as it is, the public sector must be operating at its highest capacity. Unfortunately, the South African health system is “still coping with an apartheid legacy of underfunding and skills shortage” and thus is unable to provide care for all those in need (Cluver et al 2011, p. 3). Increasingly, policies are leaning on home-based care in order to relieve some of the strain on the overtaxed public health system. The caregivers serve as a link between the clinic and the community (Department of Health, 2001). However, the number of home-based caregivers is still inadequate in the face of the large numbers of people affected by HIV/AIDS and non-communicable diseases. The onus thus often falls on the family to perform the daily tasks of caring for the critically ill.

Though the Zulu community culture is built “on a foundation of mutual support” (Holy Cross Children’s Trust 2010), the traditional family structure has been fragmented largely as a result of the magnitude of the AIDS pandemic. Sister Priscilla Dlamini recognized this fragmentation and that the effects of the pandemic reach far beyond just the infected, with the heaviest burden often shouldered by children. In the early nineties, Sister Priscilla discovered that HIV positive patients who had been rejected from their homes, for fear of spreading the disease to their family members, were moving into the sugar fields with only a blanket, surviving solely on what they got by begging from those neighboring the fields. It was this discovery that

inspired Sister Dlamini to work for the next eight years to open a hospice. In 2000, she was given abandoned stables, which she converted, largely by herself, into the hospice that exists today. Immediately upon opening the doors of the hospice, she began searching for patients in the sugar cane fields. What she found was a mother being cared for by her 5-year-old daughter. The mother was dying of AIDS and the two were living off of what the five-year-old could get from begging for food. Sister Priscilla brought two of her home based caregivers, who carried the mother out on their backs and she became one of the first patients at the Holy Cross AIDS Hospice. Today, Sister Priscilla has many projects in addition to the hospice including home based care, creches/preschools, assistance for child headed households, and a satellite feeding center for children on their way to and from school, all with a goal of providing a dignified and comfortable death to the dying, while supporting their families during the terminal stages of illness and the bereavement period.

1.2 PROBLEM STATEMENT

By 2020 the number of orphaned children in South Africa is expected to reach 2.3 million (Cluver & Gardner, 2007), suggesting that a considerable number of children are or soon will be living with a sick or dying parent and many of whom may be performing “substantial and significant [caring] tasks” (Becker, 2000). Though young carers qualify as vulnerable children and are thus eligible for government programming intended for Orphans and Vulnerable Children (OVC) without adequate research on the experiences of children caring for chronically ill adults, the needs of these children are not likely to be met.

The research on young carers in resource-limited settings is minimal. However, what research has been conducted has focused primarily on children taking care of AIDS-sick parents. There has been little research comparing the effects of taking care of an AIDS-sick parent against those experienced by a child taking care of a parent with a different critical illness despite

that “in addition to HIV/AIDS, South Africa faces a high burden of other diseases, such as diabetes and hypertension,” (Cluver et al, 2011). The public health sector is under funded and lacking the skilled staff necessary to provide adequate care to those in need. As a result, “many people with AIDS and other illnesses are cared for in the home” leaving countless children to take on the burden of performing caring tasks for their critically ill caregiver (Cluver et al, 2011).

The current research on the psychological health of orphans in South Africa suggests that children orphaned by AIDS are at “particular risk for mental health problems of depression, peer problems, post- traumatic stress disorder, and behavior problems” whereas orphanhood by other means showed no association with mental illness or behavior issues (Cluver, 2008). This difference in the prevalence of mental illness suggests that the daily lives, challenges and support systems of children caring for AIDS-sick parents are likely significantly different from those of children caring for parents with other critical illnesses. This qualitative study looks specifically at the social support systems available for children caring for adults and how the types and amounts of support available to children caring for AIDS-unwell caregivers may differ from those available to children caring for other-sick caregivers.

This study will address the following questions in order to gain a better understanding of the support available for young carers in Gingindlovu:

- What support is available to children who are the primary caretaker of a critically sick parent or guardian?
- How does the support available for children caring for AIDS-unwell caregivers differ from that available for children caring for parents or guardians with other chronic illnesses?
- What role does this support play and how does this difference manifest itself in the lives of young carers?

1.3 DEMOGRAPHICS AND CONTEXT

The Holy Cross AIDS Hospice is based in Emoyeni, a small town located in the Umlalazi municipality, yet it serves an area of fifty square kilometers stretching into the towns of both Gingindlovu and Mtunzini. The Umlalazi municipality has a population of 231, 023, of whom 23.5 percent are illiterate and an estimated 83,630 are infected with HIV, though these figures must be updated with the results of the 2011 census (Umlalazi Municipality Offices, 2000). The area has been designated an AIDS Pandemic Disaster Zone by the South African government evidenced in part by the rising number of orphans and child headed households (Annual HCTCT report 2009, p. 4).

The twenty-five caregivers employed by Holy Cross AIDS Hospice have identified and provide care to over 2914 orphans, 1182 child headed households and serve 516 patients with home-based care. Additionally, the hospice supports a feeding scheme, which provides food to over 3800 people each month and operates a creche for over 70 children, many of whom have been orphaned or affected by HIV/AIDS. The living conditions for the majority consist primarily of basic mud huts with no electricity or running water and for many Holy Cross is their only source of support (Holy Cross Children's Trust 2010). Holy Cross is primarily funded by international donors but does receive minimal funding from the Department of Social Development primarily for the three meals served each day at the creche. The government provides no assistance for the running of the hospice or the home based care program.

1.4 DEFINITION OF MAJOR TERMS

Home Based Caregivers

“The primary role of the Caregivers is to reach out to the community in the 50 square kilometers surrounding the Holy Cross AIDS Hospice and provide care and support to the most needy on a structured and consistent basis” (Holy Cross Children’s Trust 2010).

Young Carer

A young carer refer to a child under the age of 18 who “provides nursing care and support for sick, disabled or elderly relatives or guardians (regardless of HIV status) on a regular basis and play a key role in sustaining the household”. (Skovdal, 2009)

Other-Sick Caregiver

For the purposes of this study, an “other-sick caregiver” will refer to the primary caregiver of a child under the age of 18 suffering from a chronic illness other than AIDS. The researcher relied on the home-based caregivers to report the illness from which the patient was suffering.

AIDS-sick Caregiver

An AIDS-sick Caregiver or and AIDS-unwell caregiver is the primary caregiver of a child under the age of 18 who is infected with HIV and suffering from AIDS. As with “other-sick caregiver”, the researcher relied on the home based caregivers to report the illness from which the patient was suffering but oftentimes the patient revealed their status as well.

Creche

A creche is a preschool that serves children ages two to six. In this context, the creche primarily caters to children who have been orphaned or made vulnerable by HIV/AIDS. Its primary purpose is to provide a place for the older children in child headed households to bring their younger siblings so that they can continue their education.

Vulnerable Child

“A child whose survival, care, protection or development may be compromised, due to a particular condition, situation or circumstance and which prevents the fulfillment of his or her rights.” (Department of Social Development 2005).

2 METHODOLOGIES

The learner consulted both primary and secondary sources in this qualitative study in order to fully understand the reality and the needs of children providing care for their guardians.

2.1 SAMPLE

The researcher spent four weeks observing several different potential sources of social support available to children and supplemented it with visits to the homes of young carers in the community to assess the effectiveness of said support. Interviews were conducted with those responsible for providing support to the children as well as with the primary caregivers in each family and with their children whenever possible.

2.2 PRIMARY DATA COLLECTION

Primary data for this study was collected over the course of one month during which the researcher lived at the Holy Cross AIDS Hospice in Emoyeni, South Africa. Living on the property allowed the researcher to see all aspects of care and provided ample opportunity to speak with and to gain the trust and respect of the staff.

2.2.1 Case Studies

In order to conduct a comparative study of the social support available for children caring for AIDS-unwell caregivers and for those caring for other-unwell caregivers four case studies were collected, two of which involve children of AIDS-unwell caregivers while the remaining two involve children of caregivers with other chronic illnesses. The children were observed as they interacted with their parents or guardians, their siblings and as they perform daily chores

around the house. In order to get the most complete picture of their lives, their needs, and the support they receive semi-structured interview was conducted with each child identified and with the caregivers of the children if the child was not at home during the interview. More formal interviews with the home-based caregivers responsible for each child's home were conducted as well.

2.2.2 Dimensions of Social Support

The learner used the Social Support Survey, developed for the Medical Outcomes Study (MOS), to identify the dimensions of social support used in this study. The MOS was a two-year study of the “process and outcomes of care for patients with prevalent and treatable chronic conditions” (Sherbourne & Stewart, 1991). The dimensions of social support used in the survey have been emphasized in the literature as distinct types of support. Though the Social Support Survey specifically focuses on how social support affects the health of the chronically ill, the dimensions of support used in the survey have been applied to this study in order to assess the level of social support available to young carers working under the assumption that those caring for the chronically ill possess a similar need for support to those who are ill. The dimensions of social support used in this study are tangible support, emotional and informational support, affectionate support and positive social interaction.

2.2.3 Semi-Structured Interviews

Interviews with children were conducted primarily using semi-structured interviews rather than a strict set of questions. Consent forms were translated into Zulu to provide the children with the easiest and most understandable form. The translations were back translated into English to ensure that the meaning of the forms was not lost. The home-based caregivers were used as translators so that the researcher could communicate with the children and their parents or guardians in their native language.

Interviews with the parents or guardians of the children were conducted using semi-structured interviews as well. These interviews made up the bulk of the study because the young carers were often writing their exams at school during the time of the researcher's visit. These conversations were also used to form a relationship with the parent or guardian so as to ensure they were comfortable with their child being interviewed. Of course, if the caregiver was not comfortable with their child being a part of the study, the researcher directed the questions to the caregiver and asked him or her to answer to the best of their ability. Written consent was always obtained from the primary caregiver of the child if the researcher was interviewing children. Additionally, verbal consent from caregiver and child was acquired before every interview.

2.2.4 Participant Observation

Several days each week the researcher volunteered in the Bishop Mansuet Biyase Creche for orphans and vulnerable children operated by Sister Priscilla Dlamini on site at the Hospice. Many of these children were the younger siblings of children caring for adults or were members of child headed households. Thus, participating in the daily activities of the creche allowed the researcher to see an example of a support system for young carers and their families. Working in the creche also allowed the researcher to form a relationship with the principal and one of the teachers, both of whom proved to be valuable informants.

The bulk of the primary data collection for this study was conducted while shadowing several caregivers during the month-long study. The caregivers visited houses in their own communities or in the communities nearest to their homes so that the patients knew and trusted them. Largely because of this trusting relationship, the caregivers were able to act as translators during each interview. Each patient seemed at ease with the caregivers and thus the learner was able to ask fairly personal questions, even after just one visit. Shadowing caregivers provided the researcher with a sense of the living conditions of people in the communities and provided a

context in which the study could be situated. The researcher was able to spend ample time speaking with the caregivers about their work and what they believed the most pressing problems of their patients were.

2.2.5 Formal Interviews

Formal interviews were conducted primarily with home-based caregivers but also with Sister Priscilla Dlamini, teachers in the creche, the principal of the creche and the principal of a local school. These interviews provided the researcher with the opportunity both to see what the community perception of young carers is and what motivates members of the community either to support or not to support young carers. Finally, they provided the researcher with a more complete picture of what support the children should be receiving.

2.3 SECONDARY DATA COLLECTION

Secondary data was collected from a variety of sources and was used primarily to provide both a context for the primary data and a baseline expectation for what social support children should be receiving in order to grow up healthy and happy. Peer-reviewed scholarly journal articles were collected from databases such as JSTOR and Google Scholar though some were provided by primary sources. Similarly, government reports were either found on the South African Government Information website or were gathered from primary sources.

There has been very little research looking into the lives of young carers and less into the social support provided to them. The literature that is available on young carers specifically is heavily dominated by a few researchers. However, there is a plethora of research on early childhood development, thus a diversity of sources was achieved on that topic. This diversity allowed the researcher to contextualize the primary data and to better understand why social support is a necessary component of a healthy child's development. As the primary data for this

study was collected in a few small communities in rural South Africa, secondary data collection was necessary in order to assess whether this study is replicable in different settings.

2.4 ETHICAL CONSIDERATIONS AND LIMITATIONS

2.4.1 Limited Time

The short time in which the researcher was given to complete this study was one major limitation. The three weeks allotted for data collection was insufficient to fully understand the context of the situation, identify participants, gain their trust, and collect data. The caregivers had a responsibility to visit specific families a certain number of times each week thus, because of scheduling conflicts, transportation issues, and the spread out nature of the area, the number of young carers who could be reached by the researcher was limited. As the caregivers' territory is an area of fifty square kilometers, the number of patients and the ground they must cover prevented the researcher from meeting with each family more than once. Due to the personal nature of the content of this study, the researcher did not broach the more intimate questions on the first visit out of respect for the participant. As a result, some valuable data was not collected. In contrast, the researcher was able to ask more personal questions of a teacher in the creche who cared for her parents before they died because the researcher was able to form a relationship with the informant.

The specific time period in which the study was conducted was similarly limiting. The students were writing their exams during the study, which prevented the researcher from speaking to learners during a school visit in which an interview was conducted with the principal. An additional principal was eager to take part in the study but was too busy during the exam period to be interviewed.

2.4.2 Language Barrier

The language barrier was a limiting factor in many of the interviews conducted with participants. The primary language of all of the participants was Zulu, thus many of the interviews required a translator. It was not uncommon to get a translation of only a few sentences after a participant had been speaking for several minutes. The home based caregivers whom the researcher was shadowing were used as translators. The caregivers were familiar with the child's situation and thus occasionally when the researcher would pose a question the caregiver would answer without consulting the child or the child's caregiver. The most informative interviews were those conducted in English because they allowed for the feeling of a more casual conversation rather than a formal interview enabling the researcher to ask questions of a more personal nature.

2.4.3 Semi-Structured Interviews with Young Carers

The greatest ethical challenge for the researcher was the interviews with the young carers themselves. Any research involving children is mired with difficulty for a multitude of reasons not the least of which being the issue of informed consent. However, as the focus of this study is children and the support structures in place to help them deal with being the primary carer of their parent or guardian, the issues of trauma and emotional upheaval were additional factors that had to be taken into account. Indeed, the sample size was limited due to the delicate subject of the study and the researchers' reluctance to risk further discomfort. Consent forms were used and translated into Zulu to provide the children with the easiest and most understandable form. To ensure that the meaning of the forms was not lost in translation they were back translated into English by a fluent Zulu speaker. The consent form explained exactly what the study was about and what the child's role was. Additionally, it stated explicitly that the child could, at any time, decide not to participate in the study at no cost to themselves or to their caregiver. This right to withdraw is crucial because of the sensitive nature of the topic and the questions. If the child felt

sad or felt that answering a question would force them to talk about a traumatic or emotionally scarring experience, it was important they understand that they could stop the interview at any point. This was explained verbally, via a translator, as well to make sure that the child understood. Lastly, the contact information of the researcher was provided in case the child should decide later that they do not want their words used in the study. The consent form explained, and the researcher echoed verbally, that the child's name will not be used at any point during the write up of the study.

Written and verbal consent was always obtained from the child's caregiver prior to an interview. Should the caregiver feel uncomfortable with the child being part of the study, the researcher directed questions to the caregivers to answer to the best of their ability. One young carer in particular was excluded from this study because her caregiver felt she was too traumatized by time she spent caring and by the death of her mother to be able to speak about her experience.

For the interview itself, the home-based caregivers were used when necessary to translate the interview questions so that the researcher could communicate with the children. The first step of each interview, as mentioned above, was to get the consent of the parent or guardian for the child to be interviewed. The interviews with the were semi-structured rather than a strict line of questioning so as to not intimidate the children and to allow the children to take the conversation where they want. The researcher avoided bringing up the topic of HIV/AIDS unless brought up first by the child or their parent or guardian in case their status has not been disclosed to the child. Great caution was taken when approaching potentially sensitive topics and general questions were posed in the initial phase of the interview to guide the children to talk about certain issues rather than force them to talk about specific experiences that may have been

traumatic. The researcher used the knowledge of the home-based caregiver and the body language of the child to decide when it is time to stop the interview or to move on to a new topic.

If the child confided in the researcher that they have been abused or if it seemed to the researcher that the child was in a dangerous or harmful situation the researcher approached Sister Priscilla at the hospice and the home-based caregivers to discuss a possible solution. No steps were taken by the researcher alone but rather the researcher worked within the confines of the local culture and existing referral system to improve the living conditions for the child when possible.

2.4.4 AIDS-related Stigma

The researcher had to be cautious about how HIV positive caregivers were identified due to the stigma associated with the disease. In order to maintain the privacy of the patient as much as possible the researcher relied entirely on the home-based caregivers to identify the illness from which the patient was suffering. The topic of HIV was not broached by the researcher and was only discussed if brought up by the patient. This was both to protect the patient against stigma but also to maintain their privacy in the event that they had not disclosed their status to their family.

III. LITERATURE REVIEW

L. Cluver, D. Operario, T. Lane and M. Kganakga. 2011. “I Can’t Go to School and Leave Her in So Much Pain”: Educational Shortfalls Among Adolescent ‘Young Carers’ in the South African AIDS Epidemic. *Journal of Adolescent Research*, 20(10), 1-25.

This article looks specifically at the educational impacts of living in an AIDS-affected home and at the effects of acting as a “young carer” in the context of AIDS. It is both qualitative and quantitative and is one of the few studies that discuss the differences between children living in AIDS-affected homes and children living in homes affected by other chronic illnesses. It concludes that children in AIDS-affected households experience negative educational outcomes as compared to those living in other-sick homes and those living in healthy homes.

Eley, Susan. 2004. ‘If they don’t recognize it, you’ve got to deal with it yourself’: gender, young caring and educational support. *Gender and Education*. 16 (1): 65-75.

This article discusses some of the findings of a “small-scale, localized, qualitative study” that involved 11 young carers of primary or secondary school age living in the UK who were providing “substantial care” for an adult. It explores how they manage this care while they are at school and how teachers could be a potential source of support for the students. Limitations of educational support are discussed, as are the children’s views on when this support should start and of what it should consist. Though it does not deal with AIDS specifically, it was useful to see what one study found to be the effect of caring for chronically ill adults on school age learners. It should be understood when taking information from this source that the results may not be applicable to learners in South Africa.

Skovdal, Morten, Vincent Ogutu, Celestine Aoro and Catherine Campbell. 2009. Young carers as social actors: coping strategies of children caring for ailing or ageing guardians in Western Kenya. *Social science and medicine*, 69. (4). 587-595.

Skovdal problematizes the tendency to represent young carers as victims, suggesting that young carers are often competent social actors. Using individual interviews and group discussion, the study explored how 48 young carers cope with the responsibility and the challenges that come with caring for an adult. Additionally, the study included interviews were conducted with ten local adults to supplement the information gathered from the children. The authors conclude that the young carers cope with their responsibilities and by constructing positive social identities by mobilizing social support, engaging in income generating activities.

L. Cluver, F. Gardner, and D. Operario. 2008. Effects of Stigma on the Mental Health of Adolescents Orphaned by AIDS. *Journal of Adolescent Health*, 42(2008), 410-417.

In this article the authors explore the effects of stigma on AIDS orphanhood and mental health. They evaluated four risk factors on a community level including bullying, stigma, community violence, and lack of positive activities. The study included children orphaned by AIDS, children orphaned by other causes, and children who have not been orphaned. The result was that the children orphaned by AIDS reported higher levels of stigma and fewer positive activities. The authors concluded that a reduction of AIDS-related stigma could lessen the prevalence of depressive conditions among children orphaned by AIDS.

IV. FINDINGS AND ANALYSIS

4.1 RESPONSIBILITIES OF YOUNG CARERS

The following are case studies collected while shadowing the home-based caregivers working out of the Holy Cross AIDS Hospice in Emoyeni, South Africa. All names of patients have been changed to protect their privacy.

4.1.1 Case A: Mhlongo Household

Zandile Mhlongo is a 72-year-old grandmother with diabetes and hypertension. She is the primary caregiver to four children, two of whom have lost both their parents to AIDS, one of whom has lost his mother to AIDS, and one of whom was left in her care by her granddaughter. In the morning before school, the oldest children of eleven and seven years make porridge for their grandmother, give her medication, and get the younger children ready for school. Oftentimes, when Zandile is feeling particularly badly, either the seven year old or the eleven year old must stay home with her to feed her, get her water and take care of the three year old who is not yet in school. Zandile recently went to the doctor with a wound on her abdomen but was turned away by a doctor who said that she was “too old,” so she must go home and think before she decides whether or not to go to Durban Hospital for an operation. She says she prefers to die at home.

4.1.2 Case B: Zuma Household

Jikele Zuma, 87 years old, lives with his three wives in the community of Nhlababo. One of his wives suffers from epilepsy, one has recently recovered from TB, and the oldest, Dudazile, 80 years old, has been bed-ridden for more than 10 years with diabetes and joint pain. Jikele himself suffers from hypertension and severe arthritis. All four are cared for by Dudazile and Jikele's two grandchildren ages 18 and 10, whose mother died of AIDS. Before they go to school they make porridge and put Dudazile's medication within reach. When they come back from school at half past two they make food for the whole family, help Dudazile bathe and carry

her outside if she wants to leave the hut in which she sleeps and spends the majority of her day, and change and wash her linens because she is incontinent.

4.1.3 Case C: Dube Household

Ten-year-old Vuyiswa Dube is the primary caregiver for her 45 year old mother, Banisiwe Dube who is HIV positive. Before she goes to school she cooks porridge so that her mother can take her medication. Vuyiswa must also take care of her mother's grandchildren, who are 4 and 2 years old, because her older sister died of AIDS. Banisiwe cannot find work and even if she could her joint pain prevents her from being physically well enough to work consistently. She has applied for the foster care grant for her grandsons but has not yet received any money, thus this four-person family lives off the child support grant Banisiwe receives for Vuyiswa. Banisiwe cannot yet apply for a disability grant, because her CD4 count is not below 350.

4.1.4 Case D: Dlamini Household

Buselaphi Dlamini, thirty-four years old, lives alone with her fourteen year old daughter, Sesese, and her two sons of six and three years. Before she goes to school Sesese cooks food so that her mother can take her medication and she does this again in the evening when she comes home from school. In September 2011 her neighbors burned down two of her huts, leaving her with only a cooking hut because of a conflict with her brother. She lost almost everything in the fire including her daughter's school uniform, all of their clothes and food as well as her identification documents, her children's birth certificates, without which she cannot receive the grants she had been relying on. She is unemployed and, thus, currently has no income with which to buy food for her and her children. Fortunately, she is well enough to help people in the community in their fields to try to make enough money for food and for the bus to the hospital so that she can collect her medication.

4.2 TANGIBLE SUPPORT

4.2.1 The Importance of Tangible Support

The importance of material needs including adequate shelter, food, school fees and uniforms on a child's social development have been well-documented as has the effect that a primary caregiver's illness can have on these needs. In a study conducted on the educational shortfalls among young carers in South Africa, it was found that "children in sick households were less likely to have school fees paid" and, in households where the caregiver was suffering from AIDS, "22% of adolescents reported that they were constantly hungry at school" in contrast to "10% of adolescents in other-sick households and 1% in healthy households" (Cluver et al, 2011, p.3). The Stefania Maggi of the Human Early Learning Partnership at the University of British Columbia argues that "poverty puts children at risk because of the deficiencies in resources associated with poverty such as poor nutrition, including calcium, vitamins, and protein deficiencies, which are all essential elements for healthy physical development and cognitive growth" (2005, p. 11). Furthermore, factors such as "adequate maternal nutrition, maternal mental and physical health, parental stress and depression...limited or no income, housing conditions, and neighborhood quality," all negatively associated with poverty and lack of material necessities, "have important implications for both optimal child health outcomes and school achievement" (Maggi, 2005, p. 11).

4.2.2 Tangible Support Provided by Holy Cross AIDS Hospice

Sister Priscilla and the Holy Cross AIDS Hospice provide much of the material support the young carers in Emoyeni and the surrounding communities receive. The home-based caregivers make weekly visits to homes where they have identified vulnerable children. The condition of

the home is assessed and if the children are lacking any basic needs Holy Cross provides them: “at present we have 1182 families which are run only by the children...we give them food parcels, blankets in winter, and we bring them to schools” (Sister Priscilla, 2010). Additionally, Sister Priscilla has a feeding center in the area for the school-age vulnerable children to eat one meal in the morning before school and one meal in the afternoon on their way home from school. Children who are taking care of their AIDS-sick caregivers receive the same material support from Holy Cross as those who are taking care of their caregivers with other illnesses.

4.2.3 Tangible Support from the Government

At the governmental level, there are two grants that apply to children taking care of ill caregivers. The Child Support Grant (CSG) of R260 is the most commonly received grant by young carers, as all children under the age of 15 years, whose primary caregiver meets the requirements of the means test, are eligible for the grant (SASSA, 2011). According to Sister Priscilla the CSG is widely collected in the area (Personal communication, 11/5/2011). Indeed, nearly every young carer identified in this study who was eligible for the grant, regardless of his or her caregiver’s illness, was receiving the child support grant, with the exception of the grandson of Zandile Mhlongo, who was missing a birth certificate. If the children are lacking their birth certificates, Sister Priscilla takes the children to the Department of Home Affairs where they are referred to Social Welfare to get any grants for which they are eligible. She will do for Buselaphi Dlamini, an HIV+ mother who lost most of her possessions including her children’s birth certificates and her own ID in a fire set by her neighbors. Buselaphi’s three children qualify for the child support grant and have been receiving it, however, without their identification she cannot collect the grants and thus has no income, as she is not currently employed. Sister Priscilla explained that in addition to taking them to the Department of Home

Affairs, Holy Cross “will help [the Dlamini family] with what ever they need...if they don’t have it we bring them food, clothing, blankets” (Personal communication, 11/16/2011).

If the primary caregiver or parent should no longer be able to care for the child, the caregiver with whom the child now lives is eligible for the R760 Foster Child Grant (FCG) (SASSA, 2011). As HIV/AIDS wipes out a generation of parents, this grant becomes more and more relevant, as the children are cared for by members of their extended family, oftentimes their grandparents. This grant was not as readily collected as the child support grant. Zandile Mhlongo was the only caregiver located in this study receiving the Foster Child Grant for her two grandsons who lost their parents to AIDS. Vuyiswa Dube had applied for the FCG but had yet to receive any money. It is often three to four months before an applicant for the CSG or the FCG begins to receive money. One grandmother reported confusion about which grant she could apply for, believing she was eligible neither for the FCG nor the CSG, despite becoming the primary caregiver of her granddaughter when her daughter died of an AIDS-related illness. This grant primarily applies to children, who are providing care to their grandparents who are suffering from diseases unrelated to HIV/AIDS, though there are cases where the new caregivers with whom the child is placed are HIV positive as well. In one family identified in this study, the children were caring for their HIV positive grandmother after their mother, father and grandfather had died of AIDS. However, the overwhelming majority were families in which the children were caring for their grandmother, grandfather, or both who were suffering from non-communicable diseases such as diabetes and hypertension.

There are cases where children who are caring for HIV positive parents may be eligible for the FCG prior to the death of their parent. Sister Priscilla explains that “if the child’s parent has AIDS, the child can apply for a grant because they will soon be an orphan, but it is less likely

that a child whose parent or grandparent is ill with a different chronic illness will be recognized as a potential orphan, because the government knows that if a person has AIDS they will soon die but with the other diseases it is not so known” (Personal communication, 11/5/2011). In such cases Sister Priscilla takes the children to Social Welfare so they can begin the application process. In reference to the community’s knowledge about the grants, Sister Priscilla states that “everything they know, they know from us” indicating that areas not within the reach of the Holy Cross caregivers have a limited knowledge of what grants they are eligible for. Given that for many living in these communities, the grants are the only steady household income, particularly in families where the only adult is ill and cannot work, a basic knowledge of what grants for which one is eligible is crucial to ensure that the family is able to buy necessities such as food, clothing and school uniforms without the children leaving school to shoulder the burden of supporting their family.

4.2.4 Tangible Support from Schools

Though schools have the potential to provide support for orphaned children and children taking care of their parents, few have the inclination or the wherewithal to do so. According to Sister Priscilla, “there are two, maybe three, schools in the area where the principal cares, but these schools here,” referring to a primary and high school in the area, “don’t do anything like that. They don’t even know who the orphans are,” (Personal communication, 11/3/2011). Though this is now the third year that Sister Priscilla has not had to pay the school fees for children who could not afford to go to school, in the years before the government instituted no-fee schools she would write a letter for each orphan or vulnerable child explaining their situation, after which she would go to the school in person to pay each child’s fees. When she would

arrive at the school to pay the fees, the principals and teachers would have no record of which children were orphans or vulnerable, despite being told explicitly in writing just weeks prior.

The Ivukayibambe Primary School, in Gingindlovu, is one of the few schools in the area that is willing to and is particularly adept at identifying the orphans and young carers. The principal, Mr. Thembinkosi Masinga, has identified both children who are living with AIDS-unwell caregivers as well as those living with caregivers ailing from other causes. However, despite being aware of the problems associated with young caring, such as loss of household income, emotional trauma, poor health, truancy and difficulty finding time for homework, and despite being eager to provide support to these children, he is lacking the resources with which to provide such support. As such, the amount of support provided to children caring for other-sick caregivers did not differ from that provided to children caring for AIDS-sick caregivers because there was so little support available for either group. He does have a garden, which the children help to maintain, that allows him to serve the children one nutritious meal each day. Once he has identified the vulnerable children, he is able to provide them with extra food if they are clearly suffering. However, he explains that, because of the enormous need at this particular school, where “the majority of the [240] students are orphans or are living in houses where the parent is sick with AIDS,” many of whom receive their only meal of the day at school, it cannot provide extra food to every child who is in need (Personal communication, 11/14/2011). Though some of his students must stay home at times to care for their ailing caregiver or their smaller siblings, neither he nor his teachers have the resources to provide assistance: “we start at 8 o’clock and at 2 o’clock we end, so there is no extra help that we can provide to the students who fall behind because they stay home to care for their parents or brothers and sisters” (Interview, 11/14/2011). Furthermore, many of his students struggle getting school uniforms, which he estimates cost a

minimum of R85 for boys and R100 for girls, and many show up at school without shoes. He does not have the resources to remedy their situations, though, in such cases, Sister Priscilla is often able to provide the items the students are lacking, if she is made aware of the situation, which often only happens when she or the Holy Cross caregivers visit the school in person.

4.2.5 Tangible Support from Neighbors and Family

The amount of material support provided by neighbors and friends to children caring for AIDS-sick caregivers was found to be significantly different from that provided to children caring for other-sick caregivers. Every caregiver and young carer interviewed, who was affected by HIV/AIDS, reported no help from their neighbors or the community and oftentimes their extended family had abandoned them as well. Latiwe, a home based caregiver in the Nhlababo community believes that “people are afraid, that’s why they do not help...some people think that you can get infected just by eating from the same spoon” (Personal communication, 11/16/2011). According to Sister Priscilla, the frequency of external stigma or enacted stigma, whereby actual discrimination is perpetrated, has decreased, however, she explains that people still fear the reactions of friends, family and neighbors to disclosure, indicating that perceived stigma is still rampant. Indeed, Lynette Mbuyazi, a teacher in the crèche, who took care of her mother until she ultimately died of AIDS, reported “there was no one and I mean no one, it was just the two of us...I had to take her in a wheelbarrow to an area where the ambulance could reach us and there was no one to help me” (Interview, 11/15/2011). When asked why she believed that her neighbors and family refused to help she responded, “maybe they think they were going to get what she has, I don’t know. I always say that they must come to our village to teach us what AIDS is about” (Interview, 11/15/2011).

In contrast, families, in which children were providing care to chronically ill caregivers not infected with HIV, consistently reported receiving help from neighbors and extended family. Zandile Mhlongo explains that “when I feel sick but have no money for transport, my neighbor comes with a wheelbarrow and brings me to the clinic” (Interview, 11/11/2011). Jikele Zuma reported that his neighbors assist with cooking food occasionally; a huge help as the children often must come home early from school to cook for their grandparents (Interview, 11/16/2011). In another home, in which the grandmother had diabetes and could not walk around, her daughter-in-law was visiting and was observed helping to fetch water and to cook food (observation, 11/16/2011), additionally she reported that her neighbors bring her food when her grandson is at school.

Though no social support is readily available to young carers, tangible support is the most likely type of support to reach the children, as it is supplied from several outlets. Additionally, aside from solely the difference of grants that apply to each type of young carer there several palpable differences in the amount of tangible support available to children caring for AIDS-sick caregivers relative to those caring for other-sick caregivers. The lack of support provided to AIDS-affected households by friends, neighbors, and extended family suggests that the need for material support from more formal sources, such as schools, churches, organizations, and the government is greater among children taking care of their AIDS-sick caregivers.

4.3 EMOTIONAL and INFORMATIONAL SUPPORT

4.3.1 The Importance of Emotional and Informational Support

In the past several years the importance of emotional support for orphans and vulnerable children has become evident as depression, anxiety, peer problems, post-traumatic stress, delinquency, and conduct problems are increasingly found, particularly among children orphaned by AIDS. In a study conducted in 2007 by Lucie Cluver, “50% of AIDS-orphaned children fulfilled the criteria for PTSD, compared to 30% of other-orphaned children and 23% of non-orphans” (Cluver, 2007, p. 759). In the first long term study on young carers in South Africa, it was found that “children who have both AIDS related stigma and poverty, have an 83% chance of a clinical level of psychological disorder” where “clinical level psychological disorder is defined by Cluver as “the level where we would normally expect a child to have to go to a psychiatric hospital” (Riona, 2011). As Cluver put it in a presentation made to REPSSI in 2011, “it is not enough to say that children need to be fed and that they need to have shelter. They do need shelter and they do need feeding, but then we are under selling them, we are saying that they don’t need what all other children need, which is to grow up healthy and happy and to have confidence in themselves and to have confidence in their family and to know that they can grow up and have a future,” (Cluver, 2011). Emotional and psychosocial support is necessary for any child’s healthy development, but for children who are watching their parents suffer and potentially die, while taking on the responsibility of an adult, it is that much more important.

In the communities surrounding the hospice, it was clear that many of the children were in need of emotional support, particularly those children who are caring for AIDS-sick caregivers. This is primarily because they were shouldering much of the burden by themselves. In contrast, as detailed above, children caring for other-sick caregivers were found to be receiving support from their neighbors and extended family. Ten-year-old Vuyiswa Dube says that “taking care of my mother is difficult for me because I am still so young” (Interview, 11/16/2011). Ziningi

Khumalo, who began caring for her AIDS-sick mother in her late teens, but who is now twenty-five, reported that “I have no friends to talk to, there is no one. One night my mother was seizing so I put a spoon in her mouth to keep her from biting herself...it is difficult to be alone” (Interview, 11/16/2011). Lynette Mbuyazi felt similarly, explaining that taking care of her AIDS-sick mother, by herself, made her feel utterly alone. She feels now that “the pain that I was feeling at the time would have been less if I had known that what my mother had, everybody had” (Interview, 11/15/2011). Sister Priscilla has identified three children in the creche who seem to be mentally handicapped: “their mothers are sick with AIDS and I believe it has affected the children. We started late with the counseling and the psychologist. One of them was in another crèche, but they chased him away, I don’t think they understood him.” (Personal communication, 11/10/2011). Several children in the creche were withdrawn, others had extreme difficulty concentrating and still others had serious conduct problems (observation). Given that the creche is primarily for orphans and vulnerable children, it is possible that these issues are attributable to the emotional strain of being orphaned or of living with a sick caregiver, however, without investigating their home situations it is difficult to be certain of the cause.

4.3.2 Emotional Support provided by Holy Cross AIDS Hospice

Despite the overt need, emotional support for young carers was found to be just short of nonexistent in the Gingindlovu area. As with material support, it is primarily Holy Cross that is responsible for what little support there is. The home based caregivers provide counseling when they identify a child taking care of a sick adult regardless of whether the adult is suffering from AIDS or another chronic illness. The counseling, however, prior to the death of the caregiver, primarily consists of the caregivers teaching the children how to provide care safely and effectively, according to Celiwe Thobela, a caregiver at Holy Cross, (Personal communication,

11/10/2011) though Latiwe, another caregiver, explains that they do teach the children that “they should not think about their sick parent when they are in school” (Personal communication, 11/16/2011). The informational support provided by the caregivers is crucial, particularly for the children caring for AIDS-sick caregivers because of the risk associated with providing intimate care. Zandile Zungu, manager of the home based caregivers, explained that they teach the children not to do everything themselves and to go to the clinic to get treatment if their caregiver’s condition is worsening. When the child does need to provide care, they explain that “if your parent has an injury, don’t touch them without wearing gloves...if they have the bed sores we teach them to change position, how to bathe them, clean them, feed them, how to give medications, and how to talk with them” (Zandile Zungu, Interview, 11/6/2011). According to Celiwe, they also explain that “a person who is sick must always be kept clean, even the room that he or she is sleeping in must be kept clean and the dishes they use must be clean too” (Personal communication, 11/11/2011). Much of the emotional counseling the children receive from the caregivers, however, comes after the death of their parent, during the bereavement period.

Sister Priscilla takes the two children she adopted, a ten year old girl, who took care of her AIDS-sick mother until she died and her younger six year old brother, to a clinical psychologist once a week for counseling. Her two adopted children attend the crèche and next year she hopes to get this clinical psychologist working with all of the children in the creche. In the meantime, however, much of the emotional support that is provided by Holy Cross prior to the death of the caregiver is in the form of hope. As difficult as it is actually providing care for an ailing parent, one of the major stressors for the children and their caregivers is the fear of life after the death of their parents. According to the World Federation for Mental Health, children who are taking care of their dying parents often “worry about the future, where they will go and who will take

care of them” (World Federation for Mental Health, 2001). As Sister Priscilla explains, “one of the main reasons I started the Child Headed Household Program is because when people were dying, they asked me to take care of their children” (Personal communication, 11/17/2011).

Sister Priscilla and the home based caregivers inform the children and their families that, upon the death of their parent, they can provide, if necessary, housing, clothing, blankets, and assistance with the application for social grants. Additionally, until the children begin receiving the grant money, Holy Cross provides monthly food parcels for the child headed households.

4.3.3 Emotional Support in Schools

The majority of the schools in the area are unable to provide any emotional support for their students. Despite the presence of a sign in the Ivukayibambe Primary School stating that it is a “Health Promoting School” with support services including, medical screening, testing and treatment, counseling and therapy, welfare services, education support, and referral services, in reality, the school was lacking the resources to provide any of these services (observation). Mr. Thembinkosi Masinga, though very aware of the emotional trauma experienced by his students, is powerless to do much to change their situation. He explains that despite having “children coming in crying, saying that another student made fun of them for being HIV+ or for having parents who are sick with or who have died from AIDS...we don’t currently have the knowledge to provide counseling” (Interview, 11/14/2011). They deal with such a situation by explaining to the students that school is for learning and they should not be discussing things that are not school related: “I haven’t got enough manpower. You see, the school is about teaching and learning and, at the moment, all the teachers are in their classrooms and they are teaching” (Interview, 11/14/2011). He echoed this sentiment again when asked if he believed that any of his students were traumatized or suffering from depression: “we do have children who are

emotional, some from poverty, some from violence, some from houses with sick people and we find that these things are above us, because we are here to teach” (Interview, 11/14/2011). A government representative visits the school every so often to ask if there are learners who “need assistance, who are slow or who are traumatized, but all they do is write the report, we never seen anyone come to help the children” (Mr. Thembinkosi Masinga, Interview, 11/14/2011). Mr. Masinga relies on the promises the government has made and hopes that, one day, they will send someone to help the children, but until they do he can only inform Sister Priscilla and the home based caregivers when they visit the school of the children most in need.

Though there was no difference found in the amount of emotional support available to children caring for AIDS-unwell caregivers and for those caring for other-unwell caregivers the need for emotional support did appear to be greater among those children caring for the AIDS-unwell. This is primarily due to the effects of AIDS-related stigma, but also due to the heightened difficulty of many caring tasks during end stage AIDS. This greater need for emotional support, rather than a disparity in the available support, likely accounts, at least in part, for the higher rates of depressive illnesses among AIDS-orphans.

4.4 AFFECTIONATE SUPPORT

4.4.1 The Importance of Affectionate Support

Affectionate support is a crucial aspect of a child’s social and emotional development and was found to vary greatly for each young carer in Emoyeni and the surrounding communities. According to the Center on Social and Emotional Foundations for Early Learning, “affection and warmth contribute to secure relationships between children and adults...provide models of positive, gentle behavior...are linked with children’s ability to interact positively with peers” (US

Department of Health and Human Services, 2005). Parental behaviors such as “positive reinforcement, displays of warmth and affection, and consistent disciplinary strategies” correlate positively to academic ability and favorable peer relations, as well as fewer child behavior problems (WHO Commissioned Report). In a study conducted in Cape Town on the psychological well-being of children orphaned by AIDS, the orphans themselves highlighted a caring guardian as important to them and their happiness: “Children talked positively about ‘being loved’, attention, respect, ‘being wanted’, fun with caregivers and having boundaries” (Cluver & Gardner, 2007). According to the World Federation for Mental Health, “the loss of consistent nurture, which can lead to developmental problems and the loss of guidance, which makes it more difficult for the child to reach maturity and to be integrated into society” are two prominent psychological effects of HIV/AIDS on children (World Federation for Mental Health, 2001). In programs conducted in Zimbabwe and Tanzania, “educating the community on the needs of children affected by HIV/AIDS to help them respond positively” resulted in caregivers and teachers providing “the love and guidance that the child desperately needs” (World Federation for Mental Health). The need for and the benefits of affection and warmth in a child’s life are indisputable; they are not a privilege, but rather the child has “the right to parental love, care, and nurture” (Department of Social Development).

Though the amount of affectionate support provided to the children in their homes is difficult to assess in one or even several interviews, it can be evaluated using several factors including the severity of the caregiver’s illness the willingness of neighbors and extended family to help out, and the ability of teachers to devote time to each student. During the course of this study, it became increasingly clear that the affectionate support made available from outside the home to children living in the communities surrounding the hospice is minimal, with the

exception of those children fortunate enough to attend one of the six creches run by Sister Priscilla of the Holy Cross AIDS Hospice.

4.4.2 Affectionate Support Available in the Home

In order to assess the amount of affection and warmth available to the children within the home, several different degrees of illness were observed during the course of this study. Though the amount of love a child receives from a parent or guardian is not measurable, it is possible to observe the physical contact, the outward displays of affection, and the ability of the adult to provide care for their child. Those well enough to get out of bed were often able to make physical contact such as patting the child's back or holding his or her hand. Zandile Mhlongo, who suffers from diabetes and hypertension, but is able to get up from bed several times a day, was well enough to rub her grandson's back and wipe the remnants of the sweet he was eating off his face during the interview (observation). On the other end of the spectrum, Lynette Mbuyazi, explained that her mother was so ill she had to carry her on her back like a child, if she needed to leave her bed for some reason. She explained how alone she felt during this time and that "the pain would have been less knowing that somebody loved me. I was thinking that people don't love me, they can say they love you but when you need them they will not be there" (Personal communication, 11/15/2011). There was no difference in the likelihood that the children were receiving affection whether the children were caring for AIDS-sick caregivers or caring for other-sick caregivers. The only apparent difference was between children caring for seriously ill adults and those caring for adults who were able to get out of bed and move around. Even then, a comprehensive assessment of affectionate support is difficult, because love and warmth are often displayed verbally as well, such as in the case of Busisiwe Khumalo, a fifty-three year old bedridden and HIV+ mother, who expressed that "I must take care of my daughter

and my daughter must take care of me” (Interview, 11/16/2011). In general, however, as the condition of the caregiver deteriorates the amount of affection and warmth naturally decrease. Thus, it is crucial to assess the amount of love and affection available to the children outside the home.

4.4.3 Affectionate Support Provided by Neighbors and Family

The amount of affectionate support available to children caring for AIDS-sick caregivers from their neighbors and extended family is entirely absent. This is primarily because, as noted above, the children caring for AIDS-sick caregivers are not receiving *any* help from their neighbors and extended family. Though assistance from these sources was identified in a number of families where the children were providing care for other-sick caregivers, none was actually observed, thus an assessment of the affectionate support available is difficult. However, according to Celiwe, one of the caregivers based at Holy Cross, the caregivers teach the children caring for their parents that “the most important thing is love. If a person who is sick cannot find love, then he or she might think that it is better to die,” though, when asked if she believed that the children were receiving any love and affection, she explained that “sometimes we do see that, but sometimes not, because even neighbors they come for only a few moments and then go,” (Personal communication, 11/11/2011) suggesting that affectionate support for children caring for other-sick caregivers is minimal.

4.4.4 Affectionate Support Provided at Bishop Mansuet Biyase Creche

It is clear, however, that the children who attend the creche on site, at the hospice, are receiving ample affectionate support. The teachers can frequently be heard telling the students

that they love them, when the students cry the teachers either pick up the child to comfort them or rub their back and wipe away their tears, and when the children do something wrong they are disciplined (Observation). Sam Dube, the Principal, keeps a detailed log called “children who have problems” noting things such as “child appears unhappy...his attention is divided...she is a slow learner...he plays well with other children but in school work he is behind...she is always untidy...she has sores all over her body...he is always complaining of abdominal pain” and many more observations, which allow the teachers to provide extra attention to those who seem to be receiving less at home and to those who are experiencing behavioral, health, or emotional problems (Observation). The children call Sam, the Principal, “Malume”, the Zulu word for uncle, and refer to one of the other teachers as “gogo”, the Zulu word for grandmother. Without knowing each child’s home situation, it is difficult to attribute their extreme desire for attention and their constant need for physical contact, to the trauma associated with orphanhood and living with a sick caregiver. However, given that many of the children are orphans or vulnerable children, it is likely that many of these children are not receiving sufficient affectionate support at home.

4.4.5 Affectionate Support Provided in Schools

In contrast, at many of the schools in the area the student to teacher ratio is too high for the students to receive the amount of attention the children at the crèche receive, where there are on any given day 70 students for the 5 adults making the student to adult ratio fourteen to one. The schools are understaffed as Mr. Masinga of the Ivukayibambe Primary explains “we just haven’t got the manpower,” referring to his ability to pay special attention to the students who seem to be having the greatest difficulty (Personal communication, 11/27/2011). However, a significant amount of time was not spent observing the daily interactions of teachers with students so no

firm conclusion can be made about the amount of affectionate support provided to children in school.

There was no difference between the affectionate support coming from outside the home available for children taking care of AIDS-sick caregivers and that available for children taking care of other-sick caregivers, as the only support identified was that provided by Holy Cross AIDS Hospice, an organization which provides the same services to all vulnerable children regardless of the illness from which their caregiver suffers.

4.5 POSITIVE SOCIAL INTERACTION

4.5.1 The Importance of Positive Social Interaction

Positive social interaction, as defined by Stewart and Sherbourne, is the “availability of other persons to do fun things with you” (1991, p. 705). As the health of the child’s caregiver deteriorates the responsibilities of the child increase, often preventing the child from being able to go to school consistently and limiting the amount of time the child has to spend time with friends or to do fun activities he or she enjoys. The effect of this is essentially that “children lose their childhood” thus, according to Sue Jenkins, a consultant community pediatrician, the children require “recognition, support, and help in two specific ways, one as a child in need and the other as a young carer” (1994, p. 734). Lucie Cluver suggests, in a study conducted on the effects of stigma on the mental health of AIDS orphans, that “a potential protective factor is positive recreational activities, such as sports” and that there are “associations between positive recreational activities and better psychological outcomes” (Cluver et al. 2008, p. 2).

Furthermore, Cluver found in another study that “participants identified school itself as a supportive and buffering environment to reduce the psychosocial impacts of the stressor of

caregiver sickness” (Cluver et al, 2011, p. 21), suggesting that school is an ideal environment for the facilitation of these positive social interactions.

4.5.2 School Accessibility

Several of the children in this study were able to go to school fairly consistently. This is due primarily to Sister Priscilla’s implementation of a mandatory schooling program in the area: “since we started our program, it is compulsory that each and every child goes to school and if they are not we need to know why: sometimes they say they have no shoes so we supply them, sometimes they have no stationary so we supply it” (Personal communication, 11/16/2011). In addition to providing these material needs, Holy Cross has six creches, one on site at the hospice and five satellite creches, “so that children who are heading [the child headed households] can get the chance of going to school while the younger children come to the creche during the day” (Personal communication, 11/16/2011). Additionally, the advent of no-fee schools has provided an opportunity for many orphans and vulnerable children to attend school, who otherwise would not be able to afford it. Prior to the emergence of no-fee schools, Sister Priscilla was doing school advocacy for the children and was paying fees for as many children as she could. However, some, such as the grandsons of Zandile Mhlongo, must stay at home to provide care for their ailing caregiver: “If I am having a bad day and I am not feeling well, then one of the boys stays home with me to cook food, give me my medication and take care of the little one,” referring to her three year old grandson (Interview, 11/10/2011). Additionally, Sister Priscilla has come across several cases where “the neighbors or older siblings tell the young children to sit right by the bed and stay there all day to take care of their parent” (Personal communication, 10/31/2011).

4.5.3 Positive Social Interaction at the Bishop Mansuet Biyase Creche

The creche on the site of the hospice is an excellent example of an environment in which the children are safe and are encouraged to interact positively with other children as well as members of the staff. At the crèche, they have music or dance therapy each day during which the children have a chance to do something they truly enjoy and to get rid of any stress they may be feeling as a result of their home situation. As Sister Priscilla says, “At home they don’t play because they have to look after their dying parent, even from the age of five, so we give them a chance to bring back their childhood” (Dlamini, 2010). This is found to be particularly true for one student, who took care of her dying mother at the age of five and then after her mother’s death took care of her little brother until she found Sister Priscilla. She is now ten years old but still attends the creche, giving her an opportunity to relive those years of her childhood she lost, while she was responsible for caring for her mother and brother.

4.5.4 Difficulties with Attaining Positive Social Interaction in Schools

Not all social interaction, however, is positive. Simply giving the children the opportunity to attend school does not ensure that they will have *positive* social interactions. Susan Eley at the University of Stirling, UK lists several issues young carers may face at school: “being isolated from other children of the same age, having a lack of time for leisure activities and feeling that they are different from other children and unable to be part of a group” (Eley, 2004). Mr. Thembinkosi Masinga, principal of Ivukayibambe Primary points out that “the children hear about parents dying or parents having AIDS, so we do get children making fun of other children and we do have children coming into the office crying” (Interview, 11/14/2011). Mr. Dube, the Principal of the creche, explains that though many of the children may excel in the crèche, they often “lose energy when they move on to the other schools because they don’t do music or pay attention to the needs of [the vulnerable children], they are not sympathetic to their situation,”

(Personal communication, 11/1/2011). Students are expected to have their own uniforms and “who do you think is going to pay for them?” asks Sister Priscilla. Mr. Masinga explains that those without uniforms are mocked by the other students (Interview, 11/14/2011).

Similar to emotional and informational support, no difference in the amount of positive social interaction experienced by children caring for AIDS-sick vs. other-sick caregivers was found in this study. Furthermore, the need for positive social interaction was found to be equally great among both groups of young carers. Again, this is largely because there is so little of this support available to either type of young carer.

V. CONCLUSION

Though no child should have to bear the burden of caring for a loved one, nor experience the trauma of watching them die, given the size and scope of the HIV/AIDS and non-communicable disease burden, young carers have become entrenched in South African society and will continue to exist until the effects of these epidemics diminish. In order to avoid as much trauma as possible resulting from the caring experience and the death of the parent, it is necessary that the children receive adequate social support. Morton Skovdal, who has done several studies on the effects of young caring, insists that caring for a parent or guardian does not have to be an entirely negative experience and one should not immediately assume children to be victims. According to Skovdal's findings, children caring for adults can "manage to cope with the challenges of caring for ailing adults in challenging conditions" and should not immediately be construed as "victims of damaging circumstances that compromise their psychosocial well-being" (2009, 17). Indeed, largely due to her experience caring for her mother and father until they died, Lynette Mbuyazi, now 31, aspires to be a nurse because she "began to understand what people want and need," (Personal communication, 11/15/2011). Skovdal found that "the social resources available to young people have a significant impact on their coping and resilience...support from the community members and groups also remains critical to coping," (Skovdal, 2009, 17) suggesting that we could have many more cases like Lynette Mbuyazi if adequate support systems were in place.

Presently, however, there is an insufficient amount of social support available for young carers in Emoyeni and the surrounding communities. As such, despite a few significant differences, a comprehensive comparison of how the social support available to children caring for AIDS-sick caregivers differs from that available to children caring for other-sick caregivers is not substantial, because there is so little support for any young carers. It became increasingly

evident over the course of this study that without the impressive and wide-reaching services of the Holy Cross AIDS Hospice there would be next to nothing available for young carers. This discovery is concerning. Though fifty square kilometers is a large service area for one organization with twenty-five caregivers to cover, it means that potentially thousands of young carers are growing up without such services and without the essential social support needed for them to grow up healthy and happy.

Without the tangible support provided to young carers by the hospice, including food, clothing, blankets, shelter if needed, assistance with grant applications, and advocacy for schooling, the children would receive next to nothing. Oftentimes, the primary source of income in households with young carers is lost as their caregivers become too sick to work. As the R260 child support grant is not enough for a family to live on and few families were taking advantage of the foster care grant, it is crucial that they have access to these services. The hospice provides the same services for children in AIDS-affected and other-affected households, however, it was discovered during the course of this study that children caring for AIDS-sick caregivers were experiencing a greater need, particularly for financial support and food. This is largely because any type of material support from neighbors and extended family was found to be entirely absent in households affected by HIV/AIDS, primarily because of AIDS-related stigma and a general lack of knowledge about the disease and how it is transmitted. The community must be further educated on HIV/AIDS and encouraged to provide assistance to those suffering from the disease.

With the significantly higher prevalence of depressive disorders in children orphaned by AIDS in comparison to those orphaned by other causes, one would expect there to be a discrepancy in the amount of emotional support available to children of AIDS-sick caregivers and children of other-sick caregivers. This study found that in Emoyeni and the surrounding

communities there is actually little to no difference in the amount of emotional support provided to young carers based on the illness of their caregiver, primarily because there is so little emotional support available at all. However, similar to material support, the need was found to be greater in those households affected by HIV/AIDS. Again, this is primarily because of the lack of community support available for children caring for AIDS-sick caregivers.

Affectionate support available within the home was difficult to measure, given the span and duration of the study, thus no firm conclusions can be drawn. However, a comparison between the love and warmth provided to the children in the creche run by the hospice and that provided in the surrounding schools, showed that with more resources schools could be an ideal environment for providing the students with the affectionate support their caregivers may be unable to provide at home. The joy in the children's faces in the creche as the teacher held their hand, picked them up, or told them they loved them demonstrated the effect that warmth and affection can have in the lives of orphans and vulnerable children. Presently however, the majority of the schools in the surrounding area are without sufficient resources to provide adequate attention to each student, particularly because the student body of many of these schools consists largely of orphans and vulnerable children who, it has been found, require more support than the average student. The same is true for positive social interaction. Without the resources to provide such things as recreational activities, sports, music therapy and dance, merely coming to school may not necessarily be the *positive* social interaction the children need. There was no difference found in the amount of affectionate support or positive social interaction among children caring for AIDS-sick caregivers and those caring for other-unwell caregivers, again, largely because so little of each type of support was identified.

In theory, there are government policies in place to assist young carers, as children who are taking care of their parents fall under the umbrella of the Policy Framework for Orphans and other Children made Vulnerable by HIV and AIDS in South Africa. In reality, there is very little government assistance reaching the children, as is evidenced by the heavy reliance on the services provided by Holy Cross AIDS Hospice. The number of young carers is on the rise and, if the amount of support for these children is insufficient now, it is difficult to imagine the conditions these children will be living in five years down the line, when what resources are available are stretched thinner still. On a local level, an expansion of the Holy Cross AIDS Hospice to include a primary school and after-school program would benefit the community, as there is currently a lack of programming for the older age groups. On a larger scale, steps must be taken now, in order to break the cycle of poverty in which young caring inevitably results, as children living with ailing caregivers essentially become responsible for the wellbeing of their family and the upkeep of their home, often necessarily forgoing education and sacrificing any chance of avoiding the pitfalls of poverty.

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VI. RECOMMENDATIONS FOR FURTHER STUDIES

Much of the research involving young carers has been small-scale qualitative studies focused on the challenges children caring for their guardians are facing and what effects caring has on children, particularly on their mental health and their educational opportunities. More quantitative data is needed in order to get a sense of the scale of the problem and how the challenges faced by young carers vary based on the community and the resources available. Additionally, though this qualitative study has concluded that Holy Cross AIDS Hospice is successfully relieving some of the children's burden of caring, further quantitative data is needed in order to assess whether this is in fact the case. Finally, should the Holy Cross model prove to be successful, further research is needed in order to assess whether this example is replicable in other communities throughout South Africa.

APPENDIX 1: DAILY LOG

October 31. Arrived at Holy Cross Hospice in the early afternoon. I spent the afternoon settling into my room at the convent. Sister Priscilla came and got me around 4 to go with her to the Department of Social Affairs to drop off forms she had been working on that day. Sister Priscilla took me out to dinner at a restaurant in the Umfolozi Casino.

November 1. This morning I went to work in the creche and met Sam, the acting principle, and Zinhle, one of the teachers. We started the day by serving the children breakfast. First all of the children were together in one classroom while Sam taught them the Zulu and English names for wild animals and then they split up into their usual classes. I went with the six year olds in Zinhle's classroom. The teacher had no lesson plan because she said the students are about to graduate at the end of November and the syllabus is over. We spent some time counting and then I read the children a book. After about 40 minutes it was tea time and we served the children bread and juice. After about a half hour of playing with the kids on the playground we had music therapy. We danced for about 40 more minutes and then had lunch around 12:00. After the kids ate the day was pretty much over. I went to have lunch and the spent the afternoon helping Sister Priscilla with her computer.

November 2. Today was much like yesterday. I worked in the creche from 8 until 12:30. The lesson today was teaching the kids to count from 1-20. They had a really tough time with it and it was hard to teach them with a very limited Zulu vocabulary. I spent the afternoon helping Sister Priscilla with her computer again and hanging out with Thando, one of the HIV+ children Sister Priscilla has adopted.

November 3. I spent the day today with the home-based caregivers as they went on their visits in the community. Celiwe came to pick me up at the hospice at eight o'clock and we waited for about thirty minutes for the other four caregivers to join us. All six of us went from house to house until around one o'clock when we sat down at one of the patients houses for lunch. We spent about 15-20 minutes at each house except for one at which we spent almost an hour. The gogo at this house had taken her grandchild to the hospital because she was epileptic but the hospital had turned them away, apparently saying that she was "not fitting" so they couldn't give her medication. The man who lived in the house with them but was not the son of the gogo nor the father of the child had recently been released from the care of the hospice after he recovered from TB. He was still taking his TB medication but had gotten lost on his way home from the clinic and by the time he found his way home he had lost his ARVs. He has now defaulted on his ARVs. They heard from a neighbor that the bag with the pills in it was seen at a nearby bridge so they are going to check tomorrow to see if it is still there. He was also suffering from some sort of worms that he said he either vomited up or felt them crawling in his legs.

The caregivers' visits consisted mostly of education. They advise their patients on how to keep a vegetable garden, the importance of keeping a clean toilet, family planning, how to properly take medication, the importance of knowing one's status, etc. By the time I was heading home we had visited ten houses. The man who drives the children from the creche home each day picked me up around 1:30 on his way to drop the kids off. It was interesting to see where the kids live. Most of them lived in some of the poorer looking houses I've seen since being here. I was back at the hospice by 2:30 and spent the rest of the afternoon doing some research and hanging out with the kids.

November 4. I worked in the creche from eight to one o'clock and spent the afternoon hanging out with Sister Priscilla's adopted children and doing some research.

November 5-6. I spent Saturday shopping for new parts for the computers that were donated to Holy Cross by the Jewish Association of KZN. Sister Priscilla wants each department to have a computer and use it to keep records so that she can access them easily and send them to funders. It took most of the day

because we went from store to store trying to find the cheapest materials. In the afternoon I had some time alone to read to write. Sunday Sister and the kids and I went to mass at 8:30 and got out at 12:00. Sister took me out to lunch in Mtinzini and drove me around the area so I could see the big houses in town. It was incredible to see such extreme wealth just ten minutes from absolute poverty where people have nothing. I spent the afternoon hanging out with the kids and was able to get some more reading done.

November 7. At eight o'clock I sat in on the music therapy session held for all the caregivers every Monday. I spent the rest of the day giving computer lessons. I spent an hour teaching Maude, the bookkeeper, how to turn on a computer and how to use Microsoft Word and Excel. She seemed to be a quick learner and she made me take notes for her so hopefully she will now be able to enter all of her data on the computer. I spent the next hour teaching the first group of caregivers how to turn on the computer and how to open and save a document in Microsoft Word. Just as I was finishing the session the computer started smoking. After about an hour we were able to replace the monitor with a backup and I continued teaching to the next group of seven caregivers. It was the most frustrating yet rewarding thing I have ever done. I finished with the last group at 4 o'clock and then talked to Sister Priscilla for a bit about my plans for my project.

November 8. I worked in the creche from 8 to 12:30 today. One of the workers from the hospice, Ray, picked me up at 2:30 with his wife, Betty, to take me to their home for dinner. They took me to the beach and the lagoon gave me dinner and took me back to the hospice around 8.

November 9. I worked in the creche again from 8 to 12:30 after which I spent the afternoon with Thando, one of the children that Sister Priscilla adopted. She is ten but is still working on how to count from 1-20 so we worked on that as well as on how to write "my name is Thando". She still cannot spell her name. The clinical psychologist she has been seeing said that she is not ready to go to school next year so she will stay in the crèche for another year.

November 10. I worked in the creche from 8 to 11:00 when I was supposed to go to a local school for an interview with the principal who apparently does a lot of work with orphans and vulnerable children. The principal, however, became nervous at the thought of an interview and backed out, postponing the interview until Monday. I spent the afternoon with the kids and doing a bit of research.

November 11. Left the hospice at 6:30 with the driver who picks up the kids in the community and takes them to the creche. We picked up Celiwe, the caregiver I have been shadowing, and went to the community of Obajeni where we met two other caregivers, Dudu and Bonisiwe. We walked from house to house visiting patients and identifying new patients. I was able to do an interview with a gogo with diabetes and hypertension who is the primary caregiver to four children ages 3, 6, 7, and 11. The oldest three were orphaned by AIDS, though the father of the 6 year old is still alive he is living with AIDS, and the youngest was abandoned and left in the care of the grandmother. I got back to the hospice at 2. At 3 one of the caregivers came to my room and asked me if I wouldn't mind teaching her more about the computer. I spent the afternoon giving her a private lesson.

November 12-13. I stayed with one of the workers from the hospice, Ray, and his wife, Betty, for the weekend. It was a relaxing weekend and much needed break from bucket bathing and cockroaches in my bed.

November 14. I left the hospice at 7:30 with the bus driver to pick up the kids. He dropped Latiwe and I off at Ivukayibambe Primary School so that I could speak with the principal. My meeting wasn't until 10:00 so we sat in his office until about 9:30 when he showed up and we could start early. The principal dropped us off at the Hospice around 11 and I went down to the creche for the rest of the afternoon. Today we were checking the stock of books in the green class where I have been working.

November 15. I worked in the creche from 7:30 to 1:00 today and was able to interview one of the teachers about her experiences caring for her parents. In the afternoon I helped Sister Priscilla with her computer.

November 16. Sister Priscilla and I left at 8:15 for the Nhlababa community where I would be shadowing a caregiver, Latiwe, for the day. We went to six houses where there were children caring for adults. I was able to interview several adults who are cared for by their children or grandchildren and two children themselves. Sister Priscilla picked me up around 2:30 and then took me around the area so I could see how far her services reach. We stopped by one of her satellite feeding centers for children on their way to and from school and passed by the land she plans to build an old age home on once she gets permission from the chief of the area. We got back around 4 and then I helped Sister Priscilla create a new letterhead for the creche.

November 17. I left with the bus driver to pick up the kids at 7:30 and was dropped off in Esingweni community with Celiwe and Barbara, the two caregivers with whom I was to spend the day. We walked around the community registering the poor people for Sister Priscilla's Christmas food donations. I was supposed to do my last interviews with young carers today but we never reached their houses. I rode back with the bus driver and got back to the hospice around 2:00.

November 18. I worked in the creche from 8-12:30.

November 19-21. I Stayed in Mtunzini to write the bulk of my ISP.

November 22. I worked in the creche today from 8:30 to 1:00 and spent the afternoon entertaining the two children who live at the hospice.

November 23. I spent the morning from around 8:30-10:30 with Sister Priscilla teaching her different things on the computer including how to do graphs in excel for her Natural Family Planning Statistics and learning about her Family Planning program, which has had phenomenal success. The rest of the afternoon was spent working on my paper and entertaining the children.

November 24. I worked in the crèche from 8:00 to 12:30 and spent the rest of the afternoon working on my paper and presentation.

November 25. I got up at 6 and started helping with the preparation for the preschool graduation. At 10 we started practicing for the ceremony and at 11 the graduation began. The ceremony went from 11-3:00 and at 4:00 I packed up and headed back to Durban.

APPENDIX 2: INTERVIEW QUESTIONS

Questions for Home-based caregivers

1. Do you work with many children who are taking care of their sick caregivers?

2. What responsibilities do these children have? Who is providing assistance to these children?
3. What services do you provide for the children taking care of their sick caregivers?
4. Do you teach the children how to provide care? What do you teach them?
5. Do you provide counseling to the children prior to the death of the caregiver?
6. Are the children receiving any love and affection?
7. What grants are the children eligible for?
8. What has your experience with AIDS-related stigma been? How does this affect how much support the young carers receive?

Questions for Young Carers

1. Can you tell me about when your loved one first got sick? How do you care for them?
2. Do you have any other family that lives with you or that comes to help you? How often do they come?
3. What types of jobs do you do to care for your loved one? How long do you spend doing these jobs each day?
4. Does anyone help you with these jobs? How do they help?
5. Do you talk to your friends about what you have to do at home? What do you talk about?
6. Do you find it difficult to take care of your caregiver?
7. Who do you talk to when you are feeling sad?
8. Does anyone tease you or treat you badly because someone in your family is sick? What do you do when this happens?
9. Does your teacher understand your home situation? How does your teacher help/make things worse?
10. Do you go to church? How does your pastor or church community help you take care of your loved one?
11. Does anyone in your house receive a grant? Which grants do you receive?
12. Do you feel like you have enough money to buy what you need? If not, what are you missing? What do you most need?

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Appendix 6: ISP Application for Review of Research with Human Subjects

**Fall Semester 2011
School for International Training - Study Abroad**

South Africa: Community Health, Program

Student to complete all questions, and anticipate probable issues and interactions before actual research begins. Submit this document and related documents to your Academic Director(s). Should you need to interview subjects that differ from the profile(s) below, you will need to provide details to the Academic Directors for further approval. Please make inserts in **BOLD**, and email to john.mcgladdery@sit.edu

ISP Details

1. Student's Name: Flannery McArdle
2. Student Phone and/or E-mail: 0837001216/mcardlef@carleton.edu
3. Title of ISP: __ A Comparative Study of the Social Support Available for Children Caring for AIDS-sick vs. Other-sick caregivers in Gingindlovu, South Africa
4. ISP Advisor Name, Title, and Contact Telephone:
Tyler Lane, DPhil Student at Oxford University, +44 (0) 7580020717

Human Subjects Review

1. Brief description of procedures relating to human subjects' participation:

- a. Indicate proposed number of persons that may be participating per set

Experts - 2

Academics - 2

Minors - 6

Other - give descriptive details. **I would like to talk with the parents**

being cared for by the minors as well. This will, of course, be with the permission of the Home-based caregivers and the patients themselves.

- b. Provide details of any cooperative institution? What is it, who is the contact, and how was their permission obtained?

The Holy Cross AIDS Hospice in Gingindlovu is the cooperative institution. My contact at the hospice is Priscilla Dlamini and she is woman who runs the hospice. We have been in contact over email and she consented directly to allowing me to conduct my study with her institution. The details of the study were clearly spelled out in the email but verbal consent will also be attained on Wednesday, October 26, 2011.

- c. What will participants be asked to do, or what information will be gathered?

(Append

copies of interview guides, instructions, survey instruments, etc. where applicable).

The participants will be asked to discuss their experiences either as a child providing care to a sick caregiver or dealing with young carers. The young carers themselves, and their parents and guardians as well, will be asked to have guided conversation with the researcher, while more formal interviews will be conducted with the home-based caregivers and the experts who will be consulted on this project.

(Interview Questions Attached)

- d. Reciprocity – what is being given back to each participant? *(There must be something written here)* _____

The home-based caregivers and the organization will receive help wherever and whenever it is needed. The researcher is conducting participant observation and thus will not solely be observing but rather will be participating in the daily goings on of the hospice. The young carers will receive attention, praise, and acknowledgement of their hard work, which they may not have received in quite some time due to the illness of their parent or guardian. The researcher will be careful, however, not to forge strong relationships with the young carers due to the short duration of the study.

2. Protection of human subjects. Before completing this section, you must read and agree to comply

with the SIT Study Abroad Statement of Ethics. Even if no research is being done it is incumbent on any person volunteering or learning to ensure no harm might be done.

- a. Have you read and do you agree to comply with the World Learning Ethics Statement noted above?

Yes.

- b. Identify and indicate whether any participants risk any stress or harm by participating in this Study Project? If there is even a slight possibility, should this research go ahead? Why? How will these issues be addressed? What safeguards will minimize the risks? *(Even if you do not anticipate any risks, explain why)*

The researcher will interview home-based caregivers, parents and guardians, as well as young carers. The greatest ethical challenge for the researcher will be the interviews with young carers. In order to get an authentic picture of what the young carers are dealing with and what sort of support they are receiving the guided conversations must touch on topics that could potentially produce emotional or traumatic memories and feelings. The researcher will use her discretion, the knowledge of the home-based caregivers and the body language of the children to discern whether the conversation should proceed or whether a new, lighter topic should be brought up. The existing referral process the hospice uses for bereavement services will be utilized should any child seem to have been disturbed by the interview, however, it will be made clear to the children that they can at any point stop the interview with no risk of punishment.

For the children who have HIV+ parents or guardians there is the added risk of stress or harm because of the pervasiveness of stigma surrounding the disease. Every precaution will be taken to ensure that the anonymity of the participants is protected and that their status is not disclosed to the community. The study focuses on children caring for AIDS-unwell caregivers as well as on children caring for parents or guardians with other chronic illnesses thus there is little chance that the presence of the researcher will imply an HIV+ status in the household. Nonetheless, the home-based caregivers will be relied upon to bring the researcher to households with HIV+ parents or guardians and the researcher

will not broach the topic of HIV/AIDS with the patient or the child unless brought up initially by the participant.

Clearly there are several ethical challenges the researcher must keep in mind as the study proceeds. Indeed, there has been so little research on young carers and, in particular, the social support they receive, that there are likely further ethical challenges not foreseen by the researcher at this time. Nonetheless, this study should proceed precisely because of the lack of knowledge about this issue and the importance of understanding exactly what support young carers are receiving so that any gaps may be filled.

- c. Who might you need written consent from? ***(If nobody explain why)*** _____
- The researcher will obtain written consent from the Hospice for allowing me to follow their home-based caregivers and to use their organization at the base for my study. Written consent will also be needed from the parents of the young carers who will be interviewed and from the young carers themselves. A consent form has been drawn up specially for the young carers. It will be translated into Zulu to provide them with the simplest and easiest to understand form to ensure that they know what they are signing. It will be retranslated into English so that the researcher can be certain that nothing is lost in translation and that the child understands what the study is and that they can stop at any point with no consequences. _____
- d. _____
- Indicate whether any participants are minors or not likely to understand consequences of participation? If there are, how will they be protected, and who will ensure their rights are protected?
- The majority of the participants in the study will be minors, as the focus of the study is on the social support available to children caring for sick adults. As previously noted, the researcher will use her own discretion, the knowledge of the home based caregivers and the body language of the children to discern whether the interview should continue or whether a new topic should be broached. Consent will be obtained from the parents and the children themselves to ensure the maximum level of understanding. The consent form will be translated into Zulu to ensure the maximum level of understanding for the child. It will state explicitly that they child has the right to withdraw from the study at any point should they feel uncomfortable with no consequences. It will also explain what the object of the study is and what the end result will be. Should it seem that either the child or the parent is uncomfortable with the researcher's presence or with the idea of being part of the study the interview will not proceed. Because, in this situation, the parents are unwell and may not be able to protect the rights of their child the researcher will rely on the knowledge and experience of the home-based caregivers to to ensure that the children are safe. Verbal consent will be obtained from the home-based caregiver before any interview with a young carer.
- e. Will you ask questions of any persons who may appear unable to negotiate freely? How will you protect them from feeling coerced? ***(If no, explain why all are freely abled)***

No questions will be asked of any persons who may appear unable to negotiate freely. Each participant will be informed individually either verbally or in written form that they have every right to not participate in the study with no consequences and that they have the right, should they choose to participate, to stop the interview at any point, again with no consequences. If there is a situation where it seems that the young carer is unable to negotiate freely, or that their parent or guardian is speaking for them the interview will not proceed. It is crucial that each child understand that they personally have the right to withdraw or to not participate due to the sensitive nature of the topics which will be discussed.

3. Human Subject Protection Essay:

Describe who you will be interviewing and how you will ensure that the following will be protected. (Essay format – 1000 to 1500 words depending on situations)

This study will be conducted at the Holy Cross AIDS Hospice for a duration of three weeks using participant observation. The hospice setting will provide access to home-based caregivers, young carers, and sick patients. Interviews will be conducted with each in an effort to collect the six case studies of young carers - three of children caring for AIDS-unwell caregivers and three of children caring for caregivers with other chronic illnesses - that are needed for a comparative study of the social support available in each situation.

Home-Based Caregivers - Privacy and Anonymity

The intention of this study is not to evaluate the work of the home-based caregivers, thus their interviews will revolve around their experiences with young carers and the social support that is available to these children. Should they wish for any reason to remain anonymous, this wish will of course be granted. However, because the interviewer is not concerned with their work or their organization's work there is little to no chance that the caregivers' responses will reflect badly on them. The researcher will use her own discretion as to whether or not to make the caregivers anonymous should the responses the caregivers provide reflect poorly on their organization, the community or any of its members. It is well known that home-based caring is a stressful and tiring job, thus there is the chance that these interviews could stir up emotions and traumatic memories which the researcher is not equipped to deal with. In these cases the researcher will rely on the referral process that the hospice uses to ensure that the caregiver receives the help needed. However, the researcher will approach these interviews with caution and will present the caregiver with the option of stopping if at any point they feel uncomfortable proceeding with questioning.

Parents/Guardians - Privacy and Anonymity

The interviews conducted with the patients will primarily be concerned with forming a relationship in order to obtain permission to interview their children. The researcher will rely on the home-based caregivers to provide me with the medical status of the patients in terms of whether they have HIV or a different chronic illness to avoid forcing the patient to go through the potential added trauma of disclosing their status or explaining their disease to the researcher.

Because of the prevalence of stigma relating to HIV/AIDS, all identifying features of the patients will be kept anonymous unless they ask to be identified. The interviews will also be used to gather information about what the parents or guardians believe the responsibilities of their children to be and what their perception is of the social support they and the children are receiving. It is necessary to gather this information in order to assess the burden placed on the child and whether the parent or guardian is sympathetic to that burden. But again, the intention of this study is not to analyze the caregiver-child relationship and to criticize or even praise the efforts of the caregiver to raise the child but rather it is assumed that because the caregiver is ill some other type of support must supplement that provided by the caregiver.

Young Carers - Privacy and Anonymity

The greatest ethical challenge in store for the researcher is the interviews with the young carers themselves. The children and the support structures in place to help them deal with being the primary carer of their parent or guardian are the focus of this study. Consent forms will be used and translated into Zulu to provide the children with the easiest and most understandable form. To ensure that the meaning of the forms is not lost in translation they will be retranslated into English by a fluent Zulu speaker. The consent form will explain exactly what the study is about and what the child's role would be. Additionally, it will state explicitly that the child can, at any time, decide not to participate in the study at no cost to themselves or to their caregiver. This right to withdraw is crucial because of the sensitive nature of the topic and the questions. It is important that if the child feels sad or feels that answering a question would force them to talk about a traumatic or emotionally scarring experience that they understand that they can stop the interview at any point. This will be explained verbally, via a translator, as well to make sure that the child understands. Lastly, the contact information of the researcher will be provided in case the child should decide later that they do not want their words used in the study. The consent form will explain, and the researcher will echo verbally, that the child's name will not be used at any point during the write up of the study unless they would like it to be.

For the interview itself, a translator, be it one of the home-based caregivers or a hired translator from outside the community, will be used when necessary to translate the interview questions so that the researcher can communicate with the children. The first step of each interview will be to get the consent of the parent or guardian for the child to be interviewed. The interviews with the children will primarily consist of guided conversation rather than a strict line of questioning so as to not intimidate the children and to allow the children to take the conversation where they want. The researcher will avoid bringing up the topic of HIV/AIDS unless brought up first by the child or their parent or guardian in case their status has not been disclosed to the child. Great caution will be taken when approaching potentially sensitive topics and the questions will start purposely general to guide the children to talk about certain issues rather than force them to talk about specific experiences that may be traumatic. The researcher will use the knowledge of the home-based caregiver and the body language of the child to decide when it is time to stop the interview or to move on to a new topic.

Should the child confide in the researcher that they have been abused or should it seem to the researcher that the child is in a dangerous or harmful situation the researcher will approach the sisters at the hospice to discuss a possible solution. No steps will be taken by the researcher alone but rather the researcher will work within the confines of the local culture and existing referral system to improve the living conditions for the child.

Organizational Integrity

The purpose of this study, as mentioned previously, is not to critically analyze the work of the Holy Cross AIDS Hospice but rather to use this organization as a means to reach the young carers in the community. As a result, any criticisms gathered would not be relevant to the study and would thus be excluded from the final report.

Confidentiality and Coding

The researcher will ensure that all personal information and identifying features be kept separate from the data. No names will be attached to the information collected unless participants explicitly ask to be recognized or identified. The computer in which these separate files are kept will be password protected and no one will have access to them except the researcher. Once written records are entered into the computer they will be destroyed. The data collected during this study will not be used in the future.

4. Participant observation situations; Declaration:

When participating in an organization or community I will:

- a. Undertake a bilateral negotiation with the group I am participating with.
- b. Work with gatekeepers to assist in that negotiation and draw up a contract with that gatekeeper, defining roles and conditions of access.
- c. Work with the gatekeeper to communicate that contract with the group.
- d. Refrain from criticizing and intervening unless invited by the gatekeeper in consultation with the group, and even then with due tact and caution.

By signing below I certify that all of the above information is true and correct to the best of my knowledge, and that I agree to fully comply with all of the program's ethical guidelines as noted above and as presented in the program and/or discussed elsewhere in program materials. I further acknowledge that I will not engage in ISP activities until such a time that both my ISP proposal as well as my Human Subjects Participation application are successful and I have been notified by my Academic Director(s) to this effect.

____Flannery McArdle_____
Student's name (signature)

____Flannery McArdle_____
Student's name (printed)

Date: __10/19/2011__

Talking with Youth in Gingindlovu

Please read this sheet carefully and decide whether or not you would like to take part in this study project. Please ask questions if there is anything that is not clear to you after reading this.

What is this study about? This study is about young people and who supports them or helps them out when they have to deal with difficult situations.

Do I have to be in the study? No, if you are not comfortable for any reason just tell me and we can stop immediately. If you decide not to participate you will not get into trouble and it will not affect any help you are getting from anyone. If you do decide to be in the study, you can still stop at anytime with no consequences.

What would I have to do? First, you would sign a consent form and then you would spend an hour talking with me answering only the questions you feel comfortable answering.

What if the questions upset me? You have the option of stopping at any point and you do not have to give a reason. If for any reason you decide days, weeks, or months after we talk that you want your answers to be taken out of the study, I will do that immediately. If you want to contact me please email me at flnmcr@mac.com or call me at 083-700-1216.

What if I have a complaint? If for any reason you are unhappy after we talk please contact Zed McGladdery at 0846834982 or the nearest School for International Training Study Abroad Office (18 Alton Road, Glenmore, Durban).

Will what I say be kept confidential? I will use a different name if I need to use your words in the study in order to keep your identity a secret. However, anything you tell me that you would like me to keep to myself will be kept strictly confidential. You can always call me or write me after we talk to ask me not to use your words if you decide later that you want to keep them between us.

Consent Form: Check the following boxes if they apply to you:

- I have read and understand the information above and have had an opportunity to ask questions.
- I understand that I have chosen to take part and that I am free to stop at any point for any reason without any consequences.
- I agree that any words I may say during the interview can be used, without my name, in the presentation of the research and I agree to take part in the study.

....Informant A – Signature Held

Name of Participant used in study: Vuyiswa Dube

...Signature Withheld.....

Signature of Participant

Caregiver Consent

This study is about:

- The support available to the children who have a sick parent or guardian
- How the support for children living with AIDS-unwell caregivers may be different than the support for children living with parents or guardians sick from other causes.
- What role this support plays in the lives of these children.

If you give permission, your child will speak with the learner about what types of jobs they do around the house, who helps them with these jobs, how they feel about doing these jobs and about living with a sick parent and who they talk to when they are feeling stressed or sad.

If you have any questions or worries about your child speaking with the learner, please say so and the learner will not speak with your child. If at any time you are uncomfortable with the questions being asked you can ask the learner to stop or to ask a different question. If, after the learner leaves, you decide that you don't want the learner to use your child's answers just call this number: 0837001216 and explain your concerns with the learner.

- I have read the information above about this Study project and had it explained to me, and I fully understand what it says.
- I require that my child's name is kept secret. I understand that, if requested, my child's name will not be written on any questionnaire and that no one will be able to link my child's name to the answers my child gives.
- I understand that my child and I will receive no gift or direct benefit for speaking with the learner.

If you have any questions or complaints please contact Zed McGladdery (0846834982) or you may contact the nearest School for International Training Study Abroad Office (18 Alton Road, Glenmore, Durban).

...Informant B....

Name of Caregiver used in Study: Banisiwe Dube

...Signature Withheld...
Signature of Caregiver

Caregiver Consent

This study is about:

- The support available to the children who have a sick parent or guardian
- How the support for children living with AIDS-unwell caregivers may be different than the support for children living with parents or guardians sick from other causes.
- What role this support plays in the lives of these children.

If you give permission, your child will speak with the learner about what types of jobs they do around the house, who helps them with these jobs, how they feel about doing these jobs and about living with a sick parent and who they talk to when they are feeling stressed or sad.

If you have any questions or worries about your child speaking with the learner, please say so and the learner will not speak with your child. If at any time you are uncomfortable with the questions being asked you can ask the learner to stop or to ask a different question. If, after the learner leaves, you decide that you don't want the learner to use your child's answers just call this number: 0837001216 and explain your concerns with the learner.

- I have read the information above about this Study project and had it explained to me, and I fully understand what it says.
- I require that my child's name is kept secret. I understand that, if requested, my child's name will not be written on any questionnaire and that no one will be able to link my child's name to the answers my child gives.
- I understand that my child and I will receive no gift or direct benefit for speaking with the learner.

If you have any questions or complaints please contact Zed McGladdery (0846834982) or you may contact the nearest School for International Training Study Abroad Office (18 Alton Road, Glenmore, Durban).

...Informant C.....

Name of Caregiver used in the study: Zandile Mhlongo

...Signature Withheld.....
Signature of Caregiver

Caregiver Consent

This study is about:

- The support available to the children who have a sick parent or guardian
- How the support for children living with AIDS-unwell caregivers may be different than the support for children living with parents or guardians sick from other causes.
- What role this support plays in the lives of these children.

If you give permission, your child will speak with the learner about what types of jobs they do around the house, who helps them with these jobs, how they feel about doing these jobs and about living with a sick parent and who they talk to when they are feeling stressed or sad.

If you have any questions or worries about your child speaking with the learner, please say so and the learner will not speak with your child. If at any time you are uncomfortable with the questions being asked you can ask the learner to stop or to ask a different question. If, after the learner leaves, you decide that you don't want the learner to use your child's answers just call this number: 0837001216 and explain your concerns with the learner.

- I have read the information above about this Study project and had it explained to me, and I fully understand what it says.
- I require that my child's name is kept secret. I understand that, if requested, my child's name will not be written on any questionnaire and that no one will be able to link my child's name to the answers my child gives.
- I understand that my child and I will receive no gift or direct benefit for speaking with the learner.

If you have any questions or complaints please contact Zed McGladdery (0846834982) or you may contact the nearest School for International Training Study Abroad Office (18 Alton Road, Glenmore, Durban).

...Informant D.....

Name of Caregiver used in the study: Banisiwe Ndlele

...Signature Withheld.....

Signature of Caregiver

Caregiver Consent

This study is about:

- The support available to the children who have a sick parent or guardian
- How the support for children living with AIDS-unwell caregivers may be different than the support for children living with parents or guardians sick from other causes.
- What role this support plays in the lives of these children.

If you give permission, your child will speak with the learner about what types of jobs they do around the house, who helps them with these jobs, how they feel about doing these jobs and about living with a sick parent and who they talk to when they are feeling stressed or sad.

If you have any questions or worries about your child speaking with the learner, please say so and the learner will not speak with your child. If at any time you are uncomfortable with the questions being asked you can ask the learner to stop or to ask a different question. If, after the learner leaves, you decide that you don't want the learner to use your child's answers just call this number: 0837001216 and explain your concerns with the learner.

- I have read the information above about this Study project and had it explained to me, and I fully understand what it says.
- I require that my child's name is kept secret. I understand that, if requested, my child's name will not be written on any questionnaire and that no one will be able to link my child's name to the answers my child gives.
- I understand that my child and I will receive no gift or direct benefit for

speaking with the learner.

If you have any questions or complaints please contact Zed McGladdery (0846834982) or you may contact the nearest School for International Training Study Abroad Office (18 Alton Road, Glenmore, Durban).

...Informant E.....

Name of Caregiver used in the study: Dudazile Zuma

...Signature Withheld.....

Signature of Caregiver

Caregiver Consent

This study is about:

- The support available to the children who have a sick parent or guardian
- How the support for children living with AIDS-unwell caregivers may be different than the support for children living with parents or guardians sick from other causes.
- What role this support plays in the lives of these children.

If you give permission, your child will speak with the learner about what types of jobs they do around the house, who helps them with these jobs, how they feel about doing these jobs and about living with a sick parent and who they talk to when they are feeling stressed or sad.

If you have any questions or worries about your child speaking with the learner, please say so and the learner will not speak with your child. If at any time you are uncomfortable with the questions being asked you can ask the learner to stop or to ask a different question. If, after the learner leaves, you decide that you don't want the learner to use your child's answers just call this number: 0837001216 and explain your concerns with the learner.

- I have read the information above about this Study project and had it explained to me, and I fully understand what it says.
- I require that my child's name is kept secret. I understand that, if requested, my

child's name will not be written on any questionnaire and that no one will be able to link my child's name to the answers my child gives.

- I understand that my child and I will receive no gift or direct benefit for speaking with the learner.

If you have any questions or complaints please contact Zed McGladdery (0846834982) or you may contact the nearest School for International Training Study Abroad Office (18 Alton Road, Glenmore, Durban).

...Informant F.....

Name of Caregiver used in the study: Jikele Zuma

...Signature Withheld.....

Signature of Caregiver

1 Appendix 5: Consent Form For Adult Respondents in English

I can read English. (If not, but can read Zulu or Afrikaans, please supply). If participant cannot read, the onus is on the researcher to ensure that the quality of consent is nonetheless without reproach.

I have read the information about this Study project and had it explained to me, and I fully understand what it says. I understand that this Study is trying to find out about:

- The support available to the children who are the primary caretaker of their parent or guardian
- How this support may be different for children caring for AIDS-unwell caregivers vs. for children caring for parents or guardians with other chronic illnesses.
- What role this support plays in the lives of these children.

I understand that my participation is voluntary and that I have a right to withdraw my consent to participate at any time without penalty.

I understand and am willing for you to ask me questions about:

- The challenges faced by children caring for adults
- The support systems in place to assist these children
- The differences between the support systems for children caring for AIDS-unwell caregivers vs. for caregivers with other chronic illnesses
- The caretakers and supporters of young carers in Gingindlovu
- The responsibilities of young carers and the level of difficulty of those responsibilities
- The community's perception and attitude towards young carers
- The unmet needs of young carers in Gingindlovu

I **do/ do not** require that my **identity (and name)** be kept secret (*delete inapplicable*). I understand that, if requested, my name will not be written on any questionnaire and that no one will be able to link my name to the answers I give. If requested, my individual privacy will be maintained in all published and written data resulting from this Study project.

I **do/ do not** (*delete inapplicable*), give permission for a **photograph** of me to be used in the writeup of this Study or for future publication. I understand that the learnerer will not use or provide any photographs for commercial purposes or publication without my permission.

I understand that I will receive **no gift** or direct benefit for participating in the Study.

I confirm that the learner has given me the address of the nearest School for International Training Study Abroad Office should I wish to go there for information. (18 Alton Road, Glenmore, Durban).

I know that if I have any questions or complaints about this Study that I can contact anonymously, if I wish, the Director/s of the SIT South Africa Community Health Program (Zed McGladdery 0846834982).

I agree to participate in this Study project.

Signature (participant) Zandile Zungu Date: 11/7/2011

Signature (learner) Flannery McArdle Date: 11/7/2011

2 Appendix 5: Consent Form For Adult Respondents in English

I can read English. (If not, but can read Zulu or Afrikaans, please supply). If participant cannot read, the onus is on the researcher to ensure that the quality of consent is nonetheless without reproach.

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- The responsibilities of young carers and the level of difficulty of those responsibilities
- The community's perception and attitude towards young carers
- The unmet needs of young carers in Gingindlovu

I **do/ do not** require that my **identity (and name)** be kept secret (*delete inapplicable*). I understand that, if requested, my name will not be written on any questionnaire and that no one will be able to link my name to the answers I give. If requested, my individual privacy will be maintained in all published and written data resulting from this Study project.

I **do/ do not** (*delete inapplicable*), give permission for a **photograph** of me to be used in the writeup of this Study or for future publication. I understand that the learner will not use or provide any photographs for commercial purposes or publication without my permission.

I understand that I will receive **no gift** or direct benefit for participating in the Study.

I confirm that the learner has given me the address of the nearest School for International Training Study Abroad Office should I wish to go there for information. (18 Alton Road, Glenmore, Durban).

I know that if I have any questions or complaints about this Study that I can contact anonymously, if I wish, the Director/s of the SIT South Africa Community Health Program (Zed McGladdery 0846834982).

I agree to participate in this Study project.

Signature (participant)_Sister Priscilla Dlamini___Date: __11/25/2011__

Signature (learner)__Flannery McArdle___Date: __11/25/2011__

3 Appendix 5: Consent Form For Adult Respondents in English

I can read English. (If not, but can read Zulu or Afrikaans, please supply). If participant cannot read, the onus is on the researcher to ensure that the quality of consent is nonetheless without reproach.

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- How this support may be different for children caring for AIDS-unwell caregivers vs. for children caring for parents or guardians with other chronic illnesses.
- What role this support plays in the lives of these children.

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- The caretakers and supporters of young carers in Gingindlovu
- The responsibilities of young carers and the level of difficulty of those responsibilities
- The community's perception and attitude towards young carers
- The unmet needs of young carers in Gingindlovu

I **do/ do not** require that my **identity (and name)** be kept secret (*delete inapplicable*). I understand that, if requested, my name will not be written on any questionnaire and that no one will be able to link my name to the answers I give. If requested, my individual privacy will be maintained in all published and written data resulting from this Study project.

I **do/ do not** (*delete inapplicable*), give permission for a **photograph** of me to be used in the writeup of this Study or for future publication. I understand that the learner will not use or provide any photographs for commercial purposes or publication without my permission.

I understand that I will receive **no gift** or direct benefit for participating in the Study.

I confirm that the learner has given me the address of the nearest School for International Training Study Abroad Office should I wish to go there for information. (18 Alton Road, Glenmore, Durban).

I know that if I have any questions or complaints about this Study that I can contact anonymously, if I wish, the Director/s of the SIT South Africa Community Health Program (Zed McGladdery 0846834982).

I agree to participate in this Study project.

Signature (participant)_Lynette Phumelele Mbuyazi___Date: __11/15/2011__

Signature (learner)__Flannery McArdle___Date: __11/15/2011__

4 Appendix 5: Consent Form For Adult Respondents in English

I can read English. (If not, but can read Zulu or Afrikaans, please supply). If participant cannot read, the onus is on the researcher to ensure that the quality of consent is nonetheless without reproach.

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- The support available to the children who are the primary caretaker of their parent or guardian
- How this support may be different for children caring for AIDS-unwell caregivers vs. for children caring for parents or guardians with other chronic illnesses.
- What role this support plays in the lives of these children.

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- The challenges faced by children caring for adults
- The support systems in place to assist these children
- The differences between the support systems for children caring for AIDS-unwell caregivers vs. for caregivers with other chronic illnesses
- The caretakers and supporters of young carers in Gingindlovu
- The responsibilities of young carers and the level of difficulty of those responsibilities
- The community's perception and attitude towards young carers
- The unmet needs of young carers in Gingindlovu

I **do/ do not** require that my **identity (and name)** be kept secret (*delete inapplicable*). I understand that, if requested, my name will not be written on any questionnaire and that no one will be able to link my name to the answers I give. If requested, my individual privacy will be maintained in all published and written data resulting from this Study project.

I **do/ do not** (*delete inapplicable*), give permission for a **photograph** of me to be used in the writeup of this Study or for future publication. I understand that the learner will not use or provide any photographs for commercial purposes or publication without my permission.

I understand that I will receive **no gift** or direct benefit for participating in the Study.

I confirm that the learner has given me the address of the nearest School for International Training Study Abroad Office should I wish to go there for information. (18 Alton Road, Glenmore, Durban).

I know that if I have any questions or complaints about this Study that I can contact anonymously, if I wish, the Director/s of the SIT South Africa Community Health Program (Zed McGladdery 0846834982).

I agree to participate in this Study project.

Signature (participant) Mr. Thembinkosi Masinga Date: 11/14/2011

Signature (learner) Flannery McArdle Date: 11/14/2011