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**Constructing Loss:
Exploring the Traumatic Effects
of Bereavement
due to HIV/AIDS and Tuberculosis
on Aid Workers in South Africa**

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A thesis submitted in fulfilment of requirements for the degree of

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of EDINBURGH

Declaration

I hereby declare that this thesis is of my own composition,
and that it contains no material previously submitted
for the award of any other degree.

The work reported in this thesis has been executed by myself,
except where due acknowledgement is made in the text.

Vania Ranjbar

Abstract

This thesis aimed to investigate, first, the potentially traumatic effects of AIDS-related bereavement on HIV/AIDS aid workers in South Africa; second, the resources that aid workers utilise in order to cope with their work; and third, differences in the experiences of local versus international aid workers. HIV/AIDS work is associated with various stresses and burnout is commonly observed among HIV/AIDS caregivers. Care of HIV/AIDS aid workers, however, has been largely overlooked; research has typically focused on the experiences of professional health workers, and often outside of an African setting. This present study, therefore, addressed these limitations with the use of participant observation ethnography and ethnographic interviewing.

A period of one year was spent with an organisation in South Africa that provides care for vulnerable children in need and affected by HIV/AIDS. Open-ended semi-structured interviews were conducted with 63 male and female local and international staff and volunteers. The interviews were analysed using discourse analysis (DA), a methodology novel within HIV/AIDS and trauma research and particularly suitable for investigating language, social context and interaction, and identities, which are factors found to be important in HIV/AIDS work. Participants' discourses were analysed to identify how they construct their identities, concepts such as HIV/AIDS and tuberculosis, events they experienced, and how they made sense of these phenomena.

The main finding of this study was that contemporary HIV/AIDS aid work involves new challenges that have surpassed AIDS-related bereavement as the most prominent concern. The main challenges reported by participants involved the inability to control HIV/AIDS treatment and consequently inability to prevent, or control, AIDS-related death as a result of patient non-compliance. Participants

further constructed HIV contraction as controllable and, therefore, avoidable, and used this micro discourse on control to counter HIV-related stigma, particularly stigma they experienced as HIV/AIDS aid workers. This rhetorical technique, however, rather maintains the macro discourse on HIV-related stigma by maintaining the blame component of the disease. Two identity constructions emerged in participants' discourses. First, the characteristics inherent in the child identity suggested that loss is not merely a matter of death but also sadness for and on behalf of children for their various losses. Second, the caregiver identity prescribed how 'proper' and 'genuine' HIV/AIDS caregivers are expected to behave. The prescriptive nature of this identity can explain burnout among HIV/AIDS caregivers. The rewards of caregiving, however, can act as a buffer against difficult or traumatic experiences inherent in HIV/AIDS work. Managerial support and global belief systems that allow finding meaning were further identified as important coping resources for HIV/AIDS aid workers. Finally, differences between local and international participants, in terms of how they conceptualise phenomena and consequently have different needs, emphasise the role of culture in the experiences of HIV/AIDS aid workers. In the thesis I further discuss these findings in light of theories of social psychology, such as the Just World hypothesis, Cognitive Dissonance, and Identity Control Theory and Self-Categorization Theory.

I conclude that although AIDS-related death no longer is a prominent issue, care of HIV/AIDS aid workers should not be overlooked. Contemporary HIV/AIDS work simply involves new challenges and traumas, and it is important that such work is continuously researched to identify evolving needs.

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Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ARVs	Antiretrovirals
ART	Antiretroviral Treatment
CA	Conversation Analysis
CCC	Cotlands Community Centre
DA	Discourse Analysis
DSM-IV-TR	Diagnostic and Statistical Manual of mental disorders, Fourth Edition, Text Revision
DSP	Discursive Social Psychology
ECD	Early Childhood Development
HBC	Home-Based Care
HBCW	Home-Based Care Worker
HIV	Human Immunodeficiency Virus
HIV+	HIV positive
HIV-	HIV negative
HR	Human Resources
ICT	Identity Control Theory
IES	Impact of Event Scale
IES-R	Impact of Event Scale – Revised
KZN	Kwa-Zulu Natal
MDD	Major Depressive Disorder
MDR-TB	Multidrug-Resistant Tuberculosis
NPO	Non-Profit Organisation
OSP	Orthodox Social Psychology
PIS	Participant Information Sheet
POBAs	Perceptions, Opinions, Beliefs, Attitudes
PTG	Post-Traumatic Growth
PTSD	Post-Traumatic Stress Disorder

SCT	Self-Categorization Theory
SNS	Sympathetic Nervous System
STD	Sexually Transmitted Disease
TB	Tuberculosis
UK	United Kingdom
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
XDR-TB	Extensively Drug-Resistant Tuberculosis

In Memory Of

Snenhlanhla

(1996-2003)

and

Snethemba

(2000-2004)

Ngiyanithanda wena amantombazana

Chapter 1. Introduction

This thesis addresses the potentially traumatic effects of AIDS-related bereavement on aid workers in South Africa. This introductory chapter aims to briefly introduce the main topics of this thesis: Human Immunodeficiency Virus (HIV), Acquired Immunodeficiency Syndrome (AIDS), tuberculosis (TB), traumatic stress, and the relevance of these topics to the well-being of aid workers in South Africa.

1.1. HIV/AIDS

In 2009, an estimated 33.3 million people worldwide lived with HIV (UNAIDS, 2010a). Alongside this were reported incident and death rates of 2.2 million and 1.8 million, respectively (UNAIDS, 2010a). As the HIV infects the cells of the body's immune system and multiplies inside the cells, the immune system's capacity to fight other infections is in turn reduced (UNAIDS, 2008a); hence the term, 'immunodeficiency'. This renders an HIV-infected, or HIV+ (HIV positive), individual more susceptible to infections and diseases which would otherwise be atypical in an individual with a healthy immune system (UNAIDS, 2008a). As these infections make use of the weakened immune system, they are referred to as 'opportunistic infections' (UNAIDS, 2008a). The World Health Organization's (WHO) clinical classification of HIV stages is mainly based on the various symptoms associated with the different stages (WHO, 2007); the four stages range from 'asymptomatic', through 'mild' and 'advanced' symptoms, to 'severe' symptoms.

AIDS is an umbrella term referring to the later stages of an HIV infection (UNAIDS, 2008a); whereas all individuals in stage four are classified as having

AIDS, some individuals are diagnosed with AIDS already in stage three. Although the various time frames differ across individuals, if an HIV infection is left untreated, in most people the illness tends to start display itself within 5 to 10 years of the infection, and has progressed to an AIDS diagnosis within 10 to 15 years (UNAIDS, 2008a). Antiretroviral treatments (ARTs) can decelerate the advancement of the infection towards AIDS (UNAIDS, 2008a). Many HIV+ people, however, do not receive the necessary treatment (Demmer, 2006; UNAIDS, 2010b).

As HIV is found in body liquids (such as blood or semen) it is commonly transmitted in four ways: through (i) unprotected sexual intercourse, (ii) blood transfers, (iii) sharing of contaminated drug equipment, and (iv) mother-to-child in association with birth or breastfeeding (UNAIDS, 2008b). Medical staff and other care workers are thus encouraged to take safety measures (so called universal precautions) such as sterilising equipment and using gloves when handling bodily matters (UNAIDS, 2008b). HIV is, however, not transmitted through everyday contact such as handshakes, hugs, or sharing of eating utensils or toilets; neither is HIV transmitted through mosquito bites as the virus can only multiply in humans and thus only humans can be infected (UNAIDS, 2008b).

When the AIDS pandemic started, the chances of surviving for more than a few years after an HIV-infection were modest (UNAIDS, 2008c). Due to the last two decades' advancements in drug development, ARTs are now more effective in preventing the virus from multiplying inside the body and thus reducing the damaging effect on the cells of the immune system, which in turn prevents advancement of the infection and decelerates progression to AIDS (UNAIDS, 2008c). The virus, however, can mutate, and as it changes it becomes capable of adjusting to various drugs (UNAIDS, 2008c). HIV is thus commonly treated by a simultaneous combination of multiple ARV (antiretroviral) medicines which impede adjustment, and thus resistance to drugs, by hampering the reproduction process of the virus (UNAIDS, 2008c). If a particular combination of medicines stops being effective, treatment is advanced to 'second line' medicines (UNAIDS, 2008c).

1.2. Tuberculosis

Of the 8.8 million new TB cases in 2010, over one million of these occurred in HIV+ individuals (WHO, 2011). TB is airborne, caused by the bacteria *Mycobacterium tuberculosis*, and typically affects the lungs (Centers for Disease Control and Prevention, 2009). Becoming infected with the TB bacteria, however, does not necessarily entail becoming sick with TB disease, and medications can be taken to prevent the bacteria from becoming active and multiplying (Centers for Disease Control and Prevention, 2009). The bacteria tend to become active particularly in individuals with immunodeficiency, such as those who are HIV+ (Centers for Disease Control and Prevention, 2009). Where the body can resist the bacteria and hinder their reproduction, the infection remains inactive, or latent (asymptomatic), and these individuals are not contagious (Centers for Disease Control and Prevention, 2009); only individuals with active (symptomatic) TB, usually in the lungs or the throat, are contagious. The TB bacteria are spread through the air when an individual with active TB coughs, sneezes, or speaks, and others become infected when the bacteria are inhaled (Centers for Disease Control and Prevention, 2009). TB, like HIV, is thus not transmitted through handshakes or sharing of utensils or toilets (Centers for Disease Control and Prevention, 2009).

Similar to HIV, TB treatment involves taking a number of medicines simultaneously in an attempt to prevent the adjustment and resistance of bacteria (Centers for Disease Control and Prevention, 2009). Multidrug-resistant TB (MDR-TB) refers to bacteria resistant to two or more medicines, whereas in Extensively drug-resistant TB (XDR-TB) nearly all drugs are adjusted to (Centers for Disease Control and Prevention, 2009).

Table 1.1 provides an overlook of basic descriptive HIV/AIDS and TB statistics from the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the WHO.

Table 1.1

HIV/AIDS and TB statistics from UNAIDS and WHO reports (2010-2011).

Number of people living with HIV worldwide	33.3 million [†]
Number of people living with TB worldwide	12 million [*]
Number of new HIV infections worldwide	2.2 million [†]
Number of new TB infections worldwide	8.8 million ^{*1}
Number of AIDS-related deaths worldwide	1.8 million [†]
Number of TB-related deaths worldwide	1.1 million ^{*2}
Percentage of worldwide HIV+ individuals who live in Sub-Saharan Africa	67% [†]
Percentage of worldwide AIDS-related deaths occurring in Sub-Saharan Africa	72% [†]
South Africa HIV adult prevalence rate	17.8% ⁺³
United Kingdom HIV adult prevalence rate	0.2% [†]
Number of children living with HIV worldwide	2.5 million ⁺⁴
Number of new HIV infections in children (under 15 years)	370 000 [†]
Percentage of worldwide HIV+ children living in Sub-Saharan Africa	92% [†]
Number of children worldwide orphaned due to AIDS	16.6 million [†]
Percentage of AIDS-related orphans living in Sub-Saharan Africa	89% [†]
Number of people in low- and middle-income countries receiving ARTs	5.2 million ⁺⁵

[†] UNAIDS Report on the Global AIDS Pandemic 2010.

^{*} WHO Global Tuberculosis Control 2011.

¹ 1.14 million of these occurred in HIV+ individuals.

² This figure excludes TB-deaths among HIV+ cases. The HIV-associated death rate for TB is estimated to be 350 000.

³ Adults are defined as men and women aged 15 to 49 years. In most affected countries, prevalence rates are higher for females than for males.

⁴ Children are defined as 0 to 14 years.

⁵ Children are less likely than adults to receive ARTs.

1.3. Sub-Saharan Africa

As can be seen in Table 1.1, Sub-Saharan Africa is heavily affected by both HIV/AIDS and TB; the area accounts for two-thirds of all people living with HIV as well as the majority of AIDS-related deaths. A number of potential explanations

why this might have been proposed. Undeniably, one main reason for Sub-Saharan Africa's high TB prevalence rates is HIV, as high TB infection rates are coupled with high HIV co-infection (Godfrey-Faussett & Ayles, 2003; WHO, 2009a). Furthermore, the majority of the countries with highest TB incidence rates are African (WHO, 2009a). The HIV pandemic is thus seen as 'fuelling an increase in tuberculosis' (Dudley et al., 2003, p. S48). If a weakened immune system poses an increased risk of TB bacteria becoming active, then HIV+ individuals will naturally be at risk. Additionally, HIV has the potential to exacerbate a TB-infection, for example, by accelerating the development of the illness (Godfrey-Faussett & Ayles, 2003).

Second, there is the issue of poverty which on its own brings about several other concerns. The WHO has labelled tuberculosis 'a disease of poverty' (WHO, 2009b, p. 1) and TB is thought to be closely linked to poverty-related concerns such as overcrowding and malnutrition (Coetzee, Hilderbrand, Goemaere, Matthys, & Boelaert, 2004; Godfrey-Faussett & Ayles, 2003), with developing countries accounting for the greater part of TB deaths (WHO, 2009b). Seeing how TB is airborne, the implication of overcrowding in the spreading of TB bacteria is understandable. In addition to HIV, low body weight can also contribute to weakening of the immune system, further increasing the risk of a TB infection (Centers for Disease Control and Prevention, 2009). Moreover, health systems in these countries are often underdeveloped, which contributes to high death rates arising from a lack of adequate health care, partly as most countries in this region lack the capacity to diagnose MDR-TB or XDR-TB (WHO, 2009a).

The consensus across the literature with regard to the detrimental effects of HIV/AIDS and TB on society cannot be overlooked. Not only are there obvious health consequences, as discussed above, and psychological effects in terms of stigmatisation as well as caring for and losing family members, but there are also developmental and economic effects (Hunter, Kaijage, Maack, Kiondo, & Masanja, 1997; Lusk, Huffman, & O'Gara, 2000). Children are either forced to remain at home

to care for sick family members or they simply cannot attend school as sickness may have resulted in loss of income for the family (Hunter et al., 1997; Lusk et al., 2000). Furthermore, there are other expenses associated with being sick, such as treatment or even funeral costs (Godfrey-Faussett & Ayles, 2003; Hunter et al., 1997). Naturally, if children are unable to obtain an education, a country's development may be stunted. The effects of the diseases can thus be seen on both micro and macro levels.

1.4. The Role of Aid Workers in Sub-Saharan Africa

In many of these African countries, the care and support for individuals sick with HIV/AIDS and TB is provided by national or international Non-Profit Organisations (NPOs) (Godfrey-Faussett & Ayles, 2003; Richter, Manegold, & Pather, 2004). An NPO can be defined as 'any grouping of people who have a common mission to meet a particular need in their society or community, and are not formed or controlled by government' (Mazibuko, 2000, p. 1). These can take many shapes, some of the most common being as a fundraising charity organisation or as a children's home; the children's home may be small-scale with community members looking after orphaned children or as a larger-scale organisation with a board of trustees and other administrative staff. Regardless, the aim of these organisations is to meet the various needs of a community, and in many African regions the provision of medical and palliative care to people living in rural areas affected by HIV/AIDS and TB is mainly up to volunteers from these organisations (Naidu, Slied, & Dageid, 2012). These may be from the local community, or national or international volunteers (Hunter et al., 1997; Lusk et al., 2000; Richter et al., 2004). The financing and management of HIV/AIDS care programmes, and sometimes execution of government directives, in many African regions is often dependent upon these NPOs (Hunter et al., 1997; Richter et al., 2004). Throughout this thesis,

the phrase 'aid organisation' will be used when referring to organisations that address particular needs in communities.

The definition of 'aid worker' used here is the definition given by the Macmillan English Dictionary¹: 'someone who works for an international organization giving help in a place where people need it'. For the purposes of this thesis, this will relate to organisations addressing issues of HIV/AIDS and TB. A 'volunteer' can be described as an individual who systematically engages in an activity that benefits another person in some way, without financial compensation (Bakker, 2007; Crook, Weir, Willms, & Egdorf, 2006; Primo, 2007). Primo differentiates between informal and formal volunteering, the former being 'volunteering on an individual basis whereby one person is helping another' (Primo, 2007, p. 19), and the latter is volunteering as a collective. When referring to 'aid workers' in this thesis, I am referring to those individuals who formally carry out paid or unpaid work for an organisation. If this individual is specified as a 'volunteer' then the work referred to is unpaid; the individual will otherwise be referred to as a staff member. It is important to bear in mind that these individuals do not necessarily have to be trained professionals.

In 2011/12, the United Kingdom's (UK's) Gross Public Expenditure on Development totalled £8,950m (Department for International Development, 2012), and statistics from only one of the many volunteer and 'gap year' organisations show that over 5,000 young individuals engage in volunteer work every year, half of which are of British nationality (Projects Abroad; <http://www.projects-abroad.co.uk/>; I. Birkbeck, personal communication, January 19, 2010). Many of these work in areas directly related to HIV/AIDS and TB.

¹ <http://www.macmillandictionary.com/>

1.5. Traumatic Stress

When considering stress, a distinction is to be made between normal stress – that is, everyday life pressures such as exams – and traumatic stress produced by typically less common events, such as war traumas. Stress can be defined as a ‘challenging event that requires physiological, cognitive, or behavioral adaptation’ (Oltmanns, Emery, & Taylor, 2006, p. 269). Furthermore, there is disagreement within the literature whether stress is the event itself or if it is an individual’s reaction to an event (Oltmanns et al., 2006). This theoretical dilemma, however, falls outside the scope of this thesis.

Prolonged exposure to stress can have a negative impact on one’s health. Stress activates the Sympathetic Nervous System (SNS), which is involved in increased arousal performances (Oltmanns et al., 2006). Stress is also associated with the secretion of the hormone cortisol, which normally aids the body’s restoration in times of stress (Oltmanns et al., 2006); however, repeated activation of the SNS and an excess of the hormone can instead be harmful and damage the body in the long term. For example, excessive stress can result in greater susceptibility to illness due to destabilisation of the immune system by damaging the cells in the hippocampus which consequently could negatively affect functions such as learning and memory, as well as hypertension and osteoporosis (Chrousos & Gold, 1998; Dallman, 1993; Oltmanns et al., 2006; Stokes, 1995).

On a mental health note, depending on the circumstances, a number of enduring mental health disorders can come about as a consequence of traumatic events (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995; van der Kolk, Brown, & van der Hart, 1989). In addition to Post-Traumatic Stress Disorder (PTSD), traumatic experiences can also result in Dissociative Disorders, Somatoform Disorders, and Mood Disorders (Brune et al., 2002). PTSD is also one of the clinical anxiety disorders with highest co-morbidity rates (Brown, Campbell, Lehman, Grisham, & Mancill, 2001); the most common co-morbid diagnosis tends to be Major Depressive

Disorder (MDD) with co-occurrence rates of 65% (Brown et al., 2001; Brune et al., 2002).

The DSM-IV-TR (Diagnostic and Statistical Manual of mental disorders, Fourth Edition, Text Revision; American Psychiatric Association, 2000) definition of trauma for a PTSD diagnosis involves an individual having experienced, witnessed, or in some other way been confronted with actual or threatened death. The condition arose from the effects of the life-threatening experiences of war veterans (Johnson & Thompson, 2008). Typical PTSD symptoms are divided into three categories and include: re-experiencing, such as flashbacks, dreams, or visualising the event repeatedly in thoughts; hyperarousal, resulting in agitation and irritability, as well as sleep and concentration difficulties; and avoidance or numbing, such as avoiding places, thoughts, feelings, and activities associated with the event (sometimes resulting in an individual withdrawing socially), or a numbed emotional response (American Psychiatric Association, 2000).

1.6. The Thesis Rationale: The Risk of Traumatic Stress Among Aid Workers

Death of a close friend or family member is present on both the revised Life-Stressor Checklist (Wolfe, Kimerling, Brown, Chrestman, & Levin, 1996) as well as the Social Readjustment Rating Scale (Holmes & Rahe, 1967). The DSM-IV-TR also includes a separate axis (section) dealing with psychosocial and environmental problems. Death of a family member is classified as problems with primary support group, and death or loss of a close friend as problems related to one's social environment. As such, it is then evident that death in one's vicinity can have negative psychological consequences in terms of traumatic stress. As death rates due to HIV/AIDS and TB are so high in African regions, it is common for HIV/AIDS aid workers active in these regions to experience bereavement due to these diseases and it has been noted that caregivers may experience some level of psychological

stress as a result of witnessing death (Akintola, 2004). Arguably, aid workers in these regions experience traumatic stress as well as normal stress since their job involves experiencing death, sometimes repeatedly, as well as chronic exposure to the stressful events associated with these losses and the caring for terminally ill individuals.

In light of the prevalence of HIV/AIDS and TB in Africa, the probable traumatic nature of bereavement caused by these diseases, as well as the consequences of stress and the subsequent negative impact on health, it is justified to say that aid workers in these areas are likely to be subjected to these negative experiences. Traumas that are inflicted by other human beings, sudden, severe, repetitive, or prolonged are considered to pose greater risks for psychopathology (Brune et al., 2002; Saigh, 1988). Bereavement due to HIV/AIDS and TB among aid workers may neither be a sudden nor an intentionally inflicted event by other persons. It can, nonetheless, be seen as primary exposure (Stamm, 2008) to a prolonged, repetitive (multiple deaths), and thus severe experience, and as such be a source of great psychological distress. Oltmanns and colleagues (2006) suggest that reactions to traumatic stress have been of particular interest to the military because military personnel are expected to carry out standard procedures in spite of trauma. Likewise, aid workers, too, are expected to continue carrying out their tasks despite these stressful experiences. Previous research (Akintola, 2004; Bakker, 2007; Demmer, 2006) has therefore concluded that regular evaluation of HIV/AIDS caregivers' conditions is a necessity to ensure adequate resources are in place to cater for their various needs, and that further research in this area is required. Needs, in response to bereavement, that are left unidentified or attended to can result in pathological mental health (Speidel, 2000). It is important to ensure acceptable quality of life for aid workers, as poor quality of life is considered a major threat to health (Stamm, 2008). Hence the objective of this thesis: addressing the potentially traumatic effects of AIDS-related bereavement on HIV/AIDS aid workers in South Africa.

1.7. This Thesis

After this introductory chapter on the topics relevant to this thesis, the literature review in Chapter 2 will outline the existing literature on the stresses, as well as protective factors, associated with HIV/AIDS work. This includes a discussion on the limitations of previous research. Chapter 2 concludes with the aims of this study. Chapter 3 will describe the methods adopted for the data collection phase of this study, including details of the fieldwork carried out in South Africa, as well as the epistemological underpinnings. The results – that is, the analysis of the data – will be presented in the empirical chapters: Chapter 4, 5, 6, and 7. Finally, Chapter 8 will offer a concluding discussion.

Chapter 2. Literature Review

There has been limited empirical investigation into the potentially traumatic experiences of bereavement due to HIV/AIDS and TB among aid workers in South Africa. This chapter aims to summarise some of the knowledge in this area as well as empirical findings about volunteering in general. In addition, this chapter will draw on findings from two other research areas which are highly relevant to the topic of this thesis: research conducted with American gay men and their families early in the HIV/AIDS-pandemic, and war trauma research involving refugees, political activists, and military personnel. Approximately half of AIDS cases in the United States in the mid 1990s were thought to be the result of transmissions among homosexual men (Centers for Disease Control and Prevention, 1996); as such, their experiences, as well as those of other people in their proximity, will be relevant to this thesis. War trauma research is also relevant because the population sampled in these studies run very high risk of experiencing traumatic stress.

There are, naturally, some differences between the above mentioned populations and aid workers. One difference was mentioned already in the previous chapter: war trauma research almost exclusively deals with traumatic events inflicted by other individuals (so called man-made disasters), whereas the trauma aid workers potentially experience as a result of AIDS and TB-related bereavement is not inflicted by others in a comparable way. Another difference relates to the stigma surrounding HIV/AIDS and TB, for example, the notion that individuals with AIDS are themselves to be blamed for contracting the disease (Ross & Seeger, 1988). This stigma often makes caring and bereavement more difficult for family and friends of individuals passing away as a result of AIDS (Demmer & Burghart, 2008; Folkman, Chesney, Collette, Boccellari, & Cooke, 1996; Mallinson, 1999a, 1999b; Reynolds & Alonzo, 1998). Furthermore, many family members only learn about the care recipient's sexuality once AIDS has been contracted. This discovery

sometimes makes caregiving more difficult for the relatives (Siegl & Morse, 1994). On the other hand, the caregiving of aid workers who choose to work with individuals with such illnesses will presumably not be made more difficult by their patients' sexuality.

Despite these differences there are, nonetheless, similarities that make a comparison on this topic valid. As caregiving often strengthens emotional connections between a caregiver and the person they care for (Bakker, 2007; Robson, Ansell, Huber, Gould, & van Blerk, 2006), one can expect that the relationship between staff and volunteers, who live and work closely with terminally ill individuals whom they care for, may come to resemble a relationship between two relatives (Primo, 2007). For instance, the mourning which bereaved gay men experience after caring for a partner has been shown to be similar to that experienced by bereaved family members (Folkman et al., 1996). Although some have found that the combination of being an HIV/AIDS caregiver while also being HIV+ results in more psychological distress (Akintola, 2004; Bonanno, Moskowitz, Papa, & Folkman, 2005; Demmer, 2006; Folkman et al., 1996; Santiesteban, Castro, & Calvo, 2012), because of concerns regarding one's own fate, it is generally considered that HIV/AIDS caregiving and bereavement is distressful regardless of HIV status (Bonanno et al., 2005; Folkman et al., 1996; Martin & Dean, 1993).

On one hand, existing empirical knowledge suggests that bereavement due to HIV/AIDS and TB is and ought to be a traumatic experience for aid workers. On the other hand, there is reason to believe that there may be factors which render such an experience as not so traumatic. This chapter will begin with a brief summary of the existing literature on stresses associated with HIV/AIDS caregiving that aid workers face, and thereafter move on to discuss the issues that could contribute to such a bereavement being traumatic, and finally provide arguments for factors that could promote aid workers' coping and resilience and thus mitigate trauma. The first section will conclude with a discussion on limitations of previous

studies. The second section of this chapter will contain the research aims of the present study.

The Existing Literature

2.1. Stresses Associated with HIV/AIDS Care

Caring for individuals with HIV/AIDS and TB is thought to involve a great deal of stress for the caregivers (Akintola, 2004; Primo, 2007; Ross & Seeger, 1988), to the extent that such an experience is thought to change a person forever (Primo, 2007). These stresses are believed to be as a result of the AIDS care per se rather than due to different personality traits (Ross & Seeger, 1988). Among the most common types of stresses that volunteers working in HIV/AIDS and TB-related areas may experience are physical and psychological or emotional stresses, but also economic, social, organisational, and sometimes religious stresses (Akintola, 2004; Bakker, 2007; Demmer, 2002; Dieleman et al., 2007; Primo, 2007; Reynolds & Alonzo, 1998; Ross, Greenfield, & Bennett, 1999). The combination of several stresses is believed to result in substantial strain for caregivers (Akintola, 2004). Among the physical health concerns reported by volunteers are various kinds of body aches (for example, backaches due to lifting), fatigue, and a generally more fragile health system (Akintola, 2004; Primo, 2007). The emotional distress may cause individuals to experience sleep disturbances, including nightmares, and especially in relation to and around times of occurring death; eating disturbances; traumatic stress, depressive mood and anxiety, particularly in relation to death and dying; existential uncertainty; and feelings of fear, anger, despair, frustration, helplessness or guilt (Akintola, 2004; Bakker, 2007; Martin & Dean, 1993; Peabody, 1986; Primo, 2007; Reynolds & Alonzo, 1998; Ross et al., 1999). These emotional stresses can stem from having to witness other people's suffering (Hall, 2003; Sondlane, 2008). The physical

and psychological problems are often thought to go hand in hand (Hall, 2003; Primo, 2007) and sometimes these stresses can even result in volunteers terminating their volunteering (Ross et al., 1999). Often it is not an option for aid workers to remove themselves from the situation causing these stresses and thus the problems are left to continue without treatment, sometimes for a long period of time (Akintola, 2004; Primo, 2007). This situation can then result in burnout, which is characterised as emotional exhaustion, lack of motivation, and reduced effectiveness which may lead to feelings of failure or hopelessness (Bakker, 2007; Haski-Leventhal & Bargal, 2008; Ross et al., 1999; Stamm, 2009). Burnout has been found to be a key issue among caregivers in HIV/AIDS work (Bakker, 2007; Crook et al., 2006; Primo, 2007; Ross et al., 1999), especially as it contributes to attrition rates among aid workers (Ross et al., 1999). Burnout could also have a negative effect on aid workers' performance as too high levels of distress are thought to have a negative impact on functioning (Folkman et al., 1996; Mallinson, 1999b). Thus, if aid workers are to be able to continue providing care effectively, the emotional distress needs to be contained.

Finally, working with infectious diseases, there is naturally the concern that oneself might become infected. This makes working with HIV/AIDS and TB a hazardous activity, and this notion can be an added source of stress for carers (Akintola, 2004; Dieleman et al., 2007; Primo, 2007; Reynolds & Alonzo, 1998). Due to their work with these diseases aid workers can sometimes further be perceived as a threat to others' health, which can lead to aid workers, too, becoming victims of some of the stigma surrounding these diseases (Bakker, 2007; Primo, 2007).

2.2. Other Issues associated with HIV/AIDS Care

There are many issues that HIV/AIDS aid workers encounter in relation to their work and experiences of bereavement, and which give rise to the stresses

mentioned above. It is not possible to cover them all here (and not all of them are within the scope of this thesis) but this chapter will address three issues that are believed to be highly relevant to the objective of this thesis: loss and grief, multiple losses, and training.

2.2.1. Loss and Grief

For HIV/AIDS aid workers in South Africa, death is a considerable part of their milieu (Bakker, 2007) and it has been found that the psychological distress that HIV/AIDS carers suffer can be vastly attributed to the experience of witnessing death and the subsequent loss and grief (Akintola, 2004; Primo, 2007; Robson et al., 2006; Ross et al., 1999). Grief per se is considered a common element of the bereavement process and a transient reaction that varies in extent and duration across individuals (Bonanno et al., 2005; Mallinson, 1999b); pathologic responses in bereaved individuals are generally rare and experienced only by a minority (Bonanno, 2004). Bereavement as a result of AIDS, however, is believed to be related to various forms of psychological distress (Higginson, 2012; Martin & Dean, 1993). The frequent exposure to death and experience of grief can lead to emotional overload for volunteers (Ross et al., 1999); for example, bereaved individuals who lost an HIV+ partner have been found to be at risk for MDD (Folkman et al., 1996). Even before the death caregivers have been found to suffer from depressive mood (Bonanno et al., 2005) and this has been suggested to be a response to the psychological distress of anticipating various losses that are to come (such as loss of intimacy or a shared future) when having to live without the person in the future (Folkman et al., 1996; Mallinson, 1999b). These losses are not merely relevant to romantic relationships but have been found in other caregiving relationships as well (Reynolds & Alonzo, 1998). Pre-bereavement stressors are thus thought to influence post-bereavement stress reactions (Folkman et al., 1996) and stress experienced at the same time of the death can result in chronic grief (Mallinson, 1999b).

There are, however, also findings of some bereaved caregivers recovering quickly after the death of a loved one and this has been attributed to the suggestion that bereavement due to terminal diseases does not only entail feelings of loss for the caregiver but also feelings of relief; caring for an individual with such an illness, and thus observing their slow but ongoing worsening, is a very stressful experience (Mullan, 1992; Peabody, 1986). Furthermore, the gradual nature of the disease allows caregivers to be more prepared for the expected loss (Bonanno et al., 2005; Mullan, 1992). Some, however, do not feel ready for the death regardless, and continue to suffer long after the caregiving has ended (Reynolds & Alonzo, 1998; Siegl & Morse, 1994).

Another issue contributing to the lack of support for aid workers in the aftermath of loss and grief is lack of resources (Akintola, 2004; Primo, 2007; Siegl & Morse, 1994). Aid organisations often struggle with the issue of limited resources and as such they can only focus on problems deemed as more crucial. Unfortunately, the loss and grief experiences of their staff and volunteers do not often fall into this category so organisations are unable to address these issues (Bakker, 2007; Primo, 2007). This problem becomes even more profound when aid organisations are based in poor countries where conditions are even worse; caring for individuals with HIV/AIDS and TB may thus be more difficult, practically as well as emotionally, in developing countries than in a Western setting (Bakker, 2007).

A final note to make, of relevance to this thesis, is the debate on whether trauma and depression are the same or different concepts. Traumatic stress reactions and depression (and general anxiety) have many symptoms in common and, as stated previously, many of those who develop PTSD also develop MDD (Blanchard, Buckley, Hickling, & Taylor, 1998; Brune et al., 2002; Kessler et al., 1995). Post-traumatic responses also tend to be very similar to bereavement responses (Bonanno, 2004). Using structural equation modelling, Blanchard and colleagues (1998) managed, however, to show that PTSD and MDD are two distinct, albeit

correlated, responses to traumatic events. Others have found that perceived severity of a trauma predicted PTSD but not depression or anxiety (Başoğlu, Paker, Özmen, Taşdemir, & Şahin, 1994), or that cumulative trauma was more associated with PTSD symptoms than depressive symptoms (Allden et al., 1996). Thus it seems justified to investigate the effects of bereavement due to HIV/AIDS and TB in terms of traumatic stress.

2.2.2. Multiple Losses

In trauma research there is the question of whether the effects of trauma are dichotomous or continuous; that is, is there a threshold above which an experience simply is traumatic and below which it is considered as not traumatic, or is there a more linear relationship where the trauma response increases as the trauma increases (Zeiss & Dickman, 1989)? The issue of multiple losses makes relevant the concept of a dose-effect relationship between trauma and its effects: the more trauma one experiences the more traumatised one will be (Foa, Zinbarg, & Rothbaum, 1992; Mollica, McInnes, Poole, & Tor, 1998). This can be influenced by trauma characteristic such as duration (Iversen et al., 2008), intensity, and recurrence (Brune et al., 2002; van der Kolk et al., 1989). Furthermore, repetitive exposure to traumatic events is thought to result in increased numbing as a response to the traumas, and it has been found that individuals who have experienced repeated traumas (such as incest) exhibit more numbing symptoms (refer back to the PTSD symptom categories mentioned in Chapter 1) than individuals who have experienced single traumas (Foa et al., 1992). Emotional numbness has also been found among individuals who have experienced multiple AIDS-losses, and these individuals explicitly perceived the numbness as adverse (Mallinson, 1999a). The war trauma literature consistently show that cumulative trauma is associated with more PTSD symptoms (Allden et al., 1996; Johnson & Thompson, 2008; Mollica, McInnes, Pham, et al., 1998; Mollica, McInnes, Poole, et al., 1998), although the effect of cumulative trauma on symptoms seems to be

different for the different PTSD symptom categories – avoidance, intrusion, hyperarousal, and numbing (Allden et al., 1996; Mollica, McInnes, Pham, et al., 1998; Mollica, McInnes, Poole, et al., 1998). Based on these findings, one could then confidently suspect that multiple losses would cause aid workers to experience more traumatic stress. On the other hand, there are also studies that have found that once the trauma ‘threshold’ was reached, no added effects were found for increased duration or frequency (Başoğlu & Paker, 1995).

From the early HIV/AIDS-pandemic studies among gay men, multiple losses has been found to be one factor explaining why different individuals adjust differently to the loss of a partner (Folkman et al., 1996; Martin & Dean, 1993). Multiple losses has also been identified as a factor that causes aid workers stress (Akintola, 2004), impedes HIV/AIDS health professionals’ grieving process (Demmer, 2006), and leaves individuals with feelings of hopelessness, sadness, anger, fear, and emptiness or loneliness (Akintola, 2004; Mallinson, 1999a). Multiple traumas can increase the risk of PTSD (Saigh, 1988), and work pressures have been found to aggravate PTSD (Boehnlein, Kinzie, Ben, & Fleck, 1985); therefore, it is justified to suspect that aid workers may experience more traumatic stress as they are forced to not only continue working but in their work more death is also likely to occur. Aid workers in this situation face anticipatory grief in addition to unresolved grief (Maasen, 1998), and findings from the war trauma research suggest that anticipation of further trauma can cause more distress (Saigh, 1988). The pressure to continue working may, then, not allow aid workers the time and resources needed to grieve a loss properly, especially if new losses constantly arise, and this then differentiates the experience of a single loss from multiple losses (Maasen, 1998; Mallinson, 1999b). Moreover, preceding traumas (previous deaths in aid workers’ case) can heighten the effects of newer traumas, and, likewise, new traumas can in turn maintain the effects of preceding trauma (Mollica, McInnes, Poole, et al., 1998). Conclusively, the experience of continuous, unresolved deaths and grieving may induce chronic grief which overloads individuals and results in the use of adverse coping strategies and health (Mallinson, 1999b). Perhaps the

words of Garfield and colleagues best describe it: 'fulltime caregivers live and breathe a form of chronic trauma' (Garfield, Spring, & Ober, 1995, p. 261).

On the other hand, one may argue that by coping with multiple traumas one learns to better deal with subsequent events and consequently one will be less traumatised by repeated traumas (Janoff-Bulman, 2004). As death, in HIV/AIDS situations, is everywhere, individuals having to deal with this disease can become more accustomed to and thus habituated to multiple AIDS-losses (Mallinson, 1999a; Martin & Dean, 1993). There are also studies from the war trauma literature that contradict previous dose-effect findings and suggest that repeated trauma may protect against traumatic stress (Başoğlu & Paker, 1995; Başoğlu et al., 1994). Based on these findings, then, one would suspect that repeated exposure to loss and grief would habituate aid workers and thus result in less traumatic stress. Unpublished work has found that longer time in a profession that exposes one to traumatic stress is associated with less burnout and compassion fatigue (Stamm, 2009). This was, however, attributed to less resilient individuals leaving such professions early on and thus the ones remaining for longer periods are those that were more resilient (Stamm, 2009).

Finally, it may be that the dose-effect relationship looks different depending on whether one is exposed repeatedly to one single type of trauma, compared to when one is exposed to a number of different types of traumas. War trauma studies do not always explicitly state their definition of 'cumulative trauma' and thus it is not always clear what exactly it is that they are investigating (Mollica, McInnes, Pham, et al., 1998). The relationship between multiple losses and traumatic stress for aid workers thus requires further investigation.

2.2.3. Training

Not feeling adequately prepared for tasks that one has to undertake has been found to be a predictor of PTSD for military personnel (Iversen et al., 2008).

Likewise, lack of training is considered to be one of the sources of stress for aid workers and other health professionals (Armstrong, 2000; Bakker, 2007; Dieleman et al., 2007; Guinan, McCallum, Painter, Dykes, & Gold, 1991; Primo, 2007), whereas appropriate training before taking on new duties is thought to help individuals manage better (Dieleman et al., 2007). Moreover, lack of training can lead to role ambiguity for volunteers (Ross et al., 1999), impede how effectively they can carry out their role (Crook et al., 2006), or lead to burnout (Bennett, Ross, & Sunderland, 1996), all of which can be stressful on their own. These issues can partly be addressed with training (Haski-Leventhal & Bargal, 2008).

As aid organisations face so much work they cannot always afford to be picky in their selection of aid workers and so may need to make use of any person who offers their services (Bakker, 2007). Once affiliated with the organisation, volunteers do not always receive necessary training but training is typically in the form of 'learning by doing' (Haski-Leventhal, 2009; Haski-Leventhal & Bargal, 2008). More formal organisations are believed to have more trained staff or volunteers (Bakker, 2007). There are many reasons for the lack of training: lack of knowledge about how to provide this training, lack of resources, or difficulties in requesting volunteers to give up more of their time than they already do in order to be trained (Haski-Leventhal, 2009). Arguably, organisations with no systematic volunteer intake might find it difficult to provide formal training because volunteers arrive and leave constantly and thus there may not be any one right moment to run a training programme. High turnover in volunteers also imposes a burden on organisations' resources, as training volunteers is an investment that will be lost whenever volunteers leave (Bakker, 2007). Volunteers, however, generally want and appreciate training provided by their organisations (Crook et al., 2006; Stewart & Weinstein, 1997) and training has been found to increase volunteer satisfaction (Haski-Leventhal, Ronel, York, & Ben-David, 2008). As it stands, many aid workers feel that the training available is insufficient (Bakker, 2007), not least with regard to issues of death (Demmer, 2006). Many have come to see the importance and usefulness of training for HIV/AIDS aid workers: when these individuals are

professional and knowledgeable about HIV then this can contribute to them carrying out a good job and consequently contribute to the health system in crucial ways. When faced with a lack of formal training, new volunteers often turn to a trial and error system (Haski-Leventhal & Bargal, 2008); however, in a context of HIV/AIDS, strict medication programmes, and life or death, a trial and error system may not be the most suitable method for optimising one's work. Furthermore, a combination of lack of training and multiple losses can contribute to further stress for volunteers in perhaps unexpected ways. Frequent deaths sometimes lead to community members questioning volunteers' competence, and this adds to stress for volunteers on top of their own grieving (Akintola, 2004; Primo, 2007).

Arguably, the better trained one is in a certain area of work, the better one can predict what to expect. If one knows what to expect, one can then be better prepared, which in turn may give a sense of being more in control (Iversen et al., 2008). A prominent notion in the trauma literature is that traumatic events that are unpredictable and uncontrollable result in greater distress and traumatic stress reactions (Başoğlu et al., 1994). Factors such as novelty, previous beliefs and expectations, and how rapidly events unfold can influence preparedness for the event (Başoğlu et al., 1997; van der Kolk et al., 1989). Control would involve taking actions to prevent or improve the anticipated negative outcome (Başoğlu et al., 1997; Ehlers, Maercker, & Boos, 2000; Foa et al., 1992). Research does in fact show that lack of training can be a source of naïve expectations which leave volunteers less prepared (Haski-Leventhal & Bargal, 2008), and that a lack of predictability and controllability contribute to the development and maintenance of anxiety (Başoğlu & Paker, 1995). As such, considerable experience with adverse uncontrollable and unpredictable stimuli can result in generalised fear (Foa et al., 1992). Diaz and Kelly (1991) recommended early on in the HIV/AIDS pandemic that social work students need to be prepared to deal with AIDS-deaths and other issues surrounding this disease and that incorporating training on the topic of HIV/AIDS into the curricula can help students become more prepared. Preparation for adverse events is thought to reduce potentially subsequent psychological distress (Demmer, 2006; Iversen et

al., 2008; Johnson & Thompson, 2008; van der Kolk et al., 1989). In a famous study by Başoğlu and colleagues (1997), political activists subjected to torture perceived the trauma less distressing and suffered less psychological sequelae than a control group consisting of torture victims who were not political activists. It was thought that the political activists' psychological preparedness for torture had 'protected' them and lessened the effects of the trauma. Similarly, psychological preparedness in aid workers may work to 'protect' them against the traumatic effects of bereavement due to HIV/AIDS and TB.

Foa and colleagues (1992) pointed out that an event that is predictable is not automatically controllable. An event with a predictable course, however, may allow individuals to take certain actions, perhaps to alter the course, and these actions then may give individuals a sense of control (Foa et al., 1992). Likewise, for aid workers, being familiar with the course of a terminal disease (predictable event) does not necessarily allow them to control the disease (prevent death), but contemporary medication may allow them to alter the intensity of the disease, by decelerating its degenerative effect. Being unable to control the disease can lead aid workers to feel frustrated, powerless, angry, and depressed and leave them in despair (Primo, 2007). A sense that one can control at least some aspect of the disease, such as speed or symptoms, may reduce the psychological anguish for aid workers in HIV/AIDS work. Passengers in motor vehicle accidents, for example, have been found to display more psychological problems after the accident than drivers, arguably due to passengers' lesser sense of control during the accident (de Jongh, Holmshaw, Carswell, & van Wijk, 2011); and military personnel of lower rank more often suffer from PTSD (Iversen et al., 2008) possibly due to the same reasoning: lower rank military personnel perceive less control than their superordinates. If the desired effect of medication was to fail, however, then this could potentially cause aid workers distress as well: knowing that an individual is healthy now but runs a high risk of becoming critically ill later can be a source of anxiety (Primo, 2007; Ross & Seeger, 1988). Losing control that one once had is thought to be more taxing than not having control at all (Hanson, Larson, &

Snowdon, 1976). Traumatic events are thus thought to be stressful because they breach an individual's sense of control (Park & Folkman, 1997).

Perceived control in stressful situations can, however, also have negative outcomes; an individual who attributes a negative event, which they perceived they had control over, to their own actions may experience guilt (Joseph, Brewin, Yule, & Williams, 1991). Work done by Joseph and colleagues (e.g., Joseph et al., 1991) showed that passengers who attributed the negative events during the sinking of a ship internally (to themselves) had worse PTSD. There are a number of factors that can generate guilty feelings, such as guilt over the specific actions one took, or even lack of action (Joseph et al., 1991). Thus, aid workers who perceive their care of a terminally ill individual as insufficient may then experience more psychological distress upon bereavement. If this insufficient care, however, is perceived as out of their own control and attributable to another source (for example, to management), then this could potentially lessen the guilty feelings. Military personnel who could attribute negative events as a consequence of superordinates' actions, and thus out of their own control, had less long-term psychological problems (Mikulincer, Solomon, & Benbenishty, 1988).

Training could then potentially help to reduce the psychological distress of bereavement for aid workers, by ensuring that they feel prepared and competent in their area of work. It must, however, be noted that it has been suggested that caring for individuals with these infectious diseases is challenging regardless of any training individuals may have (Akintola, 2004), and that training is not the sole factor in high quality care (Bakker, 2007).

2.3. Coping and Resilience

In contrast to the factors above, which could potentially make HIV/AIDS caregiving more stressful, this section will highlight a number of factors that could

promote aid workers' coping and resilience and thus make the bereavement experience less traumatic. Not all individuals perceive the same event the same way with the same consequences; for example, not everyone who has experienced a traumatic event will develop PTSD (Foa et al., 1992; Ozer, Best, Lipsey, & Weiss, 2003), and not every bereaved individual will display elevated anxiety (Folkman et al., 1996). From the war trauma literature we can see that not all traumatised individuals develop mental health difficulties (Saigh, 1988; Steel, Silove, Phan, & Bauman, 2002). A traumatic stress response may be altered by the use of coping processes, or some individuals may simply be resilient to the effects of some traumatic events.

Coping involves thoughts and actions aimed at addressing an event perceived as stressful in order to reduce the anxiety it produces (Folkman & Lazarus, 1988). By altering the negative emotions, coping processes are thought to have a positive effect on an individual's mental health (Folkman & Lazarus, 1988). An individual will evaluate and re-evaluate a situation to assess how challenging it is, and coping efforts will change accordingly (Folkman & Lazarus, 1988). Sometimes people turn to 'vigilant coping' and attend to the demand in an attempt to find a solution, whereas other times people turn to 'avoidant coping' which involves avoiding the demand (Folkman & Lazarus, 1988, p. 311). Moreover, where vigilant coping is used, individuals can use emotion-focused coping or problem-focused coping. Emotion-focused coping aims to change the distressful emotions produced by the demand, whereas problem-focused coping aims to change the situation per se (Folkman & Lazarus, 1988). As no cure is yet available for HIV/AIDS, one may suspect that aid workers in such work may make more use of emotion-focused coping processes.

In terms of resilience to traumatic experiences, Bonanno (2004) argues that resilience is distinct from recovery. Whereas those who recover have at least at some point experienced some pathological symptoms before returning to usual functioning, resilient individuals continue to function as usual (Bonanno, 2004). As

such, resilient individuals and those who recover may not be making use of the same type of coping processes (Bonanno, 2004). Although many perceive the absence of strong grief reactions in bereaved individuals as abnormal, Bonanno (2004) argues that resilient individuals make up the majority, and studies have shown that there is nothing pathological about these individuals or their pre-bereavement relationships or adjustment (Bonanno et al., 2002). The pre-bereavement quality of a relationship is not thought to influence post-bereavement reactions (Folkman et al., 1996).

Several factors contribute to why some people experience a specific event as stressful when others do not. This section will discuss two factors that may contribute to aid workers' coping and resilience in the face of trauma such as bereavement due to HIV/AIDS and TB: social support and belief systems.

2.3.1. Social Support

Social support has been found to be an essential coping strategy for bereaved individuals (Folkman et al., 1996; Martin & Dean, 1993); likewise, being able to talk to others about one's feelings and experiences has been shown to be valuable for aid workers (Armstrong, 2000; Dieleman et al., 2007; Guinan et al., 1991; Primo, 2007; Stewart & Weinstein, 1997). It can also be seen as a means of preventing potentially overwhelming negative experiences and feelings from getting in the way of carrying out one's work, and of reducing risk of burnout (Primo, 2007; Ross & Seeger, 1988). Joseph and colleagues (1991) suggest that social support may be useful because it helps an individual to find other, external sources to which they can attribute negative events (rather than attributing them internally) and thus reduce feelings of guilt. Also in the war trauma literature has social support been found to be a prominent coping resource and protective against mental health difficulties, for refugees (Allden et al., 1996; Drozdek, 1997; Gorst-Unsworth & Goldenberg, 1998; Scholte et al., 2004; Schweitzer, Greenslade, & Kagee, 2007) and political activists

(Başoğlu & Paker, 1995; Başoğlu et al., 1994), as well as military personnel (Iversen et al., 2008).

Social support can involve networks such as family, friends, or co-workers. For HIV/AIDS carers, organisational support has been found to be important, both in terms of support from peers but also from management (Dieleman et al., 2007; Maslanka, 1996). Management, however, is not always able to provide the necessary support (Dieleman et al., 2007), often due to the aforementioned lack of resources. Inadequate management support can impede HIV/AIDS carers' coping with their work (Dieleman et al., 2007).

2.3.2. Belief Systems

Belief systems – beliefs about the world and oneself, and one's values – are thought to be an important factor explaining the variability in why some individuals develop PTSD while others do not (Başoğlu et al., 1997). For example, a belief system, such as a system of political or religious beliefs, that played an important role in an individual's life was found to predict more successful therapy outcome in refugees (Brune et al., 2002). Values are thought to be highly influential on people's motivations, goals, and behaviour, and on how important these are in an individual's life, that is, how committed an individual is to certain causes (Crook et al., 2006; Park & Folkman, 1997).

Meaning-making. Belief systems could potentially be protective in the face of trauma by providing individuals with a framework for meaning-making. Not being able to find a meaning for one's traumatic experience is thought to be an important factor in PTSD (Başoğlu et al., 1994). A belief system that enables meaning-making can thus function as a coping mechanism. Park and Folkman (1997) distinguish between two kinds of meaning: global meaning and situational meaning. The former refers to a more lasting and stable belief system and its incorporated values and assumptions. The latter refers to an individual's interpretation of a specific

event, usually in light of their global meaning. Global meaning and situational meaning both contribute to our understanding of the world and its events. In general, people tend to think of the world as a meaningful and just place, that is, people deserve what they get and there is a meaningful explanation for all events (Lerner & Miller, 1978; Park & Folkman, 1997). Some argue that it is new events and information ('reality') which challenge one's belief systems (representation of 'reality') that cause psychiatric disorders such as PTSD (Decker, 1993; van der Kolk et al., 1989). Sometimes belief systems are changed to fit this new information (accommodation), whereas other times new information is changed to fit existing belief systems (assimilation) in an attempt to make some meaning (McCann, 1990; Resick & Schnicke, 1990). Meaning-making thus involves addressing this incongruence and this process is thought to have an influence on individuals' psychological well-being (Park & Folkman, 1997). During the process, individuals may experience intrusive thoughts that may cause distress (Park & Folkman, 1997), but successful change provides individuals with resources to cope (Janoff-Bulman, 2004). For example, among a group of women who had miscarried, those who could explain their miscarriage were found to display less distress compared to those who lacked such explanation (Park & Folkman, 1997). In this thesis, I will refer to this process of meaning-making in order to address incongruence between existing belief systems and new information as 'reappraising meaning'.

For aid workers, a search for situational meaning may be less relevant. As they have themselves chosen to work with individuals who are terminally ill with AIDS, possibly due to their values and broader belief systems, it may not be relevant for them to try to find a meaning, or reason, for the subsequent bereavement they experience. The lessened need to search for situational meaning may then make their experiences less traumatic. Previous AIDS research has, however, found signs of meaning-making: for example, in order to deal with an experience of AIDS-related bereavement, individuals were found to focus on positive aspects of their experience, such as portraying it as a learning opportunity (Demmer, 2007); finding positive meaning in caregiving predicted, in bereaved gay

men who had cared for their ill partners, a faster recovery from depressive mood upon their partner's death (Folkman et al., 1996); and, the meaning of caregiving, not the burden, was found to explain variances in depressive mood (Folkman et al., 1996). Even when the disease was far progressed and caregiving became difficult, individuals still managed to find positive meaning in their caregiving, suggesting that perhaps their actions were deeply rooted in and driven by their values and broader belief systems (Folkman et al., 1996). On the other hand, aid workers may instead struggle more with global causal attributions, trying to understand why seemingly innocent individuals have to die from AIDS.

Research shows that when meaning-making is predominantly negative or self-centred it can be psychologically harmful, but a more neutral search for meaning can in fact lead to post-traumatic growth (PTG) (Calhoun, Cann, Tedeschi, & McMillan, 2000; Schweitzer et al., 2007; also see Park & Folkman, 1997, for more examples), that is, a positive outcome evolving from the trauma (Calhoun et al., 2000). By coping with their experiences, survivors of trauma often discover new resources and find themselves stronger after such an event (Janoff-Bulman, 2004). This has previously been found among HIV/AIDS family and partner caregivers (Reynolds & Alonzo, 1998; Robson et al., 2006), and so one may suspect a similar response in HIV/AIDS aid workers. Caring for stigmatised individuals and feeling like one is helping or making a difference, especially during an individual's final weeks, has been found to be a source of satisfaction among those working with HIV/AIDS patients (Crook et al., 2006; Demmer, 2006; Folkman et al., 1996; Ross & Seeger, 1988). It remains to see whether this source of satisfaction also has any protective value against the traumatic effects of bereavement as a result of HIV/AIDS.

Religion and spirituality. One belief system with great potential to become a framework for meaning-making is a religious or spiritual belief system. Whereas spirituality tends to refer to more intrinsic beliefs and meaning-making, religiosity more often tends to refer to extrinsic religious behaviour that is rooted in a

particular religion (Falsetti, Resick, & Davis, 2003; Williams & Sternthal, 2007). Although religion sometimes can have negative effects, such as guilt or prejudice, religion utilised as a positive means of coping has often been found to have a positive effect on psychological well-being (Falsetti et al., 2003; Williams & Sternthal, 2007), perhaps by being a source of hope (Mallinson, 1999a). In a study conducted by Falsetti and colleagues (2003), just over half the sample claimed they used religious beliefs to help them cope with their traumas. Religious beliefs have also been found to be a coping strategy for health workers in the field of HIV/AIDS (Demmer, 2006; Dieleman et al., 2007), and some aspects of religious beliefs may be related to PTG (Calhoun, et al., 2000). War trauma research has also often found that religion and spirituality, along with social support, function as coping strategies or sources of emotional support, sometimes because that is the only source of support individuals are able to make use of (Allden et al., 1996; Scholte et al., 2004; Schweitzer et al., 2007). Perhaps having a belief system where all events are attributed to, for example, God's will provides individuals with more meaning and thus more control and less anxiety and therefore better psychological functioning (Schweitzer et al., 2007; Wortman, 1983). As discussed earlier in this chapter, individuals fare better psychologically when negative events are attributed to an external source, rather than internally to one's own shortcomings; religion can function as such an external source (Johnson & Thompson, 2008).

Survivors of trauma also sometimes change in their religiosity after their experiences, either by becoming religious, or becoming more or less religious (Falsetti et al., 2003; Gorst-Unsworth & Goldenberg, 1998). After a traumatic event individuals often emerge with closer relationships, not only to other people but sometimes also to God (Janoff-Bulman, 2004). A traumatic event, however, may also cause people to start questioning the purpose of God's will and thus challenge their religiosity or spirituality (Mallinson, 1999b). Traumatic events, then, have the potential to profoundly change individuals' belief systems, although Falsetti and colleagues (2003) argue that it is not the trauma per se that causes the change in beliefs but, in their sample, it was rather the PTSD that was the main cause of the

change. It remains to be investigated what role religion and spirituality plays, if any, in terms of coping with and resilience to the potentially negative effects of bereavement for HIV/AIDS and TB aid workers.

Trauma in the context of culture: motivations and goals in volunteerism.

Many argue that the subjective appraisal of an event – a person's subjective perception of how distressing the event is – is more powerful in predicting the response to the event than objective notions of what may constitute a traumatic experience (Başoğlu et al., 1994; Foa et al., 1992; Iversen et al., 2008; Park & Folkman, 1997; Primo, 2007; Terry, 1994; van der Kolk et al., 1989). For example, how severe individuals perceived their experience of torture to be has been found to be predictive of their long-term PTSD symptoms, whereas the frequency of the torture did not significantly predict PTSD (Başoğlu & Paker, 1995). For HIV/AIDS caregivers, it is not necessarily the caregiving that makes their work stressful, it is how they perceive the caregiving (Primo, 2007). Thus, an event is only traumatic if it is subjectively perceived as traumatic by the individual experiencing it. As stated above, an event that contravenes an individual's values and goals may be perceived as subjectively traumatising (Park & Folkman, 1997). It is, thus, arguably, an individual's belief systems that determine what is and is not traumatic to them.

Despite the consensus that subjective appraisals of an event are more useful for determining the traumatic nature of the event, Bracken and colleagues (1995) note that researchers have largely assumed the opposite: that some events are objectively considered traumatic and that these are assumed to be traumatic for anyone in any culture or context. Furthermore, these objective notions of what constitutes a trauma are mainly based on Western ideas. The authors, however, argue that it is social, political, or cultural contexts that determine the subjective meaning of a supposedly traumatic event, as well as how the distress related to this event is experienced and recounted. In their own research from Uganda, for example, they found that even though symptoms of PTSD were identified in various reports, these were not the focus of an individual's account of their

suffering. Therefore, they argue, even though various symptoms or signs can be found across different cultures, it is not an assurance that they necessarily mean the same things in every culture. Responses to torture, for example, may be influenced by cultural differences in what constitutes a traumatic event (Başoğlu & Paker, 1995).

Different organisations most likely have different cultures, and aid organisations in particular are thought to have cultures based on strong values (Haski-Leventhal & Bargal, 2008; Stewart & Weinstein, 1997). Individuals become accustomed to an organisation's values, norms, and attitudes through organisational socialisation (Haski-Leventhal, 2009). This socialisation process is arguably a necessary condition for newcomers to become part of an organisation and to be able to operate successfully within that organisation as these cultures will be shaped in staff and volunteers and contribute to their developed commitment and help them make sense of, and cope with, their experiences (Haski-Leventhal & Bargal, 2008; Stewart & Weinstein, 1997). Also, staff and volunteers reciprocate this by contributing to the maintenance and development of the culture (Haski-Leventhal & Bargal, 2008). The possibly most comprehensive model describing the organisational socialisation of volunteers is offered by Haski-Leventhal and colleagues (Haski-Leventhal, 2009; Haski-Leventhal & Bargal, 2008) and describes the various stages and transitions, including New Volunteer, Emotional Involvement, and Established Volunteering stages, as well as Entrance, Accommodation, and Affiliation transitions. Transitions between the various stages are not merely due to time, but depend instead on events and experiences (Haski-Leventhal & Bargal, 2008). Consequently, volunteers can be seen to have a culture of their own and the interaction between the individual and the organisation thus contributes to develop an individual's belief systems (Falsetti et al., 2003). The following sections will discuss two characteristics of volunteerism – motivations and goals for volunteering – and argue for why this culture, and its associated belief systems, may protect volunteers from the traumatic effects of bereavement due to HIV/AIDS and TB.

With regard to volunteerism in the field of HIV/AIDS, the question of motivations becomes highly relevant; what causes individuals to choose this type of (unpaid) work knowing there are risks (Stamm, 2008)? Despite the general consent that caring for individuals with HIV/AIDS, and witnessing frequent subsequent deaths, can be a traumatic experience, it has also been found that grief per se does not predict burnout in such a group of caregivers (Nesbitt, Ross, Sunderland, & Shelp, 1996). One reason for this is, arguably, volunteers' motivations for volunteering (Nesbitt et al., 1996). These are often deeply rooted in their values, and volunteering and other goals allow an opportunity to express these values (Haski-Leventhal & Bargal, 2008; Park & Folkman, 1997; Stewart & Weinstein, 1997). As such, volunteering often plays a very important role in the lives of those who volunteer and giving up volunteering can be more difficult than giving up a paid job (Haski-Leventhal & Bargal, 2008). Individuals who stop volunteering for one organisation often still have a strong sense of community service and they may continue services with other organisations or in other ways (Haski-Leventhal & Bargal, 2008). Some of the most common motivations to volunteer are altruism and wanting to care for others, especially those in need (Akintola, 2004; Bakker, 2007; Dieleman et al., 2007; Haski-Leventhal & Bargal, 2008; Primo, 2007); religious beliefs and values (Crook et al., 2006; Primo, 2007); or relatedness, having had some kind of experience with the disease (Crook et al., 2006; Primo, 2007). In Mallinson's (1999a) sample of gay men it was the caregivers' values such as duty and compassion that made them *unable to not* care for an individual with AIDS. Some also start volunteering influenced by their social networks, such as family, friends, or spiritual communities (Haski-Leventhal & Bargal, 2008). There are naturally also more self-centred reasons such as self-enhancement, feeling good about one self, and networking (Crook et al., 2006; Haski-Leventhal & Bargal, 2008; Stewart & Weinstein, 1997). A distinction is also to be made between reasons why someone may start volunteering at first, and reasons why someone may continue volunteering (Haski-Leventhal & Bargal, 2008). Individuals' belief systems and values may also contribute to them having certain expectations when they join an

organisation, and if these expectations are not met then this can leave individuals with a sense of disappointment (Haski-Leventhal & Bargal, 2008). Volunteers who feel more effective in their work seem less inclined to leave an organisation (Primo, 2007).

Goals are thought to give individuals some purpose in life, and this purpose is thought to contribute to an individual's well-being (Park & Folkman, 1997). Trauma that causes changes in one's life and leaves goals unsustainable have been found to be predictive of PTSD (Ehlers et al., 2000). On the other hand, low prevalence of PTSD and depression have been found in tortured political activists (Başoğlu et al., 1997, 1994). Arguably, the activists' commitment to a political cause and their goals may have been acting as a protective factor against the torture and the trauma, which may have been perceived as a necessary 'price to pay' (Başoğlu et al., 1994, p. 361). The commitment, then, helps to make sense of their traumatic experiences (Allden et al., 1996; Başoğlu & Paker, 1995; Bracken et al., 1995). One could then argue that if HIV/AIDS volunteers' purpose is to provide end-of-life care to terminally ill individuals, then this caregiving purpose and identity makes them committed to their cause and consequently protects them from the potentially traumatic effects of the subsequent bereavement, by making sense of their trauma.

2.4. Summary of the Existing Literature

In summary, HIV/AIDS work is associated with various stresses – such as physical, economic, social, organisational, and psychological stresses – which could potentially lead to burnout among HIV/AIDS aid workers. Psychological stress, in particular, may arise from the frequent exposure to AIDS-related death in Sub-Saharan Africa, not least for members of aid organisations in such areas where lack of resources prevent the availability of sufficient support, especially in relation to bereavement.

With regard to frequent exposure to AIDS-related death, the research on trauma hitherto is unclear on the effects of multiple traumas. On one hand there is evidence to suggest that trauma is continuous and, therefore, more trauma experienced may result in more traumatic stress. On the other hand there is evidence to suggest that trauma is dichotomous with a threshold above which an experience is traumatic but below which it is not. Similarly, while research has demonstrated that multiple losses impede the bereavement grieving process and increase the likelihood of psychopathology, there is also research that suggests that multiple losses may be less traumatic due to habituation. Unpredictable and uncontrollable events are also associated with increased traumatic stress. Hence, training before undertaking any work is considered vital as training is believed to produce more accurate expectations which in turn may increase an individual's preparedness and, ultimately, their sense of control. Perceived control can, however, also be adverse: when individuals attribute negative events which they felt in control of internally, they may produce guilt. In such respect, social support may be valuable for reducing the guilt by helping an individual discover external sources to which the negative events can be attributed. In addition to social support, belief systems are considered important coping mechanisms as they allow individuals to find meaning in traumatic experiences. Events that challenge the perception of a just world where all events have a meaningful explanation are deemed more likely to cause traumatic stress; thus, finding positive meaning in difficult experiences can be protective. Religion and spirituality are examples of such belief systems. Finally, such belief systems can have a bearing on an individual's subjective appraisal of an event which in turn can influence their response to the event. As such, for HIV/AIDS aid workers, their motivations, goals, values, and commitment may act as protective factors in the face of the stresses associated with HIV/AIDS work.

2.5. Limitations of Previous Research

Despite the rich knowledge obtained through previous research, the existing literature also suffers some limitations, and I will discuss four of these below.

2.5.1. Lack of Research on Support for HIV/AIDS Aid Workers

Martin and Dean (1993) point to how there appeared to be a dose-effect relationship – the more losses, the more psychological distress – early in the HIV/AIDS pandemic but that this relationship seemed to diminish more and more after some years of the pandemic and individuals seemed to adapt better. It may be that the situation is similar for aid workers: after decades with the HIV/AIDS pandemic, expectations have changed and aid workers are now accustomed to the effects. This, however, could be a hazardous assumption to make as HIV/AIDS caregivers' needs, particularly with regard to bereavement, could lead to negative health outcomes if not identified and met (Akintola, 2004; Mallinson, 1999a, 1999b). It has been found that caregivers of HIV/AIDS and TB do not tend to tell of the difficulties they experience in their work (Akintola, 2004). Some (Akintola, 2004; Bakker, 2007; Primo, 2007) have noted how this lack of reporting is partly due to socio-cultural pressures and expectations, especially in the Zulu culture, where caregivers are perceived as the stronger party in the caregiving dyad. Aid workers then remain silent about their own difficulties and problems in an attempt not to seem incompetent or selfish (Akintola, 2004; Primo, 2007), similar to how parent caregivers prioritise their children's needs and overlook their own (Siegl & Morse, 1994). In a situation where there are many care recipients, aid workers' own needs to grieve may not be sufficiently addressed as they may feel they must continue looking after remaining patients as opposed to taking time to look after themselves. Excessive expectations on volunteers' roles, however, can lead to burnout and are further perceived by volunteers as challenging (Crook et al., 2006). Furthermore,

patients, too, will naturally benefit if their caregivers are physically and mentally well, rather than ill (Primo, 2007), and meeting the needs of aid workers may help aid organisations to prevent loss of their staff and volunteers (Crook et al., 2006).

Perhaps consequently, then, the care of aid workers is an area that has been largely overlooked in HIV/AIDS research, as well as in practice (Primo, 2007). This type of research has previously tended to focus primarily on the impact of these diseases on children, on gay men in the Western culture, or on the financial impact of the pandemic (Akintola, 2004). Research that has been carried out on HIV/AIDS caregivers have usually had a focus on Home-Based Care (HBC) (Akintola, 2004), which involves (mainly local) aid workers travelling to visit patients in their homes (mostly in rural areas) rather than living in and caring for patients in a care centre; or, even though death and dying would arise as important issues in these studies, the bereavement aspect of caregiving for individuals with HIV/AIDS was nonetheless not the focus (Akintola, 2004; Dieleman et al., 2007; Primo, 2007). Bakker (2007) points out how caring for caregivers is so apparent but nonetheless in need of more recognition and promotion. As a result, systematic support for HIV/AIDS aid workers is often lacking and there is thus a need for support programmes to be developed (Dieleman et al., 2007). As lack of support has been identified as one of the primary stress sources for aid workers (Primo, 2007), it is important to address this issue to prevent any potential shortcomings in the care of these caregivers. Studies investigating and better understanding the experiences of aid workers and their potentially unfulfilled needs are thus of outmost necessity, so negative outcomes can be prevented and resilience can be enhanced (Akintola, 2004; Demmer, 2006; Dieleman et al., 2007; Paton & Johnston, 2001; Primo, 2007). The required support systems thus need to be identified to ensure that the positive aspects of aid work compensate the drawbacks (Stamm, 2008).

2.5.2. Lack of Research on Young, Non-Professionals Engaging in HIV/AIDS Aid Work

Research on volunteerism has previously mainly focused on an adult population but it has been argued that the experiences of adult and youth volunteers differ and thus should not be treated as the same (Haski-Leventhal et al., 2008). Siegl and Morse (1994), in their study on parental experiences of HIV+ sons, argue that fathers have been overlooked in such studies and therefore the experiences of 'parents' do not necessarily take into account the experiences of fathers. Similarly, the majority of the small number of studies investigating HIV/AIDS caregiving focus on the experiences of qualified or otherwise professional or experienced health workers, often with some expertise (Demmer, 2006; Dieleman et al., 2007; Primo, 2007); as such, these studies do not necessarily include the experiences of young, mostly untrained, mostly international aid workers. Young volunteers' motivations for volunteering have been found to differ from adult volunteers' motivations (Haski-Leventhal et al., 2008); younger AIDS caregivers have been found to exhibit more burnout (Bellani et al., 1996); research on bereavement shows that bereavement early in life differs from bereavement later in life in terms of intensity of the grief reaction as well as adjustment (Bonanno, et al., 2005); age has been found to be an important factor in predicting negative outcomes with regard to volunteerism, with younger volunteers more vulnerable and more inclined to withdraw (Maslanka, 1996); and age has also been found to have various associations with trauma symptoms in survivors of war traumas (Başoğlu et al., 1997, 1994; Drozdek, 1997). Although it has been recommended that further research assessing HIV/AIDS health professionals' support is required (Demmer, 2006), it is also important that non-professionals, such as (often young) volunteers, are not neglected. Haski-Leventhal and colleagues (2008) have defined young volunteers as someone under the age of 19 years. Thus, the large number of youth who, at the age of 18 years, travel to countries such as South Africa for their 'gap year' to engage in aid work could qualify as such a 'young' person. These non-

trained individuals may be in even greater need of support to be able to cope with the experience of AIDS-related bereavement.

2.5.3. Lack of Research Conducted in an Appropriate African Setting

Culture has already been shown to be powerful in determining to what extent events are perceived as traumatic (Başoğlu & Paker, 1995). It has also been suggested that a less protected environment may expose its population to more stressors, and this increased exposure in turn renders some cultures more unaffected by traumatic stress than others (Başoğlu et al., 1994). There is thus reason to suspect that the experiences of local aid workers (from South Africa) may differ compared to the experiences of international (from outside of South Africa) aid workers, due to differences in HIV/AIDS prevalence across the globe. These differences may be further affected by another characteristic of the Zulu culture, wherein discussions of feelings and emotions is not customary (Demmer, 2006).

Additionally, much of the research focusing on HIV/AIDS caregiving has been carried out outside of an African setting (Crook et al., 2006; Hall, 2003; Ross et al., 1999; Ross & Seeger, 1988), whereas the AIDS pandemic is mainly taking its toll in South Africa. Bereavement due to HIV/AIDS in South Africa is nevertheless an under-researched area (Demmer, 2006), although scholars recommend trauma research to take into account cultural contexts (Johnson & Thompson, 2008; Stewart & Weinstein, 1997). It has been pointed out that interventions aimed at reducing stress have a greater chance to succeed if they take into account the social situation in which caregivers operate (Reynolds & Alonzo, 1998).

Finally, it has also been recommended that investigations of the meaning of traumatic experiences should be carried out in a natural setting, as opposed to laboratory studies (Park & Folkman, 1997). In order to better understand volunteer experiences, volunteers and their perspectives on the transformations and processes

they undergo need to be studied thoroughly within their natural settings and in context (Haski-Leventhal & Bargal, 2008; Naidu et al., 2012).

2.5.4. Lack of Research Utilising Appropriate Methodologies

Although research on HIV/AIDS caregiving seems to use a great deal of quantitative methods (Folkman et al., 1996; Martin & Dean, 1993; Ross et al., 1999; Ross & Seeger, 1988), there is also a substantial body of qualitative studies (see further below). To optimise the support for HIV/AIDS aid workers, it is useful to understand not only what type of support they may require (if any) but also perhaps why. Qualitative methods have been suggested to be useful for investigating the meaning of traumatic and post-traumatic experiences in cultures where such experiences have not previously been addressed (Johnson & Thompson, 2008), especially since quantitative measures often fail to adequately grasp individuals' experiences, particularly those involving meaning of phenomena (Park & Folkman, 1997; Stewart & Weinstein, 1997). Furthermore, it has been suggested that HIV/AIDS caregiving can affect an individual's identity (Reynolds & Alonzo, 1998). Some contend that identities and goals are closely linked in the sense that the aspirations that individuals construct for themselves represent their identities (Higgins, 1987; Park & Folkman, 1997) and identity has been found to be an important factor in HIV/AIDS work (Stewart & Weinstein, 1997). Previous qualitative studies in the area of HIV/AIDS have mainly employed variations of thematic analysis (Demmer, 2006; Mallinson, 1999a) or grounded theory (Crook et al., 2006; Reynolds & Alonzo, 1998; Siegl & Morse, 1994) approaches; however, research is required that utilises a methodology specifically suitable for the investigation of identities.

The Present Study

2.6. The Aims of the Study

In response to the limitations of previous research, as presented earlier, the present study has three aims:

The first, and principle, aim of this study is to investigate the potentially traumatic effects of AIDS-related bereavement on aid workers. The intention is to, first, conduct this research in a local setting in South Africa, and second, to take account of the experiences of a wide group of aid workers, including young volunteer aid workers, and not merely qualified professionals.

The second aim of this study is to investigate the resources that aid workers utilise in order to cope with the potentially traumatic effects of AIDS-related bereavement, as well as the demands of their work in general. It will be of particular interest to consider the role of training, age, social support, and various belief systems in aid workers' coping strategies, both in terms of preparation for their aid work experience as well as resources during the course of their work.

The third aim of this study is to investigate any differences in the experiences of local versus international aid workers.

In order to achieve these aims, this study will make use of discourse analysis (DA) – a methodology particularly suitable for the investigation of identities. The methodology employed for this research will be further discussed in the following chapter.

Chapter 3. Methodology

This methodology chapter will begin by describing the fieldwork carried out for collecting the data for this study; in particular, the participant observation ethnography will be explained. This will be followed by information regarding the research site and the individual participants. Thereafter, the interview procedures and materials will be described. The chapter will conclude with a discussion on the analytic technique, including the epistemological underpinnings of this study.

Ethical approval for this research was sought and obtained (ref #82-0910) from the Psychology Research Ethics Committee at The University of Edinburgh.

3.1. Fieldwork

In order to investigate aid workers in a most natural setting, this study made use of ethnographic methods as ethnographical approaches are considered useful for gaining a better understanding of people's experiences within their groups or cultures (Delamont, 2004; DeWalt & DeWalt, 2002; Emerson, Fretz, & Shaw, 2001). Another advantage of this study's ethnographic approach is that it is not a retrospective study; some (Johnson & Thompson, 2008) argue that retrospective data are sometimes unreliable in trauma research. Thus, to collect data for this study, fieldwork was carried out for 12 months in South Africa.

3.1.1. Participant Observation Ethnography

The fieldwork was conducted using a method of participant observation ethnography and ethnographic interviewing. Ethnographic work typically utilises

'unstructured data' in order to carry out an in-depth exploration of some social phenomenon (Atkinson & Hammersley, 1994). The aim of the participant observation was to try and understand the (social) world and culture of staff and volunteers at Cotlands from an inside perspective by engaging in the same routines and activities as them while simultaneously observing them in a systematic manner (Delamont, 2004; DeWalt & DeWalt, 2002; Emerson et al., 2001). Participant observation methods are further considered an advantage when analysing, or interpreting, ethnographic or other qualitative data (DeWalt & DeWalt, 2002). Ethnographic interviewing, as defined by Heyl (2001), are those whereby the interviewer has established an a priori relationship with the interviewee, which will allow the interviewee to explore and express their experiences and how they make sense of these.

Although there are differences in how much 'participation' is actually required when carrying out participant observation, or participant-as-observer, research (for example, compare Gold, 1958, to Delamont, 2004), the fieldwork conducted for the purposes of this study more closely followed the role as suggested by Junker (1952, as cited in Gold, 1958) where I lived and worked and fully participated in the same activities as other staff and volunteers while both myself and my colleagues knew my true identity. This is in contrast to, for example, complete participant (Gold, 1958) where only the researcher knows his or her true identity. There are, further, those who claim that investigations of any social world require participation in that world and thus all instances of social research qualify as participant observation research (Atkinson & Hammersley, 1994).

For this study, I undertook the role of an 'international volunteer' at Cotlands² (see Research Site below) for a period of 12 months. During this time I lived and socialised alongside other international volunteers in Cotlands House where two self-catering flats accommodate up to approximately six volunteers each (often divided between the two sexes). Likewise, I undertook work in the same

² <http://www.cotlands.org.za/>

manner as other international volunteers: assisting at Cotlands headquarters, Monday to Friday from 08h00 until 16h00. The main difference between myself and the other international volunteers in terms of the work we carried out was the areas where we worked: whereas other international volunteers mainly assisted with child care duties (for example, in Early Childhood Development [ECD] or the Hospice), I mainly carried out administrative work, the first four to five months in the Fund Development department and thereafter I spent the remainder of my fieldwork time in Human Resources (HR). International volunteers follow a weekly roster, made by the International Volunteer Co-ordinator, which assigns them to designated areas of work for two morning shifts and one afternoon shift, with lunch in-between. In my case, I typically carried out Cotlands work in the morning while afternoon slots were predominantly dedicated to 'research' time which I would, for example, utilise for conducting interviews.

3.1.2. Interviews as a Data Collection Technique

Interviews are generally considered a useful tool for thoroughly exploring individuals' experiences and their perceptions and evaluations of these (Kvale, 2008). An open-ended, or conversational, style allows interviewers to address topics of interest while at the same time providing the interviewee(s) with enough freedom to explore and reflect on a diverse number of issues, perhaps touching on subjects or introducing terminology not previously anticipated by researchers (Broom, 2005). As such, open-ended interviews as a method can be effective in exploratory research (Broom, 2005). The interview approach for this study was informed by an 'interpretive social research' concept (Broom, 2005; Rubin & Rubin, 2005): the investigation focuses on how participants make sense of an experience and how they adapt.

In recent years, however, there has been criticism put forward against the use of interviewing as a data collection technique. As an alternative, the use of

'naturalistic data' has been promoted in an attempt to remove the influence of an interviewer and capture naturally occurring interactions that are not generated by an active researcher (Edwards, 2005; Potter & Edwards, 2001; Wiggins & Potter, 2008). Mainly, the concern is how to treat and analyse data derived from interviews (Edwards, 2005). One type of criticism highlights what Potter and Hepburn call 'the possibility that a piece of interview research is chasing its own tail' (Potter & Hepburn, 2005, p. 13). A researcher that enters an interview with preconceived ideas and terminology, which they then hand over to the interviewee, runs the risk of receiving the same ideas and jargon back (Potter & Hepburn, 2005). Potter and Hepburn (2005) endorse naturalistic data partly because this method of data collection is thought to avoid participants' (forced) use of abstract concepts – what they refer to as POBAs (Perceptions, Opinions, Beliefs, Attitudes) – that stem from cognitivism. It must not be forgotten, however, that expressing POBAs have become a natural and substantial part of many people's language and are commonly used in their everyday interactions. Participants' usage of these concepts may therefore not necessarily be an artificial product of a research environment. Potter and Hepburn (2005), furthermore, claim that naturalistic data collection might introduce unanticipated and innovative research questions. Equally, some issues may forever remain undiscovered if merely using naturalistic data collection, if participants fail to introduce these without assistance from a probing researcher. Conclusively, then, interviewers need to be aware of and consider how the language, the response style, the categories, the questions they use, and even their mere presence might influence the interview and thus the answers they obtain (Antaki, Billig, Edwards, & Potter, 2003; Broom, 2005; Burck, 2005; Heyl, 2001; Potter & Hepburn, 2005; Taylor, 2001).

Second, interviewing as a method for collecting research data has been criticised for overlooking the interactional component of the technique (Broom, 2005; Potter & Hepburn, 2005). Human research subjects are not inanimate objects and social psychology research should not be treated as a physical science experiment where all conditions can be fully controlled. Thus, interviewers need to bear in mind the influence that their own presence and contribution to the

interaction has on the result, in addition to how their agenda might influence responses. It is further recommended that researchers are clear about these potential biases in their analyses and reports (Broom, 2005; Burck, 2005). As Kvale puts it 'the epistemological understanding of the interview varies from positivist conceptions of interviewing as a collection of facts to postmodern conception of interviewing as a social construction of knowledge' (Kvale, 2008, p. 22); this study treated interviews from the latter perspective. Therefore, rather than failing to recognise interviews as an interaction, this thesis took advantage of this concept. The interviews were seen as a venue to explore how aid workers construct their experiences and their 'realities', what features they make relevant, and how they go about doing all of this, when given an opportunity to interact with a 'researcher that researches psychological trauma'. The analysis (see Analytic Technique below) made use of a feature of conversation analysis (CA) that emphasises the interactional implication of each utterance's position in a sequence of turns: 'why this now?' (Edwards, 2005; McKinlay & McVittie, 2008; Tainio, 2003). Why did the interviewee make this particular utterance relevant at this very moment? An interview is arguably just another social interactional setting, albeit perhaps a peculiar one. As a final note, one must not forget that an interaction is a two-way (at minimum) street; the interviewer may influence the interviewee but one must not forget that the interviewee just as well influences the interviewer (Kvale, 2008).

3.2. Research Site

Initial recruitment was commenced by identifying seemingly relevant HIV/AIDS organisations in Sub-Saharan Africa, that is, organisations that stated publicly, for example on the internet, that they provide HIV/AIDS care. In the end, nine of these organisations were contacted via e-mail with a 'Request for participation in research project' letter (Appendix A). The letter outlined the aim of this study and asked for permission to allow me, the researcher, to volunteer at the

organisation and conduct research interviews with the organisation's staff and volunteers. A further four organisations were contacted to ask for assistance in identifying relevant organisations suitable for the purposes of this study. Of the nine organisations contacted, two were deemed unsuitable for the purposes of this study, two declined, and four did not respond. Recruitment stopped once an organisation deemed suitable for the purposes of this study accepted the request to participate in the study.

3.2.1. Cotlands

The fieldwork was carried out for a period of 12 months, between early October 2010 and late September 2011, at Cotlands headquarters in Johannesburg, Gauteng, South Africa. At the time, Cotlands was an NPO caring for vulnerable children in need, aged 0 to 12 years, in residential and community care, across six provinces in South Africa. The care provided by Cotlands is focused on three main areas: health, education, and psychosocial. (Towards the end of the fieldwork Cotlands underwent a major organisational change whereby the decision was made to close down the residential care centres and rather focus on outreach and community care. The possible implications of this change are further discussed in Chapter 8).

In Gauteng, children aged 0 to 6 years were accommodated in various units in the residential care centre based at Cotlands headquarters in south Johannesburg. The Hospice housed the youngest children as well as those with more critical health conditions. The Baby Unit housed the toddlers while the 'older' children were accommodated in the Girls and Boys Units. These three latter units were situated in an area referred to as The Sanctuary.

The headquarters further contained an ECD centre where the children received education up until Grade R (pre-school). Once children started formal schooling, they were transferred from the residential facilities based at the

headquarters to Cotlands House, a purpose-built building within walking distance of the headquarters. Cotlands House comprised of three flats: one on the ground floor and two flats on the first floor. The ground floor flat housed the school children (approximately five to eight of them) as well as one caregiver. The two first floor flats were reserved for Cotlands' international volunteers. Before the children reached the age of 12 years they were then transferred from Cotlands House to St Mary's Children's Home, another residential care centre in south Johannesburg with the capacity to care for teenagers.

In Gauteng, community care is delivered through the HBC programme which cares for vulnerable children in need, and their families, in areas such as Soweto. Here, too, the care is focused on health, education, and psychosocial programmes.

Finally, the Johannesburg headquarters also accommodate Cotlands' main administrative departments such as HR, Finance, and Fund Development, with their respective Managers. The Executive Director and National Managers for the health, education, and psychosocial programmes are also based there.

During this 12 month period, Cotlands had approximately 200 employees nationally, with roughly half of these based in Gauteng. Initially, only Gauteng (out of the six provinces) was able to accommodate international volunteers and there were a total of approximately 20 of them during the 12 month period of the fieldwork. Recently, Cotlands' Western Cape project has been receiving a small number of international volunteers as well. The projects in Gauteng and Western Cape also have a local volunteer base. The local volunteers support the daily work at Cotlands on a drop-in basis, assist with the monthly outings for the residential children, as well as 'hosting' them; that is, approved volunteers may take residential children for activities outside of Cotlands or to stay with them in their homes over weekends or holidays in order to experience a 'normal' home environment.

3.2.2. Recruitment of Individual Participants Within the Organisation

Staff members, international volunteers, and local volunteers from Cotlands in Gauteng were recruited for the interviews for this study. Potential participants were approached by myself and informed of the reason for my being based at Cotlands (to conduct research on AIDS-related bereavement). Individuals were further briefly informed of what participation would involve (completing a questionnaire and an interview), and asked if they would like to participate in the study. If accepted, an interview time suitable to both would be arranged.

In terms of staff members, a list of all Gauteng employees was obtained from HR. Factors that were taken into consideration when identifying potential participants out of all employees included which department the employee worked within and what position they held, length of service at Cotlands, and their competency of the English language since all interviews were conducted in English. No staff members approached regarding the study declined on basis other than not having relevant experience of AIDS-related bereavement. In general, international volunteers were approached if they were based at Cotlands for at least one month working with the children. Only two international volunteers declined to participate in the study. A handful of local volunteers were approached regarding the study. These were generally chosen, often in collaboration with the Local Volunteer Coordinator, because of their level of engagement or because of their length of service. No local volunteer declined; in most cases participation was not deemed appropriate as most volunteers had not experienced AIDS-related bereavement.

3.2.3. Fieldwork Participants

In total, 67 interviews were conducted with 64 participants. Three participants – international volunteers based at Cotlands for a one year period – were interviewed twice: once at the beginning of the study and once shortly before their departure after one year at Cotlands (on average eight and a half months after

the initial interview). One participant chose not to be audio-recorded. Hence, the analysis presented in this thesis is based on 66 interviews conducted with 63 participants across 13 Cotlands departments. The 63 participants (56 females and 7 males) ranged in age from 19 to 65 years ($M = 40$ years, $SD = 8.63$), had an average service length of 99 months (ranging from 1 to 347 months, $SD = 57$) at Cotlands, and were from 11 different backgrounds. The descriptive statistics can be found in Tables F.1 and F.2 in Appendix F.

3.3. Procedures and Materials

Interviews were generally carried out in offices at Cotlands headquarters. The interviews with the Home-Based Care Workers (HBCWs) were carried out at Cotlands Community Centre (CCC) in Soweto where the HBCWs meet. One volunteer was interviewed in their home.

In general, interviews were opened by asking participants to introduce themselves and their roles within the organisation; their reasons for being there; their *a priori* and any new knowledge gained about HIV/AIDS and TB; their experiences of working with individuals who are HIV+, or have AIDS and/or TB, as well as the most difficult aspects of this work; any training they may have received; their perceptions of any support they may be receiving from Cotlands in order to carry out their job; negative and positive experiences during their time at Cotlands; if there was anything they would like to change with regard to their experiences at Cotlands; as well as any advice or recommendations which they would give to others who would like to come and work with HIV+ individuals. (See Appendix D for the full interview schedule.) Interviews ended with participants being given time to reflect on the interview and how they felt about their participation. Although all participants were reassured they could approach me, as the researcher, at any time, they were nonetheless provided with a document outlining support

contacts (Appendix E) in case they required further support after participation and preferred to seek this support externally.

Interviews lasted an average of 36 minutes ($SD = 11.23$) with the shortest lasting only 11 minutes while the longest lasted 64 minutes. Efforts were made to keep interviews within the 60 minute limit in order to not tire participants too much. When calculating interview times, the posing of the first question was taken as the start point. In some cases, participants would start speaking freely before the first question had been posed, in which case this would denote the interview starting point when calculating the interview length. The end point of interviews was typically where I, as the researcher, thanked the participant for their time or, in cases where conversation followed past this point, where utterances of relevance to the topic ceased. Interview lengths, however, are not an appropriate indication of the quality or usability of the collected data simply because some individuals spoke fast or with few pauses whereas others spoke slowly or with frequent or lengthy pauses. Also, it was sometimes difficult to tell whether people did not speak much because they had nothing to tell or simply because they wanted the interview to end so they could leave the interview setting.

All interviews were recorded using an Olympus WS-550M, transcribed using Audacity 1.3 Beta, and stored as password-protected Microsoft Office OneNote 2007 files. Analysis was facilitated by the use of the qualitative data analysis software NVivo version 9.0.204.0 as well as the free mind-mapping software Freeplane version 1.0.45.

Prior to the interviews, participants who had previously experienced AIDS-related bereavement were asked to complete the IES-R (Impact of Event Scale - Revised; Weiss, 2007; see Appendix C). The IES-R is a measure of symptomatic response to a specific traumatic event. The original scale, the Impact of Event Scale (IES) (Horowitz, Wilner, & Alvarez, 1979), measures symptoms reflecting two components of a contemporary PTSD diagnosis: intrusion of thoughts and feelings, and avoidance of thoughts and images. As the IES was released before the current

DSM-IV-TR method of diagnosing PTSD, the scale did not assess the third component of PTSD which a DSM-IV-TR diagnosis considers: hyperarousal. The IES-R is thus an extension, with some changes, and assesses all three components of a DSM-IV-TR PTSD diagnosis: intrusion, avoidance, and hyperarousal. The scale is comprised of twenty-two items for which participants are asked to rate how distressful the symptom has been in the past seven days. Responses range from 'Not at all' (0), to 'A little bit' (1), 'Moderately' (2), 'Quite a bit' (3), and 'Extremely' (4). The intrusion and avoidance subscales each consist of eight items, and the hyperarousal subscale consists of six items. The mean of each subscale reflects the degree of distress (from 'Not At All' to 'Extremely') which that symptom has caused the respondent in the last seven days.

Forty-nine (out of the 63) participants completed the IES-R; those who did not were international volunteers who had not yet experienced AIDS-related bereavement. Participants generally completed the IES-R themselves after instructions; however, a few participants received help with completing the questionnaire. This was mainly due to participants' reduced eye sight but in a couple of cases the participants needed help with the IES-R due to language difficulties and reading difficulties, respectively. Furthermore, a couple of participants completed the IES-R after the interview as opposed to before the interview. This was a result of them not having experienced AIDS-related bereavement at Cotlands; however, as it was revealed during the interview that they had experienced AIDS-related bereavement elsewhere they were asked to complete the IES-R based on that event after the interview. Participants were always asked to complete the IES-R bearing in mind the most recent death of a child they worked with at Cotlands. This, however, was not applicable to everyone. Some could not remember the most recent death but they could clearly remember the death of a child they, for example, had close bonds with. For others, their (most recent) AIDS-related bereavement was not in relation to a child they worked with but rather a family member or a friend. Furthermore, the event (that is, the death) was not recorded as 'occurred X weeks ago', as is the norm when completing the IES-R, but

instead recorded as the year and month that it occurred. This was a result of the low incidents of AIDS-related deaths at Cotlands these days (this matter is further discussed in Chapter 4).

All participants were provided with a Participant Information Sheet (PIS) (Appendix B) which explained the purpose of the study and what participation would involve before commencing their participation. Participants were also given the opportunity to ask further questions to receive any outstanding information. Finally, a participant code was created for each participant and all were requested to sign a consent form.

3.3.1. Pilot Work

Pilot interviews were conducted with a number of individuals across Scotland to assess the suitability of the semi-structured interview format, as well as the procedures in general, prior to the commencement of the fieldwork in South Africa.

Participants. Pilot participants were three females: one 23-year-old Scottish former volunteer at a children's home in South Africa; one 60-year-old staff member of an HIV/AIDS service provider organisation in Scotland; and one 53-year-old bereavement counsellor at a hospice in Scotland.

Procedures and materials. Pilot interviews were conducted with the three participants in either their home or their offices. As the pilot procedures were deemed suitable, the same procedures were employed for the fieldwork; as such, the pilot procedures were the same as those described above. Regarding the order of the IES-R and the interview, for the first pilot participant the IES-R was completed prior to the interview. For the second participant, the interview was conducted prior to the IES-R to assess any probing effects of the IES-R. As no major differences were detected, the order was reversed to the original for the third participant: completion

of the IES-R followed by the interview. This order was then maintained for the fieldwork procedures, as stated above.

The pilot interviews lasted for approximately 60 minutes. As the pilot interviews confirmed the suitability of the interview schedule, the same questions were used for the fieldwork interviews with the exception of a few changes. First, the question 'Looking back now, do you think you were prepared enough' was removed for the fieldwork interviews as it was found to be too similar to 'When you first came here, did you feel prepared enough'. As participants seemed to be struggling with keeping the two questions, and their answers, distinct, the former question was deemed redundant and thus removed. Second, the decision was made to first ask about negative experiences and subsequently ask about positive questions in order to 'end on a high'. The order of the questions generally followed the order on the interview schedule. Sometimes, however, questions were re-ordered or even omitted. This was mainly because participants had already answered one question as part of their answer to another question; the question was not relevant to the participant (for example, whereas it was sometimes relevant to ask international volunteers which organisation they came with, this question would not be appropriate for a staff member); or there was a lack of time. Regardless, these were semi-structured open-ended interviews and thus were allowed to flow naturally as opposed to rigidly following a set pattern. Pilot participants were also given the opportunity to reflect and discuss the experience of their participation after the interview. The support contacts document given to pilot participants contained Scottish support contacts.

The first pilot interview was recorded using a Zoom H4n digital recorder. The subsequent interviews were recorded using an Olympus WS-550M. All interviews were transcribed using the free software Audacity version 1.3 Beta. The transcripts were stored as password-protected Microsoft Office OneNote 2007 files.

3.4. Analytic Technique

3.4.1. Epistemological Underpinnings

As noted in the previous chapter, this study will utilise discourse analysis as an innovative methodology to address its aims because DA will allow the examination of aid workers' identity constructions and how these constructions tie in with their experiences. DA can help to identify people's global meaning systems, through their discourses, and these belief systems can then be related back to their experiences. DA can thus be used to discover the characteristics specific to this sample (HIV/AIDS aid workers) in order to gain a better understanding of why they may have certain needs.

Social constructionism and 'reality'. With the use of DA, this thesis builds upon particular epistemological concepts of social psychology. At the centre rests another concept: social constructionism. Social constructionism holds that the world we perceive is a world that we humans, as social beings, have created together; social phenomena and practices, and even the language we use, are 'manufactured' within particular groups by that group's members (Gergen, 1985). Consequently, reality and meaning, as we know it, are not objective but also created through social interactions (Gergen, 1985). Knowledge is thus created this way and new group members learn by making use of already developed phenomena and simultaneously, through their interactions, help to further expand on these. It is these postulations that guide our communication, in terms of behaviour and language, and allow 'shared understandings' (Goodwin & Heritage, 1990). Thus, social interaction creates reality and meaning but reality and meaning also influence social interaction (Garrison, 1995); rather than one dictating the other, each one is used by group members to allow and guide understanding of the other (Potter & Edwards, 2001). In the words of Garrison (1995):

...all meanings, as well as the minds that manipulate them, emerge from making something common between at least two centers of action. Therefore, cognitive meanings (or truth claims) must also involve two or more persons co-intending some object. Objectivity, then, is intersubjectivity. (p. 723)

Social interaction and identities. As reality is socially constructed and there is no one objective, 'true' reality, there is thus the possibility for individuals to create their own versions of reality with the assumption that alternative versions are competing versions as different accounts imply different ideas (Potter & Edwards, 2001; te Molder, 2008; Wiggins & Potter, 2008). It is the knowledge which we have constructed together through our social interactions, and which is available to us through our social community, that allows discourse to make particular aspects of a phenomenon more or less relevant to particular situations (Tainio, 2003). Differing discourses that make different features relevant can subsequently position interlocutors differently, and differing positions, in turn, can convey different representations of the world (McKinlay & McVittie, 2008).

From a social constructivist and social psychology point of view, then, identities can be seen in terms of different 'positions'. Not only do we take (or avoid) different identities during the course of a conversation in order to make certain features (more or less) relevant than others but our identities are also the outcomes of these conversations (Antaki, Condor, & Levine, 1996; McKinlay & McVittie, 2008; Meinhof & Galasinski, 2005; Potter & Edwards, 2001). Due to the shared reality, the shared knowledge and language, and the postulations that each community has collectively created, particular identities are associated with particular meanings and consequently an identity prompts certain expectations which affect interaction (Antaki et al., 1996; Atwater, 1996; McKinlay & McVittie, 2008; Meinhof & Galasinski, 2005). Thus, identities are something that we take, within social interaction, as opposed to being some stand-alone external entities

unaffected by these interactions (McKinlay & McVittie, 2008; Meinhof & Galasinski, 2005). The task at hand, then, for the social psychologist, is to understand how this is done, that is, to understand the process underlying the production of identities during discourse as well as their practical consequences (Antaki et al., 1996; McKinlay & McVittie, 2008). Thus, since different constructs allow different inferences, discursive social psychologists are looking to find what versions, or constructs, individuals utilise when making sense of various social phenomena and how they convey these as (most) relevant (McKinlay & McVittie, 2008).

Social interaction and language. The means most commonly used for conveying a version of reality (a construction) is arguably language. The language which is jointly created within a social group shapes the knowledge of the group and thus gives meaning to an event. For social constructionism, then, language is at its heart (Atwater, 1996; Garrison, 1995). Thus, if identities prompt expectations and identities are inherent within, as well as outcomes of, processes during discourse, then it is in fact language which is responsible for these expectations (Garrison, 1995). It is a jointly, socially created, shared world and ensuing conceptions that allow an understanding of the language used to convey a particular account.

Accordingly, language is not a means for merely describing a phenomenon (McKinlay & McVittie, 2008); language is, arguably, used for conveying a particular version by making certain features of the phenomenon more or less relevant, making use of socially available postulations. As such, language is a means for doing something; language *is* action (Edwards, 2005; McKinlay & McVittie, 2008; Wiggins & Potter, 2008). Language is what makes interaction happen as it is talk, with all its social assumptions and expectations, that allows the conversation, or the interaction, to advance, referred to as 'talk-in-interaction' (Antaki, 2000). As speakers take turns to offer their version, each turn is designed carefully to ensure the co-interlocutors arrive at the desired inference(s) as opposed to other potentially possible inferences (te Molder, 2008). Thus, by taking turns 'describing' something and drawing inferences from those accounts it is possible to perform various actions

and achieve interactional goals by manipulating the constructs we choose and use (Hepburn & Brown, 2001; Potter & Edwards, 2001). As such, it is also possible to perform actions and achieve interactional goals by constructing oneself and manipulating one's identity in a specific way in a specific interaction for a specific purpose (McKinlay & McVittie, 2008). That is, a version is constructed 'on and for particular occasions' (Edwards, 1999, p. 272) and this allows language, or discourse, to perform actions.

Social interaction and discourse analysis. By studying language and discourse, social psychologists can make use of this process of encoding and decoding meaning (Taylor, 2001) in an attempt to understand social interaction. By studying what terms and phrases individuals use when constructing versions of reality; how formulations are produced; what identities and other categories are invoked; or how various features, topics, and issues are made relevant and interpreted by others, social psychologists can try and understand how members of a group make sense of their social world (Burck, 2005; Hepburn & Brown, 2001; McKinlay & McVittie, 2008). What inferences do interlocutors make available by using the kind of language they use, the way they use it? Why do speakers make a certain identity or feature more relevant than other features? What action(s) may the speaker want to accomplish; what interactional goals may they want to achieve? To help answering these questions, social psychologists can draw upon discourse analysis.

There are three main focuses of discourse analysis (Wiggins & Potter, 2008). First, DA focuses on how discourse produces, and is produced by, different constructions and how these are managed. Discourse analysts are interested in how versions of reality are represented in discourse (Potter & Edwards, 2001). Second, DA focuses on how discourse is situated; that is, DA highlights the importance of the turn-by-turn nature of discourse and the considered location, of each utterance, in time (Potter & Edwards, 2001; Taylor, 2001; te Molder, 2008; Wiggins & Potter, 2008). Finally, DA focuses on how discourse is interconnected with social action.

Discourse analysts are interested in how versions of reality are constructed in discourse to perform action (Potter & Edwards, 2001). Thus, discourse analysts pay particular attention to how language is used, variability across use and meanings derived, and outcomes of a particular discourse (Burck, 2005; Taylor, 2001).

Discourse analysts systematically 'decode' (Taylor, 2001) discourse, using knowledge obtained as members of social and cultural groups. Discursive social psychologists thus study social interaction by systematically study discourse. Since language is action, as previously argued, the main concern of DA is how (social) action is performed within a discourse (Edwards, 2005).

Discursive social psychology as a critique of orthodox social psychology.

DA, as a qualitative method and by being based on the principle that language is action and thus by studying language we can study social interaction, is in contrast to 'orthodox social psychology' (OSP) (Antaki et al., 2003). Social psychology is concerned with what it is like to be a member of a group and how this membership influences our perceptions and actions (McKinlay & McVittie, 2008). Whereas DA treats language, and consequently action, as primary, OSP regards language and action as secondary to cognition, where cognition is this separate entity inside a social being's brain that produces action (Potter & Edwards, 2001; Wiggins & Potter, 2008). Orthodox social psychologists, then, look to find and link cognitive processes and the actions, or behaviour, they are thought to produce (Hsu & Roth, 2010). Studying language is, for the orthodox social psychologist, just a means of accessing the proposed underlying cognitions (Hsu & Roth, 2010; Wiggins & Potter, 2008). Discovering these supposed cognitions, or mental processes, will then allow the (orthodox) social psychologist to explain actions (Antaki et al., 2003). For the discursive social psychologist, however, language does not permit access to some underlying mental process that produces action; actions are, rather, performed and understood within the discourse itself (Taylor, 2001; te Molder, 2008; Wiggins & Potter, 2008). In contrast to OSP, then, discursive social psychology (DSP) regards cognition, and thus reality, to be products constructed within discourse, so the

discursive social psychologist needs to understand the discursive actions in order to be able to understand 'cognition' (Potter & Edwards, 2001).

Inherent in this critique is the claim that orthodox social psychology overlooks the social nature of humans (McKinlay & McVittie, 2008; Wiggins & Potter, 2008). Social sciences cannot apply the same level of control to the human subjects participating in their experiments as physical sciences can to their inanimate objects, as these objects lack the social and interactional characteristic that is inherent in human subjects (McKinlay & McVittie, 2008). Inanimate objects are not members of social groups and therefore do not interact with other objects and neither do they process these social interactions (McKinlay & McVittie, 2008). Scientific experiments do not take into account the socially constructed aspect of our human world, and thus to study social psychology only by means of scientific experiments may arguably be methodologically flawed (McKinlay & McVittie, 2008; Wortman, 1983).

It is, however, important to note here that this study is per se not a critique of OSP. I, as the author of this thesis, am personally of the view that both quantitative and qualitative work contribute vastly to the advancement of psychology as a scientific discipline. Neither methodology, however, is always appropriate; certain research questions are best answered using quantitative methods while others require a qualitative approach. The methodology opted ought to be the one best suited for addressing the research objectives at hand. In this particular case, a predominantly qualitative and discursive method was deemed as the most suitable approach for meeting the objectives of my study.

3.5. Discourse Analysis and This Thesis

On the basis of the claims made hitherto, this study used DA to address the three research aims stated previously. Bearing in mind the main features of DA –

discourse is constructed and constructive, situated, and action oriented – participants' discourses were analysed to identify the constructions they produced, that is, the way they constructed their identities, concepts such as HIV/AIDS and TB, various events they experienced, and the way they made sense of these phenomena. The investigation further focused on the rhetorical devices participants employed and the categories they invoked in their constructions. The analysis was made bearing in mind guidelines provided by well-established discursive researchers such as Antaki and colleagues (2003) and Wiggins and Potter (2008). For each feature identified as part of respondents' discourses and deemed relevant to the research questions, the analysis offers an account of what the feature is and a case for when and how it was used by the speaker, what it was used to do, how this was done rhetorically, and what the implications were, that is, what it accomplished (Antaki et al., 2003; Wiggins & Potter, 2008). The identified features were then further examined to detect more extensive patterns in participants' discourses to generate broader themes (Antaki et al., 2003; Burck, 2005; Taylor, 2001). Thus, the analysis focused on the language that participants used and the effects thereof, that is, the interactional goals that participants achieved by producing a particular version.

Extracts in this thesis are presented using the Jeffersonian notation system (Jefferson, 2004). A list of the transcript notations is available in Appendix G.

Chapter 4. The Battle Over Control

The aim of this first empirical chapter is to illustrate how, on one hand, participants conveyed a sense of being in control over HIV while, on the other hand, accounts of loss of control (or fear thereof) were also prevalent in participants' discourses. The first half of the chapter – The Disease Management Phase – will address the former by illustrating, across four sections, how participants spoke about HIV previously being in control of them; how they spoke about now being in control of HIV; how their confidence in their levels of control was evident in their expectations as well as in their way of normalising HIV; and finally how knowledge about HIV played a role in producing this sense of control and make HIV less frightening. The second half of the chapter – The Continuing Battle – will address the latter issue. The first section will illustrate how participants communicated instances of loss of control over HIV and how they engaged in reappraisal of meaning in order to address such difficult experiences. The following section will illustrate how the high level of control at Cotlands produces a misrepresentative façade and a number of reality checks that act as reminders of this misrepresentative façade will be discussed. The third and final section will conclude the chapter by illustrating new challenges in contemporary HIV/AIDS work.

The Disease Management Phase

'... and we were now on a disease management phase ...'

The first two sections to follow will illustrate the contrasting ways in which participants conceptualised HIV in the past versus HIV in more recent years.

4.1. Previously: HIV Controlling Man

Albeit participants conveyed a sense of control over HIV, and confidence in this control – as will be illustrated shortly – this has not always been the case. HIV was referred to as initially having been a 'killer disease' out of control. The following extracts illustrate how prominent the notion of HIV as a 'killer disease' was among participants:

Extract 4.1

- 1 VR: What did you know about (.) HIV and AIDS before you
2 started at Cotlands
3 (1.8)
4 P47: HIV I knew (1.2) was a killer disease at that time
5 because as I say I worked for the airline (1.4) and over
6 the period of years I think I lost twenty friends (1.4)
7 so I knew about HIV (1.1) before I came to Cotlands

Extract 4.2

- 1 VR: And what did you know about (0.3) HIV (.) AIDS
2 tuberculosis (.) before you came to Cotlands
3 (0.9)
4 P27: Yah before I came to Cotlands I know that AIDS is the
5 killer (0.6) (who's) the killer disease of the people

In participants' discourses, HIV was constructed as something that previously killed everybody. The speakers in both extracts above refer to HIV as a 'killer disease' (Extract 4.1, *l.* 4; Extract 4.2, *l.* 5), conveying an image of an exterminator. The additional 'of the people' used in Extract 4.2 (*l.* 5) suggests that this exterminator does not discriminate and spares no one. For example, in Extract 4.1, the speaker estimates having lost twenty friends over a period of years. First, this is arguably a high number of friends to lose in a relatively short period of time. Second, the use of the fairly detailed 'twenty', as opposed to for example the more imprecise word 'many', gives the account a more factual, and thus real, nuance. Another feature which also makes the accounts above more factual is both participants' use of the phrase 'I know' or 'I knew' (Extract 4.1, *l.* 4; Extract 4.2, *l.* 4), implying that the concept of HIV as a 'killer disease' is general knowledge accepted by everyone. The participant in Extract 4.1 further states to have known about HIV before coming to Cotlands (*l.* 7), which suggests that she did not simply possess such knowledge because she worked in an HIV environment; HIV existed, and killed, everywhere.

In response to the question 'What did you know about HIV, AIDS, and tuberculosis before you started at Cotlands?' the participant below finished her answer by saying:

Extract 4.3

1 P3: So it like the basic stuff AIDS is just a disease or HIV
2 is-s the start and then AIDS the progressive and then
3 you're gonna die (.) that's like bottom line kind of
4 story

This account suggests that HIV was not only an exterminator but also one that could not be contained or controlled. First, the speaker makes use of a three-part list (Jefferson, 1990) when describing the trajectory of the illness: first it starts with HIV, then it progresses to AIDS, and finally you die. The speaker then concludes by referring to this path as 'bottom line kind of story' (*ll.* 3-4). In other

words, there is no other option: the bottom line is that HIV will eventually lead to death and there is no escaping this fate. HIV controlled man.

HIV, however, also exercised control in other respects; for example, one could be expecting a child to die and therefore one would say their goodbyes just to find that the child continued living for several more days. As such, even when one would surrender to be controlled by HIV, the control was not always acted out as anticipated, which further perpetuated one's *lack* of control.

4.2. Now: Man Controlling HIV

In 2003, Cotlands commenced their ART programme which entailed all the HIV+ children (roughly half of the total number of children) in residential care receiving ARVs in order to halt the progression of their illness, that is, halting the HIV from progressing to AIDS and terminal illness. As such, death rates changed radically: whereas pre-2003 several deaths could occur each week, today there is barely one death per year (there were no AIDS-related deaths at the residential care centre during the 12-month fieldwork period of this study). Alongside such statistics, a sense of control over HIV has emerged among Cotlands employees. Whereas previously HIV killed everyone and could not be contained, death rates are now under control and man is capable of controlling HIV. This section will thus illustrate the disease management phase:

Extract 4.4

- 1 VR: What recommendations do you have for those who want to
2 come (.) and work with HIV positive people (0.3) so what
3 advice would you give them
4 (3.8)
- 5 P29: Never to fear (1.2) HIV and AIDS (0.4) like before (0.2)
6 because (0.4) before we used to think yeh (.) it's a very
7 it's a killer disease that (.) you do- you wouldn't want
8 to see yourself (0.3) eh next to somebody with it but now

9 ah-ah (0.7) they must just (0.4) like (0.2) what they're
 10 doing their job and the (0.3) if you have a heart to work
 11 with the sick people you don't y-you won't going to to
 12 discriminate (0.2) yes (0.3) all the diseases are the
 13 same (0.8) nowadays (0.3) as long as the-the-the you can
 14 (.) be precautious (0.3) you know how to protect this
 15 prevent this from getting to you then it's fine yes

In the extract above, the notion of time is being made relevant and a distinction is made between two points in time through the use of words such as 'before' (*l.* 6) versus 'now' (*l.* 8) and 'nowadays' (*l.* 13), intersected with the word 'but' (*l.* 8). Whereas the former – before – is labelled as a time of 'fear' (*l.* 5) with further negative features such as the risk of extermination ('killer disease', *l.* 7) and social discrimination ('you do- you wouldn't want to see yourself (0.3) eh next to somebody with it', *ll.* 7-8), the latter – nowadays – is labelled as 'fine' (*l.* 15); HIV has progressed from being a 'killer disease' to being just like any other disease ('all the diseases are the same', *ll.* 12-13), and people no longer discriminate. The distinction between two points in time is further emphasised by using the past tense of the word 'use' (*l.* 6) which indicates that however negatively they perceived the earlier time point, it is a problem of the past: they *used* to think that HIV was a killer disease (which implicitly communicates that they no longer do). The concept of time is used similarly by the next participant when asked if she was prepared for her job when first starting at Cotlands:

Extract 4.5

1 P28: Yes I was prepared (0.7) I was prepared enough (1.4) but
 2 it was difficult for the first (.) few months (0.8)
 3 because children would die- wou- they were ill those days
 4 (0.4) there was no ARVs (0.8) but now it's easy (.) for
 5 everybody
 6 VR: Mm
 7 P28: Yah (0.8) it was difficult (0.7) bo- (.) like it was two
 8 thousand and one if I'm not mistaking it was difficult
 9 those days (0.4) children was dying (0.5) like two- (0.9)
 10 two at (0.3) two times a (.) a week (0.4) yah (.)
 11 [but now]

- 12 VR: [Mm]
 13 (1.1)
 14 P28: Children are (0.9) growing

This speaker also splits time through the use of ‘first (.) few months’ and ‘those days’ (ll. 2 and 3) versus ‘now’ (l. 4). The earlier time is furthermore specified as ‘two thousand and one’ (ll. 7-8), that is, some ten years prior to the interview. Once again the speaker uses past tense language – it *was* difficult (l. 7) – indicating that any past difficulties are no longer applicable. Moreover, this time period was difficult because children would die – a couple, every week (ll. 9-10). In contrast, presently children are reported to be growing (ll. 11-14). Growing children is a seemingly standard phenomenon and the use of such a statement conveys a sense that everything is under control. This would be in contrast to children are *not* growing, because they are dying from HIV, and thus things are neither standard nor under control.

In response to asking about the most difficult aspect of the job when first arriving at Cotlands, the below participant initiated the response by discussing the fear of losing the children and then concluded:

Extract 4.6

- 1 P45: Ehm but the fear of losing them to the disease (0.3) y-
 2 eventually subsided (0.5) because (0.6) I learnt that
 3 (1.1) >part of the reason< they're here is to stop that
 4 from happening

The same participant later also referred to death as a ‘horrible thing’:

Extract 4.7

- 1 VR: Why is it a horrible thing
 2 (1.6)

3 P45: Well I don't know (.) uhm (1.9) especially when it comes
 4 to a child (0.3) <it's like> >they didn't even< (0.6)
 5 have a life (0.4) its life (1.1) it's just >negative<
 6 from every aspect yo(h)u lo(h)ok at it it's not fair it's
 7 not right it's (0.7) uhm:: (3.4) you cou::ld (1.2) I'm
 8 sure some would feel guilty (.) that the::y (1.4)
 9 couldn't stop it from happening

First, by claiming that some may experience guilt as a consequence of having been unable to prevent a child from dying (Extract 4.7, ll. 7-9) presupposes that preventing a child from dying (from HIV/AIDS) is *possible*; accounts of guilt in relation to the impossible are arguably exceptional. Furthermore, the participant had previously also stated that children were partly being admitted to Cotlands in order to prevent them from dying (Extract 4.6, ll. 3-4). Such statements then communicate that HIV is manageable and controllable. Thus, HIV is no longer a 'killer disease'.

The notion of HIV as formerly a 'killer disease' but now a managed disease was also apparent in an international context. The following international volunteer spoke at the end of an interview about the discrepancy between the reality of Africa versus her expectations prior to her arrival in Johannesburg:

Extract 4.8

1 P51: But I think (0.4) in general when someone hear like HIV
 2 AIDS and like ((comic voice starts)) oh Africa like
 3 everyone has it and they're all dying ((comic voice
 4 ends)) and
 5 VR: ((Chuckles))
 6 P51: S(h)o I thi(h)nk that's more of the perception of coming
 7 here but then °once you're here you kinda realise° (0.3)
 8 how the rates have dro:pped and (.) that there are (0.2)
 9 things are >starting to make a difference< in the rates
 10 so (0.3) °hopefully it continues that way°

When speaking of HIV, rather than a time distinction, this speaker makes a space distinction between two locations: outside of Africa versus in Africa. The

speaker constructs the out-of-Africa location by referring to Africa and then using the word 'they' (ll. 2-3) which ultimately distinguishes Africa and its people from whatever other location where people might be speaking about Africa. Furthermore, when they do speak about Africa, in relation to HIV, the perception is that all Africans have HIV and they all die from it. In other words, HIV in Africa is a 'killer disease'. When the speaker then proceeds, however, by saying 'but then °once you're here' (l. 7), the outside-of-Africa perception of Africa is put in contrast to another perception obtained in a different location: the 'here' referring a location inside Africa, such as Johannesburg where the interview was conducted. The account then illustrates how the notion of HIV as a 'killer disease' (in Africa) was also prevalent outside of Africa – and still may be – but that the reality inside Africa has now changed: HIV is no longer the 'killer disease' it once was. HIV is now controlled and death rates are declining accordingly.

4.3. Confidence In Control

The previous section demonstrated how participants' discourses conveyed a sense of control over HIV. This section will demonstrate how this sense of control was illustrated in a confidence that shone through participants' accounts. This confidence was displayed in two ways mainly: first, through participants' expectations of the disease, and second, through participants' normalising of HIV by comparing it to other illnesses.

4.3.1. Expectations Reflect Confidence in Control

Participants conveyed a confidence in their sense of control over HIV when they discussed their expectations in terms of the trajectory of the illness. This confidence was apparent in the sense that HIV was no longer considered to be the

immediate death sentence it once was. For example, in response to how she felt about working with HIV+ individuals, one participant said:

Extract 4.9

1 P8: It's always fulfilling because you know (.) uhm (0.8) you
2 watch this person (0.6) this child coming (0.4) so sick
3 (0.7) and you know that (0.5) the child is going to get
4 better (0.4) and it's nice to see the child going through
5 those phases (0.4) of gaining weight (0.4) ehm (0.7)
6 gaining muscle tissue when they couldn't walk (0.3) they
7 stand up and walk i- it's a fulfilling job (0.6) it's you
8 gets a (.) job satisfaction (0.8) mmm you know that if
9 you give them the correct diet (0.4) the correct (0.7)
10 treatment at the correct times (0.3) nothing will go
11 wrong

First, the speaker constructs two contrasting states: a sick child versus a child that has gotten better. Second, the speaker conveys confidence that the child will reach the latter state in several ways. For example, she uses the word 'know' (l. 3) which, as previously stated, gives the account a factual character. The trajectory outlined (as a three-part list) – as long as the correct diet, the correct treatment, and the correct time is adhered to then nothing will go wrong (ll. 9-11) – is a *fact* rather than simply a belief, or hope, that the speaker holds and as such there is no other possible outcome. Also, the use of a strong language such as 'the child is going to get better' (ll. 3-4) and 'nothing will go wrong' (ll. 10-11) insinuates an inexorable outcome with alternative outcomes, such as a child not improving, not probable. Moreover, the participant's sense of control is communicated by chronologically describing the various phases the child goes through in order to reach the state of being better (also presented as a three-part-list): the child gaining weight, the child gaining muscle tissue, and finally the child walking (ll. 5-7). By extending the statement that that 'the child is going to get better' through an elaboration of the various phases a child goes through when and as it gets better, the participant shows that she is in control because she knows what goes on.

Another participant had spoken at lengths about the numerous difficulties that an HIV+ individual may have to live with and stated that as much as they wish to live a normal life it is not an easy task:

Extract 4.10

1 P36: Cause you know you are living with this deadl- well not
2 really but (0.7) HIV has always been (0.5) presented as a
3 deadly virus (0.4) you know and (0.3) for some for most
4 people it is (0.4) the end of life (0.6) a death sentence
5 (0.4) so it's it's not easy it's a challenge

Interestingly, despite acknowledging the perception of HIV as a 'death sentence' (*l. 4*), the speaker also does a repair (Schegloff, 1992): as she is about to refer to HIV as a deadly phenomenon ('this deadl-'; *l. 1*), she halts and repairs herself ('well not really', *ll. 1-2*). She thus addresses the possibility of being misinterpreted. Instead of 'deadly', she settles for describing HIV as a phenomenon that has 'always been' (*l. 2*) presented as deadly. This repair and the subsequent utterance suggest that despite HIV having 'always been' presented as a deadly phenomenon, it may no longer be so. It suggests that there may have been a shift in mindset; albeit perhaps slow to catch, there is nonetheless a shift.

The idea that HIV no longer is an immediate death sentence was also noticeable among international volunteers. One volunteer had been speaking about how scary she perceived non-curable diseases to be:

Extract 4.11

1 VR: So what's the scary part of it
2 (1.1)
3 P54: (Thall) the (.) there is the possibility that I ca- (0.4)
4 get HIV and then (0.4) well ha- would have to live (.)
5 with this (1.2) disease for the rest of my life
6 VR: Mm

7 P54: Which would be probably shorter than without it so (0.4)
8 that's not (0.8) that wouldn't be nice ((chuckles))

An alternative outcome in the above extract would be for the speaker to respond to the question by explaining that 'there is the possibility that I can get HIV and *die*'. If HIV was still perceived as a 'killer disease' one could certainly expect such a response. Instead of expressing a concern about contracting HIV and subsequently dying, the speaker rather expresses a concern about contracting HIV and thereafter having to live with the disease for the rest of her life. The phrase 'the rest of my life' (l. 5) gives the impression of entailing a very long time, especially given the participant's young age (late teens). Thus, albeit admitting that HIV would shorten her life, the speaker, nonetheless, presents HIV not as an *immediately deadly* non-curable disease but rather as a *life-long* non-curable disease; that is, she constructs HIV a disease which she would have to live with for some time as opposed to one that would kill her more or less immediately. For many of the international volunteers, the fact that it is now possible to live (for a long time) with HIV was one of the most important lessons learnt during their time volunteering at Cotlands. (The volunteer in the above extract had been at Cotlands for just under two months at the time of the interview.) When HIV was perceived as an immediate death sentence, many individuals did not want to know their status because they did not want to know they were dying. This phenomenon more commonly occurred before the availability of ARTs and before HIV could be controlled. The decline in such a phenomenon indicates that the perception of an immediate death sentence is no longer relevant, at least not to the same extent as previously when HIV was not under control. There has, thus, been a shift in how HIV is conceptualised; for example, a child diagnosed with HIV today is expected to live for many years after the diagnosis. Perhaps one staff member explained it best when she said that 'there's life after HIV'. At Cotlands, then, HIV is no longer an immediately lost battle. It is worth noting, however, that to some extent HIV is still regarded as a death sentence, seeing how the illness in most cases eventually leads to death. The crucial point is

that it is no longer an *immediate* death sentence because it can now be vastly controlled.

4.3.2. Normalisation of HIV

Another discursive tool which participants utilised in order to convey their sense of control over HIV and their confidence therein was comparison: in their discourses, speakers would compare HIV to other illnesses which are generally perceived as under control and less frightening. The below extracts are from responses to the final interview question 'What recommendations do you have for those who want to come and work with HIV positive individuals?':

Extract 4.12

1 P8: Uh the advice I would give them i- ehm HIV is no longer a
2 (0.7) scary disease like we used to think you know (0.3)
3 when we (.) w- years back we used to say if (1.1) you
4 have a scratch you must cover yourself we u- (.) you know
5 the infection the mode of infection people didn't
6 understand (0.8) and now that eh (0.2) HIV and people are
7 improving on (0.4) antiretrovirals (0.3) it's just like
8 diabetics and hypertension now (0.3) that is how we
9 should look at it like (.) another disease (.) you know
10 (0.3) it's no longer scary (0.2) you know (0.8) so (0.5)
11 people must just take it like (0.4) if they tell me that
12 I've got TB I know I'm going to be ill(ed) (0.4) if they
13 tell me I have hypertension (0.2) I must take treatment
14 til I die (0.2) so the same goes for HIV and AIDS (.) you
15 know (0.3) like (0.5) eh diabetics mellitus and (0.5)
16 hypertension (.) if you start taking treatment (.) and
17 you are diagnosed as that (0.3) you never stop (0.7) so
18 what makes it different for ehm from HIV and AIDS

Extract 4.13

1 P31: I can have a flu (.) I can die because of flu (0.8) I can
2 have maybe [pn]eumonia I can even die or I can survive
3 (0.2) so HIV i-it's it's like (0.8) i-it's the same as
4 those (.) other diseases

Once again, the first speaker above makes a distinction in time in the same manner as previous speakers: 'years back' (Extract 4.12, *l.* 3) is put in contrast to 'now' (*l.* 6) and past tense language is employed (for example, 'used to'; *ll.* 2 and 3). Thus, fear of HIV is a thing of the past; HIV is 'no longer a (0.7) scary disease' (*ll.* 1-2). Rather, presently, HIV ought to be treated as any other disease. The examples of other diseases given by both speakers above include TB (Extract 4.12), diabetes (Extract 4.12), hypertension (Extract 4.12), the flu (Extract 4.13), and pneumonia (Extract 4.13). In order to convince the hearer that HIV is no different to these other diseases, both speakers highlight characteristics that HIV share with these diseases. For example, the speaker in Extract 4.12 states that TB will make one ill (*l.* 12) and hypertension requires treatment for the rest of one's life (*ll.* 13-14). HIV, too, makes people ill and requires life-long treatment to be taken. Similarly, just as one can die from HIV, in Extract 4.13 the speaker stresses that one can also die from flu and pneumonia. The speaker, thus, suggests that HIV is not the only lethal disease but other diseases which may be feared less can also be deadly. After having highlighted these similarities between HIV and other diseases, the first speaker offers her concluding punch line 'so what makes it different for ehm from HIV and AIDS' (*ll.* 17-18) – an utterance that challenges the notion that there may be any difference at all.

Participants thus normalised HIV in their discourses in order to show their confidence in how HIV can be controlled in a similar manner as other less feared diseases. Perhaps the comparison of HIV, previously known as a 'killer disease', to the flu, a seemingly trivial illness, is the most striking. As such, comparisons to, for example, diabetes and hypertension may be especially convincing seeing how these illnesses too could lead to death if medication and treatment plans are not properly adhered to.

4.4. Knowledge Is Power

Participants often spoke about knowledge and the importance of it; it was soon clear that participants' sense of control over HIV largely stemmed from having knowledge about the disease. Knowledge, then, as the saying goes, was power. This section therefore aims to illustrate the role of knowledge in participants' sense of control over HIV, and in particular how knowledge made HIV less frightening partly by decreasing the fear of infection. With reference to obtaining knowledge when dealing with HIV, a couple of participants spoke about how they had to 'equip' themselves; for example:

Extract 4.14

1 VR: Did you learn anything new (.) since you came ↑here=
2 P9: =oh totally ((chuckles)) absolutely it's the only time
3 that AIDS became (.) important (.) uhm because you were
4 faced with it every single day (0.5) s- and then of
5 course learning about it because you >had to be able to
6 speak about it< (0.3) to the school groups I was dealing
7 with and to donors and (0.3) going out and you know so-
8 we had to equip ourselves

The use of the phrase 'faced with' (l. 4), in the extract above, implies a challenge. Here, the challenge involves speaking to other people about AIDS. In order to address this challenge, the participant states that they (Cotlands staff members) needed to 'equip' (l. 8) themselves. It is further suggested that learning about AIDS is a way of addressing such a challenge (ll. 5-6). Thus, knowledge about AIDS equips one to address challenges associated with AIDS. Those who are not equipped with such knowledge meet a different fate; for example, in response to asking how it feels to work with HIV+ individuals, the participant below expressed a wish to go to Kwa-Zulu Natal (KZN), a South African province where HIV rates are among the world's highest (Horwood et al., 2012), to help people by sharing her knowledge about HIV:

Extract 4.15

1 P22: In KZN people are dying just because (0.8) yah (0.8) they
2 don't have this information

In her response, the participant explicitly states a link between not having information about HIV and dying. Conversely, the argument is that if one has information about HIV then one does not need to die. Knowledge, then, can be seen as a weapon used in the battle against HIV: it is easier to control, beat, and win over your opponent if you have knowledge about your opponent.

Knowledge was crucial in this battle also in the sense that education is considered an important tool in addressing some of the cultural folklores surrounding HIV, which are seen to perpetuate the pandemic, such as myths suggesting that sexual intercourse with a virgin will cure HIV (Earl-Taylor, 2002). Dissemination of knowledge was thus seen as a crucial element for battling HIV and, for example, frustration was directed towards various South African governments for not taking responsibility for educating their people. Many participants, then, felt pride over their involvement in disseminating HIV-related knowledge. Conveniently, in that regard, knowledge is power also in one other aspect: knowledge puts an individual in an authority position. Some staff members perceived themselves to be role models in their communities and, in such a position, having knowledge enabled them to stand firm. This confident behaviour would give an authoritative impression and one needs to be perceived as an authority in order to be successful in educating people (about HIV).

One issue in relation to knowledge is the effect of AIDS-related deaths on children. While adults can obtain knowledge to consequently increase their sense of control, children, on the other hand, are often seen as incapable of comprehending such information and thus incapable of achieving such levels of control. Accordingly, there is a concern for how children are affected by what they might consider being their siblings dying (that is, in a residential home context).

Expressions of such concerns, regarding the potential effects on those who may lack the privilege of knowledge, suggest that participants saw a major benefit for themselves in having such knowledge.

4.4.1. Knowledge Makes HIV Less Frightening

Knowledge is power. ARTs, and consequently the halting of HIV as a 'killer disease', are a direct result of knowledge, and one way in which knowledge contributes to a sense of control: the trajectory of the illness can now be relatively controlled. Second, simply having knowledge about the trajectory itself, how the disease works and what it is capable of, increases one's sense of control as it allows for more accurate expectations. As stated in Chapter 2, if one knows what to expect, one can then be better prepared, which in turn may give a sense of being more in control (Iversen et al., 2008). The remainder of this section will thus focus on how participants often asserted how easy, or easier, their work was once they became knowledgeable about the disease and in particular how this came about as a result of knowledge decreasing their fear of infection.

First, however, it must be noted that it is not general knowledge about HIV that is important per se; rather, it is an individual's *subjective* sense of knowledge. This subjective sense of knowledge is, logically, linked to the extent of one's exposure to HIV. Across 66 interviews with 63 participants, including both locals (permanently living in South Africa) as well as international volunteers, there was a sense of a difference between these two categories of participants in their perceptions of HIV. Although international volunteers seemingly have joined locals in no longer conceptualising HIV as an immediate death sentence, there still appeared to be a greater sense of fear of HIV among international volunteers than among locals. For example, while many locals went to great lengths to build accounts of why one should no longer fear HIV, compared it to seemingly more subtle diseases, and even referred to the disease as something 'simple' and 'small',

some international volunteers, on the other hand, almost seemed concerned about how trivial HIV had become and how the words HIV and AIDS were being 'flipped around'. Instead of trivial, they encouraged others to take HIV seriously. (This is not to say that all international volunteers held this perception, and there is a possibility that age plays a part in the equation, with younger or first-time international volunteers appearing to be holding more HIV-related fears.) In the extract below, one international volunteer can be heard almost to be encouraging people to fear HIV:

Extract 4.16

1 VR: What did you know about (0.3) HIV (0.3) AIDS and
2 tuberculosis (0.3) before you came here
3 (0.9)
4 P61: You know d- (0.4) HIV or (0.4) AIDS (0.7) we are not
5 really confronted with this (0.7) because: you don't
6 have really in contact with HIV because you don't know
7 people (0.5) there is no (0.2) plenty people in Germany
8 for example or in my relationship (0.8) there is nobody
9 with HIV (0.9) so (0.5) but we know (0.2) that you must
10 be safe (1.4) you must be safe (here) and (0.5) you must
11 be scared this is (0.4) you are sick and you will die
12 (0.8) you know one day you'll die and never had seen your
13 (0.5) grandchildren maybe (1.5) this of course scared
14 (1.8) but not really (0.2) I mean of course I know (0.5)
15 what is the virus and what it did but (1.6) but (.) we
16 don't have really

The argument that it is not general knowledge about HIV that is important per se is evident in how the speaker qualifies the reference frame when speaking about confrontation with HIV: it is gradually narrowed from the very broad and vague 'we' (l. 4), to the somewhat more definite 'people in Germany' (l. 7), to the relatively specific 'my relationship' (that is, his social network; l. 8). For this specific group of people, confrontation with HIV is claimed to be low. Accordingly, the account of HIV more resembles the 'killer disease' accounts of the early days of HIV among previous participants; for example, 'you will die' (l. 11) suggests HIV is still

uncontrollable, and the imperative³ 'you must be scared' (ll. 10-11) counters the normalisation discourse discussed above. Seeing how Germany typically is considered a well-developed and advanced country, one would assume that HIV knowledge in Germany is not far behind the knowledge in South Africa, and at this point – late 2010 – HIV in South Africa was no longer feared to the same extent as previously. What the account then highlights is the relevance and importance of one's *subjective* sense of knowledge, and how this in turn influences the individual's subjective sense of control. Logically, if one does not experience much confrontation with HIV+ individuals then one may not perceive her- or himself to have much knowledge (and consequently also not much sense of control). In South Africa, however, where HIV is so prevalent, there are arguably more opportunities to be exposed to HIV and HIV-related issues. This may increase one's subjective sense of knowledge, which may in turn increase one's sense of control. Consequently, HIV work is perceived as easier because HIV appears less frightening. This is illustrated in the below extracts where the participant had just claimed knowing HIV and TB well:

Extract 4.17

1 VR: And do you feel that it helps (.) you (.) in your (0.5)
 2 work here at Cotlands (0.2) to [know all these things

3 P45: [Oh yeah] I
 4 mean I think uhm (1.9) at first I I'm a pretty open
 5 minded person so (0.7) it didn't bother me (.) as much as
 6 it would bother most- most people (1.1) but (1.6) even
 7 then when you don't understand it it still (0.6) does
 8 bother you to an extent no matter how open minded you are
 9 (0.7) if you're dealing with someone who's positive (1.0)
 10 but (0.2) the more you know about it (0.3) a::nd once you
 11 really get to know the disease yo::u become
 12 comfortable (0.3) dealing with positive people and it
 13 doesn't (0.4) bother you at all anymore (0.7) so yah
 14 (0.4) knowing it helps (1.1) that's why (.) we started
 15 teaching it

³ It is worth noting that the words 'must' and 'mustn't' are more commonly used in South Africa than, for example, in the UK, and they can be said to be 'less loaded' in South Africa.

The participant above first suggests that HIV work is trouble- or worrisome because it bothers people; so much that even those who generally are not easily affected will be bothered (*ll.* 4-8). Thereafter, the participant implies that this bothersome state can be attributed to a lack of knowledge: 'when you don't understand it it still (0.6) does bother you' (*ll.* 7-8). Finally, the participant confirms this attribution by claiming that knowledge makes HIV work easier. He does so by insinuating a positive correlation between knowledge and a state of comfort ('once you really get to know the disease yo::u become comfortable', *ll.* 10-12); the word 'comfortable' suggesting an absence of unpleasant feelings. The link between having knowledge and being comfortable is also referred to by the following participant:

Extract 4.18

1 VR: So:: what did you know about (0.3) HIV (0.2) AIDS (.)
2 tuberculosis before you came here
3 (2.7)
4 P44: I think just from having (0.4) worked in that field
5 because even though we done studying you know there's
6 certain amount of hours (we) have to do and hospital work
7 and whatnot (.) so I think I had a fairly (.) good (0.5)
8 understanding (0.5) uhm (.) more so of HIV AIDS than of
9 tuberculosis uhm (.) but the HIV AIDS (0.7) I think even
10 when I started at Cotlands I was fairly comfortable with
11 it (0.5) and along the way definitely I mean you (.)
12 totally (0.4) y-y-you know you always upgrading your
13 information learning new things and (0.7) but I think
14 just like (with a) (0.9) I had a good understanding

The state of being knowledgeable about HIV is, in the above extract, communicated as having a 'good (0.5) understanding' (*ll.* 7-8). This knowledge is attributed to having studied a medical field (paramedic). Studying per se implies an act with the objective of increasing one's knowledge. There is, however, also the insinuation that knowledge is a consequence of exposure to a phenomenon, in this case by implying that hospital placements played a role in reaching the state of 'good understanding' of HIV. Finally, the speaker claims to have been comfortable with HIV by the time she started working for Cotlands (*ll.* 10-11). Seeing how she

had carried out her studies before joining Cotlands, it is reasonable to conclude that the knowledge gained from her studies resulted in her eventually being comfortable.

Participants' discourses, then, suggested that exposure to HIV increases one's knowledge about HIV which in turn becomes less frightening. Many participants, including international volunteers, reported becoming less afraid of HIV as they learnt more the longer they worked at Cotlands. It must, however, be noted that the level of HIV literacy is still very low in rural areas despite HIV prevalence being very high in these areas. This suggests that there are other mediating factors involved and that exposure alone does not simply increase knowledge about HIV. At the least, an element of active educating and dissemination of knowledge seems to be required.

Knowledge decreases fear of infection. Knowledge made HIV less frightening partially by decreasing participants' concerns about contracting HIV. As knowledge about HIV increased, including knowledge about modes of transmission, the control over the disease increased as well, including control over risk of infection. The risk of infection, it appeared, was (perhaps understandably) a significant aspect of working in an HIV environment:

Extract 4.19

- 1 VR: So how do you:: feel about (0.2) working with HIV (0.7)
2 and AIDS and tuberculosis (0.3) infected individuals
- 3 P9: It <never ever> worried me because (0.4) we (0.4) you
4 know we didn't work with the children on the level of
5 having to administer injections or and we had been taught
6 universal precautions so if we had to (0.3) changes
7 nappies or that we knew we would put gloves on and (.) so
8 I <never ever> had any fear in that sense

Extract 4.20

- 1 VR: How does it feel (0.2) well maybe not so much anymore but
2 (0.5) cause you've worked here for a long time (0.4) so

3 how does it feel (.) working with individuals who are (.)
4 HIV positive (.) or have AIDS or (.) tuberculosis (0.6)
5 how do you feel working with them

6 (5.3)

7 P44: On a safety side as in (.) contracting (0.3) you know
8 (0.2) the diseases or what (0.3) from them (0.5) I can't
9 say that (0.2) worries me at all uhm (0.3) I'm very
10 comfortable (0.5) knowing that I cannot just pick up
11 (0.2) the viruses or (0.6) yeah the tuberculosis or
12 whatnot from them (2.1) knowing (.) signs and symptoms to
13 be on the lookout you know tha-that type of thing which
14 makes it a little bit easier

As seen above, participants often oriented towards the topic of infection risk in their responses, commonly in response to the questions “How do you feel working with HIV positive individuals, or those who have AIDS or TB?”, “Working with HIV positive individuals, or those who have AIDS or TB, what aspect do you find most difficult?”, and “Have you had a particularly negative experience?”. The speaker in Extract 4.19 commences her response by stating ‘It <never ever> worried me’ (l. 3) which implies that there is a concern of some kind present regardless of whether or not it worried her. She then proceeds in a manner which suggests that this concern relates to the infection risk of working in an HIV environment: she makes the issue of infection relevant by referring to ‘universal precautions’⁴ (l. 6) which are taught mainly in order to reduce infection risks in health care settings. The speaker in Extract 4.20 similarly initiates her response with reference to the infection risk by highlighting the ‘safety side’ of her work and specifying this as contracting the disease (ll. 7-8). This immediate orienting towards the infection risk in participants’ accounts suggests that this risk is still of major concern. On the other hand, such immediate orientation to the infection risk was generally followed by the participant claiming that contracting the disease was not a concern to them, and this lack of concern was attributed to their knowledge of the disease. For example, in

⁴ Examples of universal precautions are use of protective barriers such as gloves, especially when handling bodily fluids; safe disposal of equipment, such as needles; immediate and safe cleaning of spilt fluids; and frequent hand-washing.

Extract 4.19, the speaker states not having any fears 'in that sense' (l. 8). Because she has previously made the issue of infection relevant by referring to universal precautions, the speaker can then be heard to indirectly express not having any fears with regard to contracting HIV. Likewise, in Extract 4.20, the speaker first oriented towards the issue of contracting the disease and thereafter stated 'I can't say that (0.2) worries me at all' (ll. 8-9). In demonstrating why the infection risk is not a concern to them, both speakers refer to their knowledge of HIV and specifically their knowledge of modes of transmission. For example, the first speaker states having been *taught* universal precautions (Extract 4.19, ll. 5-6). As such, there is an element of education and knowledge involved. Because she has been taught universal precautions, and thus has knowledge about how the virus is transmitted as well as knowledge about how to prevent such transmission, she consequently has no fear of contracting the disease because she knows how to protect herself. Similarly, the second speaker implicitly demonstrates her knowledge of modes of transmission by saying that she 'cannot just pick up (0.2) the viruses' (ll. 10-11) and thus implicitly communicates that she knows that the virus can only be transmitted in certain ways. She also implies having further knowledge about the expression of the disease by declaring that she knows 'signs and symptoms' (l. 12). Having such knowledge makes the participant 'comfortable' (ll. 8-10) and her work is perceived as 'easier' (l. 14).

Participants generally conveyed a sense of responsibility for ensuring that they did not pose a risk to their family members by working at Cotlands; that is, they conveyed an awareness of the infection risk and how they needed to ensure that they obtained the necessary knowledge in order to protect themselves from contracting HIV and subsequently also protecting their family members from contracting HIV from them. Even though participants' discourses suggested that the infection risk may still be a significant aspect of their work, they nonetheless stated it was no longer a concern and their decreased fear of infection was attributed to their increase in knowledge of HIV.

4.5. Discussion

In summary, participants' discourses hitherto have illustrated a disease management phase whereby they feel in control of HIV, arguably as a result of increased knowledge about the disease. The role of knowledge in increasing sense of control is mainly two-fold. First, it is arguably increased knowledge that has resulted in the development of ARTs that reduced death rates and subsequently produced a sense of control among HIV aid workers, as they no longer consider HIV a 'killer disease'. This sense of control was demonstrated through participants' confidence in their expectations regarding the trajectory of the illness, as well as in their normalising discourse where HIV was compared to, and levelled with, less frightening diseases. Second, as participants obtained more knowledge about the disease it became less frightening, especially with regard to the infection risk that HIV work poses. Participants demonstrated their sense of control in relation to such fears by discussing their varying 'comfort' levels of dealing with HIV at two points in time: less comfortable early on, when their knowledge was low or less, and more comfortable later when they possessed more knowledge.

Moreover, there was a conspicuous lack of discourse on death in the interviews conducted for this study. This is an interesting feature for a study that aims to investigate AIDS-related bereavement *and where participants were explicitly informed about this*. Now, one may argue that the lack of discourse on death resulted from the lack of questions explicitly asking about death. The interview schedule (Appendix D) which guided the open-ended interviews did not contain the word death (or any related words) in any shape or form. This was deliberate in order to see if participants themselves would orient towards the topic, which one may expect they would if death is a prominent issue in their work. Although no question explicitly asked about AIDS-related death or bereavement, many other opportunities were given to raise the issue – had it been an issue – in response to questions such as “How do you feel working with HIV positive individuals, or

those who have AIDS or TB?”, “Working with HIV positive individuals, or those who have AIDS or TB, what aspect do you find most difficult?”, “Have you had a particularly negative experience?”, “If you could change anything regarding your experiences, would you change something and if so, what would you change?”, or “Is there anything else you would like to add, anything I haven’t asked that you think I should have asked or anything you just want to mention or talk about?”. One would expect that if you are invited to participate in a study that claims to investigate AIDS-related bereavement, you would take the opportunity to discuss such bereavement if you considered it to be an issue. Furthermore, if during such a study you were not asked about death, one would expect you might find this odd and perhaps enquire about this (or in any case take the opportunity to speak about the topic in response to the last question above). Out of the 63 participants interviewed, only *one* explicitly enquired about the lack of death-oriented questions and expressed their surprise regarding this. Difficulties directly related to death and bereavement were only to be found in 10 other interviews. If applying an exceptionally liberal criteria for what may constitute death-related talk, directly and indirectly, the total number of individuals who referred to death in one way or another rises to 31 – just under half the participants.

The lacking discourse on death was not the only conspicuous feature in the interviews. Another striking aspect was the large number of participants who stated they did not perceive any aspect of their work as difficult (see question 9, Appendix D), or that they had not had any negative or difficult experiences (questions 13 and 14), or that it *used* to be difficult, pre-ARTs, but *now* nothing is difficult. Even employees who had worked at Cotlands for a decade – or two – replied that they had not had a single negative or difficult experience. The reaction to such a striking claim can be summed up in the response of one participant who said ‘over thirteen years of course you are going to build up these types of things’. Some participants rephrased ‘negative’ or ‘difficult’ into ‘challenging’ and thus stripped the experience off some of its negative connotations. Others initially said ‘nothing’ but then proceeded giving an account of some difficult experience or

aspect of their work. As already stated, seldom did the responses include accounts of experiences that directly involved death. Moreover, participants generally reported low trauma symptoms on the IES-R (Weiss, 2007): on average, the participants completing the IES-R reported that they were bothered 'Not at all' or only 'A little bit' by the difficulties stated on the questionnaire, in relation to their bereavements. The means and standard deviations for the three trauma symptom category subscales of the IES-R are presented in Table 4.1.

Thus, judging by the 63 participants' discourses, 49 IES-R forms, and one year's ethnography, death as a result of HIV/AIDS appears to be under control at Cotlands. Evidently, this is my first reason for concluding that, in a Cotlands context, HIV/AIDS-related bereavement is no longer a prominent issue. My second reason for such a conclusion is that participants' discourses revealed other contemporary challenges in HIV/AIDS aid work – challenges that appear to have surpassed death as the most prominent concern, although still related to issues of control. These contemporary challenges are discussed in the next part of this chapter.

Table 4.1
Means and standard deviations of the trauma symptom category subscales of the IES-R.

Symptom category	<i>M</i> [†]	<i>SD</i>
Hyperarousal	0.57	1.05
Intrusion	0.97	1.23
Avoidance	1.07	1.29

[†] 0 – Not at all bothered; 1 – A little bit bothered; 2 – Moderately bothered; 3 – Quite a bit bothered; 4 – Extremely bothered.

The Continuing Battle

‘... you know it's not nice to lose the fight ...’

Despite participants conveying a disease management phase whereby they felt in control over HIV, their accounts also contained instances of loss of control suggesting that the battle with HIV over control is not yet over. This is the focus of this second half of this chapter. Despite having communicated a confidence in their sense of control, as illustrated previously, the first section below will illustrate how participants' responses were also interspersed with accounts of how this control was challenged. This section also builds on the role of knowledge and demonstrates how participants made use of knowledge in order to make sense of difficult experiences, such as losing control. In the second section I demonstrate how participants' sense of control consequently appeared as a misrepresentative façade, and I discuss a number of reality checks that acted as reminders of this misrepresentative façade. In the final section I raise new challenges, also related to control, in HIV/AIDS aid work.

4.6. Reappraising Meaning in Response to Loss of Control

Throughout this thesis it will be demonstrated how participants frequently reappraised meaning (see Chapter 2) in order to address various dilemmas arising from incongruence between existing belief systems and new information, and to make sense of such difficult experiences. In a context of control, where participants experienced a loss of control they reappraised meaning in order to make sense of and deal with this loss. Continuing on the knowledge theme from the previous section, knowledge was also beneficial to participants when reappraising meaning:

Extract 4.21

1 VR: So working with people who are HIV positive (0.9) what
2 aspect do you find most difficult (0.6) so what is the
3 most difficult thing with your job
4 (2.8)
5 P43: Eh-eh th-the difficult when they they they s::ick (0.6)
6 when they get th- you know that th-that (0.6) because
7 this thing is (0.3) on and off sometimes the child is
8 (0.4) today's:: (0.3) better the other times gets sick-
9 sick-sick (0.5) ay it traumatised that thing (0.8) very
10 mu-
11 (0.5)
12 VR: Mm
13 P43: Mm
14 VR: So how do you (0.9) deal (0.2) and cope (.) with (0.6) a
15 child being (0.2) fine one day (.) sick the next day
16 (0.2) and then (.) changing like this (0.4) how do you
17 cope with it
18 (0.3)
19 P43: It's difficult to cope but we::::: (0.6) try to
20 understand cause we know th- ah about this disease that
21 (0.5) it w-w- y-you'll (0.4) sometimes we will get the
22 child (0.6) very sick sometimes it's better when they (.)
23 they're very very sick (0.5) y-y-you have to::: (0.3) be
24 there (.) for that child (0.7) when she cries or when she
25 doing something you must be there all the time (0.3) for
26 the child

Extract 4.22

1 VR: So how do you feel (0.2) working with people who are HIV
2 positive (0.9) or who have AIDS or TB
3 (0.8)
4 P40: I-I-I- I- i-i- (0.4) it's easier for me because I know
5 what I'm dealing with I know like that this person's HIV
6 p- e- is she's HIV (0.4) so (.) I a- I know what to
7 expect from that person (0.6) and even if that person get
8 sick I know that (0.4) the reason might be that they
9 maybe the immune system eys eh it is low (.) things like
10 that so I know what to expect from that person

The first point to note is that both participants in the two extracts above talk about how it is potentially difficult when the care recipients 'get sick'. Interestingly, since the care recipients in question are HIV+ one could argue that they *are already* sick and therefore the utterance when/if they *get* sick seems remarkable. Due to ethnographic and cultural knowledge, as well as the experience of over 60 other interviews, the expression of 'get sick' can be explained as an attempt to describe instances when care recipients' state of health deteriorates in some way, perhaps through opportunistic infections (see Chapter 1) or when the care recipient no longer responds to treatment. The care recipient then becomes noticeably and physically ill. It could also, for example, refer to a situation where a new child is admitted to Cotlands who already is in this deteriorated state. (As will be discussed later, the HIV+ children at Cotlands were generally not considered being sick.) Thus, the extracts above contain accounts of deterioration, or a loss of control over the illness. The construction of two contrasting states is further evident in Extract 4.21 where the speaker says 'on and off' (l. 7) and 'today's:: (0.3) better the other times gets sick-sick-sick' (ll. 8-9). 'Off', then, represents a state of control where the disease is under control and the child's health is better. 'On', on the other hand, refers to when the disease is expressing itself and the child becomes noticeably ill; that is, the disease is not under control. The speaker further reports having been traumatised by 'that thing' (l. 9) – that is, the HIV – indicating that the experience of HIV expressing itself and thus causing a sense of loss of control is a difficult experience.

Two options available to an individual who is faced with a difficult experience are, one, leave it and possibly continue experiencing unpleasant emotions, or two, reflect on the experience in order to find some meaning that will make sense of the experience and help reduce the unpleasant emotions. In the specific context discussed here, participants did the latter: they reappraised meaning in order to address the loss of control. For example, in Extract 4.21, the speaker states that in order to cope with the difficult experience of losing control over the disease one needs to 'try to understand' (ll. 19-20). In other words, she suggests that

rather than leaving the experience as incomprehensible, one can make sense of it by trying to understand the contrasting states that give rise to the difficult situation. The speaker in Extract 4.22 also highlights the importance of making sense: she speaks about knowing 'the reason' (l. 8) when a person becomes ill.

Both speakers thereafter suggest that knowledge about the disease may be a useful factor when attempting to make sense of a difficult and perhaps ostensibly incomprehensible situation: the participant in Extract 4.21 reports knowing about the disease (l. 20) as a way of understanding, and the participant in Extract 4.22 uses similar phrases, 'know what I'm dealing with' (ll. 4-5) and 'know what to expect' (ll. 6-7). The latter speaker then expands on the role of knowledge in finding meaning by demonstrating specific knowledge that may accomplish the task: she provides a low immune system as a potential reason for why a person may become ill (ll. 7-9), and in doing so utilises her knowledge in order to make sense of her loss of control.

Another participant spoke about being hit with the realisation that one of the children she worked most closely with was 'wasting away':

Extract 4.23

1 VR: How do you (0.3) deal and cope with (.) moments of such
2 realisations
3 (0.6)
4 P51: U:::hm (1.3) I think the (0.4) biology and the science
5 person inside of me (.) tends to look at it (0.5) from
6 more of a (.) science perspective (0.3) and think (0.3)
7 OK well you did the research like you know this is how it
8 works it's just difficult because now you know the person
9 that's going through it (0.5) so that made it a little
10 difficult

This participant, too, used her knowledge in order to make sense of her experience. For example, she uses phrases similar to the participants in Extracts 4.21 and 4.22 that highlight the importance of knowledge in understanding and making

sense of an experience: 'know this is how it works' (*ll.* 7-8). Such a statement likely refers to her operational knowledge of HIV. This is further evident in how the participant draws on a specific identity and attempts to apply relevant knowledge when reappraising meaning. By referring to 'the (0.4) biology and the science person inside of me' (*ll.* 4-5) the speaker further makes relevant the notion of knowledge and education, and knowledge in one specific field. The field of biology is arguably most relevant in this context as it deals, for example, with the study of cells and thus symbolises knowledge that is highly applicable to understanding HIV (see Chapter 1) and consequently rationalising why someone may 'waste away'.

Interestingly, the participant then goes on to say that knowing the person 'made it a little difficult' (*ll.* 9-10). One may then ask 'made what difficult?'. The response to such a question could be 'made rationalising a little difficult' which would suggest that participants, however subconsciously, express some awareness of their own actions of rationalising and attempting to reappraise meaning. This awareness of is highlighted in the following extract where the speaker had just discussed the difficulty of having developed educational programmes that did not always produce the intended effect in the HIV+ positive children due to their developmental delays:

Extract 4.24

1 VR: And what aspe::ct (.) of working with HIV positive
 2 individuals do you find most difficult
 3 (4.9)
 4 P5: I think sometimes (0.5) the (0.4) the fact that the
 5 children develop much slower (1.1) you know so (0.4) we
 6 put lots of programmes in place lots of intervention
 7 (0.3) lots of (0.2) and on a child you know (1.2) who is
 8 negative not affected (0.3) those would have astounding
 9 results (0.8) and so:: it can at times be demoralising
 10 when you realise in this setting it doesn't (0.5) it
 11 doesn't produce the same results (0.5) and so sometimes
 12 you (.) you question your own abilities (.) is it cause
 13 I'm not doing it good enough am I not doing (.) enough
 14 (1.3) I think you have to remind yourself what the
 15 capabilities of the children are what their previous

16 delays are (0.4) and that so that (.) at times can be
 17 demoralising where you feel (0.9) shoh (.) if other
 18 children (0.2) who are not infected or affected (0.4) had
 19 these same opportunities (0.9) it would have very
 20 different results

21 (1.3)

22 VR: So how do you cope with those feelings of (0.4) starting
 23 to doubting yourself

24 (2.0)

25 P5: I think I just work harder ((chuckles)) y'd- I think you
 26 do (.) I think you (0.3) you know every time I write a
 27 programme I spend far more time analysing it and far more
 28 time (0.6) wondering am I doing the right thing am I not
 29 (.) and (0.5) and not in self dou::bt (0.2) but in (.) in
 30 that sense in (1.4) I need to know that I know that I've
 31 given these children the best (0.2) programme possible
 32 (0.3) so that when we don't receive those achievements
 33 (0.3) I can almost remove myself from it and say it's not
 34 my fault (1.0) so (0.3) maybe it's the wrong way to work
 35 (0.2) but it's j-just I think I-I manage

First, the speaker here is more or less explicitly describing the reappraisal process. She makes sense of the absence of achievements by shifting the locus of control: she attributes the absence of achievements to the children's developmental delays (external locus of control) as opposed to her own ability of writing an effective educational programme (internal locus of control). That way she can 'remove' herself from the problem and reduce the difficult emotions (guilt; 'it's not my fault', ll. 33-34) associated with it. Furthermore, the speaker also proceeds by saying that 'maybe it's the wrong way to work' (l. 34) but that it is how she manages. The choice of the word 'work' implies that there is some action being carried out. Now, this 'work' could be referring to her actions of developing educational programmes, that is, her actual work. One could, however, also argue that this 'work' refers to her actions of trying to manage; that is, her reappraising meaning. By using the word 'manage' (l. 35) she insinuates that a difficulty is being experienced which she is trying to address. One could then argue that she is

experiencing a dilemma which she is attempting to make sense of; she is reappraising meaning.

The fact that the speaker herself reflects on whether this is the right or wrong way of addressing her difficulties suggests that she has some degree of awareness of the reappraisal process; she is aware that she is engaging in activities to make sense of her difficult experience and emotions. The speaker's doubt regarding the suitability of her method for managing, as well as the previous participant's claim that it was 'a little difficult' to rationalise in that specific situation (Extract 4.23), suggest that attempts to reappraise meaning may not always be successful. Regardless, all of the extracts above show that despite the pervasive sense of control in participants' discourses, the knowledge of HIV which they possessed also rendered them aware that, first, HIV+ individuals are at increased risk of opportunistic infections, and second, that HIV can be an unpredictable illness. As can be seen in the extracts above, participants could use the knowledge they had about the illness to rationalise why they may suddenly no longer have the control they once had. This highlights what may be seen as a contradiction in participants' discourses: on one hand they feel in control because they have knowledge about the disease and thus know what to expect, but on the other hand they also use knowledge to rationalise when there is a loss of control because the knowledge also informs them that the disease is unpredictable.

4.7. Misrepresentative Façade

Thus far it has been demonstrated that a sense of control over HIV was prevalent in participants' discourses but also that these were interspersed with accounts of loss of control. The overall impression, then, was that environments such as Cotlands are misrepresentative façades in the sense that they are high-control environments which almost give the sense that HIV, and other hardships,

have been defeated. This section will illustrate how this misrepresentative façade appeared in participants' discourses, how it stemmed from HIV having 'lost its face', and how there were reality checks that acted as reminders of this misrepresentative façade.

As stated above, Cotlands is a high-control environment. The HIV+ children in Cotlands' residential care centre follow a strict ART programme whereby the duty nurse administer their medication at the exact times, morning and evening. Compliance with medication is thus not a problem at Cotlands residential care centre: first, the children are, arguably, too young to debate this strict programme; second, typically the children eventually become habituated to the routine lifestyle at Cotlands, and medication is part of this routine; and finally, the question remains whether the children would have a choice with regard to their ARTs in any case as it is such a crucial part of the care they receive. Due to the consistent HIV treatment that they receive, (AIDS) death rates are very low and the majority of the children are not noticeably sick. Furthermore, as the participant in Extract 4.26 below describes, the children's various other needs are also met. At Cotlands, then, hardships are controlled and 'it's like everything's OK'.

A more in-depth look, however, reveals that the battle continues, especially outside of Cotlands residential care centre in less controlled areas, such as rural areas. HIV and its associated hardships are then not defeated; rather, the *appearance* of control present at Cotlands is simply a misrepresentative façade. This high-control environment makes Cotlands distinct from how the situation may look in other parts of the country and some participants presented an awareness of this:

Extract 4.25

1 VR: How do you feel (0.5) working with people who have HIV or
2 AIDS or tuberculosis
3 (1.5)
4 P17: It's OK I feel I feel alright because (1.2) back at home
5 (1.0) my younger sister (1.1) she does hav::e HIV (0.7)
6 and (0.9) I think (0.6) she's the one who motivated me

7 (0.5) the most to help other people this side because
8 (1.0) some people are helping her (0.3) the other side
9 (0.5) (w-wa-) (0.5) and (0.3) she's she's now eh uhm
10 (0.6) motivational speaker that side so (1.5) I thought
11 (0.2) why don't I do help other people this side (.) and
12 get some information because (.) you know at the rural
13 areas (.) the information is just (1.3) it's not like (.)
14 broad like this side (.) so I learn this side (0.5) when
15 I go home (0.4) I help her (0.4) there and there there
16 and there

17 (0.7)

18 VR: So when you say this side and that side do you mean rural
19 [and urb]an

20 P17: [rural and urban]

21 P17: Mmmm

The participant in the extract above distinguishes between two spaces: an urban environment, which she refers to as 'this side' (l. 7), and a rural environment which she refers to as 'that side' (l. 10). One aspect in which she differentiates between these two spaces is in the level of information (about HIV) that is available to the people in these areas. The rural area, 'that side', is reported to be not as progressive in comparison to the urban area, 'this side', where people benefit from more extensive information (ll. 13-14). Thus, the rural areas require the assistance of the urban areas where opportunities for learning, and thus controlling HIV, are reported to be far greater.

Similarly, the participant in the extract below had just spoken about how she visited a hospital in an impoverished area the previous day and was struck by all the hardship that the neglected children of South Africa were still facing:

Extract 4.26

1 VR: Do you think that going to the hospital yesterday (0.4)
2 brought about feel[ings and memorie]s

3 P9: [Yes:::] yes very definitely
4 because at Cotlands it's li- (0.2) the residential
5 facility it's like everything's OK (0.3) uhm (0.2) the

6 facilities are good the children have clothes and good
7 food and (0.6) care there's volunteers around them all
8 the time they're receiving a good education (0.3) so you
9 kind of become (0.7) uhm (0.7) not complacent but you've
10 kind of become well everything's OK (0.7) until you go
11 outside and see the reality of (0.2) the other work that
12 we're doing within the (0.3) outreach programmes and you
13 realise everything's not OK (0.5) uhm ten years down the
14 line (1.1) there's (.) very little progress being made in
15 terms of the (0.5) the things I've just mentioned

16 (1.1)

17 VR: Would you say that (.) the international volunteers who
18 come to Cotlands (0.6) and if this is all they see (0.5)
19 would you say that they're getting the wrong picture=

20 P9: =yes totally (0.3) even visitors who come here who only
21 see this (0.3) part (0.3) are getting th- (.) the wrong
22 picture (.) uhm that's been a problem we've had because
23 (.) Cotlands was known as a baby sanctuary (0.5) an::d
24 (.) so so many of our donors and (0.3) just individuals
25 out there think we still only care for these sixty
26 children and that we're such a wealthy organisation
27 because we've got everything we need here (0.6) but if
28 they go out and see the real (0.4) uhm (0.3) problems
29 that we face and the real work that we have to do (0.4)
30 then they would get the true picture (0.8) and even
31 though I've been here for ten years and I've been to
32 visit the (0.3) the outreach projects over and over
33 there's not one time that I go ou::t (0.7) and I come
34 back and I'm not affected (.) every single time I go it
35 affects me even if I'm just taking a group of people
36 (0.4) uhm (0.5) and I'm supposed to be showing them deep
37 down it still (0.6) affects me: immensely

38 (0.5)

39 VR: So it's not your choice to go you have to go because it's
40 part of y[our job]

41 P9: [Yes] yes (0.6) yah

42 VR: Would you choose to get rid of that part of your job=

43 P9: =no not at all I'd like to go more often (1.0) because
44 even though it's difficult you come back more inspired
45 (0.5) to make sure you raise more funds because you wanna
46 (0.3) help those people (0.6) no I (.) it's a it's a very
47 important part (.) to keep it real (0.8) very important

This participant gives a rather overt account of how Cotlands and similar environments can be understood as misrepresentative façades. In giving this account, the speaker does two things. First, she, too, distinguishes between two physical environments: Cotlands 'residential facility' (*ll.* 4-5), and 'outside' (*l.* 11), that is, the rural communities where Cotlands HBC Outreach programmes are employed. The participant first speaks about Cotlands and thereafter about going 'outside' and she associates 'outside' with the Outreach programmes; thus, she implicitly constructs Cotlands as 'inside' – a phrase that others also used when attempting to distinguish Cotlands residential care centre from some other place. 'Inside' is further depicted as an acceptable environment where the children have good facilities, good clothes, good food (in line with the ART requirements, the children are fed at specific times to suit their medication and they are fed generously), and they receive care, including care that addresses psychosocial aspects of their well-being (*ll.* 6-8). In other words, 'inside' depicts what one would typically expect 'normal' children to have and thus 'everything's OK' (*l.* 10). This environment, however, is put in contrast to another situation – the 'outside' – where 'everything's not OK' (*l.* 13) because here the above factors that make 'inside' acceptable are not developed to the same extent. 'Outside', then, hardships are yet not under control.

Second, the speaker refers to this 'outside' environment as 'the reality' (*l.* 11) where the 'true picture' (*l.* 30) can be obtained, whereas 'inside' gives the 'wrong picture'. (It should, however, be noted that the speaker's use of the phrases 'wrong picture' and 'true picture' are presumably a result of my use of 'wrong picture' in the question). This suggests that 'outside', where hardships remain abundant, characterises the more accurate nature of states of affair which further reinforces that the high-control environment at Cotlands, where hardships are under control, is a misrepresentative façade. Finally, the speaker concludes by stating that it is important to go 'outside' and visit in order to 'keep it real' (*l.* 47). This suggests that if one stays 'inside', at Cotlands residential care centre, for too long then one may be consumed by this false environment and lose touch with reality.

4.7.1. HIV Has Lost Its Face

'... it makes me feel like that there is no face of AIDS ...'

The misrepresentative façade revealed in participants' discourses mainly stemmed from the fact that everything *looks* 'normal'. As HIV can now generally be controlled, it can no longer manifest itself to the same extent; accordingly, HIV has lost its face. This was evident in how participants did not perceive the HIV+ children at Cotlands to be sick until they became physically and noticeably sick (recall the previous discussion on participants' use of the phrase 'get sick'). This was briefly touched upon in previous extracts and further evident in the below extracts:

Extract 4.27

1 VR: So how do you feel (.) working with people who are (.)
2 HIV positive (.) or who might have AIDS or TB
3 (0.5)
4 P48: Mmm (0.4) you don't really notice it (0.2) I don't think
5 (0.5) u::hm (.) I suppose also cause (1.0) I don't know
6 we never see the medicine taking side (.) of things
7 unless the children are in the flat being hosted (0.6) so
8 (0.5) they seem like perfectly normal children

Extract 4.28

1 VR: And (0.3) you've already touched briefly on (0.4) what it
2 is like to work here that it brings you hope and stuff so
3 my specific question is (0.4) how does it feel (.) to
4 work with HIV positive individuals
5 (2.5)
6 P3: I don't think I treat or feel (.) different to a normal
7 person (0.5) uhm (.) and aeh for me honestly I think
8 again the reasons why you know it (0.6) but you don't see
9 it so that's why it's not an issue [...] honestly if they
10 don't look sick for [me]
11 VR: [Mm]

12 P3: I- (.) if I don't know (0.6) if I do know they look the
13 same so why treat them any different

Both participants above refer to the disease in a visual manner. For example, the speaker in Extract 4.27 claims not to *notice* the disease (*l.* 4) and also that she does not *see* the HIV medicine being administered (*l.* 6). The second speaker, likewise, says 'you don't see it' (*ll.* 8-9) as well as 'if they don't look sick' (*ll.* 9-10). Both participants further associate this lack of visual manifestation of the disease with a state of 'normal': the first speaker by referring to the HIV+ children as 'perfectly normal children' (Extract 4.27, *l.* 8) and the second speaker by claiming that she does not perceive an HIV+ individual any different to a 'normal person' (Extract 4.28, *ll.* 6-7). Because HIV is no longer physically noticeable, it is also no longer distinct (for example in comparison to other diseases such as diabetes to which participants commonly compared HIV).

Such accounts of how 'normal' their work environment is as a consequence of HIV not being visible were common features of participants' discourses. Because the children were living seemingly healthy lives, their HIV status was often forgotten about. Thus, at Cotlands, where it is not possible at first glance to tell which children are HIV+, everything appears 'normal' – because it *looks* 'normal'. HIV has thus lost its face. This appearance of 'normal' contributed to participants' sense of control over the disease; however, since it is only an *appearance*, it also highlighted that such an environment is a misrepresentative façade.

4.7.2. Reality Checks

Although HIV may have lost its face (at least in a high-control environment such as Cotlands), it seems, however, that it has not fully lost its powers, which further reinforces the image of misrepresentative façades. As demonstrated previously, participants' accounts contained incidents of loss of control. Examples of such incidents include children 'getting sick' (that is, deteriorating or looking

physically/noticeably sick), children not responding to treatment, children seemingly recovering (or hopes thereof) but then passing away the 'next minute', or fears relating to the unpredictability of the disease. Thus, despite a general sense of control, participants were also surrounded by reminders of what they are actually dealing with. These reminders are labelled in this thesis as 'reality checks' because they were moments of realisations in participants became conscious of the reality they are actually dealing with – a serious and most often terminal disease – and how fragile their sense of control is and how easily it can be lost. Reality checks, then, disrupt the superficial appearance of 'everything's OK' or 'normal' or 'everything's under control' and highlight how this sense of control is a misrepresentative façade. Three reality checks in particular were recurring in participants' discourses and these will be discussed below.

Children going to hospital. The extracts below illustrate how Cotlands children being taken to hospital functions as a reality check:

Extract 4.29

1 VR: And what aspect of working with (.) HIV positive
2 individuals do you find most difficult
3 (6.5)

4 P3: Be honest what I can think of is only like (.) like
5 ((child diagnosed with AIDS)) now (0.4) if it is that
6 (0.2) ah yeah she's gone to hospital cause she's very ill
7 (0.2) every time she goes to hospital she's obviously
8 very ill (0.6) and (.) it's for me a scary thought that
9 she might not come back (0.6) uhm (0.3) yah so I think
10 the-the the scary part is that (0.8) if they're gonna die
11 what (.) how you gonna feel how you gonna react you know
12 uhm (0.3) I think years ago when the kids did die (.)
13 more (.) than what they nowadays beco- before
14 antiretrovirals (0.3) it was hard working here I think
15 the staff went through a really really hard time (0.5)
16 uhm (0.4) but yah no if say if if they look healthy and
17 they're fine I don't have a problem dealing with them or
18 interact with them but it's if (they's) (.) taken away
19 (0.6) and you're actually not sure are they gonna come
20 back uhm (0.3) it's kind of like yah (0.4) it's scary

Extract 4.30

- 1 VR: You mentioned before tha::t (.) you get worried when the
2 kids are taken to hospital
- 3 P48: Yeah=
- 4 VR: =why is that:
- 5 P48: I don't know (0.5) be- I think it's becau::se when we::
6 (0.6) when I came here in January (.) to check it out for
7 the day (.) everyone's like oh yeah ((child diagnosed
8 with AIDS)) hasn't got long left (0.4) and it's so it's
9 like (0.8) >every single time< a child goes to hospital
10 you're like ((comic voice starts)) oh no what if
11 something's really wrong ((comic voice ends)) because
12 obviously if they if they do have a (0.5) a weakening of
13 the immune system they are likely to pick up more things
14 and obviously (0.3) they can develop qui- (.) more
15 seriously as () they can de'lop more seriously if you
16 are positive (0.2) is that right
- 17 VR: ((nods))
- 18 P48: I think (.) uhm
- 19 VR: ((chuckles))
- 20 P48: I don't know (0.4) I'm not worried cause (0.4) °I know
21 there's nothing to worry about but° (0.5) it's a bit
22 weird ((chuckles)) (0.7) yeah

The discourses of the participants above display two similar features. First, both participants convey a sense of control. They do so by talking about 'every time' (Extract 4.29, *l.* 7) or '>every single time<' (Extract 4.30, *l.* 9) children go to hospital. The use of such a phrase implies that children going to hospital is a recurring event and, paradoxically, this is what contributes to participants' sense of control. This phenomenon becomes more comprehensible when applying the principles of operant conditioning: behaviour is a function of the environment and altered or maintained depending on the consequences (Oltmanns et al., 2006). Therefore, 'every time' a child goes to hospital – and subsequently returns to Cotlands – it is highlighted to participants' that the child did not die on this occasion either which

gives a sense of still being in control. This sense of control is then reinforced by each occurrence, that is, 'every time' a child goes to hospital (and returns).

On the other hand, both participants also convey an awareness of the risk of suddenly losing this control and perhaps also a fear associated with this awareness. When participants say that 'she might not come back' (Extract 4.29, *l.* 9) or 'what if something's really wrong' (Extract 4.30, *ll.* 10-11), they are, despite having first given the impression of feeling in control, also expressing that this control could be lost anytime and that there are events that highlight this to them. The fact that the second participant states that she is not worried because she *knows* there is nothing to be worried about (Extract 4.30, *ll.* 20-21) only reveals the contradiction in her discourse where, on one hand, the impression of control is given while, on the other hand, a fear of losing this control is oriented towards in her account.

These features of participants' discourses raise interesting links to the story of the boy who cried wolf⁵: the recurring hospital trips are generally false alarms but there is an awareness, and concern, that every single one of them could potentially be a real case of tragedy.

Children bleeding. A second reality check that frequently recurred in participants' discourses was children bleeding:

Extract 4.31

- 1 VR: And how do you feel about (0.4) working with (.)
2 individuals who have HIV or AIDS or tuberculosis
3 (1.0)
- 4 P55: I didn- I don't really think about (0.2) the disease it's
5 for me I just see the children and (0.6) yeah (0.8) I
6 don't really (0.2) think about the (0.3) I mean of course
7 if somebody's bleeding (0.3) you know what to do and not

⁵ A shepherd's boy would time after time call for help, claiming that wolves were attacking his sheep. Every time people would come to rescue, just to find the boy had been hoaxing. One day wolves did in fact attack his sheep and the boy once again called for help. This time, however, people no longer believed the boy and did not come to his rescue (Gibbs, 2003).

8 to (0.7) yeah to protect yourself but (0.6) yeah I don't
9 see the kids as HIV infected kids (0.3) I just see them
10 as normal kids

In the above extract, the speaker first constructs a 'normal' state of affairs where HIV is off the radar and she is simply working with 'normal' children as opposed to a constant conscious awareness that she is working with HIV+ children. This ordinary state, however, is abruptly interrupted with the introduction of blood: as soon as someone starts bleeding the need to protect oneself becomes obviously relevant (*ll.* 6-8). The use of 'of course' in this context, similar to 'you know', implies that this phenomenon is common knowledge, at least among HIV/AIDS aid workers, and almost taken for granted with no debate challenging the validity of the claim (Holmes, 1988). Thus, the risk of infection has implicitly been made relevant and acted as a reminder that the environment may not be so 'normal' after all.

A similar pattern of events is present in the following extracts. The first participant below had just been asked what recommendation or advice she would give someone who wished to come and work with HIV+ individuals:

Extract 4.32

1 P48: Read that manual because (0.3) it's f-so straight forward
2 (0.4) uhm (.) not manual it's like a book (0.2) really
3 straight forward and simple to understand (0.4) u::hm
4 (0.3) as you work with the children >just treat them<
5 like normal children (0.2) then there's nothing wrong
6 with them (0.6) and they don't act like there's something
7 wrong with them so just pick them up ((chuckles)) and
8 toss them around (0.6) uhm (2.0) you don't know their
9 background and you don't know which ones are positive and
10 which ones are negative so (0.5) like I said treat them
11 all the same but (1.1) I remember when ((child)) fell
12 over (0.8) in the playground (.) a:nd she smacked her
13 chin open and there was blood everywhere and I was like
14 (.) ↑aaahhh HIV ((chuckles)) like that's the first thing
15 went through my head and ((child)) wasn't positive (.)
16 and I was like ((own name)) that was really stupid

The second participant was describing how she felt about working with HIV+ individuals:

Extract 4.33

1 P56: I've stopped worrying about it I've kind of like I've
2 (0.6) I've just sort of been like (0.7) oh (0.2) like I
3 d- (.) I know (as) I think it's probably a bad thing
4 because (0.5) like (0.4) I mean I would never change
5 their nappies or anything like that without gloves but
6 (1.0) ehm (3.5) like I'd I don't know it's just something
7 that (0.2) doesn't bother me anymore it's just (1.2) °I
8 don't know° (0.6) I s- I think just (.) after been here
9 for so long it's just (0.3) you put on ru- (.) gloves and
10 then you clean them and then (1.4) I don't know (.) just
11 t-t- (.) d'you sort of forget about it (1.0) I think
12 because there isn't uh like there's not on a daily basis
13 a kid falling over and really badly hurting themself
14 (0.5) so then (0.3) when when they do fall over and hurt
15 themselves like (0.7) you clean it up and then you're
16 like (0.4) oh (1.0) like I forgot to put gloves on or
17 something (.) so then you quickly run and wash your hands
18 and then you panic for maybe (0.3) five minutes but (0.7)
19 then you completely forget about it so

Similar to Extract 4.31, the participants in the two extracts above first give the impression that everything is 'normal'. For example, the speaker in Extract 4.33 claims to have stopped worrying about the fact that she is working with HIV+ individuals (*l.* 1; also note how she implies that exposure has increased her comfort levels by stating that after having been at Cotlands for so long she is no longer bothered anymore, *ll.* 7-9); meanwhile the speaker in Extract 4.32 is heard to recommend others to simply treat the children 'like normal children' (*ll.* 4-5). She encourages others to be playful with the children ('toss them around', *l.* 8), which is how one would expect to behave with children under usual circumstances. At first glance, then, speakers are heard to depict the work environment at Cotlands as one that is seemingly 'normal' and under control with nothing to worry about.

Both participants, however, then proceed to talk about instances of disruption to this seemingly 'normal' environment: events where blood is involved.

Although initially recommending others to treat the children 'like normal children', the first speaker then proceeds by giving an account that can be heard as an instance of when she herself failed to treat the children 'like normal children': her use of the word 'but' (*l. 11*) indicates that the due utterance is in contrast to what has previously been stated. While she has previously urged others to treat the children 'like normal children' she then describes when one of the children fell and was bleeding and her first thought was 'HIV' along with a fear emotion ('and I was like (.) ↑aaahhh HIV', *ll. 13-14*). The contrasting nature of this account suggests that as hard as participants try to maintain an appearance of 'normal' and 'under control', events do occur that disrupt this appearance and one type of these events is when children bleed. In Extract 4.33, the realisation did not occur simultaneously as the reality check (bleeding); it was only later that the participant had the realisation that she had been dealing with blood – blood that was potentially not 'normal' blood but HIV-infected blood – and subsequently panicked. Children bleeding, then, acted as a reality check that reminded participants that the sense of control and appearance of 'normal' may simply be a misrepresentative façade. Furthermore, the notion of bleeding as a reality check that was often oriented towards in participants' discourses reinforces the claim previously made that the infection risk continues to be a significant aspect of working in an HIV environment.

This pattern, of first talking about how 'normal' their work environment is to thereafter proceed by giving an account of how this was disrupted by children bleeding, was fairly common in international volunteers' discourses. Many international volunteers raised the issue of children bleeding as a response to the question asking about the most difficult aspect of their work with HIV+ individuals (question 9, Appendix D) or the question asking about how they feel working with HIV+ individuals (question 8). This specific pattern was, however, and interestingly, very rarely displayed in local participants' discourses. This highlights yet another difference between local and international participants.

Children with physical signs of illness. The final reality check that recurred in participants' discourses was children with physical signs of being sick. This relates to HIV having lost its face as well as the discussion earlier on the phrase 'get sick' and the meaning thereof: children were not considered sick merely by being HIV+, they were only considered sick once they were noticeably sick, such as when they displayed physical signs. Whereas the former gave a sense of control, the latter was a reality check that highlighted the misrepresentative façade. Physical signs of illness as a reality check was often made relevant in the participants' discourses by referring to one of the Cotlands children, the only one with HIV having progressed to AIDS:

Extract 4.34

1 VR: And how do you feel about (.) working with individuals
2 who (0.2) might have (0.3) HIV (.) or AIDS (.) or
3 tuber°culosis°

4 P57: I I uhm (0.3) yeah tuberculosis I (.) don't work with
5 individuals I have tebercus so I can't say anything to
6 that (0.5) but uhm I'm quite uhm uh surprised of myself
7 (0.4) when I came here I had many uhm I was thinking a
8 lot of that (0.4) so (.) I w- I eh in my work (.) whole
9 the day with uhm gloves (.) something like that (.) and
10 when I came here and the children came to me and I'm like
11 (0.2) f- completely (0.4) out of my uh mind (0.5) that
12 they are HIV positive that was (0.2) I f- I think for me
13 it was good (0.3) of course I'm (0.3) I'm when they are
14 bleeding or something like that I'm (0.4) uhm (0.9) uh
15 euh I take attention (0.3) I'm careful (0.4) but uhm (.)
16 I'm very surprised of myself that I can (0.7) handle with
17 it quite well and not always think about (0.4) they (.)
18 will die sometimes I think when I see () for example
19 ((child diagnosed with AIDS)) (0.4) in Hospice (0.7) that
20 is quite then I think oh (0.2) when every- everyone of
21 these children (.) some one day (0.5) are looking similar
22 it's:: (0.2) quite scary (1.0) but yah (0.3) to work with
23 them:'s (0.3) better than I thought yeah

The above extract closely follows patterns previously discussed: first, the speaker depicts a relatively 'normal' work environment, after which he proceeds by introducing reality checks. The former is accomplished implicitly by the speaker

illustrating a mismatch between his expectations and reality. While his comments on one hand suggest that he expected HIV to be far more noticeable ('I'm like (0.2) f-completely (0.4) out of my uh mind (0.5) that they are HIV positive', *ll.* 10-12) and with greater implications on their everyday work ('in my work (.) whole the day with uhm gloves', *ll.* 8-9; refer back to the infection risk and universal precautions), the fact that he found it difficult to grasp that the children were HIV+ and that he is not wearing gloves the whole day every day while at work suggest that the situation is not as bad as he expected – HIV is simply not as noticeable. The speaker, however, then proceeds by delivering the first reality check: 'of course I'm (0.3) I'm when they are bleeding' (*ll.* 13-14) then HIV becomes noticeable and he starts paying attention (*l.* 15). In other words, as noted above, blood was an interruption to the seemingly 'normal' work environment and prompted the participant to take notice that the work environment was actually one involving HIV. There is, however, one more reality check in this account: the misrepresentative façade is further interrupted when the speaker sees the one child who displays physical signs of illness (*ll.* 18-19). He is then reminded that one day all the children may look like that, and that is a scary thought, presumably because it is a reminder of a time when HIV was perceived as a 'killer disease'. Such thoughts are quite the contrary to the otherwise 'normal' work environment where HIV is under control and no longer feared. Children with physical signs of illness work as reality checks because they replace the face lost by HIV/AIDS as a result of increased access to ARTs and subsequently increased control. Physical signs highlight the misrepresentative façade. The use of this one particular child as a reality check was primarily evident in the international volunteers' discourses; it was more or less absent from the other participants' discourses. One rare exception is the first extract illustrating children going to hospital as a reality check (Extract 4.29).

Conclusively, in participants' discourses, different geographical areas appeared to be associated with differing levels of control and in this scenario high-control environments such as Cotlands are the tip of the control iceberg, followed by urban areas and finally rural areas where, in fact, control is more or less absent.

Such high-control environments, then, can be seen as misrepresentative façades, and one of the international volunteers was unfortunate enough to experience this the hard way. International volunteers are given the opportunity to visit the families being supported by the Outreach programme together with the nurse in charge of the Outreach. The volunteer in question took this opportunity, without being prepared for what was waiting. She returned to Cotlands headquarters and Cotlands House distraught and in tears as a result of the privation she had witnessed in the rural areas. In her interview, the volunteer spoke about this experience in response to the question asking for a particularly negative or difficult experience, although she would not label the occasion as 'negative' but was in fact glad to have experienced it because she 'needed to see it'. Other participants, too, made a distinction between the residential care centre and the Outreach project in their interviews, in a way that depicted the former as a highly controlled environment.

This highly controlled environment, however, was occasionally interrupted by reality checks, such as children going to hospital, children bleeding, or children displaying physical signs of illness. Thus, whereas participants' discourses, on one hand, conveyed a sense of control over HIV, these reality checks, on the other hand, also highlight how fragile this sense of control is and how easily it can be lost at anytime. The reality checks, then, act as reminders that the sense of control over HIV at Cotlands is in fact a misrepresentative façade.

4.8. The New Challenges

'... we've come a long [way] but now there're different challenges ...'

The battle over control, then, continues. Although the death rates appear to be under control (at least at Cotlands), HIV/AIDS aid workers are nonetheless faced

with new or other challenges that have the potential to jeopardise their sense of control. One such challenge, dominating participants' discourses and frequently raised as the most prominent work-related difficulty, was a lack of compliance. This final section of this chapter will discuss lack of compliance, mainly in terms of non-adherence to medication, as a barrier to control.

4.8.1. Lack of Compliance As a Barrier to Control

'... I think the most important thing is to get them to buy into going for a test and taking antiretrovirals ...'

The number of participants who raised compliance issues explicitly as a response to questions asking about work-related difficulties equalled the number of participants who raised direct death issues. Closely related to the problem of compliance were also the issues of denial and disclosure (both referring to one's potentially positive HIV status). These three concepts – compliance, denial, and disclosure – were frequently discussed throughout interviews, implicitly as well as explicitly. The first participant below had just been discussing cultural issues, such as Cotlands employees adhering to myths or not wanting to disclose their HIV status, and she was asked to elaborate more on how she dealt with such issues:

Extract 4.35

1 P1: The one staff member that recently passed away (0.4) the
2 one that I've (.) referred to there (0.5) she::: started
3 presenting symptoms that we could all recognise (0.5) and
4 uhm (0.8) and our nursing staff:: (.) uh counselled her
5 and encouraged her to go (.) to be tested which she did
6 (0.4) she we- she she was (0.3) well (.) f-at first (0.4)
7 she resisted (1.5) and uhm (1.1) then eventually she went
8 to (.) uhm (.) she went for a check up (0.6) and uhm
9 (0.5) it was then determined that (.) that she had TB
10 (1.4) but she refused to have an HIV test (0.8) she was
11 prepared to have other tests but not an HIV test (0.7)
12 and uhm (1.7) that was (.) very (.) very difficult (0.2)
13 uhm for me because (.) I was very frustrated (1.6)

14 because I just I couldn't understand I mean we would we
15 were trying to help her (1.0) and she just dug her heels
16 in and she <refused> and she (0.6) she got sick after
17 that she got sick very quickly and she left (0.5) a:::
18 uhm (1.4) a four- (.) I think it was a fourteen year old
19 daughter

The participant then continued by discussing some of the cultural issues impacting on denial and disclosure and finally returned back to the one staff member she was previously referring to:

Extract 4.36

1 P1: This particular staff member (0.4) when (.) sister ((name
2 of employee)) spoke to her and she tried to encourage her
3 to be tested (0.4) she just said no::: (.) and eventually
4 sister ((name of employee)) was quite (0.3) came out
5 quite bluntly with her and said to her you know what
6 (1.3) we you know that we've treated this and you know
7 that we know a lot about it and w- the symptoms that you
8 are presenting (0.4) indicates to us that you have (0.8)
9 uhm so (0.4) there is help so (0.6) why don't you go get
10 tested (0.4) let's have a look and then so that you can
11 be put onto the regime (0.9) and she just said no she
12 doesn't have it (1.2) so that was: it was just (0.3)
13 complete denial she just refused to go

First, the speaker in the extracts above refers to the IES-R (Extract 4.35, ll. 1-2; recall that participants were asked to complete the IES-R bearing in mind the last person they knew who passed away from AIDS). Thus, when she subsequently speaks of familiar and recognisable symptoms in the staff member, she is implicitly specifying HIV and AIDS as the issues under discussion. Second, the speaker further makes relevant that their concerns regarding HIV was communicated to the staff member (Extract 4.36) the symptoms were highlighted, and she was encouraged to get tested and treated for HIV. Despite having drawn the staff member's attention to the possibility of her being infected with a potentially lethal virus, the staff member is nonetheless reported as having refused to get tested for HIV. By reporting this scenario, the speaker orients towards the issue of denial:

despite being aware of the risk of HIV, the individual in question refuses to address this risk, and continues to maintain that the risk is not relevant to her. Eventually, the speaker also explicitly states this denial (Extract 4.36, *l.* 13). Third, the consequence of the staff member's denial is reported as the staff member having passed away. This is implicit in the speaker reporting that the staff member left a teenage daughter behind (Extract 4.35, *ll.* 17-19).

In relation to the scenario above – where the staff member is spoken to about the high likelihood of her being HIV positive, the staff member refusing to get tested or treated, and finally the staff member passing away – the speaker conveys frustration which is attributed to her unsuccessful attempts to *help* the staff member (Extract 4.35, *ll.* 12-15). Here, help can be conceptualised as a two-component act: treating the HIV and preventing death. For HIV/AIDS aid workers, being able to control these two components is important. It has been shown previously in this chapter that these two components *can* be controlled and this is also evident in the extracts above. For example, the speaker explicitly says 'you know that we've treated this' (Extract 4.36, *l.* 6). Furthermore, an association is being made between controlling death and controlling treatment: death can be controlled – or at least premature death can be prevented – if treatment can be controlled. After first having accounted for how they were prevented from controlling treatment of the HIV, the speaker then presents the death of the staff member as a consequence by using the phrase 'after that' (Extract 4.35, *ll.* 16-17). Conclusively, the implication is that if only the participant had been allowed to help by treating the HIV and preventing death, she would have been able to control these matters. As the situation unfolded, the staff member's lack of compliance acted as a barrier to the participant's sense of control, and this was perceived as difficult.

The participant below also speaks of compliance issues when discussing the most difficult aspect of her work:

Extract 4.37

1 P12: I find most difficult is the people that (0.5) they
2 default their treatment (0.9) yah because (0.6) I can't
3 to:: (0.5) go there (.) early in the morning (0.4) maybe
4 seven o'clock if the person is take the tablets seven
5 o'clock (0.4) I can't go there (0.3) seven o'clock (1.0)
6 and seven at night (0.8) you see (0.8) sometimes we find
7 that (0.3) you ask the person you take the pills yes
8 (1.3) and (.) you find that she's lying
9 (3.1)

10 VR: And why is that the most difficu::lt (0.4) aspect
11 (2.6)

12 P12: The most difficult
13 (0.2)

14 VR: Why is it (0.2) when people default (0.4) why is that
15 difficult for you
16 (1.6)

17 P12: Because I-I I want to help but I don't know how (0.8)
18 because I can't be there (0.2) early in the morning (0.3)
19 and I can't be (.) there (0.5) late (.) in the evening
20 (1.8) you see (1.2) so::: (0.8) I find this hard to me
21 (0.4) I am supposed to (.) t- speak to the family (0.5)
22 ask one person that they can look (.) after this (1.9)
23 person (0.5) because (0.4) some o- the mother the parent
24 (0.4) she's passed away (0.9) last year December (1.2)
25 yah (0.4) last year December (0.5) because it she was
26 defaulting (2.8) we try our best (.) but (3.6) when she
27 saw me (0.2) he take the pills (0.8) when ah I'm::: not
28 (.) in (0.4) they don't (0.5) they tell their family they
29 don't want to drink the pills (2.9) is end up passed away
30 leave three children (2.1) with no (1.6) father you see

In terms of compliance, the above participant first makes relevant the problem of non-adherence to medication. (This is in relation to outreach work and mainly with adults; as previously stated, medication adherence is not an issue at Cotlands residential care centre.) The participant reports this non-adherence as being the most difficult aspect of working with HIV+ individuals (*ll.* 1-2), as did many other participants. The lack of adherence to medication is explicitly

mentioned by the participant when she speaks of defaulting treatment. It is also implicitly referred to by the participant implying that if she was able to go to a person's home every morning at seven o'clock and every evening at seven o'clock⁶ then she could ensure that the medication was taken. Second, after having given an example of a client who did not comply with the HIV treatment, the speaker makes a link between non-adherence and death by attributing the death of the client to her non-adherence to medication ('because it she was defaulting', *ll.* 25-26), similar to how the participant in Extracts 4.35 and 4.36 attributed death to denial. (Please note that many South African vernaculars don't have the words 'she' and 'he'. Consequently, when speaking English, many individuals use the English words 'she' and 'he' interchangeably.) Furthermore, this participant, too, states having wanted to help (*l.* 17) and once again – by implying that if she could find a way of visiting the client twice a day at time of medication then she would be able to help (*ll.* 2-6) – help can be conceptualised as a two-component act whereby one, first, controls HIV treatment and, consequently, prevents (premature) HIV-related death.

Finally, the situation is once more conveyed as one associated with feelings of frustration and helplessness. For example, not only does the speaker choose this scenario as an example of the most difficult aspect of her work, but she also reports being lied to (*l.* 8), clients defaulting and passing away despite her doing her best (*l.* 29), and wanting to help but not knowing how to (*l.* 17). The participant in the above extract has, then, clearly expressed how lack of compliance poses a challenge to her as an HIV/AIDS aid worker.

Moreover, some participants initially worked with HIV+ adults through other organisations but eventually transferred to Cotlands in order to work with children (although Cotlands' outreach work also involves working with adults as part of supporting the children's families) because compliance-related challenges were less of a concern with children; however, one could also face the issue of children growing older and subsequently becoming more inquisitive and rebellious

⁶ ARVs need to be taken at certain time intervals, commonly every 12 hours.

with regard to compliance with medication. The work of the HBCWs could include experiences such as receiving information from the hospital about new clients but then arriving at the house where the child was residing and finding the caregiver in denial and refusing assistance from the HBCW. Other kinds of challenges could involve clients who, albeit not in denial, refused to disclose to their family members, which risks limiting the scope for helping.

4.9. Discussion

In summary, on one hand, participants' discourses conveyed a disease management phase whereby they feel in control of HIV, as a result of their increased knowledge of the disease, and thus HIV is no longer considered the 'killer disease' it once was. This disease management phase was evident in participants' confidence when speaking of and conceptualising HIV. Furthermore, there was a lack of death talk in participants' discourses which further reinforced the idea that HIV is now under control. On the other hand, participants' discourses also contained accounts of how their sense of control over HIV was challenged and sometimes lost; consequently, this sense of control appeared as a misrepresentative façade. Thus, although death rates are now under control, contemporary HIV/AIDS aid work involves new challenges. Today, help in an HIV/AIDS context can be conceptualised as controlling HIV/AIDS treatment and consequently preventing, or at least decelerating, and thus controlling, HIV/AIDS-related deaths. The difficulty, then, which present-day HIV/AIDS aid workers face, is to know that such control is possible but be prevented from exercising it, at any of the two stages. In the participants' discourses it was evident that lack of compliance, denial, and disclosure acted as barriers to such control and consequently posed a challenge to them. In the new era of HIV work, as is the case at Cotlands, where knowledge and ARTs are accessible and consequently the trajectory of the illness can be controlled and immediate death can be prevented, death is no longer a prominent issue nor the

trauma it once was; rather, new challenges have arisen in the form of other barriers to control.

Chapter 5. The Micro and the Macro: Control Discourse's Maintenance of HIV Stigma

In the previous chapter, it was illustrated how participants' discourses communicated a disease management phase where man was now in control of HIV, as opposed to the opposite. This sense of control was partly a result of increased knowledge about HIV. Furthermore, this knowledge made HIV less frightening, for example, by decreasing infection concerns. The present chapter elaborates on this notion of increased knowledge and control in relation to infection concerns. Specifically, the aim of the first half of this chapter – The Stigma of HIV – is to explain the role of the micro discourse on control, and blame, in maintaining the stigma attached to HIV. This involves illustrating how participants in their discourses constructed 'rules' – that is, Dos and Don'ts – in relation to HIV, including how, in these discourses, men were considered transgressors of such 'rules'. The aim of the second half of this chapter – Addressing the Stigma of HIV – is to illustrate a sensitivity towards HIV-related stigma among participants and how they managed such issues through normalising discourses and reappraisal of meaning. This chapter, then, endeavours to portray the complexity of HIV discourse and the interplay between micro and macro discourses on the topic.

The Stigma of HIV

5.1. The 'Rules' of HIV: Dos and Don'ts

'... you have to understand the rules ...'

Participants' discourses clearly communicated that there are 'rules', or Dos and Don'ts, of HIV; that is, there is encouraged behaviour that one ought to engage in, as well as condemned behaviour that one ought to avoid. A number of these Dos and Don'ts will be introduced and discussed across the two sections in this first half of the chapter. The imperatives in participants' discourses were applicable to pre-HIV infection as well as post-HIV infection and introduced, for example, by referring to the *responsibility* or *lifestyle* of HIV+ individuals:

Extract 5.1

1 VR: And what is your job here
2 (1.1)
3 P20: My job is to::: make sure that the clients that I have
4 (1.0) they >do take< their medication (0.4) the way they
5 should (0.5) and they take full responsibility of their
6 lives

Extract 5.2

1 VR: The HIV manuals that you mentioned earlier
2 P1: Mhm
3 VR: What did they cover
4 (1.0)
5 P1: Ehm they covered ehm (0.5) what was::: (0.2) uhm: HIV (.)
6 what was AIDS (.) the difference (0.4) uhm (0.4) the (.)
7 uh b-bit of history (0.5) as to (1.2) people's beliefs or

8 reports on how it started (0.3) and where it started
 9 (0.5) uh the transmission: uhm:: (.) the (.) preventions
 10 (0.4) uhm (1.1) eh the stages (.) of the disease (0.5) uh
 11 the symptoms (0.9) uhm and then a- and then the treatment
 12 >and the different types of test< that you could take and
 13 (0.3) what the different tests would be (0.4) yah and
 14 and-and ah and and lifestyle in in (.) that would (0.8)
 15 make some o-or >that would< ehm make someone more
 16 vulnerable to to ehm (1.6) to getting ill

The word 'responsibility' (Extract 5.1, *l.* 5) advocates a duty to carry out certain acts and in this case the responsibility refers to acts in relation to the client's (the HIV+ individual's) life. The speaker further refers to the way clients 'should' take their medication (*l.* 5), insinuating that there is a correct way, and conversely a wrong way, of managing medication. Likewise, the word 'lifestyle' (Extract 5.2, *l.* 14) is typically associated with activities of some kind; for example, a healthy lifestyle usually evokes images of activities such as eating healthy food and exercising. In the extract above the participant argues that there are certain lifestyles that would make an individual 'more vulnerable' to getting ill. Thus, if the goal is to not get ill, which is ordinarily the case in situations involving HIV, individuals need to ensure they pursue a lifestyle that does not make them vulnerable to getting ill; that is, they need to pursue particular activities in order to minimise the risk of getting ill.

These accounts mainly illustrate that there are Dos and Don'ts in relation to HIV; however, with the exception of the first participant's imperative regarding medication, these accounts do not specify what these Dos and Don'ts may be. The following extracts elaborate on this to some extent. The first speaker below had just stated that denial (of one's HIV status) was the most difficult aspect of working with HIV+ individuals, upon which I asked her to elaborate on this:

Extract 5.3

1 P35: You know (.) because you you wanna help you know that you
 2 can help (0.5) you have the necessary resources tools
 3 (0.4) but then (.) obviously you can't force it on

4 clients (.) to t-to-to (0.5) get help (.) w- (.) y-you:
 5 have to make sure that i- you are the same level with
 6 them (0.6) they are ready to get help (0.3) they have
 7 accepted that (.) now (.) I have this disease and then
 8 this is these are the steps that I need to take (0.4) so
 9 you find y-you want them to get out of the denial and
 10 (0.4) they're still (.) there (0.4) you know (0.6) uh:m:
 11 (0.4) you can't be discouraged you keep on trying (0.4)
 12 but then unfortunately sometimes it ends up being late
 13 (0.4) you know and (0.4) when they are almost dying (0.2)
 14 now they wanna accept they wanna tell the truth

This participant focuses on a Do, that is, something that HIV+ individuals ought to do. First, the speaker has previously raised denial as an issue. Additionally, she speaks of being on the 'same level' (l. 5) as the client. With regard to HIV status, HIV/AIDS aid workers are generally of the opinion that a positive status should be accepted, as opposed to denied. This acceptance is often a pre-requisite for HIV/AIDS aid workers being able to help their clients (as illustrated in Chapter 4). Being on the 'same level', then, refers to clients having accepted their positive status; the speaker later explicitly states this – 'they have accepted' (ll. 6-7). Second, the speaker states a consecution: 'now (.) I have this disease and then this is these are the steps that I need to take' (ll. 7-8). With the use of the words 'now' and 'then', the speaker constructs a link between an initial event – that is, having a disease – and what is necessary ('need', l. 8) to follow – that is, various steps to be taken. Finally, the participant reports how it sometimes 'ends up being late' (l. 12) and individuals almost die. The effectively accusing manner in which this is formulated – 'now they wanna accept they wanna tell the truth' (l. 14) – suggests that stopping denying and instead accepting one's positive HIV status, and subsequently taking necessary actions to treat the disease, is something that the individual *should have done* sooner. Ultimately, among the 'rules' of HIV, the purpose of this Do – accepting one's positive status – is to postpone death. This is arguably also the goal of another Do briefly touched upon above in reference to Extract 5.1 where the speaker insinuates a correct way of managing medication: adhering to treatment, the purpose of which is also to postpone death.

The following extract is from a response which exhibited the typical pattern of international volunteers' responses to the question 'How do you feel about working with individuals who are HIV+ or who have AIDS or TB?'. The response initially contained a statement about how normal the work felt as well as an account of blood as a reality check (see Chapter 4), but thereafter the participant proceeded:

Extract 5.4

1 P57: Like I had this (moment) all the time especially with the
2 Cotlands House children (0.4) standing on the balcony and
3 saw them playing and then always thinking like (0.6) they
4 can never really have like (0.4) proper (0.2) they can
5 obviously but (0.8) it's so dangerous for them to have a
6 proper relationship with sex- sexual ehm (1.4) ehm (.)
7 yeah sexual what is it
8 (.)
9 VR: Intercourse
10 P57: Inter[course yah]
11 VR: [Relationship]
12 (.)
13 P57: Yah they (.) they actually not- (0.3) able to (0.2) like
14 (0.6) if you see it from a (0.6) uhm theoretic p- they
15 shouldn't be (0.3) should should do it (.) but obviously
16 they want to do it one day

This participant focuses on Don'ts, that is, something that HIV+ individuals ought not to do. The Don't in question is sexual activity. The speaker commences with an Extreme Case formulation (Pomerantz, 1986) that appears to be a statement that navigates towards the lines of 'the Cotlands House children *can never* have a proper sexual relationship' (ll. 1-7), bearing in mind that many of the Cotlands House children are HIV+. The speaker, however, does a repair (Schegloff, 1992) and clarifies that they 'can obviously but' (ll. 4-5). Finally, the participant qualifies his statement and reformulates it into an imperative: 'they shouldn't' (ll. 14-15). This reformulation of 'can' into 'shouldn't' changes the nature of the statement from one

that is practical into one that is moral; that is, although HIV+ individuals *physically can* engage in sexual activity, *morally they should not*.

Accordingly, one of the Don'ts among the 'rules' of HIV is to not engage in sexual activity; however, this statement may also require some clarifying or further explanation. First, HIV is considered a Sexually Transmitted Disease (STD); sexual transmission accounts for the majority of HIV infections (Royce, Sena, Cates, & Cohen, 1997; UNAIDS, 2010b). Additionally, the participant claims that it is 'dangerous' for them (HIV+ individuals) to have a relationship that involves sexual activity. For an HIV+ individual, then, engaging in sexual activity may involve harm. Altogether, it is not the sexual activity per se that is the issue here; rather, it is the danger, or risk, that sexual activity poses in terms of HIV transmission. This risk undeniably increases in the case of unprotected sexual activity and anecdotal and empirical evidence suggest that condom use is not customary in South Africa (Maharaj & Cleland, 2005). As such, the purpose of this Don't – not engaging in (unsafe) sexual activity – is ultimately to not pose a risk to others.

5.1.1. Men as Transgressors of the 'Rules' of HIV

Of those addressing the 'rules' of HIV, a small number of participants' discourses indicated that there may be a gendered aspect to the topic in the sense that men were often portrayed as transgressors of the 'rules' of HIV. For example, it was illustrated above that in order to not become ill one should lead certain lifestyles while avoiding others. Participants' discourses firmly suggested that, first, with regard to the 'rules' of HIV, polygamy was a condemned lifestyle because it was considered perilous; and second, that such a perilous lifestyle was typically framed as one where a man had many female partners as opposed to a woman having many male partners:

Extract 5.5

1 P1: They weren't prepared to make (.) a lifestyle change
2 (0.5) they said it was their tradition (.) to do (.) you
3 know to to have more than one wife or (0.3) whatever the
4 case is

Extract 5.6

1 P61: You know I mean every culture is nice culture you know
2 (.) you can't say that they are bad or good and better
3 >you know what every< culture because the people living
4 from the culture you know (0.4) you can't say (that)
5 (0.7) is bad (0.3) °(no) you can° (0.2) for example the
6 people here (0.4) if they have ah four woman (0.3) for
7 one man (0.8) is not my problem you know

In the two extracts above, both speakers use the example of men having several female partners as opposed to, for example, the opposite. This is explicitly stated in Extract 5.6 (*ll.* 6-7), whereas in Extract 5.5 this conclusion can only be inferred through the speaker's reference to an entity referred to as 'they' (*l.* 2) which has a tradition that allows this entity to have one or more wives. Since polygamy in South Africa almost exclusively entails polygyny (a man having several wives; Budlender, Chobokoane, & Simelane, 2004), rather than polyandry (a woman having several husbands), one can presume that the lifestyle in question in Extract 5.5 is polygyny.

Furthermore, both accounts suggest that polygyny is a problematic topic. The first speaker says 'They weren't prepared to make (.) a lifestyle change' (Extract 5.5, *l.* 1), suggesting an unwillingness ('weren't prepared') to effect some necessary change. The second speaker claims that a culture where men have several women is not his 'problem' (Extract 5.6, *l.* 7), suggesting that this may in fact be a perceived problem, even though he does not make it his. He also advises that one should not speak of different cultures as being bad or good, suggesting that such cultural evaluations are in fact being carried out. Finally, the two statements

together suggest that a culture where men have several women has been evaluated and generally so in a negative light, hence being perceived as a (potential) problem.

The speaker below expands on why polygamy, or polygyny, is considered a perilous lifestyle and therefore condemned:

Extract 5.7

- 1 P57: And the woman (.) woman as well (0.4) like the- there's
2 no problem if you have a boyfriend you can have (0.5) ehm
3 (.) especially the boys if they have a girlfriend they
4 have <five> girlfriends >or even have the< if they have a
5 wife they still have girlfriends (.) and that is one
6 thing I can't understand [...] it's not ((chuckles)) it's
7 not ehm (.) productive (0.4) for the i- m- for
8 (resolving) the issue yah
9 (0.6)
- 10 VR: Why do you think it's not productive
11 (0.3)
- 12 P57: Eh because (.) HIV AIDS (.) I mean (0.4) the most thing
13 that people get infected is is sex (0.6) ehm (0.4) I mean
14 I-I think so ((chuckles)) it is is sex (0.5) ehm even if
15 there are other ways to eh get infected I think sex is
16 the most important one (0.4) and if you have like five
17 girlfriends in a country where maybe every third °or
18 fourth woman I don't know the statistic exactly° (0.4)
19 ehm has HIV AIDS and you have fi(h)ve girlfriends then at
20 least one (.) statistically has HIV AIDS (0.3) and then
21 if (.) the man does it it's (0.4) kind of (.) that (.)
22 all five woman get get it as well and then (0.8) yah
23 (0.5) you- (0.5) you can't without w-with having so many
24 girls and girlfriends then why ((chuckles))
25 -s can't (it might be) () you can't (0.4) get hold of
26 it's eh sexual transmitted disease (0.2) which is not
27 (0.3) able to be cured yet (.) properly

The interview then proceeded with a discussion on breastfeeding and eventually returned to the topic of reducing infection rates upon which the participant continued:

Extract 5.8

1 P57: Yah and then all the issues like how (.) how ma::n (0.2)
2 treat woman and then they say uhm (1.4) th- the w-wife
3 brought bro(h)ught HIV in the family but everyone knows
4 that the (0.4) bo- the husband has four girlfriends
5 anyway and the (.) wife never cheated on him

Although this speaker does to some extent implicitly acknowledge the existence of polyandry (Extract 5.7, *ll.* 1-2) – and this existence can be confirmed by ethnographic data – this phenomenon was rarely present in participants' discourses; as a matter of fact, the participant instead proceeds with 'especially the boys' (*l.* 3), once again underscoring men and polygyny as problems.

That sexual transmission accounts for the majority of new HIV infections and that condom use is not customary have already been discussed previously. The speaker above, then, can be heard to use this knowledge in combination with statistics and logic (*ll.* 12-22) in order to justify the construction of men as 'perpetrators': men who continue to engage in polygamy are being held accountable for preventing the containment of the STD HIV by engaging in sexual activity with several partners. (Although the speaker's argument is based on an assumption that these men engage in sexual activity, this is often the reality as opposed to merely an assumption.) Thus, men are being held accountable because they violate a Don't: they engage in (unsafe) sexual activity and subsequently pose a risk to others. The participant lastly claims that women are often blamed for infecting their families with HIV although 'everyone knows' it is the husband who has several partners (Extract 5.8). In Chapter 4 it was discussed how the use of the word 'know' gives an account a factual character as opposed to conveying simply a belief, and the speaker here can be heard to construct his claim about women erroneously receiving blame when men are in fact at fault as general knowledge. In participants' discourses, then, men were being oriented towards as 'the perpetrators' with regard to failures to contain HIV. It was, however, not only polygyny that resulted in men being held

accountable; men were generally seen as leading perilous lifestyles, often in a sexual manner, and not adhering to the 'rules' of HIV. The following participant had just reported feeling angry and frustrated on behalf of HIV+ individuals, and in particular children, and asked what this frustration was directed at:

Extract 5.9

1 P62: I get- (0.3) angry at other people's ignorance (1.0) uhm
2 (0.3) and when I say that I mean governments for not
3 educating (0.8) uhm (.) I get (0.4) angry at people for
4 not taking precautions like (0.3) when you just
5 constantly hear stories about (1.2) m- fathers that
6 impregnate (0.7) mothers full well knowing that they're
7 HIV positive and not telling them and uhm (1.2) for
8 people not getting tested

Once again, in the account above, men are the focus of condemned behaviour. The behaviour in question involves impregnating another person despite being HIV+ and having knowledge about this (*ll.* 5-7). More specifically, the example provided by the speaker involves a man impregnating a woman. Arguably, women cannot impregnate men; nevertheless, when providing an example of people 'not taking precautions' (*l.* 4), the example offered by the speaker was one involving *men* not taking precautions because they engage in unsafe sexual activity and consequently pose a risk to others; ultimately, men were depicted as not following the 'rules' of HIV.

The next participant had just stated that men could be very 'ignorant':

Extract 5.10

1 VR: Why do you say that male can be ignorant
2 P36: >Well I mean< most of m-m- (.) males that I've come
3 across are actually very ignorant (.) when it comes to
4 HIV (0.2) they don't wanna go for HIV testing (0.4) they
5 don't wanna know about HIV they know HIV's there but they
6 (.) choose not to know about it (0.3) and they >choose
7 not to talk about< it (0.3) and yet they engage in very
8 unsafe (0.2) sexual behaviour (.) >you know what I'm

9 saying< (0.4) a:nd (.) you and you ask them (0.4) are you
 10 using condoms why should I use condom (0.8) how many
 11 sexual partners do you have (0.2) three (1.1) hello
 12 ((chuckles)) you know and eh (.) all of those things and
 13 you ask them have you been for an HIV test (0.2) no I
 14 haven't been but why (0.3) no I don't need to (.) you
 15 know

First point to note is the speaker's use of the phrase 'most of' (l. 2), a discursive technique for generalising and thus implying that men in general are ignorant in relation to HIV. To be ignorant of something is to not know something one ought to know, or not know the correct way to behave. When the speaker then proceeds with her three-part-list (Jefferson, 1990) – 'they don't wanna go for HIV testing', 'they don't wanna know about HIV', and 'they >choose not to talk about< it' (ll. 4-7) – it suggests that getting tested for HIV, having knowledge about HIV, and talking about HIV are things that everyone should know or do in relation to HIV; she thus constructs a number of Dos. Men, however, do not do these things and therefore men are labelled 'ignorant' because they do not behave according to the 'rules' of HIV. Furthermore, when the participant enacts a hypothetical conversation between an enquirer and a man who claims not to be using condoms, and the participant eventually concludes by saying 'hello' (ll. 9-11), the 'hello' (and the succeeding chuckle) serves to signify knowledge that is obvious. The speaker's frequent use of the phrase 'you know' (ll. 8, 12, and 14-15) further functions to obtain agreement that her statements are 'mutual background knowledge' (Östman, 1981, p. 17; also see, Holmes, 1986). The participant then constructs the importance of condom use in preventing HIV transmission as a widely known and accepted phenomenon, as well as men's failure to comply with such expectations. By highlighting the role and importance of condom use, the speaker conveys another Do, once again with the purpose to not pose a risk to others: using condom when engaging in sexual activity. Men's violation of the 'rules' of HIV is thus two-fold: they simultaneously violate the Don'ts (not engaging in unsafe sexual activity) and the Dos (using a condom when engaging in sexual activity).

A final Do is presented in Extracts 5.9 and 5.10: getting tested (for HIV). Ultimately, in order to be able to postpone death and not pose a threat to others, one needs to know if one is HIV+; thus, one needs to get tested. In Extract 5.9, the speaker completes her three-part-list by stating that she gets angry at people for 'not getting tested'. In Extract 5.10, too, the speaker can be heard as denouncing men for not getting tested ('have you been for an HIV test (0.2) no I haven't been but why', *ll.* 13-14). She also constructs getting tested for HIV as the first Do of her three-part-list (*l.* 4). Another participant also said while discussing disclosure of one's HIV status:

Extract 5.11

1 P26: And the male they must go and get tested (0.4) <because
 2 males they don't go and get tested> (0.5) until their
 3 (0.5) female partner get pregnant (.) that's (where) they
 4 (0.3 (I) say oh (I will) (0.5) have the () (0.3)
 5 when she's negative (0.3) I know I am negative (1.5) you
 6 must go out and get tested too

The Do getting tested is explicitly stated by the speaker above in the form of an imperative: 'must go and get tested' (*l.* 1). In particular, the speaker directs this imperative towards men; she is not speaking of people in general getting tested, but rather she is instructing men specifically to go and get tested because they are considered not to be adhering to this Do (*ll.* 1-2). Yet again, the participant speaks of men not getting tested in a generalised way – through the plural 'males' (*l.* 2).

Conclusively, participants constructed a number of 'rules', or Dos and Don'ts, of HIV in their discourses, such as getting tested for HIV, accepting one's positive HIV status, adhering to treatment, and not engaging in (unsafe) sexual activity by using condoms – the purpose of these being postponing death and not posing a risk to others. Furthermore, participants could be heard as perceiving men as not adhering to these 'rules', and for this the men were being held accountable in participants' discourses.

5.2. Micro Discourses on Control Maintain Macro Discourses on Stigma

The notion that the micro discourse on control maintains the macro discourse on HIV stigma is based on HIV contraction being perceived as controllable. This section will, first, illustrate how participants in their discourses constructed HIV contraction as more controllable than TB contraction, and thereafter how HIV contraction, because it is perceived as controllable, consequently is also constructed as avoidable and blameable.

5.2.1. HIV Contraction is More Controllable than TB Contraction

‘... I think people seem to be more accepting of going for a TB test than an HIV test ...’

Albeit heavily focused on HIV, this thesis and the interviews conducted for it also address the issue of TB, as these two diseases are largely interrelated (see Chapter 1). As a result of the ethnography, it can be established that this association is readily acknowledged; for example, one nurse presented HIV and TB as ‘twins’ during a training session. The two diseases were, however, also differentiated. For instance, the imperatives that were prevalent in participants’ HIV-related discourses were generally absent from their TB-related discourses. One possible explanation for this phenomenon, as demonstrated through the extracts below, is that HIV contraction is considered to be more controllable than TB contraction.

The first speaker below had just been asked how he felt about working with HIV+ individuals. It is noteworthy that although in most instances this interview question (question 8, Appendix D) addressed HIV, TB, and AIDS, in this particular

case the question only addressed HIV. The participant's response involved stating that he thought 'a lot of people would be completely freaked out':

Extract 5.12

1 VR: Why do you think it would freak most people out
2 (1.0)
3 P45: It's just not a normal thing to deal with I don't think
4 (0.2) nn (0.6) people are scared of disease (.) obviously
5 (0.6) nn (0.6) especially- such serious °ones° (0.6) and
6 the and to be honest they should be scared of:: things
7 like tuberculosis because it does spread pretty easily
8 (1.1) °and it can° (.) be quite severe

The next participant was describing the most important thing she had learnt about HIV/AIDS and TB since she started at Cotlands:

Extract 5.13

1 P29: Eeh:::: (0.6) the most important things I've learnt about
2 the three is that (0.6) ↑you (0.2) can (0.7) prevent
3 yourself from getting <HIV> (1.3) eh:: (0.3) (by those)
4 () the-they-they-they- they teach us because we go to
5 the courses then they will talk that this is how you get
6 AIDS and HIV (0.3) then if you ↑stick to that and keep it
7 in mind that oh (0.4) I don't want to be really (0.2)
8 affected or in- infected especially (.) >I don't want to
9 be infected with this then you stick to that< (0.5) you
10 (0.4) avoid (0.3) anything that they said you were going
11 to catch it (0.3) yah but with TB (0.7) eh it's still a
12 problem (0.2) even now because you still can get it in
13 even in a taxi (0.2) wherever where's there's (.) public
14 (0.4) eh::: people gather together still there's a risk
15 (0.3) so:: I don't think there's anything that I can do
16 to-to run away from TB (.) anytime I can get it

In both these extracts there is an implicit statement that TB is less avoidable than HIV. The first speaker, for example, only refers to TB, but not HIV, as a disease that is severe, spreads easily, and that one should be scared of (Extract 5.12, ll. 6-8; recall that the interview question only addressed HIV, and not TB, in this instance).

In Chapter 4 it was argued that increased knowledge made HIV less frightening partially because it decreased infection concerns. This participant justifies being scared of TB by how easily it spreads. The second participant also addresses the ease of TB transmission and concludes that there's nothing she can do 'to run away from TB' (Extract 5.13, *ll.* 15-16). She also states that TB is 'still a problem' (*ll.* 11-12). By contrast, most importantly she has learnt that HIV contraction can be prevented (*ll.* 1-3): *if one wishes not to contract HIV then one needs to avoid all the modes of transmission that one has learnt about (ll. 4-11)*. If-then formulations are commonly used discursive resources for inferring temporal sequence, causality, and accountability (Edwards, 1997; Sneijder & te Molder, 2005). There is thus an implicit undertone in these accounts that although TB is still a problem and cannot be escaped, HIV is no longer such a problem as it does not spread as easily because transmission can be controlled. Contracting HIV is, thus, not only *more* controllable than contracting TB, but HIV contraction *is* controllable whereas TB contraction is not.

5.2.2. HIV Contraction is Controllable, Avoidable, and Blameable

The following extracts further illustrate how HIV contraction is perceived as controllable *and* avoidable. The first participant below was responding to whether it ever worried her to come to an area so badly affected by HIV:

Extract 5.14

1 P58: Never even crossed my mind (.) uhm (0.5) I think I
 2 must've (0.2) had a basic understanding of transmission I
 3 guess and I just (0.3) I knew it's not something that you
 4 catch from just being around people who are positive
 5 (0.4) u:hm (.) yah so I guess I knew the basics about
 6 that and that (0.3) it really takes uhm (0.9) fairly (.)
 7 significant contact be that sexual od or needle sharing
 8 or blood contact and- fluids and things so (0.6) <I> was
 9 fairly su:re that I (.) >that I'd be able to take< (.)
 10 necessary precautions for that not to be a risk for me

Extract 5.15

1 VR: And how do you feel about (.) working with (0.2)
2 individuals who are HIV positive or who have AIDS or TB

3 P62: Mmm (0.6) °uhm I don't have a problem with that at all°
4 (1.1) uhm but as I said my background I've dealt with (.)
5 a lot of people with different disabilities mental
6 physical (0.6) uhm (1.1) >and I've always been< raised to
7 treat people equally (0.8) so (0.2) °that doesn't affect
8 me at all like I'd° (1.5) ((coughs)) I don't have
9 concerns about myself catching it because I know (0.7)
10 I'm extremely careful and I take precautions (0.8) uhm
11 (.) >all the safety precautions that you're supposed to
12 take<

There are three main points to be made about the two extracts above. First, the response in the second extract contains a feature highlighted in Chapter 4: participants orienting to the topic of infection risk (*ll.* 8-9) in response to the interview question 'How do you feel about working with individuals who are HIV+ or who have AIDS or TB?'.

Second, both participants produce utterances that suggest that HIV contraction is controllable and avoidable. For example, they talk about 'basic understanding of transmission' (Extract 5.14, *l.* 2) as well as (necessary) 'precautions' (Extract 5.14, *l.* 10; Extract 5.15, *ll.* 10 and 11). Whereas the second participant states not being concerned about catching HIV *because* she is careful (Extract 5.15, *ll.* 8-10), presumably because of the precautions taken, the first participant was fairly confident she could take 'necessary precautions' for HIV contraction 'not to be a risk' for her (Extract 5.14, *ll.* 8-10). These 'because' and 'for' formulations resemble the if-then formulation discussed above: if one does X, then Y will follow. In sum, the two participants are implying that as long as they take the necessary steps they are able to control and avoid becoming infected with HIV.

This, then, relates to the third point: that pre-HIV infection Dos and Don'ts were prevalent in participants' discourses. The Do in Extract 5.15, 'the safety precautions that you're supposed to take<' (*ll.* 11-12), corroborates the claim that

participants' discourses contained Dos and Don'ts in relation to HIV, that is, legitimised behaviour that one ought to engage in ('that you're supposed to') and condemned behaviour one ought to avoid, pre-HIV infection as well as post-HIV infection (as discussed above).

These 'rules' of HIV, however, contribute to maintaining the stigma attached to HIV. They do so because they maintain the *blame* component of the disease. HIV stigma is routinely coupled with the perception of an individual's character and *lifestyle*, which in turn are often dependent on the prevailing norms in any given society. These norms, then, define the 'rules'. HIV contraction is often perceived as resulting from certain behaviours, or lifestyles, that in many societies are not highly regarded, such as promiscuity. As such, HIV contraction is often perceived as a transgression of 'rules'. When participants suggest that it is possible for them to control and avoid HIV contraction by following certain Dos and Don'ts, it implies that it is possible also for other people to control and avoid it by adhering to the same rules. Thus, if an individual subsequently contracts HIV, in a context where HIV contraction is perceived as avoidable, it implies they failed to take necessary action to prevent such contraction; consequently, it is their own fault that they are now HIV+. This is further reinforced by statements such as '>I don't want to be infected' (Extract 5.13, ll. 8-9) – the word 'want' implying that HIV contraction is a *choice*. Perhaps an extreme case can be found in the following extract where the participant is heard to say that HIV will not be contracted 'if you're sensible':

Extract 5.16

1 P48: It's not like (0.2) you're gonna touch them and you're
2 gonna get it like it's under the very rare and
3 unfortunate circumstances if you do (0.2) I think (0.3)
4 and if you're sensible then (0.9) °you don't get it so°
5 (0.9) don't freak out

This speaker, too, rejects HIV transmission as an easily occurring phenomenon. Furthermore, an if-then formulation is produced (l. 4) in which being

sensible precedes not getting HIV. Thus, by exercising sound judgement one can avoid becoming infected with HIV.

The line of argument here is understandably very bold and very controversial. It is, however, by no means to say that participants were purposely stigmatising HIV+ individuals. In fact, a further analysis reveals that participants employed such talk in order to *avoid and counter* stigmatising of HIV+ individuals. For example, the participant in Extract 5.14 above states that 'it's not something that you catch from just being around people who are positive' (ll. 3-4), and the latter speaker says similarly 'It's not like (0.2) you're gonna touch them and you're gonna get it' (ll. 1-2), while the speaker in Extract 5.15 initiates her response by reporting how she has no problems dealing with HIV+ individuals because she has extensive experience in the past dealing with individuals with various disabilities. Both groups of individuals – those who are HIV+ and those who have disabilities – are often stigmatised, and associating with stigmatised individuals can sometimes be stigmatising in itself (this claim is further discussed below). As such, participants can be heard to counter this stigmatisation by stating that they do not perceive such associations to be troublesome. The predicament only emerges when they begin to account for this: they state they have no fears ('don't have concerns', Extract 5.15; 'never even crossed my mind', Extract 5.14) because they *know how to avoid infection*. Thus, the participants' micro discourse on HIV knowledge and control may, on one hand, be explained as an attempt to avoid and counter stigma, but, on the other hand, can be found to effectively backfire and instead maintain the macro discourse on HIV stigma by maintaining the blame component.

This final extract below, in which a participant is discussing a lady who supposedly lost both her daughter and her son as a result of AIDS, illustrates several points made hitherto:

Extract 5.17

1 P11: The boy (0.7) had just (0.3) he had known lo:ng long ago
2 (0.7) and he was he himself was living in denial (0.4)

3 and he just lived his life recklessly (0.5) until it
4 started like (0.5) eating him up inside (0.4) and he he
5 died of (0.5) (at) some swelling or something (0.5) that
6 that he eventually was diagnosed () the whole thing
7 (1.0) but (0.2) til the end you know (0.7) did-didn't say
8 you know what (.) this is the real actual reason [...] it's
9 not that I'm saying broadcast to everybody oh this one
10 had HIV and AIDS oh (0.6) but to yourself I think (0.4)
11 to work it for yourself and (0.4) to work it for your
12 family you know like close family (0.7) just say you know
13 what that's the reality of the situation cause we're not
14 gonna judge you (0.5) they were two adults (0.7) they-
15 they made their own decisions (0.3) for themselves (0.4)
16 so

17 (1.5)

18 VR: So why do you think they were in (.) denial like why
19 would anyone be in denial when they have such a disease

20 (1.8)

21 P11: Because they don't believe that the disease is rea- (.)
22 is a reality (0.4) firstly (0.3) and secondly for the
23 (0.2) eh tf- they're ignorant (0.2) and then thirdly for
24 (a) reputation (0.5) you know (0.2) they would then be
25 (.) be (.) be labelled (1.2) you know [...] you know what
26 (0.8) open up (.) you don't have to open up to everybody
27 (0.4) but you know (0.3) open up and own up (0.4) to:
28 that I lived a life that was reckless and irresponsible
29 (0.4) an- (0.6) this is my consequence an- (0.5) I think
30 they would've lived much longer (0.4) if they had done
31 that (0.4) because (0.2) they th- you know (0.2) they
32 also just (.) then they just live their lives (0.8)
33 without worrying (1.4) and and (0.3) for me the girl
34 lived just continued to live a life that was (0.4) just
35 not good and yet she knew she had two kids (1.1) and if
36 anything happened those t-two (.) those kids would be
37 left behind

First, the extract illustrates Dos and Don'ts that appeared in participants' discourses. For example, the speaker addresses a Do and a Don't raised by other participants: accepting one's positive HIV status as opposed to denying it. When the speaker (implicitly) refers to HIV and AIDS as the 'real' and 'actual' reason for the person's death (ll. 4-10) it implies that any other explanation for the death is simply a sign of denial. The speaker further advises that although one may not want to

disclose one's HIV status to everybody, one should at least be honest about 'the reality of the situation' (l. 13) with oneself and one's family.

Second, it illustrates that HIV stigma is coupled with particular lifestyles and an individual's character, and that this maintains the macro discourse on HIV stigma by maintaining the blame component of the disease. For example, the speaker talks about the two people passing away having previously lived 'reckless and irresponsible' (l. 28) or 'not good' (l. 35) lives, with the former phrase in particular insinuating, first, that the HIV/AIDS and death were consequences of prior actions, and second, that the person acted disregarding of the consequences. The person is subsequently held accountable for the consequences (having contracted, and subsequently died from, HIV/AIDS) of their actions (the lifestyle they led), not least through the use of the phrase 'own up' (l. 27) which suggests that a person has engaged in negatively valued behaviour. Furthermore, the speaker concludes a three-part-list by claiming that individuals who disclose being HIV+ subsequently suffer being 'labelled' and acquire a 'reputation' (ll. 21-24), two words that, albeit theoretically neutral, in everyday speech generally have negative connotations. The phrase 'they would then be' further implies that such labelling is an inevitable consequence of HIV disclosure, and the phrase 'you know' once again seeks agreement with this statement as common knowledge.

Finally, the extract illustrates some degree of awareness of the tension between the micro and the macro, that is, between perceived controllability and blame and stigma. For example, the speaker says 'we're not gonna judge you' (ll. 13-14). This statement suggests, first, that such judgements are generally being made (as later illustrated throughout this extract), and second, that participants themselves were sensitive towards being perceived as making such judgements.

5.3. Discussion

In summary, this chapter has so far demonstrated that participants in their discourses introduced a number of Dos and Don'ts applicable to pre- and post HIV-infection and aimed at postponing death and preventing risk to others. These 'rules' of HIV defined legitimised and condemned behaviour, and participants' discourses further suggested that men were often perceived as transgressors of these 'rules'. These 'rules' also contributed to HIV contraction being perceived as controllable, and therefore avoidable. Participants drew on this notion in order to counter the stigma of associating with HIV+ individuals: they claimed that working with HIV+ individuals did not worry them because they knew how to avoid infection. Due to HIV contraction being perceived as controllable and avoidable, it was consequently also perceived as blameable: individuals who contract HIV are perceived as not having adhered to the 'rules' and are, therefore, held accountable for their fate. The micro discourse on control, then, maintains the macro discourse on HIV stigma by maintaining the blame component of the disease. Participants' discourses further suggested they were sensitive towards stigmatisation of HIV+ individuals and the next section will illustrate how participants in their discourses addressed the stigma of HIV.

Addressing the Stigma of HIV

‘... it is just another disease ...’

This second half of this chapter will demonstrate how participants’ discourses indicated that HIV work is problematic, due to stigmatisation, and how participants normalised HIV, for example by comparing HIV to other illnesses (similar to the normalisation discussed in Chapter 4). This chapter will conclude by demonstrating how participants reappraised meaning in response to stigma.

5.4. HIV Work as Problematic Work

Earlier in this chapter it was claimed that associating with stigmatised individuals can sometimes be stigmatising in itself. This section aims to illustrate this claim. The objective of this study was to investigate the potentially traumatic effects of AIDS-related bereavement on HIV/AIDS aid workers. As such, all participants were asked how they felt about working with individuals who are HIV+ or who have AIDS or TB (see question 8, Appendix D) in the hope that they would raise negative or difficult aspects of their work, perhaps by discussing the issue of AIDS-related bereavement, their experiences thereof, and any emotions associated with such experiences. The question generally elicited three types of responses. The first category of responses contained a range of miscellaneous answers: it is fulfilling, it is sad, it is an important job, it was difficult before (when people were dying) but no longer, and a few participants stated they felt ‘nothing’. A second category of responses included a number of participants who responded that working with HIV+ individuals was *not a problem*; additionally, some said there was ‘nothing wrong’ with such work or they were not ashamed, bothered, or

worried. This second category of responses is interesting discursively and interactionally, as will be explained next.

The concept of an adjacency pair in conversation refers to how a *particular* first utterance – the first part of a pair – by one speaker, requires a *particular* second utterance – the second part of a pair – by the next speaker; for example, if the first utterance is a question, the appropriate second utterance then is an answer (Schegloff, 1992; Woffitt, 2005). Extending this concept, by analysing the second pair-part (the answer), the second speaker's understanding of the first pair-part (the question) may be inferred. In other words, by analysing the participants' responses it is, arguably, possible to infer how they treated the interview question(s). When participants respond to the question 'How do you feel about working with individuals who are HIV+ or who have AIDS or TB' by stating that such work is not a problem, it suggests that such a question can be heard as insinuating that this kind of work may be problematic. This type of response is present in Extract 5.15 where the participant replies 'I don't have a problem with that at all' (l. 3) as well as in the following three extracts which all were responses to the above stated question:

Extract 5.18

1 P30: Me I'm quite comfortable with them (0.4) there's no
2 problem totally

Extract 5.19

1 P31: You know I don't have a problem with that I don't

Extract 5.20

1 P37: You know what it was difficult when (0.3) this eh (1.0)
2 uhm (2.3) what we called (2.0) when we was work- we start
3 working with the kids e- HIV (0.3) positive it was
4 difficult (0.6) because (0.5) even (0.3) at (0.3) by the
5 street (0.6) once you wear the: (.) clothes or Cotlands's
6 name or what Cotlands uniform (0.9) ((patronising voice

7 starts)) don't (.) go to nearby (0.5) she's working with
8 the (0.7) HIV (.) e::h kids (0.5) you'll be infected
9 ((patronising voice ends))

In Chapter 4, it was demonstrated how infection risk is still a concern among HIV/AIDS aid workers and that this risk is not only a concern with respect to themselves but also with regard to their families. This highlights how HIV/AIDS aid work may be perceived by others, that is, as a threat.

The latter speaker above describes how others would shy away and avoid her ('don't (.) go to nearby'; *l. 7*) when they discovered (through her Cotlands branded clothes; *ll. 5-6*) that she worked with HIV+ individuals. The speaker further claims people would shy away because they believed they would otherwise become infected with HIV ('you'll be infected', *l. 8*). Other people, then, presumed that because the speaker worked with HIV+ individuals she, too, was now infected and that she would subsequently infect anyone in her vicinity. The participant also labelled this kind of experience as 'difficult' (*l. 4*). Thus, HIV/AIDS aid workers may be perceiving their work as potentially problematic in two ways: first, there is the issue of their own concerns about infection risk, and second, there is the issue of how others may perceive them as a risk. The latter suggests that it is not only HIV+ individuals who struggle with the stigma attached to the illness but that HIV/AIDS caregivers also may be experiencing some of this stigma. This, then, is arguably one reason for why the question 'How do you feel about working with individuals who are HIV+ or who have AIDS or TB?' is heard as insinuating that such work is problematic. Consequently, participants' responses would assert that they did not consider the work, or the potential stigma, problematic.

5.5. Normalisation of HIV

The third category of responses was those stating that it felt 'normal' to work with HIV+ individuals. These responses relate back to the discussion in Chapter 4 regarding high-control environments such as Cotlands as misrepresentative façades where everything *looks*, and thus feels, 'normal'. (Recall that these responses were particularly prevalent among international volunteers and often followed by an account of infection concern or bleeding as a reality check.) Responses from this category often included a comparison with how it feels to work with a 'normal' person:

Extract 5.21

1 VR: How does it feel to work with HIV positive individuals
2 (2.5)
3 P3: I don't think I treat or feel different to a normal
4 person

Extract 5.22

1 VR: So how do you feel about working with individuals who are
2 HIV positive
3 (1.1)
4 P46: They're just another normal person like (.) you and I
5 (0.4) a- (0.3) doesn't even (.) enter my brain

Intuitively, one may then wonder how a 'normal person' may be defined. The answer to this could arguably be found by turning to the original question being posed to the participants, that is, the first pair-part. First, participants' answers – the second pair-part – contain an element of comparison and contrast: the entity in question is being compared, and contrasted, to a 'normal person' – in Extract 5.21 by emphasising a lack of difference and in Extract 5.22 by emphasising

similarity. This entity is defined in the original question as an 'HIV+ individual'. In contrast to this, then, a 'normal person' may then be defined as an 'HIV- individual' (HIV negative). This line of argument is further corroborated by the second extract where the speaker continues the 'normal person' phrase with 'like (.) you and I' (l. 4) (both HIV- individuals).

By comparing HIV+ individuals to 'normal' persons it is not to say that participants see HIV+ individuals as *abnormal*. On the contrary, such terminology is arguably employed in an attempt to normalise HIV in order to reduce the stigma attached to the disease. In a similar vein, stating that working with HIV+ individuals is 'not a problem' fulfils a similar purpose. Conclusively, the formulations of participants' responses imply that HIV+ status as well as HIV/AIDS aid work is associated with stigma, that inherent in the interview question is an insinuation that HIV+ individuals are different in a negative way, and, finally, that participants are sensitive towards engaging in such stigmatising behaviour.

5.5.1. Comparison of HIV with Other Illnesses

In Chapter 4 it was illustrated how participants compared HIV to other illnesses which are perceived as under control and less frightening (such as the flu, diabetes, hypertension, or asthma) in order to show that HIV, too, is under control and less frightening than it used to be. Participants also employed this discursive technique in order to address the stigma associated with HIV. For example, the first participant below was discussing the frustrations of dealing with HIV+ individuals in denial who refuse treatment:

Extract 5.23

1 P2: I mean somebody who has (0.6) who knows that they're
2 diabetic is not gonna refuse treatment (0.3) you know
3 tha- (.) yah or who has a heart condition is not gonna
4 refuse treatment so why would they refuse treatment

Extract 5.24

1 VR: Is there anything that you want to add (.) anything that
2 I (0.4) haven't asked you (.) that you feel is important
3 to mention (1.0) or anything (.) that you want to talk
4 about or

5 P26: I like to say thanks to et- to the ARVs treatment (0.4) I
6 wish our government can supply °them more often° (0.4)
7 and I wish the mothers to be (.) they can go to the
8 clinic get tested (.) as early as possible (0.2) those
9 that they know that I am positive (.) they must go and
10 take the treatment (.) it's free (0.3) in our government
11 hospital (0.4) °they mustn't° (0.6) die (0.4) because the
12 treatment °is free° (0.2) they mustn't be ashamed (1.0)
13 because HIV is like asthma (0.7) any (0.4) cough (.)
14 headache (0.2) (this) nowadays (0.2) you know is need not
15 to be ashamed of anything

The accounts above suggest that the stigma associated with HIV plays a role in preventing treatment (which subsequently leads to death); for example, the second speaker advised that HIV+ individuals 'must go and take the treatment' (ll. 9-10) and that they 'mustn't be ashamed' (l. 12; in other words, she formulated Dos and Don'ts). The first speaker questions why someone with HIV would refuse treatment when someone with diabetes or a heart condition would not refuse treatment. Generally, diabetes and heart conditions lack the stigma that surround HIV. Thus, by suggesting that someone with HIV refuses treatment while someone with a less stigmatised illness does not refuse treatment, the speaker's rhetorical question can be heard as insinuating that it is the stigma that differentiates the illnesses in terms of willingness to accept treatment. The second speaker, likewise, reassures that the reason why HIV+ individuals should not be ashamed is 'because HIV is like asthma (0.7) any (0.4) cough (.) headache' (ll. 13-14); that is, she equates HIV with a number of other health problems, none of which suffer stigma like HIV (including some that may be considered quite trivial).

Thus, since stigma appears to be a barrier to controlling HIV, and preventing HIV/AIDS-related deaths, efforts to reduce this stigma are essential. Such efforts are

observable in participants' discourses when they compare HIV to less stigmatised illnesses in order to assign some of the non-stigmatised characteristics of these illnesses to HIV – similar to how this was accomplished in relation to control in Chapter 4. Participants thus normalised HIV by comparing it to less stigmatised illnesses.

5.6. Reappraising Meaning in Response to Stigma

In Chapter 4 it was illustrated how participants used reappraisal of meaning as a resource to address dilemmas arising from difficult experiences. Similarly, participants could also be heard to reappraise meaning in response to dilemmas arising from stigma. In a context where HIV-related imperatives are widespread, where HIV contraction is perceived as controllable and avoidable, and thus HIV+ individuals risk being blamed for their (positive) HIV status, there is a sensitivity towards being perceived as stigmatising or being judgemental. In such situations, participants could be heard as reappraising meaning. The participant below was speaking of the most difficult aspects of her work:

Extract 5.25

1 P36: I feel like (.) OK I'm (0.3) losing the battle (1.0)
2 cause we teach them (.) you educate them (0.6) you give
3 them information >you give them support<(0.2) the next
4 thing they do the very same mistake (.) the next thing
5 she is pregnant (0.2) knowing her status (0.2) she has an
6 HIV positive child (0.3) already who is in our programme
7 (0.3) but then yet she's pregnant again (0.3) which means
8 (0.4) she is not taking care of herself (0.6) you know
9 (0.4) and I I will not judge them and I will not (0.6)
10 say why are they doing this well of course why but (1.1)
11 when you look at the situation (0.3) they are trying to
12 make means (0.3) and the only way is to get a man (0.3)
13 to give them money to buy them food

In this extract, the speaker refers to the actions of a client, namely, becoming pregnant, as a 'mistake', and in doing so suggests that the act was a wrong-doing and she should not have become pregnant, especially not since she had been taught differently (*ll.* 2-5). When the participant later also says 'knowing her status' (*l.* 5), this statement makes the accusation HIV-related. Such a formulation, then, could potentially be heard as judgemental; indeed, the participant continues by stating that 'I will not judge' (*l.* 9), indicating an awareness of a potential controversy and a sensitivity towards being perceived as judgemental (similar to the speaker in Extract 5.17). The participant can subsequently be heard as reappraising meaning: she provides an explanation ('they are trying to make means', *ll.* 11-12) that could justify why the client may have made such a 'mistake'; that is, instead of judging the incomprehensible behaviour, the speaker is instead heard to try and make sense of it.

A similar pattern is evident in the next extract in which the participant was also describing the most difficult aspect of her work:

Extract 5.26

1 P18: When he-e-he (0.9) when (0.4) they ar- (.) when they are
 2 (.) bedridden (0.7) understand (0.4) because (0.3) you t-
 3 educate them every day (0.2) when you go there educate
 4 (0.3) but you find the person he: (0.3) they don't want
 5 to use a condom
 6 (3.4)
 7 VR: Why do you think they don't (0.2) listen
 8 (3.0)
 9 P18: ((Chuckles)) (0.6) they're ↑stubborn (0.2) sometimes
 10 sometimes because (0.7) ah they are angry (.) they are
 11 stressed they're depressed

First, this speaker too formulates a criticism of a similarly incomprehensible behaviour: the client acts against what they have been taught, does not use a condom, and subsequently becomes so ill they are bedridden. This criticism could

potentially be heard as condemning: the client is bedridden because they did not adhere to instructions. When asked why the client may be acting against advice, the participant first says 'they're ↑stubborn' (l. 9) – which may be perceived as judgemental – but thereafter provides another explanation. This time the client's behaviour is justified by reference to a three-part-list outlining difficult states of mind: 'they are angry (.) they are stressed they're depressed' (ll. 10-11). Such states of mind convey an understanding for why people may suddenly do things they do not normally do. Under normal circumstances one may expect an individual to engage in behaviour that could be classified as sensible, such as heeding health advice. When an individual is angry, stressed, or depressed, however, they cannot be expected to engage in the same kind of sensible behaviour in such a (difficult) state. Participants, then, engaged in reappraisal of meaning in order to address dilemmas arising from stigma-sensitive situations.

5.7. Discussion

In summary, widespread in participants' discourses were HIV-related 'rules' in form of Dos and Don'ts, that is, behaviour in relation to HIV that is legitimised or condemned. These imperatives were perceived as violated more commonly by men than by women. In participants' discourses, HIV contraction, unlike TB-contraction, was further constructed as controllable and avoidable: if one follows the 'rules' of HIV, one will not become infected with HIV. While participants used these imperatives as well as the inherent micro discourse on control to avoid and counter HIV-related stigma, this technique often backfired and instead contributed to maintaining the macro discourse on HIV-related stigma by maintaining the blame component of the disease. Participants' discourses further suggested that HIV work, too, can be stigmatising. Finally, participants employed various discursive techniques in order to address HIV-related stigma, including normalising and reappraisal of meaning. Such attempts suggest that participants are aware of and

sensitive towards HIV-related stigma. This chapter, thus, illustrates the complexity of HIV discourse.

Chapter 6. The Child Identity

As stated in previous chapters, this thesis will use discourse analysis in order to address the three research aims: investigating the potentially traumatic effects of AIDS-related bereavement on aid workers, investigating the resources that aid workers utilise in order to cope with the potentially traumatic effects of AIDS-related bereavement, and investigating any differences in the experiences of local versus international aid workers. DA was deemed particularly useful as it is a technique which allows the identification of constructions that speakers produce in their discourses, for example, constructions of various identities, concepts, events they experience, and the way they make sense of these phenomena.

Two identities were particularly prominent in participants' discourses. One of these, the caregiver identity, will be discussed in the following chapter. The other, the child identity, is discussed in this chapter. The first part of the chapter – Children versus Adults – will illustrate how participants introduced the child identity and how they constructed children as different to adults. The second part – The Characteristics of a Child Identity – will discuss some of the characteristics inherent in a child identity, such as children are innocent, children are to be loved and cared for, and children are not meant to die. This section will also highlight some of the implications of these characteristics for the participants, especially in relation to death and loss.

Children Versus Adults

6.1. Introducing the Child Identity

‘... you can't label a child but ...’

In Chapter 4 it was briefly touched upon how participants referred to the Cotlands children as ‘normal’ children. Furthermore, as illustrated both in Chapter 4 and 5, participants frequently employed normalising discourses. This is further evident in the below extracts which are all responses to the question ‘How do you feel about working with individuals who are HIV+ or who have AIDS or TB?’:

Extract 6.1

1 P39: Me all the children whether you are sick or (.) you are
2 not sick I just take you as a normal child (1.2) even
3 when I was still at the crèche (0.4) I just take you as a
4 normal child

Extract 6.2

1 P63: M::ost of the time I I don't think about that (0.6) is
2 (.) just a child and-and (0.2) you don't think oh maybe
3 it's HIV positive or you don't know (0.5) but if I see
4 that someone is bleeding or they come with the blood then
5 I always think oh now you have to (0.5) to take care
6 (1.2) yeah but (.) most of the time it's-it's like a
7 normal child

Extract 6.3

1 P34: I don't see them as anything but (0.6) little children
2 (0.3) uhm (.) it doesn't worry me uhm (.) what irritates
3 me more is when they come and they've got grotty hands
4 and they wanna >rub it all against my leg and I'm like<
5 (0.5) and I gotta whole day to actually work can you just
6 (.) t-k- keep your hands off my black pants you know like

7 nnn (0.6) uhm (0.3) rather than actually if a child's
8 bleeding not to actually go to it

An initial note to make with regard to the extracts above, is how the latter participant states that she is more concerned about the children's 'grotty hands' (l. 3) rubbing all over her trousers when she still has a whole working day ahead, than she is about assisting a bleeding child. Such a statement arguably has two functions. First, a comparison with 'grotty hands' and soiled clothes trivialises HIV and conveys a sense of control over the disease, similar to that discussed in Chapter 4. Second, 'grotty hands' on one's clothes is arguably a concern more commonly associated with child care than are concerns regarding infection when a child is bleeding (ll. 7-8). Consequently, the statement is normalising: it normalises the Cotlands children and the Cotlands work environment. Such normalising is perhaps even more important considering the stigma attached to HIV as illustrated and discussed in the previous chapter. Extracts in that chapter were also used to demonstrate how participants compared HIV+ individuals to a 'normal' person, that is, an HIV- individual. It was argued that such a comparison was utilised as a discursive tool to normalise HIV in order to reduce HIV stigma. The participants in the extracts above employ a similar discursive technique: by referring to the HIV positive children as 'normal' (Extract 6.1, l. 2; Extract 6.2, l. 7) they group these children with, supposedly, HIV- children and assign to them similar, and allegedly less stigmatised, characteristics. It is important to note that such a discourse could simply be a result of the misrepresentative façade (see Chapter 4) of Cotlands as a high-control environment: everything feels 'normal' because it looks 'normal'. It could, however, also be that such a normalising discourse is deliberately employed in order to counter stigma and discrimination.

Moreover, the participants above extend this discursive resource. A closer look reveals that whereas the interview question asks about HIV+ *individuals*, the participants' responses refer to *children*. Compared to an 'HIV+ individual', an 'HIV+ child' contains two possible (identity) categories for speakers to draw upon:

HIV+ and child. Thus, by introducing the child identity, the participants introduce a discourse with connotations other than those relevant to a discourse that regards, for example, an HIV+ adult. (It is worth noting that participants' introducing the child identity most likely is a result of the fact that Cotlands as an organisation cares for children.) As will be demonstrated further in this chapter, within participants' discourses children are constructed as different to adults and adult attributes, and this child identity was often drawn upon as the most salient aspect.

6.2. Children are Different to Adults

Participants' discourses not only introduced a child identity, but they also demonstrated that this identity has particular characteristics that make children different to, for example, adults. In order to show that children are different to adults, participants would compare and separate the two:

Extract 6.4

1 VR: And how do you feel (.) about working with individuals
2 who are HIV positive (0.3) or have AIDS or have
3 tuberculosis (0.5) how do you feel working with them
4 (0.7)
5 P35: Uhm (3.0) I i-i-it's a matter of you know (0.2) uh I I do
6 not see them as victims (0.7) eh and that is more on
7 adults (0.6) >but then< if it's a child that's HIV
8 positive

Extract 6.5

1 VR: What aspect do you (0.3) do you find most (0.4) difficult
2 (3.8)
3 P1: Uhm (0.6) OK l-y- (.) let me say let me separate it uhm
4 into adults and children

In Extract 6.4, the participant is asked about what aspect of her work she finds most difficult and in her response she first refers to adults and thereafter uses the word '>but' (l. 7) before referring to children. In such a case, the word 'but' can serve as a discursive technique to contrast the succeeding proposition to the preceding one, that is, contrast children to adults. The second speaker explicitly states to be *separating* (l. 4) adults and children. By separating the two, she distinguishes one from the other, suggesting that they are different. Both speakers, then, demonstrate that they perceive working with HIV+ children to be different compared to working with HIV+ adults.

The distinction that generally appeared between adults and children in participants' discourses was one of practical versus emotional: whereas adults were addressed and dealt with mainly in a practical manner, children were generally related to in an emotional manner. This practical versus emotional distinction is highlighted in the following extract where the participant described why she felt a booklet developed by Cotlands for assisting children to deal with bereavement was interesting and useful:

Extract 6.6

1 P60: Cause I didn't know how they would deal with those kinda
2 (.) situations and if they would deal with them and (.)
3 how they would like uhm (0.2) guide the kids who would
4 stay behind or guide the kids who lost their parents or
5 (.) if one of the other kids died how do we (they would)
6 (.) help the other kids (0.7) with dealing with their
7 grief and dealing with their loss (0.2) and uhm (0.4)
8 ((name of employee)) showed us (0.4) these little (.)
9 books (0.4) with like (.) uhm (0.4) puzzles and colouring
10 pages and (.) everything build around grief (0.5) with me
11 it was really good to see that they'd actually do
12 something (0.6) with that grief and actually do something
13 to (0.4) try to help those kids through that difficult
14 time (0.8) cause I kinda thought they (.) wouldn't (.)
15 really be dealing with it (.) at all cause I haven't seen
16 it hadn't seen it and I hadn't heard anything about it
17 (0.7) so (0.7) >for me it was< good to see that there was
18 actually some- like a programme

19 VR: Mhm

20 (0.2)

21 P60: Set up for (.) those kinda situations

22 (0.9)

23 VR: But this was only for eh children was there anything for
24 staff or volunteers

25 P60: Yeah there was a (0.3) another (0.3) little book (0.4) I
26 think it was especially for (0.7) adults but it was more
27 practical guide how to deal with:: (.) the fact that
28 someone dies (and then) (0.3) what do you have to do when
29 (.) a person (.) close by (0.6) uhm passes away (1.0) so
30 I think it was more practical (1.0) all the stuff you
31 have to arrange and have to set up and (1.8) <I'm not
32 sure> if there was anything (0.7) (like f-) emotional

When the speaker above describes the booklets for the children, she speaks of them containing information on how to guide children who have 'lost their parents' or one of the other children at the residential care centre (*ll.* 4-6), information on how to help children 'dealing with their grief and dealing with their loss' (*ll.* 6-7), and generally information on how to help children through a 'difficult time' (*ll.* 13-14). When she speaks of the books for adults, however, she speaks of information about chores that need to be done ('what do you have to do', *l.* 28) and arrangements and preparations that need to be made ('all the stuff you have to arrange and have to set up', *ll.* 30-31). While she labels the latter kind of information – the one for adults – 'practical' (*ll.* 27 and 30), she also suggests this information did not contain emotional guidance for bereaved adults (*ll.* 31-32). Moreover, when the speaker confirms there were books for adults and then continues 'but it was more practical' (*ll.* 26-27), this practical-not-emotional information for adults is contrasted (with the use of 'but') to the information previously spoken about for children. Given how the information for children is said to be dealing with issues of grief and loss, this information could then be classified as addressing the 'emotional', that is, feelings rather than chores. Conclusively, children and adults were treated differently, not only in participants' discourses but also in practice.

6.3. Discussion

In summary, participants introduced in their discourses a child identity and further demonstrated their belief that children are different to adults. In doing so, participants' discourses on HIV+ children had different connotations, and implications, to their discourses on HIV+ adults. Finally, while the participant in Extract 6.5 is very overtly stating that a distinction between adults and children is about to follow, the participants in the other extracts make the distinction more implicitly. Both techniques were employed also by other participants as illustrated in the next part of this chapter which aims to highlight some of the attributes associated with the child identity.

The Characteristics of a Child Identity

'To speak of someone's social identity is to speak, at the very least, of what attaches to them in virtue of their membership of a category, usually a category constituted by social consensus or imposition' (Antaki et al., 1996, p. 473). The child identity emerging in participants' discourses was attributed certain characteristics which, to differing extents, distinguished a child from an adult. The remainder of this chapter will focus on describing three of these characteristics, illustrating the discursive tools participants made use of in order to convey these characteristics, as well as the effects of them. The first characteristic to be discussed is that children are innocent. This section will also illustrate how the innocence arises as a result of children being perceived as lacking agency, because agency in participants' discourses was age-dependent. Consequently, adults were held accountable for children's HIV contraction. Thereafter, the second and third characteristics to be discussed are that children are to be loved and cared for, and children are not meant to die. I will also demonstrate how participants reappraised meaning in response to

holding adults accountable for children's HIV contraction as well as children dying. The chapter will conclude with a discussion on the construction of an optimal childhood in participants' discourses, and the loss thereof. Thus, as this chapter shows, loss, in participants' discourses, was not merely a matter of death.

6.4. Children are Innocent (and Therefore Evoke Sympathy)

'... you just sometimes don't understand why that happens to someone who doesn't deserve it ...'

One very prominent feature of participants' discourses was that children are innocent and in the specific context of this research study this innocence was predominantly referring to one particular aspect of the children's lives, that is, their (positive) HIV status:

Extract 6.7

- 1 VR: And you mentioned about (0.3) treating the kids
2 differently (0.4) do you think that if you knew that this
3 child is HIV positive and this one isn't that you would
4 treat them differently
- 5 P47: No (0.3) no (.) mm-mm (1.0) cause they're children it's
6 not their fault (1.2) no you never treat children
7 differently (0.2) one is maybe a bit backward (0.5) other
8 one's bright you can't treat them differently no

Extract 6.8

- 1 VR: So what would you say is the most difficult aspect of
2 working with HIV positive individuals
3 (2.1)
- 4 P62: Uhm (4.7) it's feeling angry and frustrated for them
5 (0.3) on their behalf (1.3) uhm (1.2) especially because

6 you work with children (1.1) it means that (0.2) however
 7 they contracted it was not their choice (1.5) ((coughs))
 8 and was not something that they could've prevented (0.8)
 9 and tha- (.) like frustration and anger is probably the
 10 biggest thing to deal with

The first participant above conveys that children are innocent in quite an explicit manner by stating that 'it's not their fault' (*ll.* 5-6). Seeing how the interview question addresses treatment of children in relation to their HIV status, any response offered can, and will, most likely be interpreted in this light. Thus, the account implies that children are *blameless* in terms of being HIV+ simply because ('cause', *l.* 5) they are children; that is, children are innocent.

The second participant orients towards children's innocence more implicitly by expressing anger and frustration on behalf of the children because they are HIV+ ('they contracted it', *l.* 7), when they did not choose this themselves ('not their choice', *l.* 7). First, this statement implies that HIV contraction is a choice, similar to how the participant in Extract 5.13 in Chapter 5 stated '>I don't want to be infected'. Second, the speaker states that 'especially because' the work involves children 'it means' (*ll.* 5-6) that the HIV contraction was not their choice. This statement implies that the reason why the choice of contracting, or avoiding to contract, HIV does not apply to children is simply because they are children. Thus, when the choice of HIV contraction is considered not applicable to children, HIV+ children become blameless for their positive status, and consequently considered innocent.

Another point to make with regard to participants' constructing children as innocent is that this innocence brings about yet another characteristic specific to children: children evoke sympathy. This is clearly stated by the following participant:

Extract 6.9

1 VR: So the high death rates thirteen years ago (0.7) did that
 2 ever: cross your mind to:: not take the job at Cotlands
 3 or not work for Cotlands

4 (0.4)
 5 P44: No (0.6) no (1.4) I understand that (y-) (3.4) a lot of
 6 people do take children lot more harshly because it's
 7 little kids and we all know little kids pull your
 8 heartstrings

That children evoke sympathy is conveyed through the speaker's use of the idiom 'pull your heartstrings' (*ll.* 7-8), an expression that conveys feeling sympathy. When the speaker claims that children are taken 'more harshly' (in response to the interview question about death; *l.* 6), 'because it's little kids' (*ll.* 6-7), it suggests children evoke more sympathy than other individuals simply because they are children. Finally, the speaker says 'we all know' (*l.* 7), implying that children invoking sympathy, and more sympathy than other individuals, is general knowledge.

When the participant in Extract 6.8 expresses anger and frustration *on behalf* of the children, for suffering from something which they should not be suffering from, she also communicates sympathy. That children are innocent and subsequently evoke sympathy is further illustrated in the below extract where a participant explains a difficult aspect of her work:

Extract 6.10

1 P55: I find it difficult when::: (0.4) like I ahm I spend a
 2 lot of time in the Hospice (.) and when we get (.) new
 3 children like (0.6) there was just (0.4) one new kid
 4 (0.6) which is really yeah which looked pretty sick and
 5 (0.3) like the typical (0.3) big belly and the thin arms
 6 and (1.0) yeah (0.9) when they come they don't yeah (0.4)
 7 the kid was not (0.6) he wouldn't smile (.) or do
 8 anything would just sit there (.) and (0.8) yeah that is:
 9 (.) difficult I think (0.7) because I always feel sorry
 10 for for the kid (.) cause it's so young and i- I think
 11 it's just unfair

The speaker above commences her response by depicting an adverse situation that a child was in. She speaks of the child presenting with the 'typical

(0.3) big belly and the thin arms' (l. 5); that is, she is describing the stereotype of a suffering child as well as an awareness of doing so (through her use of 'typical'). She also reports that the child 'wouldn't smile (.) or do anything would just sit there' (ll. 7-8), which is in contrast to how healthy and well-adjusted children are typically depicted: full of life and playing around. The speaker then labels witnessing such an event as difficult (l. 9) and continues 'because I always feel sorry for for the kid' (ll. 9-10). To 'feel sorry', then, communicates the sympathy she feels for the child for its suffering. Finally, the speaker accounts for this sympathy by stating that the child is 'so young' and that she thinks 'it's just unfair' (ll. 10-11). The word 'unfair' implies that the situation, involving a child suffering, is wrongful or even *not deserved*, that is, the situation did not come about as a result of an individual's own actions (may this be referring to a beneficial or harmful event). In this case, this suggests the suffering did not come about as a result of the child's own actions; hence, the child is innocent with regard to his hardships.

Conclusively, then, participants constructed children as innocent with regard to various hardships they may experience and specifically in relation to their (positive) HIV status. Children were perceived as innocent because the hardships they were subjected to were considered not a result of their own actions. As such, children are not only innocent but they also evoke sympathy for the adverse situation which they are in but not considered to deserve to be in.

6.4.1. Children are Innocent Because they Lack Agency; Agency is Age-Dependent

The extracts above illustrated how participants constructed children as blameless and not accountable for their hardships, and therefore as innocent. With regard to the children's (positive) HIV status this innocence was, in participants' discourses, accounted for as a result of the children's age. This relates back to the micro-macro discourse of control and blame discussed in Chapter 5: there are 'rules' of HIV – that is, Dos and Don'ts – that people are expected to adhere to in order to

avoid HIV contraction. As such, HIV contraction is perceived as controllable and thus avoidable. Consequently, an HIV+ individual may be seen as having violated the 'rules' and therefore perceived as responsible, and blamed, for their own fate which subsequently contributes to maintaining the stigma associated with HIV; however, in order to be held accountable in this manner, an individual must be perceived as responsible for the actions that brought about the HIV. In participants' discourses, such responsibility, or agency, was age-dependent: those who are older, such as adults, were attributed agency whereas those who are younger, such as children, were not. Accordingly, because children are perceived as too young to have agency, they are also perceived as incapable of having acted in a manner that caused them to contract HIV. Conclusively, they cannot be held accountable for their fate and thus they are labelled innocent.

This reasoning is evident in Extract 6.8 above where the participant, first, expresses anger and frustration on behalf of the children, and second, accounts for this with the explanation that however the children contracted the HIV was not their choice, which implies that such a choice does not apply to children. Children are thus constructed as lacking the agency which qualifies them to make choices regarding HIV contraction. Consequently, children are constructed as innocent with regard to their own HIV contraction. The participant in Extract 6.7 above insinuates a similar distinction in agency between children and adults by first stating that children may not be blamed for being HIV+ because they are children ('cause they're children it's not their fault', *ll.* 5-6), and further by arguing that 'you never treat children differently' (*ll.* 6-7). The response, then, insinuates that although adults may be treated differently according to their actions, children may not be treated differently regardless of their situation because they are children.

The following extracts further illustrate how participants constructed agency as age-dependent; that is, adults were ascribed an agency that children escaped. The first participant below had just stated that dealing with adults would be different to dealing with children:

Extract 6.11

1 VR: Why do you think it would be different if you were
2 dealing with adults
3 (1.4)
4 P48: Ehm we had this woman come and talk to us at school (0.4)
5 and she was positive (0.4) uhm (0.7) °and she was talking
6 to us about it and she° (1.2) °she just° (1.3) she's very
7 much defending herself the whole entire time (0.5) and I
8 I don't know if that's because it's a lot society's view
9 on people with HIV or AIDS and the pressure they feel
10 from it (0.8) uhm (1.4) but (.) I don't know I think if
11 you're if you know that you have it I don't know (0.2)
12 it's something (0.7) in my- eh I know if I had it I would
13 feel very differently about myself if I didn't (0.7) so I
14 don't know that's just an assumption

The speaker recounts how an HIV+ woman giving a speech about her status was 'defending herself' (l. 7) and subsequently offers 'society's view on people with HIV or AIDS' (ll. 8-9) as an explanation for the defensive behaviour. The use of the word 'defending' suggests behaviour employed in order to counter criticism. In this particular case, the defending behaviour could be heard as countering potential criticism from a society that views HIV contraction as controllable and, therefore, views HIV+ individuals as responsible for having contracted HIV – as demonstrated in the previous chapter. Finally, because the participant has already separated children from adults and stated that dealing with adults would be different, it suggests that the accountability and need for defensive behaviour which is applicable to HIV+ adults does not apply to HIV+ children. Children thus escape the agency ascribed to adults.

The next participant had just reported finding it difficult that young children had to deal with ART programmes:

Extract 6.12

1 VR: Do you think it would be different if (0.3) they weren't
2 so young if they were older (.) aadults or teenagers

3 (0.9)

4 P10: ((Chuckles)) uhm (0.6) no: not really I guess I think
5 (0.3) I think for me the part is that (0.9) you know like
6 (0.5) °and not that (.) it's better that (.) (p-) adults
7 have it or something° but you know like (0.4) I mean it's
8 like (0.7) uhm adults more of them (0.5) got it I guess
9 you know throu:gh (0.2) something that they did maybe and
10 (.) and you know which they >probably shouldn't have<
11 ((chuckles)) you know like ((chuckles)) uhm whereas the
12 kids and tis not (.) that's not good either but you know
13 like but the (0.5) uhm but the kids I mean especially
14 yeah and-and the teenagers I mean the younge- the younger
15 kids I guess uhm (0.8) they they didn't do anything (.)
16 to (.) deserve it you know or a ta- you know they
17 shouldn't have it (.) you know like it's nothing that
18 they did (0.5) uhm (.) to get it yeah I guess

This speaker commences by suggesting that most adults who have contracted HIV ('got it', *l.* 8) not only did something, but they did something which they should not have done (*ll.* 9-10). The imperative in this utterance communicates some kind of violation and a sense of responsibility, or blame even. In other words, adults did something (which they ought not to have done) which resulted in them getting HIV; consequently, adults are held responsible for having gotten HIV – they are ascribed agency. Despite having initially stated that he perceives no difference between young children, teenagers, and adults, he nonetheless puts HIV+ adults in contrast to HIV+ children, with the phrase 'whereas the kids' (*ll.* 11-12). Thereafter, the speaker initially refers to teenagers (*l.* 14) but then does a repair (Schegloff, 1992) and speaks of 'the younger kids' (*ll.* 14-15) and how they 'didn't do anything (.) to (.) deserve it' (*ll.* 15-16) and therefore they 'shouldn't have it' (*l.* 17). Such an argument clearly links an individual's HIV status with the individual's prior actions, and thereby maintains the blame component in HIV stigma as discussed in Chapter 5: if children who did not do anything consequently do not deserve having HIV, the same logic can be applied to argue that adults do deserve having HIV because they did do something. Children, then, escape the agency ascribed onto adults.

Moreover, the speaker's repair, in which 'teenagers' was replaced with 'younger kids' (ll. 14-15), suggests that although younger children may not be perceived as responsible for having contracted HIV, the situation may be different for teenagers, and that teenagers can to some extent be perceived as having done something that renders them deserving of having HIV. This gradual increase in accountability, across younger children, teenagers, and adults, illustrates how agency in participants' discourses was age-dependent.

6.4.2. Holding Adults Accountable for Children's HIV Contraction

Because HIV infection, in participants' discourses, was considered controllable, the notion that an individual might at random contract HIV was absent. For adults, who were constructed by participants as having agency, HIV contraction was perceived as a consequence of the individual's (inappropriate) behaviour, most commonly as a result of some violation of the 'rules' of HIV. Children, however, were constructed as lacking agency due to their young age, and consequently they were perceived as incapable of making choices and behaving in a manner that would result in HIV contraction. Rather, the responsibility for the children's HIV contraction was, once again, placed on the adults. In participants' discourses, then, children were innocent while adults were held accountable for having violated the 'rules' of HIV and blamed for the children's positive HIV status. The participant below, for example, had just explained that the most difficult aspect of her work was knowing that the children did not need to have HIV, that it could have been prevented:

Extract 6.13

1 VR: How could it have been (0.4) p[revented]
2 P56: [Like just] if they were
3 born with it like (.) their mothers could've done took
4 the drugs while they're pregnant or (0.5) if they've
5 gotten it (0.3) through abuse or whatever then (.) it all
6 could've been prevented if they've been cared for

7 properly that's (0.7) the hardest part (0.2) just to see
8 them all here and (1.6) they just (.) needed (.) someone
9 to love them and stuff so

The participant also stated at a later point:

Extract 6.14

1 P56: Like it's not their fault they have HIV (0.5) cause they
2 were (.) like (0.5) because they're children it's not
3 like they went out and had unprotected sex they were
4 given it (0.7) by (0.9) by an adult (0.9) someone who is
5 supposed to look after them so

The speaker above gives two specific examples of how children could have been prevented from contracting HIV. First, she claims that if children contracted HIV through birth, the contraction *could have* been prevented if the mothers had taken drugs (*ll.* 2-4). Second, she claims that if the children contracted HIV through abuse, it *could have* been prevented if they had been cared for properly (*ll.* 4-7). When the speaker uses the phrase 'could've been' (*l.* 6), it suggests that someone ought to have done something that they did not do. This someone could be a mother, as referred to in the response, or this someone could be any adult in general, seeing how the participant says 'if they've been cared for properly' (*ll.* 6-7) and the norm sees that adults care for children. This is then explicitly stated in the second account where the speaker refers to 'an adult' as 'someone who is supposed to look after them' (Extract 6.14, *ll.* 4-5). As such, it is insinuated, that children contract HIV because adults fail to prevent such contraction by failing to care properly for the children. Adults were thus blamed for children having contracted HIV. The participant does in fact state this explicitly when she says 'they were given it (0.7) by (0.9) by an adult' (*ll.* 3-4). In this extract it is also suggested that children have no agency and are thus innocent: they did not act in a manner that resulted in them contracting HIV ('it's not like they went out and had unprotected sex', *ll.* 2-3), simply 'because they're children' (*l.* 2), and therefore 'it's not their fault' (*l.* 1).

The following account also suggests that adults are accountable for children contracting HIV. The participant had previously stated 'she's kind of just slowly wasting away which I find very strange thinking of how young she is' and was subsequently asked:

Extract 6.15

1 VR: Do you think it would've been different if she wasn't so
2 young if she was an adult for example
3 (0.6)
4 P51: U:::hm (1.8) I'm not sure that's a good question I think
5 (0.4) when it comes to children in general (0.4) things
6 are more like these kind of like sicknesses or disease or
7 famine or things like that are (0.3) more difficult to
8 cope with when it is a child just because (0.4) they're
9 so young and innocent [...] I think it is more difficult
10 when it comes to a child whereas if it is an adult (0.5)
11 then I'm almost oh back up with a child too I always feel
12 a little (1.0) I guess (0.2) maybe anger but not quite
13 that they have HIV because (0.3) they most likely (0.3)
14 contracted it from their mother having it through birth
15 so it's like this (0.2) child that just had (.) <done
16 nothing wrong> except (0.2) come ou(h)t of the birth
17 canal (.) and that (.) get stuck then with this like
18 awful disease so (.) that makes me upset too that (0.3)
19 when it's an adult then I wonder (0.6) well maybe like
20 you should've like used protection or you made a bad
21 decision or (some'in) that maybe (.) you didn't realise
22 it was a bad decision in <this culture> (.) back home it
23 was like a no brainer to use a condom or something like
24 that

This extract highlights several points. First, with the use of the word 'whereas' (l. 10) a distinction is made between how adults and children are perceived to have contracted HIV. While the speaker considers adults to have contracted HIV as a result of a 'bad decision' (ll. 20-21), she generally considers children to have contracted HIV from their mothers through birth (ll. 13-14). The word 'decision' implies a choice and an active role in the events; to simply 'come ou(h)t of the birth canal' (ll. 16-17) does not. Thus, while adults are ascribed agency and held responsible for their HIV contraction, children are instead constructed as

passive recipients. Moreover, the speaker expresses anger (*ll.* 11-13) with regard to the manner in which children contract HIV. Anger, being a typical response to ill or unfair treatment, suggests that the speaker perceives children contracting HIV from their mothers as a sign of mothers' ill treatment of their children. This is similar to how the speaker in Extract 6.13 perceived adults as not caring properly for (HIV+) children. Adults, then, are held accountable for children's HIV contraction.

Second, whereas the speaker refers to the hypothetical decision made by adults as a 'bad' decision, children are reported to have '<done nothing wrong>' (*ll.* 15-16). Instead, children are described as 'young and innocent' (*l.* 9) in a manner that almost suggests a link between the two: those who are young are also innocent. This further corroborates that agency was constructed as age-dependent in participants' discourses.

Finally, the speaker expresses sympathy for these young and innocent children. In addition to feeling anger, she also reports feeling 'upset' (*l.* 18) because the children are stuck with (*ll.* 17-18) this awful disease. As being stuck with something implies being burdened by something, the speaker reporting feeling upset is, then, heard to convey sympathy for the children's burden. This speaker, then, has communicated sympathy in a similar way as previous speakers, such as the speaker in Extracts 6.8 who felt angry on behalf of the children, the speaker in Extract 6.10 who felt sorry for the children, or the speaker in Extract 6.9 who claimed that little children pull your heartstrings. The speaker above also explicitly states that hardships are 'more difficult to cope with when it is a child' (*ll.* 7-8). Given the link between 'young and innocent', this statement suggests that perceived innocence and sympathy increase as age decreases. Thus, while adults were assigned agency and received blame, children were bestowed innocence and received sympathy.

Reappraising meaning in response to holding adults accountable for children's HIV contraction. Interestingly, it was not only participants who held adults accountable for children having contracted HIV. A few participants also

reported how children themselves did so as they became older. In both instances a number of speakers would attempt to reappraise meaning in order to avoid attributing blame. Such a reappraisal process can, for example, be seen in Extract 6.15 above where the speaker attempts to explain the 'bad decision' of not using a condom when engaging in sexual activity with reference to prevailing cultural norms as opposed to an individual's careless behaviour (and failure to adhere to the Dos and Don'ts of HIV). In the extract below, the participant can be heard to reappraise meaning when discussing children dying:

Extract 6.16

1 P6: Some (.) that we had at Cotlands just didn't make it
2 (0.5) e- (.) because they'd come too late (.) and it
3 wasn't the thing of (0.2) the child's fault or th- (.)
4 you know (0.4) th-th- the mommy was scared (1.2) and she
5 didn't know what to do with this ill baby (.) so by the
6 time they got to hospital it was always too late

First, the participant constructs the child as innocent by stating that dying as a result of the delay in accessing help was not the child's fault (*ll.* 2-3). Then, however, rather than unsympathetically holding the mother accountable for the death of the child, the speaker attempts to make sense of what appears to be neglect by the mother by attributing her behaviour to factors such as fear and her not knowing what to do (*ll.* 4-5). The death, then, is not constructed as a result of a *deliberate* act of failure by the mother to care properly for her child; as such, she is not held responsible.

The next participant had just raised the dilemma of children challenging their HIV infection upon which I enquired what they tell children in such situations:

Extract 6.17

1 P17: That's when we start telling them (0.8) ma- you mother
2 maybe your mother (.) breastfed you and your mother
3 was not supposed to breadfeed you (0.7) and you- she'll
4 tell you (.) but they say HIV you got HIV from blood
5 (0.6) so (.) I was drinking milk (0.4) I mean breast is

6 milk (0.4) so you have to sit down and explain this:
7 breast milk (0.4) if your mother (.) maybe breastfed
8 you (0.6) uhm (1.1) what do you say this time again (3.0)
9 we say breastfeed what (1.9) so your mother was supposed
10 to give you (0.5) only breast milk=
11 VR: =Right=
12 P17: =That
13 VR: [Yeah]
14 P17: [Time] exclusively (.) excluslive (.) exclusively (0.5)
15 something like that ((chuckles))
16 VR: Right=
17 P17: =Your mother was supposed to give you only the breast
18 milk (.) not mix the breast milk with the bottle or
19 whatever (.) so (in) () that erosion (0.6) that's where
20 >the the< HIV comes in (1.1) or you got that this HIV
21 (0.6) during delivery time (1.1) >maybe there's< there's
22 lot of blood (.) when when a person delivers so that
23 erosion that scratches (0.6) the blood (0.7) get into and
24 (0.3) °you were (.) infected°

In the extract above, rather than explaining the child's HIV status with, for example, the mother's failure to care properly for the child, the speaker refers to factors such as the birth situation (*ll.* 20-24) and breastfeeding (*ll.* 17-20) as alternative explanations. These factors are seemingly, first, out of the mother's control, and second, an act of caring for a child. The breastfeeding, however, is insinuated to have been in the mother's control – but only conditionally. The speaker above attempts to explain why the child may have contracted HIV with reference to the mother not breastfeeding exclusively, that is, feeding the child also other fluids or foods. The failure to breastfeed correctly (that is, exclusively) may only be seen as a violation of the 'rules' of HIV if one is aware that exclusive breastfeeding during a child's first six months reduces the risk of mother-to-child HIV transmission⁷. Because HIV is considered predominantly a sexually transmitted

⁷ Powdered, formula, or animal milk is considered more damaging to a baby's not yet fully developed stomach, whereas the nutrients in breast milk strengthen the stomach. Consequently, breast milk reduces the risk of HIV infection for the child, whereas powdered,

disease, or through blood as stated in this extract (l. 4), contraction through birth and breastfeeding are not as obvious and such knowledge is not as widespread as knowledge about sexual or blood transmissions. Such reasoning about knowledge may therefore be utilised by participants to make sense of the given situation and avoid blaming adults unsympathetically for children contracting HIV by once again shifting the locus of control (see Chapter 4).

Conclusively, in participants' discourses adults were ascribed agency and held accountable for having contracted HIV, while children were perceived as innocent because they lacked agency due to their young age. As a result, children received sympathy while adults received blame, both for their own HIV contraction as well as the children's. Some participants, however, were sensitive towards blaming adults and therefore engaged in reappraisal of meaning in order to make sense of the children's (positive) HIV status without blaming adults.

6.5. Children are to be Loved and Cared For

In participants' discourses, children were not only innocent and evoked sympathy but children were actively to be loved and cared for. For example, throughout the interviews participants frequently expressed a passion for children. One of the interview questions explored participants' reasons for working at Cotlands, and their responses would typically involve accounts of how much they loved children:

Extract 6.18

1 P26: >First of all< I love children

formula, or animal milk reduces the stomach's ability to protect against HIV infected breast milk (Coovadia et al., 2007).

Extract 6.19

1 P34: Uhm (1.1) >I think it was< >because I love kids<

Extract 6.20

1 P32: Bes- because I-I love it I love looking after the
2 children

Due to the large number of participants that reported a passion for children, especially as a reason for working at Cotlands, it is reasonable to believe that participants themselves perceived this kind of passion as a requisite for working in an environment such as Cotlands. This argument is not least evident in the following extract where the participant had been asked to account for why she wanted to work for Cotlands and she had explained that initially she worked for Cotlands on a casual basis but eventually she was offered a permanent position:

Extract 6.21

1 P44: And then (0.3) Cotlands offered me a job (1.0) so:: (1.2)
2 I think I've >stuck it out< all this time (0.6) you know
3 yes there's that thing of (.) the love for the kids: an:d
4 (0.8) y- you know it's all definitely there- (0.6) >but I
5 think< one of the other reasons is because I have been
6 able to (0.3) take on so many different positions

When comparing the above account to the responses in Extracts 6.18 to 6.20, the first point to note is the absence of a first person avowal: whereas the three previous speakers all say 'I love' in reference to either children or looking after children, the speaker above states that 'there's that thing of (.) the love for the kids:' (l. 3). In comparison to 'I love', 'there's that thing' is a depersonalised statement, not attributed to a specific individual although still applicable to the speaker. Rather, the statement conveys the existence of a phenomenon in the world, a phenomenon whereby a relationship exists between 'love' and 'kids'. Although the speaker does

offer this phenomenon as a reason for why she works at Cotlands, she says 'but' and proceeds by offering other reasons (*ll.* 4-6), which consequently downgrades the initial reason of 'love for the kids'. This depersonalised and downgraded manner in which 'love for the kids' was offered as a reason for why the speaker works at Cotlands suggests that such a reason is treated by the speaker herself as a reason that one needs to give for why one works at Cotlands.

The link between love, care, and children is further illustrated in the below extract where the participant is discussing the child on which she based her responses for the IES-R:

Extract 6.22

1 P34: She was dying I mean it was obvious she was gasping she
2 had that like uhm (.) death rattle °like everyone calls
3 it° (0.6) and (0.4) she was lying in the cot and I was
4 like ((chuckles)) no (0.6) this is bullshit no this is
5 like cruel (0.7) so (0.3) I think because (0.9) I'm so
6 passionate about my career and about what I do (0.4) my
7 instinct was to pick up and hold her and I did I held her
8 until she died and she died in my arms and (0.6) th-th-
9 that that was it (0.3) uhm (0.2) I couldn't leave her in
10 a cot and just stand there and look at her (.) I had to
11 (0.6) do something physical (0.7) to make the child: (.)
12 comfortable (0.4) and I think yah I think that's (0.7)
13 obviously >like a lot of people say oh it's a special
14 gift< but I I don't see it that way I just see it that
15 that's (0.4) me that's what I do and (0.7) the child
16 needed to be comforted (0.7) you know I mean yah that
17 sound of her breathing (1.2) (bill beev) in my ears
18 forever but I mean ((clears throat)) (0.5) no I think
19 (1.8) >because I mean that profession< that's my job I
20 have to (0.9) I have to hold the kids I have to love the
21 kids until they're no longer there (0.8) uhm (0.2) you
22 know so (1.6) yah maybe it is my training but maybe it's
23 just me as well I mean I d- I don't know uhm (0.6) I
24 can't (0.5) not go and pick up a child and (0.8) comfort
25 them if there's something wrong (1.2) >that someone
26 always says to me< why do you always have to touch a
27 child (0.5) like cause they're kids

The participant above explicitly states 'I have to love the kids' (*ll.* 20-21), a statement that further corroborates the existence of a relationship between 'love' and 'kids'. In addition to this, however, she also argues that if a child needs comforting, she must comfort it ('I can't (0.5) not go and pick up a child and (0.8) comfort them if there's something wrong', *ll.* 23-25). This suggests that children's needs should be attended to – children should be cared for. Specific to this participant's account, loving, comforting, and caring for a child is associated with physical acts, as demonstrated by the speaker saying that she 'had to (0.6) do something physical (0.7) to make the child: (.) comfortable' (*ll.* 10-12) or by giving a concrete example of an occasion when she did so: rather than letting a child die in a cot, she picked the child up and allowed the child to die in her arms (*ll.* 3-8). Not doing so would have been, according to the speaker, 'cruel' (*l.* 5). The speaker further reports that 'a lot of people say oh it's a special gift' (*ll.* 13-14), suggesting that the need to love and care for children is a unique skill only bestowed onto a few. She rejects this idea, however, and in her reasoning she initially attributes the need to love and care for children to her social work profession ('maybe it is my training', *l.* 22) and constructs it as a professional requirement ('that's what I do', *l.* 15, and 'that's my job I have to', *ll.* 19-20). The speaker had previously also stated, in reference to the example given of the dying child, 'I'm so passionate about my career and about what I do (0.4) my instinct was to pick up and hold her' (*ll.* 5-7), which also suggests that her social work career plays a role in her caring for children because caring for children is in social workers' nature ('instinct'). She then, however, amends this as well and considers the possibility that it may be attributable to her own character after all ('but maybe it's just me', *ll.* 22-23). Finally, when the speaker justifies always having to 'touch a child' (*ll.* 26-27) with the mere fact that they are children ('cause they're kids', *l.* 27), and she has previously linked physical acts with attending to and caring for children, she attributes the need to care for children simply to the fact that they are children.

That children should be loved is evident in the next extract in which the participant was describing the most difficult aspect of her work:

Extract 6.23

1 P54: They probably won't get real (0.5) parents (0.5) a- like
2 because (0.2) nobody will want a kid (.) with HI- (0.2)
3 that's HIV positive (0.2) so they will just go from
4 children home to children home with- (0.3) out (0.5)
5 parents (0.4) which makes me really sad when I think
6 about it (0.7) for the children (.) because they're (0.6)
7 °as loveable as any other kids°

By stating that the HIV+ children at Cotlands are ‘°as loveable as any other kids°’ (l. 7), the characteristic ‘loveable’ is constructed as universal in relation to ‘kids’ and extendable to any child. The speaker, however, suggests that the Cotlands children may not benefit from such love because they are orphans or HIV+, and for this the speaker expresses sympathy for the Cotlands children (‘which makes me really sad’, l. 5). The speaker’s account, then, suggests that all children should be loved.

Conclusively, participants’ discourses communicated that children should be loved and cared for simply because these characteristics are inherent in their child identity. Furthermore, love for children and caring for children were treated in participants’ discourses as requisites for working for an organisation that cares for children.

6.6. Children are Not Meant to Die

‘... it's like they didn't even have a life ...’

The final characteristic of a child identity to be discussed in this chapter is that children are not meant to die. In their discourses, participants clearly demonstrated that children should not die, due to their young age:

Extract 6.24

1 VR: And how do you think that (0.2) burnout came about:
2 (2.2)
3 P2: Th- th- amongst the staff
4 (0.3)
5 VR: Yeah=
6 P2: =Yah (.6) well you know children shouldn't die
7 ((chuckles))

Extract 6.25

1 P45: Kids shouldn't die it's no::t it's not right
2 VR: Mm=
3 P45: =Yeah (0.6) uhm (1.7) I mean the difference between a
4 child dying and an eighty year old dying doesn't even
5 need to be explained (0.6) you know (0.2) one has lived
6 their whole life one didn't even have (1.0) uhm (0.8) a
7 chance

First, both speakers above explicitly claim that children should not die (Extract 6.24, *l.* 6, and Extract 6.25, *l.* 1). The second speaker further elaborates on this claim by comparing the death of a child to the death of an 80-year-old (Extract 6.25, *ll.* 3-7). Whereas one is claimed to have lived their life in complete ('whole life', *ll.* 5-6), the other is claimed to not even have had a chance at life (*ll.* 6-7). Knowledge, logic, and common sense suggest that the former refers to the 80-year-old – that is, an individual who has lived for 80 years – and the latter refers to the child – that is, someone who has only lived for maybe a decade, or two at most. The speaker has already said that children dying is 'not right' (*l.* 1). He has also stated that there is a difference between a child dying and an 80-year-old dying (*ll.* 3-5). This, then, implies that death occurring at the beginning of life during childhood is wrong, and that a more appropriate time for death to occur is during old age after an accomplished life. Death, then, is constructed as an event that

should only occur at the end of a life, and therefore children should not be subjected to death because childhood does not qualify as the final phase of a life.

Finally, both speakers use the phrase 'you know' (Extract 6.24, l. 6, and Extract 6.25, l. 5) in relation to the claim that children should not die, and the second speaker further claims that his comparison of an 80-year-old dying and a child dying 'doesn't even need to be explained' (ll. 3-5). Thus, both speakers treat the claim that children should not die, and possibly the second speaker's rationale for it, as common and widely accepted knowledge (Holmes, 1986; Östman, 1981).

6.6.1. Reappraising Meaning in Response to Children Dying

'... if you think that this little child's dying and then that's it I think it would be harder to cope with ...'

Children, as perceived by participants, are not meant to die. In reality, however, nearly 2 million people die from AIDS every year – a figure which includes children (UNAIDS, 2010a). Thus, in response to children dying, participants would reappraise meaning. The first participant below was describing her expectations regarding working at Cotlands prior to commencing this work:

Extract 6.26

1 P9: You know if I got attached to the children so what it
2 wasn't gonna be a problem and it never has been it it it
3 is just difficult to know that (.) you can lose these
4 children (0.4) but through all of it I think we (0.4) we
5 all discover that even if they're only here for a little
6 time (.) they (.) all had a lesson a life lesson to teach
7 us (0.6) uhm (0.3) so (0.2) even though i- (.) it's (0.3)
8 horrific (0.3) there there is a positive side to it if
9 (.) if there c(h)an be (0.4) a positive side to children
10 having to die

Extract 6.27

- 1 VR: And when they do die (0.4) how do you cope
2 (2.4)
3 P46: Through prayer (1.9) and because I saw them suffer (0.8)
4 I thank God a million times over °for (0.5) giving them
5 peace (1.0) that's how I cope°

In order to cope with the difficult concept of children dying, participants needed to find a reason for such an incomprehensible event or for the child's short stay on Earth. Therefore, they engaged in the reappraisal process in order to find aforementioned reasons to enable them to make sense of such dilemmas. For example, the first speaker above finds consolation ('even though i- (.) it's (0.3) horrific (0.3) there there is a positive side to it', Extract 6.26, *ll.* 7-8) in the discovery that the children's short stay on Earth has a purpose: each child has a 'life lesson to teach' (*l.* 6) to their fellow human beings during their 'little time' (*ll.* 5-6) among them. The statement 'only here for a little time' (*ll.* 5-6) reinforces the argument that participants considered death to be an event that should only occur after completion of a long life and that childhood did not represent the end phase of a long life.

Similarly, the latter speaker copes by finding a purpose in children dying: whereas the children were suffering before due to their illness, they are now at peace. By associating death with peace and life with suffering, death is depicted as a *better* option or outcome. Both participants above, then, reappraise meaning in an attempt to find some positive meaning in an otherwise seemingly negative event.

6.6.2. Loss is Not Merely a Matter of Death

In participants' discourses, however, the concept of loss was not merely a matter of death and the loss of a child's life. Participants also made relevant the concept of loss in other domains, for example, the loss of an optimal childhood (as constructed by participants). For example, as a result of the ARTs, HIV+ children –

and adults – are now living longer. Survival is no more the challenge it once was because immediate death can be prevented; however, as children are now living beyond childhood, other challenges are surfacing, as discussed in Chapter 4. In participants' discourses, one prominent such challenge was that HIV is an obstacle to a 'normal' life; HIV+ children's lives may no longer be immediately lost but their chances of living a 'normal' life, as compared to that of an HIV- child, are lost because HIV+ children are perceived as facing additional challenges. Some of the new challenges raised by participants were developmental. Developmental delays were evident in the children in various ways, for example, through educational and intellectual delays, including speech; or physical delays, including fine and gross motor skills. Others raised challenges such as dealing with the children's behavioural difficulties or challenges in relation to their psychosocial needs. These challenges, however, were not only seen in an HIV context but also in a context of orphans in general. Participants not only conveyed through their discourses that children should not die but further that children should be entitled to a certain kind of childhood (that involved being loved and cared for). Being an orphan was communicated by participants as one of the predominant factors indicating loss of an optimal childhood. This was touched upon in Extract 6.23 where the participant spoke about the sad realisation that HIV+ children were less likely to ever get 'real parents'. Other participants said:

Extract 6.28

1 P60: For me they're just normal kids (.) well not normal of
2 course >cause they're living in this institution but<
3 (0.9) they're just kids (0.6) yeah

Extract 6.29

1 VR: And >is there anything about your< (.) experiences or
2 anything here at Cotlands that you would like to be
3 different (1.1) if you could change (.) one thing in the
4 last seventeen years (0.5) what would that be
5 (1.0)

6 P46: ((Squeaky voice starts)) to get parents for all the
7 children (0.5) that's all ((squeaky voice stops)) (0.9)
8 just so they can (.) all have (0.4) their own (.) home
9 (0.7) with two loving parents even just one (1.6) °not
10 have to grow up in an institution°

The response of the first speaker involves the typical referral to the Cotlands children as 'normal kids' (Extract 6.28, *l.* 1). This description, however, is subsequently qualified by the participant when she repairs herself and retracts the 'normal' label with the explanation that the children live in an institution ('not normal of course >cause they're living in this institution'); living in an institution is, thus, not considered 'normal'. Note the participant's use of the phrase 'of course' which insinuates taken-for-granted knowledge (Holmes, 1988). The second speaker further claims that if the Cotlands children could be given parents, they would not have to grow up in an institution (Extract 6.29), which suggests that children who live in institutions do not have parents. Put inversely, then, having parents can be seen as representing a 'normal', or optimal, childhood. When the second speaker constructs not having parents as a loss, by choosing 'to get parents for all the children' (*ll.* 6-7) as her number one priority for change, one may argue that not having parents is a loss of an optimal childhood. Furthermore, she speaks about 'loving' parents, which suggests that the optimal childhood would involve children having parents as well as children being loved, as discussed previously.

It is noteworthy that while reappraisal of meaning in response to children dying was almost exclusively demonstrated by local participants and lacking from international participants' discourses, international participants differed from local participants when discussing various losses in relation to the optimal childhood: international participants commonly highlighted the Cotlands children's loss of optimal childhood by comparing these children's childhood to their own. This discursive technique was, on the other hand, lacking in local participants' discourses.

The international participant below had just recounted an incident where some of the children had been sick and the participant perceived the staff to have failed to adequately care for the children. The perception of such failure came about as a result of a comparison to the participant's own experiences of having been sick as a child:

Extract 6.30

1 P58: I just know as a kid >I would always be< so upset when I
2 was feeling sick and when I was vomiting I hated
3 physically (.) the a- act-ion of vomiting (0.5) and felt
4 so gross and awful and (0.4) the only thing that made it
5 bearable was that mum was there to sort of stroke my head
6 and get me a glass of water and (.) you know brush my
7 teeth and whatever to make me feel better

Extract 6.31

1 VR: So working with (.) HIV positive individuals (.) what
2 aspect do you find most difficult
3 (2.8)
4 P59: Oh (0.4) ehm (3.1) I think it's the coming to terms that
5 they won't be able to have the life that you have (.) I
6 think (1.3) because I know that now I'm going home (.)
7 I'm going off to university (0.5) ehm (0.3) hopefully
8 then to get some (.) lovely job settle down have a family
9 and do- (.) and have (1.0) I don't want to say the
10 stereotypical li(h)fe but I want that's (all) what I feel
11 my future path is set out to be (and) (0.3) having been
12 brought up in a (1.4) being completely honest been
13 brought up in a sort of upper middle class lovely area of
14 ((name of city)) with such (.) a-all (0.6) lovely
15 gorgeous families around me and it's knowing tha- (.)
16 this child is so (0.5) set apart from what (.) sort of
17 bubble life style I've grown up in so (0.7) that's the
18 most difficult bit it's the coming to terms with the fact
19 that (0.8) I know I've got so much laid out in front of
20 me (0.2) and they-they don't have that so (0.5) that's
21 (0.2) challenging I think

Both participants above speak of various privileges which they had as children. The first participant describes a difficult childhood experience and, in doing so, she constructs the events as rather negative: she was *sick*, which she *hated*, and she was *upset*, and felt *gross* and *awful* (Extract 6.30, ll. 1-4). She thereafter reports that having a parent who cared for her ('stroke my head', 'get me a glass of water', 'brush my teeth', ll. 5-7) and made her 'feel better' (l. 7) was 'the only thing' (l. 4) which made the experience bearable. In contrast, the Cotlands children, who do not have parents, were not adequately cared for when they were sick. By comparing the Cotlands children's childhood to that of her own, the speaker highlights the losses which the Cotlands children suffer.

The account of the second participant has similar implications. This speaker characterises her own childhood as privileged by reporting having grown up in an area described as 'sort of upper middle class' and 'lovely' (l. 13), with 'lovely gorgeous families' (ll. 14-15), and how she is due for a 'lovely job' (l. 8) in the future. In addition to 'lovely', this life is further labelled as a 'sort of bubble life style' (ll. 16-17). The expression 'the bubble bursts' is typically used to refer to the ending of a happy or successful period. By referring to 'bubble', then, the speaker can be heard to refer to her life as happy and successful. Previously, she has also claimed that 'they won't be able to have the life that you have' (l. 5), thus putting the Cotlands children's childhood and lives in contrast to that of her own. (Although the interview question enquires about their work with HIV+ individuals, the participants often responded with specific reference to their work with the Cotlands children.) Once again, through a comparison with her own privileged childhood and life, the speaker has highlighted the losses inherent in the Cotlands children's lives as orphans or HIV+ children.

Participants' comparisons, then, highlighted losses such as not having parents or not being loved and cared for. In participants' discourses, the presence of such factors was clearly associated with the presence of an optimal childhood. Children, as constructed by participants, are not meant to die. Nor are children

meant to not have parents, or not being loved and cared for. AIDS-related death may no longer be a prominent issue at Cotlands but the problem of children not having parents or not being loved and cared for still stand. Thus, the new era of HIV work simply involves new, or other, types of losses.

6.7. Discussion

In summary, participants introduced the child identity into their discourses and consequently demonstrated that children are different to adults because inherent in the child identity are characteristics that adults lack. For example, children are perceived as innocent and therefore they evoke sympathy. This perceived innocence comes about from a lack of agency; agency is age-dependent and, therefore, whereas adults can be held accountable for their actions children are perceived as too young to have agency and thus they cannot be subjected to the same accountability. Subsequently, where children are experiencing hardships, such as being HIV+, they are not held responsible for this but rather adults are generally being blamed also for the children's hardships. Further characteristics inherent in the child identity are that children are to be loved and cared for and that children are not meant to die. When children do die, attempts are made to find purpose in order to make sense of such otherwise incomprehensible events. In a time of successful ART programmes, children dying may no longer be a prominent issue; however, the new era of HIV work faces new, or other, challenges. One such challenge is that HIV these days acts as a barrier to a 'normal' life. Loss, then, is not merely a matter of death but aid workers who today work with HIV+ children also experience sadness for and on behalf of the children for their loss of an optimal childhood.

Chapter 7. The Caregiver Identity

As stated in the previous chapter, two identities were particularly prominent in participants' discourses. Chapter 6 illustrated how participants introduced the child identity into their discourses and how they constructed children as different to adults, with certain characteristics inherent in a child identity and implications in terms of accountability in relation to one's HIV-status. The present chapter addresses the second identity constructed in participants' discourses: the caregiver identity. The first half of this chapter – The 'Rules' of Caregiving – will, first, illustrate how participants constructed caregiving as a female activity, and, thereafter, how caregiving is prescriptive. There are Dos and Don'ts associated with 'proper' and 'genuine' caregiving and this chapter will discuss three of these: caregivers do not put children at risk, caregivers sacrifice, and caregivers take action. (It should be clarified that although the first one relates specifically to children, the latter two refer to caregiving in general.) The second half of the chapter – The Caregiver Identity as a Double-Edged Sword – will illustrate how the caregiver identity can simultaneously be advantageous and disadvantageous. First, caregiving is perceived as rewarding and thus the caregiver identity can act as a buffer against the otherwise often difficult and exhausting experience of caregiving; however, in their discourses participants also constructed personal gains from caregiving as selfish and thus negative. Participants' sensitivity towards being perceived as selfish will be illustrated, and a number of discursive techniques which participants employed in order to convey their authenticity as caregivers will be discussed. Second, the final section of this chapter will illustrate that while the caregiver identity can act as a buffer, its highly prescriptive nature also makes caregiving taxing.

The 'Rules' of Caregiving

In their discourses, participants constructed a number of identities that could be considered as providing care or meeting needs in different ways and to varying extent, such as mother, nanny, nurse, educator, saviour, martyr, or activist. These different identities each have their own associated characteristics; however, it is not the aim of this chapter to explore them all in detail. Rather, three characteristics which are applicable to caregiving in general will be discussed shortly. The first section below, however, will illustrate how caregiving was constructed as a female activity.

7.1. Caregiving Is a Female Activity

*'Wathint' abafazi, wathint' imbokodo'*⁸

In participants' discourses, caregiving was frequently coupled with being a woman. This close association was partly evident in how a large number of the female participants introduced themselves in response to the first interview question 'Could you please tell me a little bit about yourself':

Extract 7.1

1 P40: My name is ((name)) eh ((full name)) (0.6) I am: (.)
2 staying in ((area)) I'm working here at Cotlands I've got
3 two children two daughters (0.5) I am a married woman

⁸ 'You strike the woman, you strike the rock' – political protest chant (Castelyn, 2008)

Extract 7.2

1 P19: OK:: (3.0) OK I'm ((chuckles)) I'm married I'm a mother
2 of <three> boys

Extract 7.3

1 P29: I am a mother of three boys (1.0) e:::h (0.6) I stay with
2 all of them right now and my husband

Extract 7.4

1 P1: Shoh (0.2) ehm::: (2.1) I::: hoh where do I start
2 ((chuckles)) ehm (0.2) I would <sa:y> tha:tt uhm (0.2) I'm
3 mom (0.4) I'm married

All participants above state that they, one, are married, and, two, have children. As such they speak of being a 'wife' and a 'mother'. The fact that 'wife' and 'mother' were such immediate and prominent features of the female participants' responses suggests that participants perceived these to be significant aspects of their personas. Traditionally, 'wife' and 'mother' carry caregiving and nurturing connotations (Bozalek, 1999; Stanfield, 1985). The female participants, then, can be heard as conveying that caring and nurturing are significant aspects of their identities.

That caregiving was closely associated with women was further evident in how participants would make references to mothers, but not to fathers, when speaking of, for example, caring for children or the household:

Extract 7.5

1 VR: And (.) how (0.2) do you feel (.) about working with
2 (0.2) children who have HIV or AIDS or TB (0.6) how does
3 it feel
4 (0.6)

5 P13: For the first time I was painful (0.7) now (3.5) now I
6 (1.4) >you know what< I don't (0.7) no I d- I didn't take
7 this seriously (0.7) becaus::e (1.2) >even if I< know
8 that the child is got TB I- advise the mother (0.6) they
9 must go to do: >even if< n- (.) when I don't I don't know
10 that the child is (0.2) got TB (0.5) we advise about s-
11 t- to go to do TB screening

The above participant speaks of the medical care of a child both in terms of ensuring the child's health, for example, through medical examinations such as screening for TB, as well as addressing ill-health, for example, if the child is already suffering from TB. The speaker further says 'I- advise the mother' (l. 8). By advising the mother about these aspects of care it implies that the speaker expects the mother to then apply this knowledge, which ultimately holds the mother responsible for such care. More importantly, there is no reference to the father in relation to the child's medical care. This discursive feature is also displayed in the below extract where a Home-Based Care Worker had just been asked to describe what her job involved on a daily basis:

Extract 7.6⁹

1 P12: I check the register (0.2) I:: sign that I count the
2 pills (0.5) the mother (.) is give the child OK eh right
3 dose (1.2) and then (1.1) I look around (.) the house
4 (1.5) if it's not (.) clean (1.6) I teach the mother the
5 mum (.) about hygiene (1.2) I teach the mum about
6 nutrition (1.2) I teach the mum abou- about general (.)
7 education lik:e (1.3) mm::: (0.7) take care for himself
8 (1.3) go to the clinic to check himself (0.5) whatever
9 (0.3) sugar diabetes (0.3) high blood (0.9) because when
10 you come in y-you get a lot of problems (1.1) in e-e-et
11 (.) th- i-i-i-in house (0.3) so you know you are not
12 looking after (.) the child only (1.1) so (0.8) I advise
13 the mum to >go to the clinic< do this (0.8) eh TB test
14 (0.7) HIV test if: th-they don't know y-eh- their status
15 because some of the mothers (0.5) you find that (.) she
16 have (0.6) a child e- side the child is (.) eh he's she's
17 HIV or (.) °HIV° (0.8) but (.) the mother (0.2) is not

⁹ Recall from Chapter 4 that many South African vernaculars don't have the words 'she' and 'he'; consequently, many use 'she' and 'he' interchangeably when speaking English.

18 her mother (0.5) the bau- () mother (0.2) is just (0.5)
 19 the:: (0.7) girlfriend of (0.6) his father of the child

In her account, the speaker explains that her job involves ensuring that a child is given the correct medication and further says 'the mother (.) is give the child OK eh right dose' (*ll.* 2-3). In doing so, she is insinuating that administration of medication to the child is the responsibility of the mother; once again, there is no mentioning of the father's role in relation to the child's medical care. The speaker further touches upon other aspects of care, such as hygiene and nutrition, and once again states 'I teach the mother the mum (.) about hygiene (1.2) I teach the mum about nutrition' (*ll.* 4-6). Similar to the speaker in Extract 7.5 above, by teaching the mother about these aspects of care there is an implicit expectation that the mother is to subsequently apply this knowledge. Consequently, the mother is once again held responsible for such care; the father is still lacking from the picture.

Now, it is possible to argue that caring for a child is the responsibility of parents, and because a mother is a parent it is thus her responsibility to care for the child; however, the woman whom the speaker in Extract 7.6 is speaking of appears to not be a biological parent. For example, although the speaker first refers to the woman as 'the mother' she then does a repair (Schegloff, 1992) and alters 'the mother' to 'the mum' (*ll.* 4-5). This suggests that the speaker perceives a 'mum' to be distinct from a 'mother'. Moreover, the speaker states that 'the mother (0.2) is not her mother' (*ll.* 17-18) and further elaborates that the woman in question is 'just' (*l.* 18) the girlfriend of the father of the child. Here, the word 'just' appears to have a depreciatory function that serves to minimise 'the significance of some process' (Lee, 1987, p. 378). In the account above, 'girlfriend of father' would be what Lee (1987) labels the 'focal' process, which is the process being minimised in reference to a 'referent' process (p. 379); here, the referent process is explicitly stated as 'mother'. Thus, the speaker's account suggests two things. First, it is possible to infer that whereas 'mother' and 'father' appear to have biological connotations, 'mum' does not because it is distinct from 'mother' (and is arguably more in line with 'girlfriend

of father'). Second, the word 'just' and its depreciatory function suggest that perhaps a biological parent (mother) would have more legitimacy as a parent than a non-biological parent (mum or girlfriend of father). As such, the woman in question, the 'mum', is not the child's biological mother. Yet it is the 'mum' that is taught about hygiene, it is the 'mum' that is taught about nutrition, and it is the 'mum' that is advised to go to the clinic – not the (biological) father. If childcare was perceived to be the responsibility of parents, the father would presumably be expected to take a more central role in the child's care given his superior legitimacy as a biological parent. Yet the speaker makes no reference to the father's role in relation to the child's care; rather, she is attributing the responsibility of caregiving (both child- and household care) to the 'mum'. The speaker, then, is constructing caregiving as a female activity. Scholars have previously noted that the concepts of 'mother' and 'caregiver' are 'central to understanding womanhood' (Walker, Reid, & Cornell, 2004, p. 50), especially in South Africa (Castelyn, 2008). With regard to HIV caregiving in particular, Demmer (2010) has previously noted how the 'burden has fallen on women' (p. 8).

7.2. Caregiving is Prescriptive

'... it's what we do ... we all live it we live what Cotlands does ...'

Participants' discourses frequently suggested that caregiving is prescriptive: if one wants to be a 'proper' and 'genuine' caregiver then one needs to follow certain 'rules'. This section will show how caregiving was constructed as prescriptive in participants' discourses. The subsequent sections will discuss three ways in which caregivers were expected to demonstrate their authenticity.

The interviews conducted for this study would generally conclude with the two questions 'If you could change anything about your experiences here at

Cotlands, would you change something and if so what would you change?' and 'What recommendations do you have for those who want to come and work with HIV positive individuals?'. In response, a number of participants highlighted how they believed things *should* be:

Extract 7.7

- 1 P33: Eh:: it's not easy (0.3) eh Vania (1.6) because is rea-
2 av- as I've said before that (0.3) as we are workers here
3 (.) we are not the same (1.6) we ho- we have different
4 people here destructors some are destructors some are
5 dominators some are show off you know (0.5) forgetting
6 why we are here (1.9) I wish they can jus::: (0.3) make
7 (1.6) maybe our supervisors they can make in a bold
8 letters >the policy for this place< (.) so that
9 >everybody must know< (0.4) why they are here (1.1)
10 because it seems as if some of them they are not (2.3)
11 interested I don't know I can say it's interested or
12 aware (0.2) why are they are here (0.9) °you know° (0.6)
13 and that thing it i- (0.4) it let me down (1.5) it let me
14 down=
15 VR: =°Mm°
16 (1.3)
17 P33: Because first thing must know >the policy for this place<
18 (2.3) <because> this place it's::: this place because of
19 the kids (1.6) if those kids are not here we won't be
20 even here (0.6) we won't even have that job (0.7) yes
21 (1.0)
22 VR: So why do you think people: come to work in a place like
23 Cotlands if they don't have the passion for it
24 (1.5)
25 P33: I think is it because they are >stranded about the job<
26 not to say that they are coming to help peop- >the-the
27 kids< eh the sometimes you can see (0.9) the way they are
28 acting (2.1) °it's not acceptable° (0.8) °it's not
29 acceptable°

That caregiving is prescriptive is evident in the above speaker's account of how she believes that some staff members seem to have forgotten why they are working at Cotlands. The phrase 'forgetting why we are here' (ll. 5-6) implies the

existence of a predetermined purpose or mission that everyone is, or ought to be, working towards. Likewise, the speaker refers to '>the policy for this place<' (l. 8), which also suggests a predetermined plan of action that ought to be followed. The speaker further expresses disappointment in what she perceives to be staff members failing to comply with this predetermined mission or policy ('it let me down', l. 13). The speaker, then, is insinuating that such staff members are not behaving appropriately because they are not behaving according to predetermined regulations (or expectations). In a Cotlands context, where staff members are there to provide care, this translates to such staff members not behaving according to prevailing caregiving norms. This is further reinforced by the speaker condemning such staff members for being at Cotlands for the wrong reasons. When the speaker offers 'because they are >stranded about the job<' (l. 25) as a possible explanation for why someone may work at Cotlands without being sufficiently passionate about their job, there is an insinuation that such individuals simply wanted *a* job as opposed to *that particular* job; that is, they were desperately looking for *any* job as opposed to specifically looking to become caregivers at Cotlands – they were there for the wrong reasons. Finally, the speaker claims that the actions of such staff members are unacceptable (l. 28; and she has previously also stated that 'it's not easy' (l. 1) when staff members differ). Altogether, this implies that such staff members do not adhere to the 'rules' that determine acceptable behaviour. As Hewitt and Stokes previously have noted, 'A discussion of problematic events aids in the reformulation of the link between culture and behavior'; it is through the consideration of problematic events that culture becomes conscious and, thus, 'visible' (Hewitt & Stokes, 1975, p. 1). To imply that certain staff members do not adhere to the 'rules', subsequently implies that such 'rules' do in fact exist. Conclusively, the speaker has constructed the reasons for being at Cotlands – that is, caregiving – as prescriptive.

The participant below also legitimises and criticises certain practices:

Extract 7.8

- 1 VR: What recommendations (.) do you have (.) for (.) those
2 who want to come and work with (.) HIV positive
3 individuals (.) so what advice would you give to people
4 (.) who want to come and do this wor:k
5 (0.5)
- 6 P26: They must do it out of love (1.1) they must have a
7 passion (1.0) love them (.) they mustn't dis- (0.4)
8 discriminate (0.5) they mustn't come here to work (0.2)
9 because they want to see the HIV AIDS child (.) what does
10 she or he looks like no (0.8) they must have the passion
11 that I'm going there (.) to work (.) to help those kids
12 (.) give them what I've got because everyone's got (0.2)
13 his or her special talent (0.2) that we don't have
14 (1.4)
- 15 VR: Do you feel that people sometimes come here (.) just
16 because they want to know what an HIV [child looks]
- 17 P26: [Yes]
- 18 VR: Like
19 (0.4)
- 20 P26: Yes †some they do ask (1.0) does this child have ei- (.)
21 HIV (0.3) this is HIV o- positive or what
22 (1.5)
- 23 VR: And how does that make you feel
24 (0.8)
- 25 P26: Ba:d (0.5) I feel like I can klap them (0.8) sometimes
26 but it's not in my power

The speaker above is asked to provide some advice for individuals who want to engage in HIV/AIDS aid work. In response, she offers a number of imperatives: they must do it out of love and passion, and they must not discriminate or simply be there because they are curious about what children with HIV or AIDS look like (*ll.* 6-10). In other words, when the speaker offers these imperatives as recommendations, she is heard to communicate that if one wishes to succeed as an

HIV/AIDS caregiver then one needs to behave in certain ways. Moreover, the speaker reports negative emotions in response to those who violate these imperatives (ll. 23-25). Such a report has a two-fold function. First, to state that some people are violating the 'rules' of caregiving and thereafter state that such a violation provokes negative emotions in her can be heard as an attempt by the speaker to communicate that she, on the other hand, is not violating the 'rules' of caregiving. Identity is just as much a discourse of belonging as it is a discourse of *not* belonging, or a discourse of the 'other' (Condor & Abell, 2006; Meinhof & Galasinski, 2005). Second, to classify certain practices in relation to caregiving as negative suggests that caregiving is prescriptive: caregivers ought to adhere to certain practices while avoiding others. Thus, parallels can be drawn between the 'rules' of HIV, as discussed in Chapter 5, and the 'rules' of caregiving, as discussed in this chapter.

Before moving on to discussing some of the ways in which caregivers are expected to demonstrate their authenticity, one final extract will be used to demonstrate that Dos and Don'ts of caregiving were perceptible in participants' discourses. In the following account, the participant was describing the moment when she learnt that an acquaintance had passed away from AIDS:

Extract 7.9

1 P58: It was ((name)) who told me and (0.4) uhm: (0.2) I >have
2 a lot of respect< and >time for ((name))< and she's a
3 very warm and gentle person an- (.) and I can't actually
4 remember it physically but I'm >almost a hundred percent
5 sure< she would've given me a big hug

First, the employee referred to in the above extract is described as a 'warm and gentle' (l. 3) person. When describing an individual, a reference to qualities such as 'warm' and 'gentle' conveys the impression of a caring character. In addition, the employee in question was in fact a nurse (known to both interviewer and interviewee), which by itself carries caring connotations. Second, the speaker

then proceeds to claim that the employee, in that moment, most likely had given her a hug (ll. 4-5). When an individual has just been informed of the death of an acquaintance and subsequently receives a hug from someone they respect, the hug is generally considered a caring and positive act. Interestingly, however, the speaker admits that she cannot fully remember this caring and positive act (ll. 3-4); rather, she is convinced that events must have unfolded in such a manner. In other words, she is convinced that the hug must have occurred because a caring person ought to have acted in a caring manner in such a sensitive situation. Thus, the speaker has constructed an association between a certain behaviour and a certain character. What the above account suggests, then, is that a caring person is expected to behave in a particular manner.

7.3. Caregivers do Not Put Children At Risk

'... it all could've been prevented if they've been cared for properly ...'

The previous section illustrated that participants constructed the caregiver identity as prescriptive; that is, in order to be perceived as a 'proper' and 'genuine' caregiver, one has to behave in certain ways. This section, and the following two sections, will discuss three ways, two Dos and one Don't, in which caregivers are expected to demonstrate their authenticity. This first section will discuss the one Don't of caregiving – caregivers do not put children at risk – as well as reappraisal of meaning in response to situations where children have been put at risk.

Chapter 6 illustrated how in participants' discourses children were constructed as innocent and adults were blamed for the children's positive HIV status. Because the norm sees that adults care for children, children contracting HIV was perceived as a result of adults' failure to care properly for a child. The notion of caregivers not putting children at risk is related to this; in order to be perceived as a

'proper' caregiver, one is expected to behave in a manner that demonstrates to others that one is not putting children at risk:

Extract 7.10

1 VR: >And is there anything that you find< particularly
2 difficult
3 (2.0)
4 P53: ((Sigh)) not really I- I find (0.3) maybe ah (1.8) I find
5 it difficult (.) walking away from the children knowing
6 that they've just been looked after by workers all the
7 time °I think every child deserves a mother and a father
8 (.) but I can't change the world either°
9 VR: Mm
10 P53: And it's also face that knowing that the °parents have
11 put them there or the parents have died of AIDS (.) and
12 why did they have children (.) when (0.3) the child is
13 gonna come° (0.8) that's (0.3) maybe what I've learnt (.)
14 not learnt °but it's (n)° (0.3) I can't do anything about
15 it but it (1.5) I can't understand it °to be honest°
16 (0.6) so I find that hard to (0.2) °sort of absorbing it
17 (.) in my head (0.7) you know why do people have children
18 if they can't look after them why do they have children
19 (0.6) when they're gonna give them HIV° that's something
20 I do find hard (0.6) °so when you were saying that
21 >before about fi-<° that yes th- that I do find hard
22 (0.5) why they're here in the first place that [I find]
23 VR: [Mmm]
24 P53: Hard

The first point to make regarding the extract above is how the phrase 'the °parents have put them there' (ll. 10-11) reinforces the argument made in Chapter 6: in their discourses participants held adults accountable for hardships faced by children. In this particular context, 'there' refers to Cotlands, a children's home. As further argued in Chapter 6, the optimal childhood involves children having parents as well as children being loved and cared for; being an orphan was constructed by participants as one of the predominant factors indicating loss of an optimal childhood. Thus, when the speaker above holds parents accountable for having put

their children in a children's home, it implies that such parents have failed to care for their children properly; the parents were not 'proper' caregivers.

Second, the speaker poses a number of rhetorical questions, such as 'why do people have children if they can't look after them' (ll. 17-18) and 'why do they have children (0.6) when they're gonna give them HIV°' (ll. 18-19). As HIV is an incurable and deadly virus, infecting children with HIV indisputably qualifies as putting children at risk. Likewise, as children are generally considered incapable to care for themselves, procreating without subsequently being able to care for one's children also qualifies as putting children at risk. Questions, however, are not always asked in order to obtain information; rather, they may be posed in order to uphold one's standpoint or to challenge the message in the question (Chiang, 2010). Thus, when the speaker poses such rhetorical questions, she is not necessarily in search of answers; rather, she can be heard to challenge the message in those questions. Here, the speaker above can be heard as insinuating that people ought not to have children if they cannot care for them or that individuals who are HIV+ ought not to have children, because such practices would constitute putting children at risk. The speaker does further state that she 'can't understand it' (l. 15) or 'I find that hard to (0.2) °sort of absorbing it (.) in my head' (ll. 16-17). With the use of such statements, the speaker communicates that she regards practices that put children at risk as incomprehensible; proper caregivers ought not to put children at risk.

The following account illustrates the difficulty experienced by a staff member who perceived herself as putting a child at risk:

Extract 7.11

- 1 VR: In these ten years (.) have you had an experience that
2 was especially (0.2) negative or difficult for you
3 (0.8)
4 P40: °Yes I did° oh and that one I don't rem- a-a-I- I
5 do(h)n't wa(h)nt to go there (.) you kn[ow]
6 VR: [That's fi]ne°

7 P40: One of the eh the child w-we were having eh well have a
8 little accident (0.7) there was ehm (0.8) this acid for
9 cleaning eh the drain (0.4) so: you have a: blocked drain
10 in the unit (0.4) so it happened that (0.3) eh (.) th-
11 (0.4) thell men who was (.) eh (0.6) eh (0.3) eh (0.2)
12 busy in the unit eh (.) blocking the drain (0.3) he left
13 that container there (0.5) accidentally the child asked
14 °to go to toilet and he° took that eh container and he
15 tries to drink it (0.4) <and> that think i- he burn the-
16 the child burn eh his mouth luckily he didn't swallow it
17 (0.4) he just burn himself and it was: (.) it was
18 difficult for me at that night I didn't sleep (0.4)
19 because that child had to go to hospital (0.5) for
20 treatment

21 (1.8)

22 VR: Why was that so difficult for you

23 (0.6)

24 P40: Because I felt that I failed the child (0.3) if I I went
25 there first I should have removed that container (0.5)
26 that child wouldn't be in such a (bad state)

The speaker above initially states she does not want to revisit the work experience which she perceived as most negative or difficult, which suggests the experience indeed affected her rather negatively, and perhaps even that the experience was perceived as shameful. The statement 'that night I didn't sleep' (l. 18) further accentuates the difficult nature of the experience; sleep disturbances are considered a common effect of, for example, traumatic experiences (Wilson, Friedman, & Lindy, 2004). The experience accounted for involves harm to a child: the child burnt himself and subsequently required hospital treatment. The speaker then explains that if she had arrived at the scene before the child then she could have eliminated the risk of harm to the child (ll. 24-26). As it turned out, however, the child had been put at risk (albeit unintentionally). Finally, the speaker reports that the experience was difficult because she had 'failed the child' (l. 24). The word failure implies that she did not meet certain expectations, which in turn suggests that expectations do exist. Here, such expectations arguably relate to the

prescriptive nature of caregiving and how 'proper' caregivers do not put children at risk.

That caregivers ought not to put children at risk was not an opinion held solely by the study participants; such a mindset was reported to be prevalent also in the wider society. The next extract highlights issues faced by a staff member who would bring her own children to Cotlands:

Extract 7.12

1 VR: So do you find that (0.5) other people seem to have an
2 issue with you having your children amongst >other HIV
3 positive children<
4 P5: Definitely (0.2) absolutely ↑not everybody (.) some
5 people (0.5) don't even question it or query it (0.6) but
6 i- (0.2) for me has always been an amazing thing that
7 people are OK with the fact that I work with those
8 children (0.6) but the minute I expose my ↑children to
9 those children it seems to be a completely new thing
10 (0.5) and often that's questioned yah

The participant reports how, to her astonishment, the fact that she exposed herself to HIV+ individuals was perceived by others as acceptable, but the fact that she exposed her children to HIV+ individuals was not taken as lightly. In theory, both scenarios involve the same risk: exposure to HIV+ individuals, and consequently exposure to the risk of contracting HIV. One difference between the two, however, is that the participant is an adult, a parent, a caregiver. Her children, on the other hand, are just that – children. Accordingly, the two scenarios were treated differently on this basis: whereas the risk involved in her working with HIV+ children was perceived as acceptable, the risk involved in exposing her children to HIV was questioned. The speaker's use of words here is also of interest. Whereas 'work with' (l. 7) has neutral connotations, 'expose' (l. 8) carries more negative connotations. Questioning a behaviour equates to doubting that behaviour, and questionable practices may be perceived as unsatisfactory, disappointing, or substandard. The fact that putting children at risk carries such negative

connotations further supports the argument that caregiving is prescriptive and caregivers who put children at risk are perceived as violating the 'rules' of caregiving.

7.3.1. Reappraising Meaning in Response to Putting Children at Risk

As illustrated in previous chapters, participants would reappraise meaning in order to deal with and make sense of otherwise difficult and incomprehensible experiences. Accordingly, participants also engaged in such reappraisal processes when faced with situations where children had been put at risk. The following participant had reported that Police bringing abandoned children to Cotlands at night was the most difficult aspect of her work when she first started at Cotlands:

Extract 7.13

1 VR: Why was that dif[fi]cult]
2 P42: [Because] you have to ask yourself lots
3 of question what kind of woman is doing this to their
4 child (1.2) you know and afterwards I I I teach myself
5 not to judge (1.5) because there's so lo- (0.2) lot of
6 various reasons why (0.4) people are doing what they're
7 doing (1.0) so some of them did- (0.9) yeah (.) leave the
8 child abandon the child (0.3) but it's not because they
9 wanted to do that it was the situation that they were in
10 (2.2) so it's why I taught myself that we have to (0.6)
11 you know sometimes: put ourself in other people's shoes
12 and (0.6) it's not the (goids) it's not the good thing
13 but we don't know (0.5) maybe there are reasons that have
14 pushed that person to do that

In the extract the speaker questions 'what kind of woman is doing this to their child' (ll. 3-4), 'this' referring to abandoning the child whereby the Police consequently has to bring the child to a children's home. Such an event was argued earlier as a sign of parents having failed to properly care for their children. First, it is noteworthy how the speaker refers to women only, and not men, further supporting the claim that participants frequently associated caregiving with women. Second,

this phrase, too, can be considered a rhetorical question, similar to the questions posed in Extract 7.10. The purpose of the question is, thus, not to obtain answers but rather to uphold a standpoint. Here, the character of a woman who does not care properly for her child with the child subsequently appearing in a children's home is constructed as an incomprehensible event, and questioned. The fact that such behaviour is viewed in a negative light is further evident in how the participant speaks about learning not to judge (ll. 4-5): the word 'judge' implying criticism of behaviour considered to be morally substandard.

On the other hand, the fact that the speaker tries to teach herself not to be judgemental suggests she is sensitive towards being judgemental and being perceived as such. In order to not be judgemental she seeks to make sense of the events; by reappraising meaning, the speaker attempts to find *reasons* to explain the otherwise incomprehensible act of a woman putting her child at risk by not caring properly for the child. In her attempt, the speaker reconstructs the events and shifts the locus of control: instead of constructing the child arriving at a children's home as a result of an *active* choice made by the woman to not care properly for her child – that is, an internal locus of control – the events are rather constructed as resulting from the woman *passively being forced* to act the way she did – that is, an external locus of control (ll. 7-9). Rather than attributing internally and holding the woman accountable, any negative consequences were attributed externally to the situation.

Extract 7.12 above highlighted issues faced by a staff member bringing her own children to Cotlands. The following participant was describing how bringing her children to Cotlands has affected her:

Extract 7.14

1 P44: ((Sighs)) it has affected me (0.9) in a negative way
2 (0.4) in the sense of when they were (0.2) >still very
3 little and they actually< attended the nursery school
4 here (2.3) you know it doesn't matter ((clears throat))
5 how well (.) trained you are or how much you know (0.4)
6 when there is an accident or gh- as a mummy you
7 instinctively worry that your child has you know (0.7)

8 contracted something or whatnot (0.3) so I think always
 9 were those little incidents where (0.2) >(you know)< like
 10 going to bit of a scuffle and they scratched each other
 11 <open> and (.) that type of thing (1.4) but on the (.)
 12 other hand it's also been (0.5) a very (0.2) positive
 13 thing because (0.4) it has tau::ght (0.7) my two children
 14 life lessons that I don't think others receive (0.5) so
 15 now even you know n- (0.9) nine and seven years old (0.6)
 16 they're very compassionate they understand (0.7) the
 17 predicaments (.) they understand without me having to be
 18 (0.3) >a mummy that has forced it down their throat and
 19 said you better eat your food because other kids go
 20 hungry< (0.3) but they do understand that because they
 21 see (0.2) you know the children that just (.) live here
 22 at Cotlands and know there are no mummies there's nobody
 23 for them (1.1) so I think yah really the (2.5) the good
 24 that has come out of it (0.9) you know is is far more
 25 than (0.5) >the little bits and pieces here that have
 26 kind of got you worried< for a while that (1.1) you know
 27 (0.3) ((whispering voice starts)) my child has scratched
 28 ((whispering voice ends)) open
 29 VR: [((Chuckles))]
 30 P44: [Does] he have a virus yah

In this extract, caregiving is once again associated with women. The speaker above claims that 'as a mummy you instinctively worry that your child has you know (0.7) contracted something' (ll. 6-8), a statement that sustains the traditional view of mothers as caring and nurturing. A child contracting something – in this case a potentially deadly virus – implies harm to a child. To claim that worrying about harm to their children is something mothers do 'instinctively' is to claim that worrying about harm to their children is in a mother's nature: they have a natural tendency to do so, it is behaviour they engage in without too much thought, it is hardwired and will not be affected by any degree of education, knowledge, or 'rationalism' ('it doesn't matter ((clears throat)) how well (.) trained you are or how much you know', ll. 4-5). In other words, worrying about risks to their children is what mothers do.

The first half of the account, then, is constructed as a negative state of affairs where the potential for risk to children is high: there are accidents, there are worries,

there is the risk of children contracting HIV, and there are children physically hurting each other ('they scratched each other <open>', ll. 10-11). This negative construction, however, is put in contrast to a different situation, a positive one: after her initial negative account, the speaker then flips the coin by saying 'but on the (.) other hand' (ll. 11-12), and proceeds by constructing a positive version of the events. In this construction, rather than the situation having resulted in the mother putting the children at risk, the children have gained something from the situation. The speaker states that her children have been 'taught' 'life lessons' (ll. 13-14) which implies an enrichment of their lives. The speaker further provides concrete examples of what exactly the children may have gained, which make the argument more plausible. For example, the children are described as compassionate, understanding, and eating their food because they possess an awareness that less fortunate children go hungry (ll. 16-20) – all of which are generally considered desirable qualities in children.

That the speaker is reappraising meaning in order to make sense of a difficult experience is evident in her statement 'the good that has come out of it' (ll. 23-24), which indicates that she (however unintentionally) searches to identify positive outcomes from an otherwise potentially negative or difficult situation. As a matter of fact, not only does she search for positive aspects among the negatives in order to address the dilemma, but the positive aspects are in fact claimed to be 'far more' (l. 24) and thus the positive construction of the event is posited as outweighing the negative ('the good that has come out of it (0.9) you know is far more than (0.5) >the little bits and pieces here that have kind of got you worried<', ll. 23-26).

Conclusively, in participants' discourses caregiving was prescriptive, and in order to demonstrate oneself as a 'proper' or 'genuine' caregiver one is expected to adhere to certain Dos and Don'ts. One such Don't is that caregivers do not put children at risk, such as the risk of contracting HIV – a potentially deadly virus – or risks associated with being an orphan, or not being properly cared for in general.

When participants faced dilemmas in terms of caregivers putting children at risk, whether they perceived themselves or others to be doing so, they would attempt to reappraise meaning in order to make sense of such dilemmas. Sometimes this reappraisal process would involve seeking positive aspects of the experience which could outweigh the negative aspects of having put children at risk.

7.4. Caregivers Sacrifice

'... we can't let the poor kids die just because we're scared ...'

Another way in which caregivers could demonstrate their authenticity was by sacrificing. 'Proper' and 'genuine' caregivers sacrifice; they sacrifice their own needs in order to prioritise the needs of others. In some participants' discourses, a true HIV/AIDS caregiver resembled a martyr. For example, the following participant was asked at the end of an interview if he wanted to add anything:

Extract 7.15

- 1 P10: U:hm nothing too much I guess (.) uhm (0.6) yeah I mean
2 obviously it's a (0.4) >it is difficult thing< to work
3 with (0.4) to work with kids who have HIV uhm (0.6) °it
4 is it's very difficult (0.3) it can it can be° I mean
5 it's great it's amazing °you know like I said the kids
6 need so much love and support too and° (.) and they
7 deserve it too there's yeah °there's nothing wrong with
8 them° (.) so (0.5) uhm (0.4) yeah but it's (.) >but it's
9 good< (.) yeah and it's really hard to lose (0.3) to lose
10 somebody (.) from (.) >from it as well< especia-
11 especially kids it's °crazy (.) yeah but (0.5) uhm >but
12 it is good< (0.2) yeah
13 (0.6)
14 VR: So how come you choose to do it even though it's so
15 P10: ((Chuckles))=
16 VR: =Difficult (.) why not just let somebody else
17 [do it]

- 18 P10: [((Chuckles))]
 19 VR: ((Chuckles))
 20 P10: ((Chuckles)) >cause nobody else will d(h)o i(h)t<

Although the speaker does claim that working with HIV+ children is ‘great’, ‘amazing’, and ‘good’ (*ll.* 5 and 9), he also refers to his work as ‘difficult’, ‘hard’, and ‘crazy’ (*ll.* 2, 4, 9, and 11). Furthermore, he offers an account which depicts this kind of work as very challenging. First, the work in question – working with HIV+ children – involves enduring illness, and the speaker refers to this work as difficult (*ll.* 2-4). Second, the work involves losing people (to HIV) and thus it involves enduring death; the speaker refers to losing somebody as hard (*ll.* 9-10). Third, the speaker claims that it is especially hard to lose kids (to HIV; *l.* 11); therefore, because the speaker works at Cotlands, and as such he works with kids, his job can then be inferred to be in the harder category.

After this account, which depicts his job in such a challenging manner, the participant is asked why he nonetheless chooses to engage in such work, to which he responds ‘>cause nobody else will d(h)o i(h)t<’ (*l.* 20). (It should, however, be noted that this response may have been elicited by my question suggesting that he let somebody else do the work.) Such a response contains a number of features associated with martyrdom. First, a martyr voluntarily sacrifices something valuable, such as his or her life or freedom, for the sake of a cause, and consequently endures suffering. Such features are also evident in the extract above: the caregiver who sacrifices his own well-being for the sake of caring for terminally ill children, despite suffering as a result of the difficult nature of the work. Furthermore, with the use of the Extreme Case formulation (Pomerantz, 1986) ‘nobody else’, the speaker insinuates that the burden of accomplishing the task rests on him and him solely. Thus, the attainment of caring for the children depends on his sacrifice. Second, a job described as one that nobody else will do contains an element of opposition. In martyrdom, people other than the martyr often oppose the cause

which the martyr sacrifices for. A proper caregiver, then, will sacrifice to the extent of attempting the most unattractive job, such as caring for terminally ill children. Finally, martyrdom involves courage and commitment in spite of being aware of the risks involved in pursuing the cause. In the account above, the speaker explicitly states the difficulties involved in HIV/AIDS caregiving – it is ‘difficult’, ‘hard’, and ‘crazy’ (not to mention the risk of HIV infection) – but nonetheless expresses a commitment to the cause. Thus, like a martyr, a ‘proper’ HIV/AIDS caregiver sacrifices his or her own needs for the sake of the cause: HIV+ children’s need to be cared for.

That caregivers are expected to sacrifice their own needs for the sake of caregiving is also evident in the account below where an international volunteer is discussing issues one may face when travelling to a different country:

Extract 7.16

1 P52: Also if you are allocated to a organisation like (.) an
 2 orphanage (0.2) and when they are (.) deaths °and all
 3 this° kind of stuff (0.8) ehm (0.2) you must be like
 4 (0.6) ehm (2.5) °ehm how to say° (.) it >you just have
 5 to< cope with this you- (.) it's it mustn't touch you too
 6 much (0.2) that you are not able to work on (1.1) yes
 7 (0.3) you must be sensitive of course but you (0.5)
 8 mustn't like go down and say o::h (.) this kid died I
 9 don't want to work for s- (0.2) five months now

In his response, the speaker raises death as an issue that one may face when working at a children’s home. Bereaved individuals commonly experience a number of distressing emotions, such as deep sadness, and may require a period of time dedicated to mourning and recovering; such a recovery time may include leave from work. In the extract above, however, such a generous recovery period is not granted those who work in a children’s home. The imperatives used by the speaker (‘you must’ and ‘>you just have to<’, ll. 3-5) prescribe how one must be able to continue working in spite of bereavement, even if potentially distressing. For example, the word ‘cope’ (l. 5) insinuates the existence of some difficulty that must

be overcome. The speaker, however, is also careful to stress that although one must not be too affected by bereavement, one must neither be entirely *unaffected* (ll. 7-9). A balanced view, then, is constructed where unaffected and callous are placed at one extreme and too affected and incapable of working at the other extreme. The appropriate midpoint of the scale is constructed as a continuation of carrying out one's caregiving duties in the face of difficulty.

Thus, the accounts above suggest that caregiving is prescriptive and 'proper' caregivers sacrifice their own needs in order to continue caring for others. Even when facing death, 'proper' caregivers are obliged to continue caring at the expense of their own psychological needs.

7.5. Caregivers Take Action

So far it has been argued that 'proper' and 'genuine' caregivers demonstrate their authenticity by not putting children at risk, and by sacrificing their own needs in order to prioritise the needs of care recipients. The final Do of caregiving to be discussed in this chapter is the expectation that 'proper' caregivers take action; that is, 'proper' caregivers act on every opportunity to 'do good'. Taking action, as presented in participants' discourses, involved making a difference and proactively investing resources, both of which will be discussed individually below. This section will conclude with a discussion on how participants reappraised meaning in response to lack of action.

In relation to the expectation that 'proper' caregivers take action, one participant responded to the first interview question 'Could you please tell me a little bit about yourself':

Extract 7.17

1 P8: I believe I was here for a purpose because I brought so
2 many changes to the organisation (0.4) and u:h we also

3 pioneered the:: (0.5) antiretroviral programme because
 4 when the (0.4) when I started in >two oh oh< one (0.5) we
 5 had eighty nine deaths: (0.2) that (.) year (0.5) and it
 6 was tr- quite traumatic for us to watch children (0.2)
 7 just dying (0.4) and uh (0.1) they used to die (.) when
 8 they turned (.) five or six (.) they would just die (0.7)
 9 so we had no control on that until we said well (0.3)
 10 wha- how long are we going to wait and see our children
 11 dying like this (0.3) and we decided to put pressure on
 12 the (.) fundraising team then (0.4) >so that they<
 13 campaigned for money (0.5) <for ARVs>

The first point to be noted about the above response is the speaker's ability to account for the events in a detailed manner. For example, the speaker expands on her statement 'when I started' (*l. 4*) by providing the exact year – 2001 – and proceeds by stating the exact number of deaths – 89 (*l. 5*) – that occurred that year, as opposed to using a more general expression such as 'almost a hundred'. She also expands on the broad claim that children used to die by stating precisely when they would die: at age five or six (*ll. 7-8*). As stated in Chapter 4, detailed accounts appear as more factual and thus more 'real' or convincing.

Moreover, in the account, the speaker depicts a negative situation: events involving high death rates and that are traumatic and out of control (*ll. 5-9*). In response to such a negative situation, the speaker then offers two possibilities: a passive response and a proactive response. Initially, as reported by the speaker, she and her colleagues queried 'how long are we going to wait and see our children dying like this' (*ll. 10-11*). The phrase 'wait and see' suggests a passive response, that is, one where action is lacking. It also insinuates that the individuals lack control over the proceedings. Moreover, the use of such a rhetorical question (as previously discussed) challenges the notion of passively waiting and seeing, and portrays such inactivity as objectionable. In contrast, the statement 'we decided to put pressure on the (.) fundraising team then (0.4) >so that they< campaigned for money (0.5) <for ARVs>' (*ll. 11-13*) suggests a proactive response. 'We decided' insinuates the individuals have, and take, control over the situation. This contrast in level of control is further communicated in the phrase 'we had no control on that

until' (l. 9) where the word 'until' suggests a change in events (and, here specifically, control). Words and phrases, such as 'put pressure on' and 'campaigning', as well as 'pioneered' (l. 3) used by the speaker early in the response, further communicate that this response is proactive in nature as these words and phrases suggest action. Finally, the mere reference to campaigning for ARVs implies a proactive response to a negative situation: ARVs decelerate the advancement of HIV and therefore reduce the risk of premature death. Thus, in the extract above, whereas passivity is constructed as objectionable, at least in an HIV/AIDS caregiving context, proactively taking action, such as preventing AIDS-related death, is encouraged.

7.5.1. Caregivers Make a Difference

While participants in their discourses highlighted the importance of taking action, taking action was merely the beginning: it was simply a prerequisite in order to make a difference. Participants' discourses additionally highlighted the importance of making a difference:

Extract 7.18

1 VR: And as a final question (0.2) uhm (.) what
2 recommendations would you give to those (0.3) who want to
3 come and work with HIV positive individuals (.) what
4 advice would you give them
5 (2.3)
6 P3: I think first of all (.) they need to: (1.4) like I said
7 have (1.1) have knowledge (.) of (.) the disease and what
8 it can and can't (0.5) I think you also need to a certain
9 degree have a passion in my mind for kids (0.6) <if you>
10 just gonna come here cause it's around the block from
11 your house and it earns you a nice salary and you live
12 comfortably (0.6) you can't make a difference in my eyes
13 it's like yo-you: (.) you have to come with the right
14 heart if you wanna work here you you need to wanna make a
15 difference [...] but mostly yah have a passion for kids and
16 have a passion for (0.2) wanting to make a difference
17 cause if you just wanna (.) go because it's a comfort
18 zone and around the block (0.6) you you're not giving

19 your all and you actually not making a difference you
20 actually just fooling yourself

In Extract 7.8, the speaker offered imperatives as recommendations in relation to HIV/AIDS aid work, and it was argued that she was heard to communicate that if one wishes to succeed as an HIV/AIDS caregiver then one needs to behave in certain ways. Extract 7.18 displays the same feature: the speaker offers imperatives ('need to' and 'have to', *ll.* 8 and 13) as recommendations and thus conveys that HIV/AIDS caregiving is prescriptive. The speaker offers three imperatives. First, one needs to have knowledge about HIV (*l.* 7). In Chapter 4 the role of knowledge as a weapon in the battle against HIV was highlighted. Second, one needs to have a passion for children (*l.* 9). In Chapter 6 the importance of caregivers having a passion for children, including loving and caring for them, was highlighted. Third, one needs to have a passion for making a difference (*l.* 16).

In order to be able to adhere to the final imperative, the speaker claims that one is required to engage in HIV/AIDS caregiving with 'the right heart' (*ll.* 13-14). By stating that there is a 'right' aspect of a phenomenon, the speaker implies there is also a 'wrong' aspect. In this regard, caregiving which stems from a passion to make a difference is regarded as 'right', whereas caregiving which stems from convenience is regarded as 'wrong'. First, caregiving which stems from convenience is constructed as entailing external incentives, such as living, working, and earning comfortably ('a nice salary', 'live comfortably', 'comfort zone', and 'come here cause it's around the block from your house', *ll.* 10-12 and 17-18). Such caregiving lacks effort ('not giving your all', *ll.* 18-19) and thus cannot accomplish any difference ('you actually not making a difference you actually just fooling yourself', *ll.* 19-20). In contrast, caregiving which stems from a passion to make a difference is constructed as entailing an emotion – passion – and thus it is characterised as intrinsically motivated. Conversely, such caregiving involves making every effort to achieve change. Intrinsically motivated caregiving is further constructed as 'right' and superior to extrinsically motivated caregiving through the speaker's

employment of the word 'just' at two occasions: '<if you> just gonna come here' (ll. 9-10) and 'if you just wanna (.) go' (l. 17). Once again, the word 'just' in these instances has a depreciatory function (Lee, 1987). As such, caregiving which stems from convenience is trivialised and constructed as inferior in comparison to caregiving which stems from a passion to make a difference. Conclusively, in the account above, the speaker is conveying that in order to be successful as an HIV/AIDS caregiver, one must engage in such work with the aim to make every effort in order to make a difference.

Caregivers are drawn to difficulties in order to make a difference. In order to have an opportunity to make a difference, one logically needs to be in a situation that calls for a change. Situations in need of change typically involve some difficulty. As a consequence of participants' need to take action and make a difference as caregivers, participants' discourses further illustrated how they, as caregivers, were drawn to difficulties. For example, when asked why they wanted to work for Cotlands, two participants said:

Extract 7.19

1 P26: I wanted to experience (.) and share (0.5) with them (.)
2 their pain (0.5) °to sympathise with them° (0.3)
3 especially when I started working here at Cotlands (0.3)
4 the kids were dying (0.7) because there were no ARVs
5 (0.7) they get <sick> you see them <every day> (0.3)
6 getting worse day by day (.) deteriorating (0.4) so that
7 thing it wasn't easy

Extract 7.20

1 P13: I do this because I know myself (0.2) and then that is
2 why I would like to work with children >that are< H (0.3)
3 those who are HIV positive [...] I don't want the children
4 that they've got parents no (1.4) I'm going to look for
5 those who are HIV positive (.) or orphans (0.9)
6 vulnerable child (0.4) you see (0.3) abused child those
7 who are epilep-

Both speakers above portray difficult and challenging circumstances. The first speaker not only presents such circumstances but she further constructs an escalation of these: it starts with sickness, which thereafter deteriorates, and eventually leads to death. Despite labelling the events as difficult ('it wasn't easy', *l. 7*) and involving pain, the participant, nonetheless, reports subjecting herself to such difficult circumstances through a voluntary and active choice ('I wanted to experience (.) and share (0.5) with them (.) their pain (0.5) °to sympathise with them', *ll. 1-2*). The second speaker similarly communicates difficult and challenging circumstances involving illness and potentially death (HIV and epilepsy), deprivation (orphans or 'I don't want the children that they've got parents', *ll. 3-4*), maltreatment or cruelty ('abused child', *l. 6*), and a general reference to potentially harmful conditions ('vulnerable child', *l. 6*). Once again, despite such a negative portrayal of events, the participant reports actively seeking out ('I'm going to look for', *l. 4*) such circumstances.

Children who are healthy and have parents who treat them well are, arguably, not in a situation in need of a change; however, children who are ill and deprived would presumably benefit from a change of circumstance. Individuals who wish to take action and make a difference need to ensure they have the opportunity to do so. Consequently, such individuals seek out situations in need of a change, such as caring for children who are ill and deprived, in order to have the opportunity to make a difference.

7.5.2. Caregivers Proactively Invest Resources

One way for caregivers to demonstrate that they take action is to proactively invest resources. Resources do not necessarily have to be monetary; simple time and effort are also considered valid investments. In participants' discourses, investing resources was a sign of caring. This was often evident in how participants spoke about various management practices:

Extract 7.21

- 1 VR: So once you came here (0.4) did Cotlands give you any
2 other kind of training
3 (0.6)
- 4 P50: Yah I got a training from (.) one of the nurses (0.8)
5 u:hm (0.8) which was not (0.8) that new for me so I knew
6 all the stuff and (0.5) but at least we got something and
7 they (2.3) then we kn- we knew that they <care> about us
8 and (0.3) they care about uhm (0.2) the HIV thingy

For international volunteers, such as the participant in the extract above, training upon arrival at Cotlands was a major issue. At Cotlands, training (formally referred to as Induction and Orientation) is provided in order for new employees and volunteers to learn about HIV/AIDS and TB, Cotlands practices, and Cotlands in general. Such investment of resources is based on the assumption that this type of training will facilitate carrying out the work. In general, the objective of training is to learn something new, which will presumably be beneficial. In the extract above, however, the speaker states that he already possessed the knowledge offered to him through training. As such, there is an inference that the training provided was redundant. The speaker, however, then says 'but at least we got something' (l. 6). If the speaker's previous statement 'I knew all the stuff' (ll. 5-6) conveyed a drawback, because it rendered the training as redundant, the speaker's use of the phrase 'at least' can be heard as an attempt to highlight an advantage in the face of such drawback. Here, the statement 'but at least we got something' conveys that training, even if redundant, is better than no training. The speaker further clarifies that 'then we kn- we knew that they <care> about us' (l. 7). 'They', in this sentence, refers to those who provided the training, that is, Cotlands management. In an organisational hierarchy, management can be considered a type of caregiver: they care, or ought to care, for their workforce. The 'we' refers to those who received the training, that is, volunteers (or employees). Where management is the caregiver, the volunteers and employees – that is, the workforce – are under the care of

management. The 'then' indicates that *subsequent to* the training, the volunteers knew that Cotlands management cared about them. In other words, proactively invested resources, even if redundant, serve an important function because they demonstrate that the investor, or the caregiver, cares about the entity that they invest in.

Moreover, the speaker states 'and (0.3) they care about uhm (0.2) the HIV thingy' (l. 8). In this context, caring about the 'HIV thingy' can be heard as an implicit reference to the infection risk involved in HIV/AIDS aid work; thus, it is a reference to caring about safety. Arguably, then, the account above suggests that when Cotlands management provides training for their workforce, they demonstrate that they care about these individuals. The act of caring is inherent in how the management is taking action and investing resources. In an HIV/AIDS context specifically, HIV/AIDS training that, for example, teaches about modes of infection is considered an act of caring because the caregiver takes action and invests resources in protective measures which demonstrates that the caregiver is mindful of and cares about the safety of the individual to whom the training was offered.

While international volunteers were mainly concerned with HIV/AIDS and TB training, local employees frequently raised the need for counselling:

Extract 7.22

- 1 VR: And do you feel that Cotlands gives you enough support
2 (0.3) to cope with your job
3 (1.1)
4 P30: It does:: (0.6) because (0.3) eh at times they get
5 counsellors to come and talk to us: so it (0.6) °really
6 they do it°

Extract 7.23

1 VR: Do you feel that Cotlands gives you: (.) enough support:
2 (0.4) <to:> (.) cop:e with your job
3 (1.6)
4 P12: Before (0.4) °she was give u-° giving us (0.3) enough
5 support (0.5) but now not (.) because before (0.4) we was
6 hav:e the counsellor (0.6) if you:: <feel like> depressed
7 or you need for go to counselling (0.5) you was just
8 phone to Cotlands they arrange y-you go there °for
9 counselling° but now >if you want to go< for counselling
10 (0.4) you supposed to see yourself

Extract 7.21 illustrated how Cotlands management providing HIV-training to the workforce was perceived as management being mindful of and caring about the safety of the workforce. This conclusion can be extrapolated to the two extracts above: when Cotlands management provides counselling to the workforce then this is perceived as management being mindful of and caring about the psychological well-being of the workforce. For example, both speakers above consider Cotlands management to be supportive, or to have been supportive, because management provided counselling (Extract 7.22, *ll.* 4-5; Extract 7.23, *ll.* 4-6); that is, the speakers felt supported because management invested resources to care for their psychological needs ('if you:: <feel like> depressed', Extract 7.23, *l.* 6). The invested resources can be classified as effort: the management made the effort to 'get' (Extract 7.22, *l.* 4) or 'arrange' (Extract 7.23, *l.* 8) counselling. (Where the counselling services required payment, management can also be argued to have invested financial resources.) Such efforts demonstrated caring (or support at a minimum). The second speaker, however, highlights how such efforts are no longer being invested; now, the onus is on the employees themselves to care for their psychological needs. As a result of management withdrawing their investing of resources, the speaker no longer feels supported, or cared for, as evident in her use of past language ('Before (0.4) °she was', *l.* 4) and contrasting the past with the present ('but now', *l.* 5).

Conclusively, in order to demonstrate their caring, caregivers are expected to take action and proactively invest resources to meet care recipients' needs.

7.5.3. Reappraising Meaning in Response to Lack of Action

In Chapter 4 it was illustrated how being unable to control HIV/AIDS treatment and consequently prevent AIDS-related death were the main challenges faced by contemporary HIV/AIDS aid workers. Closely related, the importance of taking action as a caregiver has been illustrated in this chapter. In Chapter 4 it was further illustrated how participants found it difficult when they were unable to exercise the above mentioned control; similarly, participants' discourses revealed that they found lack of action (as a caregiver) difficult. When there was a risk of lack of action being attributed to oneself, participants communicated guilt. When lack of action was attributed to others, participants communicated blame. These two situations, discussed individually below, evoked reappraisal processes in participants.

Reappraising meaning in response to guilt as a result of one's own lack of action. Participants presented with a sensitivity towards events that could be perceived as resulting from their lack of action. In order to avoid or address the guilt that could ensue, participants would reappraise meaning:

Extract 7.24

1 VR: <So working with HIV positive individuals> (0.6) what
2 aspect do you find most difficult
3 (1.6)
4 P14: The most aspect that we find more difficult (0.5) if the
5 person doesn't take (0.9) her medication (0.8) it makes::
6 (0.9) it makes me that (.) makes me that (0.2) I'm not
7 doing (0.8) my job (0.4) maybe let me say like that I'm
8 maybe or I'm not doing the right things to them (0.3) so
9 it's how (0.2) we always s- (0.5) make them educating
10 them (0.6) nen telling them to must go to the clinic:
11 (0.4) and go and fetch their medication (0.3) and maybe

12 must (0.2) eat (0.3) how to eat (0.3) the:: (0.4)
 13 nutrient- the nutrition food you see (0.4) to be (.) to
 14 (.) t-to become (0.9) well
 15 (2.0)
 16 VR: Do you ever feel (0.4) guilty if you feel that (0.3) I'm
 17 not doing my job properly
 18 (0.9)
 19 P14: Yes you feel guilty because (0.3) if (1.0) I'm the one
 20 (.) who'll looking after you (0.9) I'm getting you (.)
 21 sl- maybe you are not well that day >o-yor or you are
 22 not< (0.4) you see (0.3) so I told myself that mm-mm
 23 (0.5) maybe here (0.4) <I'm not> (0.3) educating well
 24 (0.3) or I'm not doing my job well (0.3) or either (0.7)
 25 that person (0.7) it's ignorant (2.0) she don't want to
 26 listen to you maybe I don't know

The speaker above provides a three-part list (Jefferson, 1990) outlining some of the objectives of her job as a health educator. These include educating her clients about the importance of attending medical appointments ('go to the clinic', *l.* 10), adhering to medication ('go and fetch their medication', *l.* 11), and ensuring a nutrient diet ('how to eat (0.3) the:: (0.4) nutrient- the nutrition food', *ll.* 12-13) in order for her clients' health to improve. The speaker, however, reports that sometimes this task fails: the client does not take their medication or they are not well. As a result, the speaker queries her ability to carry out her job as a health educator (*ll.* 6-8); reservations that give the impression of guilt. When the speaker is challenged about this potential guilt (*ll.* 16-17), she immediately confirms: as a health educator it is her job to care for her clients, so when her clients are not well the task has failed. Such a failure can be addressed in two ways: once again, the locus of control can be placed internally or externally. The speaker initially acknowledges the former possibility: she places the locus of control internally, holds herself accountable for the failure, and consequently expresses guilt – the task failed because she failed to adequately carry out her job (*ll.* 19-23). The speaker, however, then also acknowledges the second possibility: the locus of control can be placed externally which would hold the client accountable for the failure – the task failed

not because of the speaker's inability to carry out her job but because the client did not comply (ll. 24-26).

Thus, participants conveyed that as caregivers they need to take action. When events arise that suggest lack of action, and there is a risk of these events being attributed to the caregiver, guilt may ensue. In order to address such negative emotions, participants would reappraise meaning in order to make sense of the dilemma differently. A different perspective could then involve a shift from an internal locus of control – that is, lack of action attributed to self and resulting in guilt – to an external locus of control – that is, lack of action attributed to others and resulting in blame. Such a scenario could, however, also evoke reappraisal processes in participants, as discussed next.

Reappraising meaning in response to blame as a result of others' lack of action. When participants perceived that others failed to take action, they would attribute blame. This phenomenon was evident also in Extract 7.24 above where the speaker shifted from an internal explanation for lack of action, entailing guilt, to an external explanation, entailing blame. The speaker's task to educate her client in order to improve the client's health failed and this was attributed to the client's lack of compliance because 'she don't want to listen' (ll. 25-26). The word 'want' suggests an active choice made by the client and, due to the client playing an active role in the events that resulted in the task failing, the client is then attributed the blame for the failure. Some participants, however, were sensitive towards being heard as attributing blame and consequently they would reappraise meaning in order make sense of the perceived lack of action differently:

Extract 7.25

- 1 VR: So you mentioned that it's <scary> (.) to see children
2 like (.) ((name)) for e[xam]ple
3 P57: [Mm]
4 (0.3)
5 VR: Scary in what way

6 (0.2)

7 P57: Yeah how can we I mean they (.) they never they never did
8 anything wrong in life (and something) (0.5) and then
9 they end up like this (0.3) just because uhm (0.7) just
10 becau(h)se maybe (0.2) may- we can start with that a-as
11 well maybe the a- (.) the father of ((name)) (0.5) ehm >I
12 don't know< if that's the case now but >maybe the father
13 of ((name)) gave it to the mother the mother didn't know
14 so she couldn't do preventive< (0.5) things before
15 ((name)) was born

The speaker above initiates his response by stating that 'they', meaning the children, 'never did anything wrong in life' and yet they 'end up like this', 'this' referring here specifically to a state of severe illness, that is, AIDS (*ll.* 7-9). Chapter 6 illustrated how participants in their discourses constructed children as innocent and rather held adults accountable for any hardships children may be experiencing, including children's positive HIV status. Thus, the speaker is at once orienting towards attributing blame. There is a further implicit attribution of blame where the father infected the mother with HIV and the mother consequently infected the child; mother-to-child transmission through birth or breastfeeding is considered one of the main modes of HIV transmission, in addition to sexual activity (UNAIDS, 2008b). Previously this chapter has demonstrated how, in participants' discourses, caregivers are expected to, first, not put children at risk, and second, proactively take action. In the account above, therefore, there is an implicit expectation that the mother ought to have proactively taken action in order to prevent HIV-transmission to her child. The speaker, then, faces two options: blame the mother for her lack of action, which resulted in her putting a child at risk and thus failing as a caregiver, or reappraise meaning in order to identify alternative explanations for making sense of the dilemma and avoid attributing blame. The speaker appears to do the latter: he claims that perhaps the mother did not know and consequently she could not 'do preventive< (0.5) things' (*ll.* 13-14). It is reasonable to argue that in order to expect the mother to take preventive measures, she needs to be aware of the existence of HIV (in herself or her family); in other words, she cannot be expected to act upon or

prevent a phenomenon which she has no knowledge of. When the speaker claims that the mother *could not* prevent the transmission, as opposed to *would not* prevent the transmission, he constructs her as *unable* as opposed to *unwilling*. Recall how the client in Extract 7.24 was constructed as playing an active role, through the use of the word 'want', and consequently the client was held accountable and attributed blame. In contrast, in Extract 7.25, the mother's role is minimised and consequently she is not held accountable to the same extent. The reappraisal process in which participants engaged in response to their own lack of action, and the reappraisal process in which participants engaged in response to others' lack of action produced, it would seem, the same result: a shift in locus of control from internal to external where an internal locus of control suggests a failure to act due to the individual lacking in some respect, whereas an external locus of control suggests that taking action is out of the individual's control and thus their actions cannot be criticised.

7.6. Discussion

In summary, participants' discourses suggested that caregiving is gendered and prescriptive. With regard to the former, the caregiver identity was frequently associated with women, and especially with concepts such as 'wife' and 'mother'. With regard to the latter, the caregiver identity was constructed as prescriptive because 'proper' and 'genuine' caregivers were expected to behave in certain ways in order to demonstrate their authenticity. First, caregivers are expected to not put children at risk. Second, caregivers are expected to sacrifice their own needs in order to prioritise the need of others. Finally, caregivers are expected to take action; that is, they are expected to act upon every opportunity to make a positive difference. As a result, caregivers are drawn to difficult conditions in order to have an opportunity to make a difference. Finally, taking action also involves proactively investing resources.

When participants were faced with dilemmas arising from violations of the 'rules' of caregiving, whether they perceived themselves or others to be responsible for the violations, they would reappraise meaning in order to avoid experiencing guilt, or avoid attributing blame. Such reappraisal processes often involved reconstructing the events by shifting the locus of control from internal to external; that is, rather than attributing the violation to a failure by the individual, the violation is attributed to some external force, out of the individual's control.

In a Cotlands context, the implication of the prescriptive nature of caregiving was a mentality where staff and volunteers were expected to be there for the right reasons: caregiving was expected to be intrinsically motivated as opposed to driven by extrinsic incentives. By adhering to the 'rules' of caregiving caregivers could demonstrate their caring and, therefore, that they were at Cotlands for the right reasons. Participants' discourses also illustrated various ways in which they would construct their caregiving as authentic; these will be discussed in the next part of this chapter.

The Caregiver Identity as a Double-Edged Sword

This second half of this chapter will illustrate how the function of the caregiver identity is two-fold: the caregiver identity can act as a buffer while also being detrimental or taxing. In participants' discourses it was evident that, despite the potential for difficult or traumatic experiences, such as death or children subjected to harm, caregiving can also be rewarding to the caregiver. The first section below will highlight this, as well as how the rewards of caregiving can act as a buffer. Participants' discourses, however, also implied that caregiving ought to be intrinsically motivated; consequently, rewards from caregiving were treated as extrinsic incentives and thus perceived as selfish and negative. The second section of this chapter will illustrate participants' sensitivity towards being perceived as

selfish, and also demonstrate a number of ways in which participants would convey their authenticity. The final section of this chapter will illustrate how, despite the aforementioned buffer, the caregiver identity can also be taxing due to its highly prescriptive nature as illustrated previously. The caregiver identity, then, was constructed in participants' discourses as a double-edged sword.

7.7. The Caregiver Identity as a Buffer

'... I think Cotlands is therapeutic for the volunteers as well as for the children it's a two way street ...'

Despite reporting some difficult and potentially traumatic experiences, participants more commonly described HIV/AIDS caregiving, at least in a Cotlands context, as rewarding. Many participants, such as the first participant below, reported caregiving to be *fulfilling*, and the second participant below was describing how nursing was her calling in life:

Extract 7.26

1 VR: As a final question uhm (.) what recommendations do you
2 have for (0.5) those who want to come and work with HIV
3 positive individuals (0.2) so what advice would you give
4 to people
5 (2.0)
6 P20: I would just say it's a ((sighs)) (1.5) it's a
7 f:ulfilling (1.1) >it's something that is fulfilling< to
8 know that you can (.) be there for someone (0.7) who
9 might not have anybody (1.2) some they do have their
10 families but then they need that person °that they can
11 really count on° (1.0) you see I would just invite them
12 (.) please they can come and help (.) wherever it's
13 possible >especially with the children< (1.5) °especially
14 with the children° it's a fulfilling thing it gives you a
15 sense of value (0.8) you feel so valuable (0.4) you're
16 giving something to some people

Extract 7.27

1 P26: You know I like to take care of (0.3) people who are sick
2 (0.9) giving them lo::ve (.) hug and everything (0.3)
3 that I can
4 (0.4)
5 VR: Mm
6 P26: That's why I persuade nursing
7 (0.9)
8 VR: And how does that make you feel (.) when you (0.3) are
9 able to nurse people who are sick and you're able to give
10 them love and care (0.3) how does that make you feel
11 (0.4)
12 P26: It makes me feel proud like I am a sh- a (.) what a hero
13 or shero (0.6) mm (0.3) that at least I'm doing something
14 (.) I'm giving back to <my> community

The two extracts above display similar features in terms of highlighting the benefits of caregiving. To begin with, the first participant orients towards caregiving by constructing herself as a person who can 'be there for someone (0.7) who might not have anybody' (*ll.* 8-9), and being the one whom such individuals can 'count on' (*l.* 11). The second participant, likewise, constructs herself as someone who nurses 'people who are sick' (*l.* 1). 'People who are sick' typically entail individuals in need of care, while 'someone who might not have anybody' implies, especially in an HIV/AIDS context, an individual who lacks another person to potentially care for them. Both participants, then, speak of individuals who are in need and particularly in need of care (medical or otherwise). Furthermore, both participants suggest they meet these needs by providing the required care: the first participant claims to be someone for those in need of care to rely on ('count on'), and the second participant speaks of nursing those who are ill. In doing so, participants implicitly construct themselves as both needed as well as caring for those in need.

Moreover, both participants express positive emotions in relation to feeling needed and caring for those in need. For example, the first speaker states that being the reliable person discussed above is *fulfilling* (ll. 7 and 14), while the second speaker states that she feels *proud* (l. 12) when nursing those who are ill. Additionally, the first speaker claims that such experiences give her a sense of *value* (l. 15). A dissection of the words *fulfilling*, *proud*, and *value* suggest a satisfying experience that leaves the individual pleased with their achievements mainly because it gives them a sense of worth and thus makes them feel useful; recall how 'proper' caregiving involves making a difference. In other words, participants can be heard to communicate that they obtain satisfaction when they feel needed and care for those in need because they feel they have made a difference and thus they feel worthwhile and useful; participants, then, are conveying 'positive sentimental attachment' (Condor & Abell, 2006, p. 57) in relation to their caregiving identity. It is worth noting that the two phenomena feeling needed and caring for those in need do not necessarily result in satisfaction independently; rather, it is the combination of the two – when the supply meets the demand – that produces the feeling of satisfaction. Such satisfaction and pleasure as a result of caregiving make caregiving rewarding.

Participants' discourses further suggested that the rewards of caregiving can act as a buffer against the difficult and potentially traumatic aspects of caregiving. The protective role of rewarding experiences was alluded to in the following participant's response:

Extract 7.28

- 1 VR: Have you had any ((chuckles)) particularly positive (0.3)
2 experiences
- 3 P45: Many (0.2) ((laughs)) of course yah (0.3) uhm (0.5) I
4 don't think anybody would stay if it was all negative

Previously in this chapter, the imperative whereby caregivers are expected to sacrifice their own needs in order to meet the needs of their care recipient(s) was discussed. Such altruism would require caregivers to endure difficulty perhaps exclusively. The utterance in Extract 7.28, however, suggests that such absolute altruism may be more idealistic than realistic: no individual is thought to have the capacity to endure caregiving if only entailing negative experiences. Negative experiences are generally considered to exhaust an individual's coping resources. Caregiving that is exclusively negative is thus likely to eventually exhaust caregivers. The account above, then, suggests that in order to prevent exhaustion and endure caregiving, positive, or rewarding, experiences are required. This is further evident in the below extract where the participant had previously described her work as 'stressful' and 'hard going'. When enquired about her endurance she explained that the rewarding experiences of her work made it worthwhile and then proceeded:

Extract 7.29

1 P34: Sometimes when you haven't had that for a while (0.5) it
 2 becomes very you get very de- (.) very down and and it's
 3 kinda like depressing >cause you think it wouldn't kids
 4 are never gonna move what I'm gonna do:< (0.8) and then
 5 something happens and you think OK you know what (.) I've
 6 now saved one child so (.) OK that's (0.4) that's >and-
 7 and< that (.) that they've (0.6) this refeeds you until
 8 the next one until the next time it happens and then
 9 you're actually fine again so (0.6) yah it's kinda like a
 10 rollercoaster (.) ride as to how you feel (0.9) uhm (.)
 11 but yah it can be very difficult °it can be° (0.6) quite
 12 hard

In her account, the participant describes her work as a 'rollercoaster ride' (l. 10); that is, the journey involves ups and downs. The downs are referred to as relatively long periods of time without a rewarding experience that are 'depressing' (ll. 1-3). The ups, then, can be said to be the rewarding experiences of the work, that is, those that make her endure her stressful job. The example of a rewarding experience provided by the speaker is one where she saves a child. A saved child

implies a child in need: in need of protection and care. As such, saving a child would meet the criteria of feeling needed and caring for those in need, as previously discussed, as well as having made a difference; therefore, saving a child would qualify as a rewarding experience. In a milieu where children are to be loved and cared for (Chapter 6) and protected from harm (the first half of this chapter), and where caregivers are to engage in caregiving in order to make a difference, the act of saving a child would most probably entail the kind of satisfaction and pleasure as demonstrated above.

The speaker further claims that such a rewarding experience ‘refeeds’ her (thus constructing such experiences as the ups of the rollercoaster ride); that is, rather than a depressing, continuous downwards caregiving experience with potential to exhaust her, intermittent rewarding experiences prevent such exhaustion, refuel her, and allow her to endure such ‘stressful’ and ‘hard going’ work for some time longer. In other words, the rewards of caregiving act as a buffer against the otherwise often difficult and potentially exhausting experience of caregiving.

7.8. Sensitivity Towards Caregiving as a Selfish Pursuit

*‘... there’s also a thing about volunteering that is very selfish
I mean a lot of people volunteer not to help people
but because they wanna me- they wanna feel good about it ...’*

In Extract 7.18 above, the speaker was heard to encourage individuals to engage in caregiving ‘with the right heart’. In her account, ‘the right heart’ entailed an intrinsic motivation to make a (positive) difference to a care recipient’s life. In contrast, caregiving stemming from external incentives, such as convenience, was frowned upon. The first half of this chapter further concluded that the prescriptive

nature of caregiving resulted in a mentality whereby Cotlands staff and volunteers were expected to engage in caregiving for the right reasons: participants' discourses implied that caregiving ought to be intrinsically motivated, rather than driven by extrinsic incentives. Rewards of caregiving – such as satisfaction and pleasure – despite being protective, as illustrated previously, were nonetheless often treated as extrinsic incentives. Consequently, caregiving for the sake of such rewards was referred to in participants' discourses as selfish and thus frowned upon (although this was primarily the case in relation to caregiving in a volunteering context as opposed to paid caregiving). Subsequently, this section will, first, illustrate how participants in their discourses displayed a sensitivity towards being perceived as selfish, and, second, how they employed a number of discursive techniques to convey their authenticity as caregivers.

The participant in the second extract below had previously explained how her application forms for becoming a Cotlands volunteer had been left on the dining table for two weeks while she was 'soul searching' before she felt ready to submit them. The first extract below is a response to the standard interview question asking participants if they had had a particularly positive experience during their time at Cotlands:

Extract 7.30

1 P59: I've beco:me (0.6) fairly attached to one (0.3) girl
2 called uhm ((name)) (0.5) and (0.2) uhm (0.4) seeing her
3 (0.6) ehm (0.8) seeing her progress in class (0.3) and
4 actually seeing he:r and >this is an< incredibly selfish
5 thing to say but it's the reality (.) seeing he:r (0.2)
6 uhm (0.4) get attached to me as well (0.3) and (.)
7 actually having a connection with the child is so: (0.2)
8 rewarding and >incredibly satisfying and< (0.4) it is (.)
9 very selfish thing

Extract 7.31

1 VR: While those application forms were sitting on the dining
2 table (0.4) and you did your soul searching (0.5) what do
3 you think you found
4 (3.9)
5 P46: I f:ound (1.5) what I definitely (0.9) wanted and needed
6 in life (1.0) children were growing up (0.6) doing their
7 own thing (0.8) sometimes they say a volunteer's (0.3)
8 job is a selfish job because you're wanting to do (0.4)
9 something it's actually more for your feeling (0.6) than
10 for what you are doing (.) for the child

The two extracts above illustrate, first, *that* participants were sensitive towards being perceived as selfish, as well as *why* they may have had such concerns. The latter point will be addressed first. In her account in Extract 7.30, the speaker reports developing a bond with one of the Cotlands children. As an orphan with no dedicated caregiver, the child in question can be seen as in need of a caregiving figure to attach to. With the opportunity to become that attachment figure, the speaker then is in a position to feel needed. When she subsequently bonds with the child and becomes the desired attachment figure, she has met the child's need; that is, she has cared for a child in need. With these two premises met, the experience fulfils the criteria for a rewarding experience; indeed, the speaker herself refers to the attachment experience as 'rewarding and >incredibly satisfying' (l. 8). With reference to the interview question, which asked for a positive experience while based at Cotlands, there is then potential for the speaker to be heard as stating that the positive aspects of her caregiving are associated with extrinsic incentives as opposed to an intrinsic motivation to be entirely altruistic.

With regard to the second extract, looking at the interview question, the question can be heard as asking why the speaker decided to volunteer for Cotlands. After the 'soul searching', the speaker obviously decided to become a Cotlands volunteer; thus, whatever she may have found while 'soul searching' can be understood as her reasons for volunteering. The speaker subsequently begins her

response by explaining that she found what *she* wanted and needed (*l.* 5). Subsequently, there is potential for her volunteering at Cotlands – that is, her caregiving – to be heard as being more of benefit to her, the caregiver, as opposed to the children at Cotlands, the care recipients. In other words, her response has potential to be inferred as suggesting that her volunteering is motivated by extrinsic incentives (rewarding experiences) as opposed to intrinsically motivated.

Both speakers, then, have offered responses that could be seen as potentially difficult in a context of prescriptive caregiving. This is arguably *why* they are sensitive towards being perceived as selfish. *That* they are sensitive is evident in both speakers' pre-emptive orienting towards the topic very early on in their responses; the speakers' orienting towards the topic of selfishness is arguably a disclaimer aimed at deflecting potentially negative typifications of their character (Hewitt & Stokes, 1975). The use of such a disclaimer demonstrates the speakers' awareness that their accounts may be heard as selfish and consequently become a motivation for typifying them as selfish. While both speakers make use of the word 'selfish' in a disclaiming manner (Extract 7.30, *ll.* 4 and 9; Extract 7.31, *l.* 8), the issue of intrinsic versus extrinsic motivation is only implicit in the first extract whereas the second speaker addresses the issue explicitly ('it's actually more for your feeling (0.6) than for what you are doing (.) for the child' (*ll.* 9-10)).

Interestingly, the question responded to in Extract 7.30 asks for a positive experience for the participant. For such a question, an ego-oriented response of a rewarding character would more or less be expected. Despite this context, the speaker felt the need to label her positive experience as 'selfish'. One possible explanation for such an approach could be that the speaker does in fact feel that she is putting her own interests above the interests of the child. Another, arguably more plausible explanation given the context, would be that both speakers' framing of the events as selfish is rather a technique for displaying their awareness of the prescriptive norms governing caregiving, whereby caregivers need to demonstrate their authenticity, especially in the face of extrinsic incentives. The 'selfish'

disclaimer can, thus, be understood as a discursive tool for the speakers to restore and maintain their caregiver identity (Hewitt & Stokes, 1975).

7.8.1. Conveying Authenticity as a Caregiver

*'... the nursing profession yah has always been my dream
from since childhood it's just a calling ...'*

The need to convey one's authenticity as a caregiver was not only in response to the risk of being perceived as selfish but participants would frequently throughout the interviews attempt to convey their authenticity through the use of various discursive techniques. This section highlights how identity is a discourse of alignment (Meinhof & Galasinski, 2005), how speakers not only construct identities and their features but also demonstrate how they possess those identities (Antaki et al., 1996). I will highlight this through a brief discussion of four of the most common techniques employed by participants for conveying authenticity as caregivers: caregiving framed as beneficial to others, caregiving in contrast to monetary incentives, the caregiver identity as originating in childhood, and the caregiver identity as a calling.

Caregiving framed as beneficial to others. One of the techniques most frequently used by participants when attempting to demonstrate that they were 'genuine' caregivers was to highlight how their caregiving was beneficial to the care recipient(s). The following extract was a response to the question asking for a positive experience while based at Cotlands:

Extract 7.32

1 P10: >I think probably the best one< >one of the best times
2 I've had was< (0.5) uhm when me and ((wife)) took uhm (.)
3 >you know those< the two ((name)) and ((name)) for for
4 Christmas >you know that was great< that was so
5 [cool]

6 VR: [((Chuckles))]
 7 P10: Just to (0.4) to have them for the day and you know just
 8 (.) °yeah >so that they< make them feel like they have a
 9 family you know like° yeah (there is) good it was really
 10 nice

The speaker's most positive experience while based at Cotlands is reported to be when he and his wife took two of the Cotlands children home over Christmas Day. The experience is, first, very positively appraised: 'great', 'cool', 'good', and 'really nice' (*ll.* 4-5 and 9-10). More importantly, however, the experience is framed as beneficial to the two children because it allowed them to feel like they had a family (*ll.* 8-9). In Chapter 6 it was illustrated how participants in their discourses constructed having parents as inherent in an optimal childhood; consequently, not having parents, as is the case for many children at Cotlands including the two referred to in the extract above, represented loss of an optimal childhood. By being able to take the children home and make them feel like they had a family, and thus parents, the speaker had offered the children the experience of an optimal childhood; hence, his caring for the children was beneficial to the children, regardless of how rewarding it may have been for him. By highlighting the benefits of his actions for others, the speaker can be heard as presenting himself as a 'genuine' caregiver who acts with the best interest of his care recipient(s) in mind.

The method of framing one's caregiving as beneficial to others in order to convey one's authenticity as a caregiver could, however, backfire and necessitate an even greater need to convey authenticity. When caregivers framed their caregiving in such a way, their caregiving was ultimately framed as rectifying damage inflicted by preceding, failed caregivers. Such rectification would, in turn, reinforce one's own caregiver identity and consequently put caregiving in a rewarding light. Such rewards would then necessitate the need for the caregiver to convey their authenticity and in doing so they would frame their caregiving as beneficial to the care recipient(s) as opposed to (merely) rewarding to themselves – and so an eternal process would be maintained. This process is illustrated in Figure 7.1.

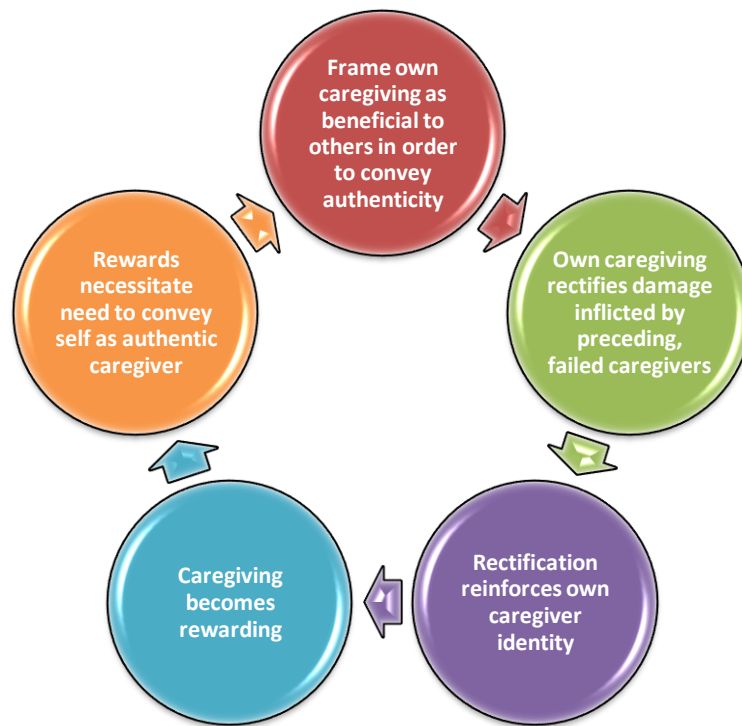


Figure 7.1. The eternal process of obtaining rewards from caregiving and conveying authentic caregiving.

Caregiving in contrast to monetary incentives. Alternatively, participants would highlight that they were intrinsically motivated to provide care by contrasting their motives with monetary incentives. The following participant, for example, was speaking of how knowing that she was making a difference provided her with the necessary strength to continue working at Cotlands:

Extract 7.33

1 P1: I suppose that's why I'm: here after sixteen years
 2 because (.) I've had (0.5) other opportunities I've had
 3 oth- o-other offers (1.8) and uhm (.) when I've weighed
 4 them up (0.2) and even thou:gh they would've bee:n
 5 financially (0.5) way (.) more viable for me to to
 6 consider (0.6) u:hm (0.6) it was just (0.9) the basic
 7 idea of of of (1.7) what I was doing here you know

In Extract 7.33, the speaker first reports having had other job offers and thus other job opportunities. By highlighting that she is working at Cotlands despite these other job opportunities, she is constructing her Cotlands job as only one among several options. As such, she is constructing herself as working at Cotlands because she actively chooses to do so, as opposed to she is working at Cotlands merely because she is desperate for a job. Thus, she was not driven into caregiving because of external, situational factors, but she chose to become a caregiver because of an intrinsic motivation.

Second, the speaker points out that these other job offers were financially more viable (*l. 5*); that is, they would pay better than her job at Cotlands. The discursive technique of contrasting intrinsically motivated caregiving with monetary incentives presumes a philosophy whereby ‘money makes the world go round’ and a higher paying job is the more attractive option. Based on such philosophy, the speaker would leave her job at Cotlands and pursue one of the other job offers, presumably the one that pays the most. Her job choice would then be driven by extrinsic, monetary incentives. The speaker, however, has not done this. She is still working for Cotlands, despite earning less. Rather, she reports that it is the *idea of what she is doing* at Cotlands (*ll. 6-7*) that is driving her. Such a statement suggests a different philosophy than the one previously mentioned: this philosophy is based on a specific belief (‘the basic idea’, *ll. 6-7*) and working for a cause (‘what I was doing’, *l. 7*). When the speaker claims to be engaged in caregiving driven by a belief in a cause, as opposed to money, she is heard to claim that her caregiving is intrinsically motivated as opposed to driven by extrinsic incentives.

The caregiver identity as originating in childhood. Many participants would demonstrate their ‘genuine’ motivations for caregiving by stating that their caregiving ambitions originated in their childhood:

Extract 7.34

1 VR: Why are you here why do you want to work as a nurse here
2 at Cotlands=

3 P29: =It's been my dream (.) ever since I was young to be a
4 nurse

Extract 7.35

1 VR: How long have you been (.) wanting to be a doctor for
2 (0.5)
3 P57: U:hm (0.4) ((chuckles)) it's kind of funny I started to
4 thinking that in in primary school

An adult who claims to have been wanting something since a young age, is heard to have been wanting that for a long time. Such a desire is thus heard to be stable, as opposed to transient. Whereas a transient desire may be perceived as an impulsive idea that is simply fashionable and thus extrinsically driven, a stable and enduring desire gives the impression of a personality trait which is intrinsically driven. Caregiving, then, is not an activity which the individual attempted at random one day; rather, caregiving has been an aspiration ('my dream', Extract 7.34, l. 3) which the individual has deliberately worked towards for a long time. In Extract 7.35, the speaker pinpoints primary school specifically as the origin of his caregiving aspiration. As stated elsewhere in this thesis, such specific recollection makes the claim of a stable desire to engage in caregiving appear more realistic or convincing.

Another very common discursive tool employed by many participants across many situations was the use of the word 'always':

Extract 7.36

1 VR: So how come you decided to have this career change
2 (0.7)
3 P34: >I think I< I always wanted to work with kids

The word 'always' fulfils a similar function to the approach above where an adult refers to his or her childhood as the origin of a phenomenon: it conveys stability and endurance. 'Always' conveys in a simple and concise way two kinds of continuity: first, something that has always been in a certain way has not been subjected to any alterations, and second, something that has always been in a certain way leaves no room for other options. With the use of the word 'always', then, participants could communicate, in a simple and concise manner, their true and complete dedication to caregiving.

The caregiver identity as a calling or fate. The final technique for conveying authentic caregiving to be discussed here is how participants framed caregiving as their calling or their fate:

Extract 7.37

1 VR: Why did you come here for this job (0.4) why do you want
2 to do this
3 (0.5)
4 P42: ((Chuckles)) I think it (does) ju(h)st a calling (1.2)
5 because really I didn't (0.4) look for a job (1.0) I just
6 find the job (0.7) unexpected^lly (1.0) and as I started I
7 didn't think that I could have stayed this long (1.1) but
8 I (.) been here since from nineteen ninetysix (0.9) it's
9 for fourteen years now

Extract 7.38

1 VR: An:d why do you think that you've always wanted to be a
2 nurse
3 (0.9)
4 P20: E:h (0.5) I've had a passion I guess (0.4) for it because
5 I've tried to do other things but (I've always)
6 prete(h) (h) (h)nd because my mind is always been (0.6)
7 where I wanted to be and (0.4) as I was (0.7) past few
8 years (.) as I was growing (0.4) up until this age (0.2)
9 I find myself in situations where (.) I'ma I'm just
10 helping all the sick and everything so I just thought
11 (0.3) since I enjoy doing this: for me (.) brings a sense

12 of value (0.4) maybe I should go and do it (.)
13 professionally

Both speakers above convey a sense of having been directed towards caregiving. The first speaker, for example, states having found the job unexpectedly without having been looking for one in the first place (*ll.* 5-6). Such a statement can be heard to make two claims. First, because she was not actively looking for a job, she was not driven by extrinsic incentives (such as money). Second, because she came across this job despite not actively looking for jobs, the job was destined for her. Caregiving, then, is her vocation. Likewise, the second speaker states ‘I’ve tried to do other things but’ (*l.* 5) which insinuates that she has attempted alternative careers although (‘but’) these attempts have not been successful for one reason or another. Additionally, despite reporting a prior passion for caregiving, the speaker also reports having repeatedly found herself in situations where she was helping the sick and thus providing care for others. The phrase ‘find myself’ (*l.* 9) has a function similar to that of ‘I didn’t (0.4) look for a job (1.0) I just find the job’ (Extract 7.37, *ll.* 5-6): it implies a lack of active involvement by the speaker and rather suggests that those situations happened to her repeatedly because they were destined for her; that is, it implies she was meant to be in those situations providing care and therefore she was meant to be a caregiver. (Also note the second speaker’s reference to her childhood – ‘as I was growing (0.4) up’, *l.* 8).

Many participants who spoke of caregiving as a calling or fate also insinuated that such a fate cannot be defied. This is also evident in the two extracts above. For example, the first speaker states that she initially did not think she could stay in that profession for long (*ll.* 6-7); however, fourteen years later she was still a caregiver at Cotlands. She had, thus, for reasons untold, been unable to leave the caregiving task. Similarly, the second speaker claims to have attempted other paths and yet always found herself in nursing situations. She eventually decided to focus on nursing. Both participants, then, almost speak of having surrendered to their

calling or fate. Thus, someone who cannot defy their caregiving fate is destined to be a caregiver – they are a ‘genuine’ caregiver.

Conclusively, while the caregiver identity could act as a buffer against the difficult aspects of caregiving due to rewards such as satisfaction and pleasure, such rewards could also be detrimental to the perception of a caregiver’s motivations for caregiving and thus necessitate the need to convey authenticity, behaviourally as well as discursively. The caregiver identity, then, is a double-edged sword.

7.9. The Caregiver Identity as Taxing

*‘... yes I want to do it
but I just I don't feel strong enough to do it ...’*

Further to the notion of the caregiver identity as a double-edged sword, participants’ discourses also highlighted that while the caregiver identity acted as a buffer it could also be taxing due to its prescriptive nature. This final section of this chapter aims to illustrate, first, how the demands of (‘proper’) caregiving made such work taxing, and, thereafter, that caregivers, too, have limitations. Addressing the first point, the two extracts below highlight the type of predicament that renders caregiving taxing:

Extract 7.39

1 VR: Is there anything tha::t you want to <add> (0.4) anything
2 that I haven't asked you that (0.3) you think I should've
3 asked or (0.3) anything you just want to mention
4 (1.6)
5 P12: OK sometimes you find that the mother the child (0.8)
6 he's sick (1.5) the mother is (.) y:- he don't have money
7 to take the child to the (0.7) hospital (1.4) really
8 (1.0) he make me feel (0.3) feel (.) very (.) bad (0.5)
9 because sometimes I end up to took my money °and give° to

10 (0.4) and then there's no one can pay me back that money
 11 (1.2) you see (0.7) but when I think about the child
 12 (0.9) I can't leave the child like that I saw the child
 13 is sick (0.8) and (0.9) I too- I have money but I can't
 14 help the mother (1.1) m:m: (.) is that the problem we
 15 have

In Extract 7.39, the speaker refers to a sick child, and so a child in need of care. The child, however, cannot receive the necessary care because the mother lacks money to take the child to hospital (*ll.* 5-7). The 'rules' of caregiving state that a 'proper' caregiver does not put children at risk, does sacrifice, and does take action. The speaker above acts accordingly: she gives of her own money in order for the child to be taken to hospital, commenting that 'I can't leave the child like that' (*l.* 12). The speaker, however, also then remarks that 'then there's no one can pay me back that money' (*l.* 10); that is, by helping the child she has lost money. The predicament that caregivers face, then, is whether to act in the best interest of the self or in the best interest of the care recipient. The prescriptive nature of caregiving promotes the latter, and, in the scenario above, the speaker helps the child but at the cost of compromising her own financial situation. Her orienting towards loss of money suggests that this is an issue for her, and she further refers to such situations as 'the problem we have' (*ll.* 14-15). Adhering to the 'rules' of caregiving, then, can be taxing.

A similar pattern of events unfold in the following extract:

Extract 7.40

1 VR: So what's the most difficult (.) aspect (.) of working
 2 with people who are HIV positive (0.5) or have AIDS or TB
 3 (0.6) what's the most difficult thing about your job
 4 (0.6)
 5 P52: The most difficult I think (.) the most difficu(h)lt
 6 thing is when they are bleeding (1.2) and (0.5) yeah
 7 (0.3) you need to (0.2) get gloves right now ((chuckles))
 8 somewhere (0.6) and you don't know where they are (0.3)
 9 >°something like this:°< so you g- it's like a dilemma
 10 you want to help the children right now (0.5) °or this°

11 (.) child right now but you have to (0.6) °take care of
12 yourself (.) first (0.7) yes (0.3) I think that's (.)
13 most (0.5) difficult°

First, the speaker refers to a child in need of care: a bleeding child. Once again the child cannot receive the necessary care; in this case because there are no gloves readily available for the speaker to protect himself. As discussed in Chapter 4, the reference to gloves is a discursive technique for making the risk of HIV infection interactionally relevant. Taking account of the 'rules' of caregiving, the speaker's predicament, then, is whether to help a bleeding child in need of care (acting in the best interest of the care recipient) or to protect himself from the risk of HIV infection (acting in the best interest of himself; although, taking a risk and consequently contracting HIV would arguably not be in the best interest of anyone). The speaker further classifies such a predicament as the most difficult aspect of his job; the prescriptive nature of caregiving is, therefore, taxing.

It is important to note here that one instance of such a predicament is not what makes caregiving taxing; rather, it is the repetitive nature of such predicaments that makes caregiving taxing. This is alluded to in the two extracts above where the first speaker says 'sometimes you find' (l. 5) and the second speaker says 'when they are bleeding' (l. 6): neither speaker is referring to a single specific occasion but rather they speak of such situations in general terms, which suggests they have encountered such situations more than once.

7.9.1. Caregivers Have Limitations

Participants' discourses not only suggested that caregiving can be taxing but caregivers were also shown to have limitations with regard to how much they can adhere to the 'rules' of caregiving. The first extract below is a participant's account of a child's death before the interview had formally begun:

Extract 7.41

1 P7: And then they did his fu- the his funeral in the
2 community (0.5) and I don't know cause of my association
3 with him I mean I was so unprepared I mean they had this
4 open coffin thingy (0.3) and they asked me to: (0.3) talk
5 (.) >about him< (0.2) but after that I didn't come back
6 to Cotlands for (1.2) I didn't come back 'til I started
7 working again I got i- and since then (1.0) now I've
8 never <got attached> to: (0.5) to anyone like that

Extract 7.42

1 VR: And <how> (0.2) was that balancing (.) <your own grief
2 with> (0.3) trying to look after the kids
3 (1.7)
4 P9: There was one child in particular that passed away (0.3)
5 and then (.) for me afterwards I withdrew (0.4) from
6 going to see the children >and that in< becoming attached
7 (0.3) I kind of built a barrier (0.5) a:nd (1.1) the
8 children who passed away after him I didn't really even
9 (0.3) know who they were or didn't affect me as badly

Both participants above speak of how they experienced the death of a Cotlands child which they were attached to, and how they subsequently withdrew from interacting or bonding with further children. Such withdrawal is presumably the result of the heavy emotional pain caused by experiencing the death of a child; recall that Chapter 6 illustrated how participants in their discourses constructed a child identity to which they ascribed certain characteristics, one of which implied that children were not meant to die. The withdrawal, then, is arguably an attempt to protect oneself against more emotional pain. For the speakers above, such withdrawal involved avoiding future attachment as well as avoiding visiting the children, including terminally ill ones (Extract 7.41, *ll.* 5-6; Extract 7.42, *ll.* 5-6). Another characteristic inherent in the child identity constructed in participants' discourses was that children are meant to be loved and cared for. Although the two children referred to specifically in the extracts above had passed away, other

children remained at Cotlands who were still in need of love and care. By withdrawing, in order to protect themselves, the two speakers would be unable to provide such love and care to the remaining children. Consequently, with regard to the 'rules' of caregiving discussed previously whereby 'proper' caregivers ought to sacrifice their own needs in order to prioritise the needs of others, the two accounts above demonstrate that caregivers, too, have limitations in terms of how much they can adhere to the 'rules' of caregiving. As such, they demonstrate that caregiving can become too taxing.

7.10. Discussion

To summarise, in their discourses participants constructed a gendered and prescriptive caregiver identity whereby 'proper' and 'genuine' caregivers were expected to behave in certain ways in order to demonstrate their authenticity. Caregivers were expected to not put children at risk, sacrifice their own needs in order to prioritise the need of others, and take action; that is, caregivers were expected to act upon every opportunity to make a difference. Such 'proper' and 'genuine' caregiving was further expected to be intrinsically motivated as opposed to driven by extrinsic incentives. As a result, the caregiver identity functioned as a double-edged sword. On one hand, it acted as a buffer: when caregivers felt needed and subsequently cared for those in need they obtained satisfaction and pleasure – rewards that protect against the difficult and potentially exhausting aspects of caregiving by making caregivers feel fulfilled, worthwhile, and useful. On the other hand, such a buffer could also be detrimental: participants treated rewards of caregiving as extrinsic incentives, and caregiving for the sake of such rewards was referred to as selfish and thus frowned upon. This necessitated an increased need to demonstrate one's authenticity as a caregiver; consequently participants frequently employed various discursive techniques to that effect.

The caregiver identity functioned as a double-edged sword also in another way: despite acting as a buffer, it was also taxing. On one hand, as explained above, participants obtained rewards such as satisfaction and pleasure from feeling needed and caring for those in need, and this subsequently acted as a buffer. On the other hand, the prescriptive nature of such work and the requirement to constantly fulfil one's duty to care for those in need repeatedly left participants in predicaments where both fulfilling as well as resisting to fulfil such duties was problematic. Participants' discourses thus highlighted that HIV/AIDS caregivers have limitations with regard to how much they can adhere to the prescriptive 'rules' of caregiving. Such limitations, and the taxing nature of HIV/AIDS caregiving, are arguably the basis for HIV/AIDS aid workers' need for counselling (as evident in Extracts 7.22 and 7.23).

Chapter 8. Discussion

In Chapter 2 the aims of this thesis were stated to be, first, to investigate the potentially traumatic effects of AIDS-related bereavement on aid workers; second, to investigate the resources that aid workers utilise in order to cope with the potentially traumatic effects of AIDS-related bereavement, and the demands of their work in general; and third, to investigate any differences in the experiences of local versus international aid workers. This final chapter summarises the main findings of this study in relation to these three aims, and discusses the findings in light of existing literature and theories of social psychology. The implications of this study as well limitations and suggestions for future research will also be addressed before concluding remarks.

8.1. Main Findings

8.1.1. The Potentially Traumatic Effects of AIDS-Related Bereavement on Aid Workers

The main finding of this study was that AIDS-related bereavement – at least in a Cotlands context – is no longer the prominent issue or trauma it once was. This conclusion was in part a result of the conspicuous lack of discourse on death in the interviews conducted for the study, but further supported by the low trauma symptoms reported by participants on the IES-R, and not least by ethnographical observations. Rather, participants' discourses mainly conveyed a disease management phase whereby they felt in control of HIV death rates as a result of their increased knowledge of the disease which enabled them to prevent (premature) AIDS-related deaths. Despite participants' confidence in their sense of control, their discourses nonetheless contained accounts of challenges to this sense of control. The main challenge reported by participants was patients' lack of

compliance and non-adherence with medication. This was challenging because non-compliance acted as a barrier to participants' ability to control HIV/AIDS treatment and consequently their ability to prevent, or control, AIDS-related deaths. Thus, contemporary HIV/AIDS aid work involves new challenges that have surpassed AIDS-related bereavement as the most prominent concern, but that are still related to issues of controlling the disease.

The issue of control in this study supports the notion prevalent in the trauma literature that uncontrollable events are perceived as more traumatic and causing more distress (e.g., Başoğlu & Paker, 1995; Başoğlu et al., 1994), as well as the finding that HIV/AIDS aid workers who are unable to control the disease experience negative emotions such as helplessness, frustration, and anger (Primo, 2007). Control would involve being able to take action in order to prevent an anticipated negative outcome (Başoğlu et al., 1997; Ehlers et al., 2000; Foa et al., 1992); for example, control would involve being able to treat HIV in order to prevent death. Where HIV/AIDS aid workers previously experienced helplessness as a result of being unable to control the disease and prevent death because this was not possible, contemporary HIV/AIDS aid workers similarly experience helplessness as a result of being unable (due to patients' non-compliance) to control treatment and prevent death when in fact this is now possible.

Furthermore, in participants' discourses, HIV (unlike TB) contraction was constructed as controllable and, therefore, avoidable: if one follows the 'rules' of HIV, one will not become infected. While participants used the micro discourse on control to avoid and counter HIV-related stigma, particularly the stigma they experienced as HIV/AIDS aid workers, this rhetorical technique backfires and rather maintains the macro discourse on HIV-related stigma by maintaining the blame component of the disease. The accountability and subsequent stigma attributed to individuals with terminal illnesses is not exclusive to HIV/AIDS (e.g., Ross & Seeger, 1988) but has also been demonstrated in relation to, for example, smokers diagnosed with lung cancer (Chapple, Ziebland, & McPherson, 2004); both illnesses

are often perceived as controllable and thus avoidable, HIV by following universal precautions and lung cancer by not smoking. Participants' discourses, however, reinforced the notion that it is not only HIV+ individuals who experience stigma but HIV/AIDS aid workers, too, feel stigmatised (Bakker, 2007; Primo, 2007).

Another finding was the identities constructed within participants' discourses. The caregiver identity, for example, prescribed how 'proper' and 'genuine' caregivers were expected to behave in order to demonstrate their authenticity. This identity acted as a double-edged sword: on one hand it acted as a buffer against potentially difficult or traumatic experiences because caregivers obtained satisfaction and pleasure when they felt needed and cared for those in need; on the other hand, the prescriptive nature of the caregiver identity was taxing because caregivers were constantly required to sacrifice their own needs in order to fulfil their caregiving duties. Even in the face of death, HIV/AIDS aid workers were expected to continue caring at the expense of their own psychological needs. The prescriptive nature of the caregiving identity, and the criticising and legitimising discourses and activities of participants, suggest the presence of organisational socialisation in HIV/AIDS organisations whereby individuals become accustomed to an organisation's culture, values, and norms – a process necessary for being able to operate successfully within an organisation (Haski-Leventhal, 2009; Haski-Leventhal & Bargal, 2008). Just as organisational culture, values, and norms are shaped in members through socialisation, members also contribute to the maintenance and development of such cultures, values, and norms (Haski-Leventhal & Bargal, 2008), as demonstrated by participants constructing the caregiver identity in their discourses as prescriptive. The prescriptive nature of the caregiving identity, and the requirement to maintain duties even when faced with difficult or traumatic experiences, can feasibly explain the burnout often found among HIV/AIDS aid workers (Bakker, 2007; Crook et al., 2006; Primo, 2007; Ross et al., 1999). In this regard, the use of DA has proven particularly useful for addressing the aims of this study as it enabled the identification of various identities

constructed in participants' discourses which consequently enabled a greater understanding of the challenges HIV/AIDS aid workers may face.

Finally, participants also constructed a child identity in their discourses. Children were constructed as different to adults and attributed certain characteristics; for example, children are perceived as lacking agency (because agency is age-dependent) and can therefore, unlike adults, not be held accountable for the hardships they experience, such as being HIV+. Consequently, children are perceived as innocent and they evoke sympathy, while adults, who do possess agency, are blamed for children's hardships. Furthermore, participants' discourses characterised children as meant to be loved and cared for, and not meant to die. Although dying children is no longer a prominent issue due to ARTs, HIV nonetheless acts as a barrier to an optimal childhood and a 'normal' life. Participants' discourses thus highlighted that loss is not merely a matter of death but aid workers who today work with HIV+ children also experience sadness for and on behalf of the children for their various losses.

Given the above said, perhaps the trauma of losing a child becomes exacerbated by the construction of children as lacking agency and adults as accountable for children's hardships. Man-made, or interpersonal, traumas – that is, traumas inflicted by other human beings – are assumed to increase risk for psychopathology in comparison to, for example, natural disasters (Brune et al., 2002; Saigh, 1988). Thus, by holding adults accountable for the HIV-related hardships endured by children, including AIDS-related deaths, such events can arguably be characterised as traumas inflicted by other persons and subsequently increase the risk of a traumatic stress reaction among aid workers.

Conclusively, this study primarily shows that while AIDS-related death did not appear to be a major traumatic concern in this study specifically, characteristics inherent in the identities constructed by the participants can explain when and why AIDS-related bereavement can become traumatic.

8.1.2. Resources Utilised by Aid workers in order to Cope with AIDS-Related Bereavement

As mentioned above, the caregiver identity constructed by the participants in their discourses acted as a double-edged sword. While its prescriptive nature could lead to HIV/AIDS aid workers experiencing burnout, the caregiver identity was simultaneously one of participants' main resources for coping with the potentially exhaustive experience of HIV/AIDS aid work: the rewards of HIV/AIDS aid work – that is, the satisfaction and pleasure obtained when participants felt needed and cared for those in need, such as terminally ill HIV+ individuals – could also act as a buffer against the difficult or traumatic experiences inherent in such work. Participants' desire to care for those in need reflects motivations identified by previous studies in relation to volunteering (Akintola, 2004; Bakker, 2007; Dieleman et al., 2007; Haski-Leventhal & Bargal, 2008; Primo, 2007), and the protective power of their commitment to this cause, against difficult or traumatic experiences, supports the literature on war trauma (Başoğlu et al., 1997) and belief systems (Park & Folkman, 1997).

In addition to the protective nature of their caregiving identity, when faced with difficult experiences, participants would frequently attempt to reappraise meaning in order to make sense of and cope with otherwise incomprehensible events. Participants would, for example, reappraise meaning in response to loss of control as they would use their knowledge about HIV (and its unpredictable nature) to rationalise loss of control over the disease. Or, in response to children dying, participants would attempt to find a purpose for the child's short stay on Earth, or they would depict death as a better outcome or option in comparison to the life the child was living. Or, in response to lack of action, participants would, in order to avoid experiencing guilt (own lack of action) or attributing blame (others' lack of action), attempt to shift the locus of control for an event, such as harm to a child, from an internal locus of control, whereby the individual was *unwilling* to act to protect the child, to an external locus of control, whereby the individual was *unable* to act to protect the child.

Participants' accounts of the difficulty experienced when they felt in control but subsequently lost this sense of control support, first, the notion that losing control can be more distressing than not having control at all (Hanson et al., 1976), and second, the notion that traumatic events are perceived as stressful because they interfere with an individual's sense of control (Park & Folkman, 1997). When the reappraisal process resulted in a shift in locus of control, the goal, however, was to portray themselves or others as *not* in control in order to avoid experiencing guilt or attributing blame. As research has previously highlighted, individuals who feel they were in control of negative events may subsequently experience guilt, but when the events are attributed to an external source then this may alleviate the guilt and associated psychopathology (Joseph et al., 1991). In instances where participants felt a loss of control over the disease, it appeared they attempted to reappraise meaning in order to find situational meaning (Park & Folkman, 1997), that is, an interpretation of a specific event. Finding situational meaning was often an attempt to assimilate (Resick & Schnicke, 1990) information into their global belief systems, such as when participants would interpret the death of a child in a manner that allowed such a death to fit their global belief system that stated that children are not meant to die. One such interpretation – participants' depicting the death as a better outcome – is in line with some of the limited previous research on AIDS-related bereavement that illustrated how bereaved individuals focus on the positive aspects of their experience (Demmer, 2007). Once again, DA was particularly useful because it allowed the identification and examination of participants' global belief systems which in turn enabled a greater understanding of how participants make sense of (difficult) experiences.

Finally, in terms of resources for coping with their work, participants frequently raised the need for counselling and HIV/AIDS and TB training. In participants' discourses it was evident that not only did the prescriptive nature of HIV/AIDS aid work render the work taxing but also that HIV/AIDS aid workers have limitations with regard to how much they can adhere to the prescriptive rules. Counselling, then, as an activity intended to alleviate psychological anguish,

functions as a resource for HIV/AIDS workers to cope with their taxing work. Moreover, counselling arguably provides opportunities for meaning-making, or reappraisal of meaning. With regard to training, as participants gained more knowledge about HIV/AIDS the disease became less frightening and participants felt increasingly comfortable dealing with the disease and thus their work. In essence, training and education enables HIV/AIDS aid workers to have more accurate expectations of the diseases, which ultimately increases their sense of control. Knowledge is a weapon in the battle against HIV and TB – a weapon obtained through training and education.

The role of HIV/AIDS and TB training in increasing participants' expectations and preparedness and consequently their sense of control reflects findings on the role of training in the military (Iversen et al., 2008). Moreover, participants' construction of training and counselling provided by management as an act of support reinforces the claim that managerial support is important to HIV/AIDS aid workers (Dieleman et al., 2007), not least in terms of providing training for volunteers (Haski-Leventhal et al., 2008). Thus, the findings of the present study highlight what specific type of managerial support HIV/AIDS aid workers may find particularly useful as well as why; for example, counselling is found useful because it ties in with HIV/AIDS aid workers sometimes taxing caregiving identity.

Conclusively, this study shows that global belief systems that allow the finding of meaning as well as managerial support are important coping resources for HIV/AIDS aid workers.

8.1.3. Differences in the Experiences of Local Versus International Aid Workers

With regard to the last aim of this study – the investigation of any differences in the experiences of local versus international aid workers – a number

of differences were identified. First and foremost, there was a difference in the conceptualising of HIV. Although it appeared that internationals have joined the locals in no longer conceptualising HIV as an immediate death sentence, there was still a greater sense of fear of HIV among international volunteers than among local participants. While the latter normalised HIV, the former expressed concerns that HIV may have become too trivialised; however, international volunteers, too, made attempts to normalise their work environment. Their discourses often followed a pattern of first describing how 'normal' their work environment was, to thereafter proceed by giving an account of how this 'normality' was disrupted; these instances of disruptions were in this thesis referred to as reality checks. This pattern was, however, rarely displayed in local participants' discourses.

Although the child identity constructed by local and international participants reflected similar characteristics, the two groups differed in their responses to children's various losses and the optimal childhood. Local participants, in their discourses on HIV and children, mainly addressed death and the loss of a young child's life, and subsequently attempted to reappraise meaning in order to make sense of this experience in the face of a global belief system that states that children are not meant to die. International volunteers, however, more commonly highlighted the children's loss of an optimal childhood, which would involve children having parents and being loved and cared for. The volunteers highlighted this loss by comparing the children's childhood to their own childhood, which was often referred to as having been privileged. A number of reasons may explain such differences. First, the majority of the international volunteers had not experienced a child dying from AIDS, whereas they worked with orphaned and underprivileged children on a daily basis. As the latter heavily dominated their experiences, it is not surprising that their discourses maintained such a focus. Second, the international volunteers were on average almost a decade younger than the other participants. As such, the international volunteers were closer in time to their own childhood than the locals were, and because their childhood was more easily retrieved in memory one could argue that a comparison of childhoods was consequently easier, and more

relevant, for international volunteers than other older participants. Finally, many of the international volunteers came to South Africa and Cotlands specifically in order to care for underprivileged individuals, that is, those who were not fortunate to experience the same kind of privileged childhood as they were. Perhaps the local volunteers had become accustomed to the numerous underprivileged children in South Africa and subsequently were less fazed about this matter. Culture has previously been found to influence what may constitute a traumatic event (Başoğlu & Paker, 1995; Başoğlu et al., 1994; Bracken et al., 1995).

Finally, local and international participants differed in their emphasis on type of support wanted. Although both locals and internationals wanted counselling and HIV/AIDS and TB training, local participants generally emphasised counselling whereas international participants emphasised training. Perhaps the findings discussed above have an influence on this difference in emphasis: if there is a greater sense of fear of HIV among international volunteers, then it seems sensible if they emphasise the need for HIV/AIDS training more than locals. Likewise, if locals are more focused on death of children, it makes sense that counselling that may alleviate any consequent psychological anguish is of high importance to them. (Another possible explanation is time: locals, who were mainly staff members, may be in greater need of counselling simply for having spent more time at Cotlands and in this kind of work.)

Conclusively, this study shows that culture may play a role in the experiences of aid workers, and further that DA is a useful method for identifying and understanding differences between local and international aid workers, for example in terms of how they conceptualise various phenomena differently and consequently may have different needs.

8.2. Main Findings in Light of Theories of Social Psychology

8.2.1. Just World Hypothesis

The Just World hypothesis states that '[i]ndividuals have a need to believe that they live in a world where people generally get what they deserve' (Lerner & Miller, 1978, p. 1030), or deserve what they get, and that appropriate consequences follow actions (Lerner & Simmons, 1966). The hypothesis holds that the idea that innocent people can suffer is unbearable and, therefore, a person suffering must deserve this due to previous actions. If an individual believes that innocent people can arbitrarily suffer, the implications of such a belief is that they too, as an innocent person, can arbitrarily suffer; however, if the suffering is explained in terms of prior poor behaviour, the individual can rest assured that they will not suffer because they will not behave poorly.

The micro and macro discourses on HIV in terms of control and stigma can possibly be explained in the light of the Just World hypothesis: HIV contraction is a result of previous actions. The idea that an innocent person would suffer the anguish of HIV/AIDS is incomprehensible; however, if the person is perceived to have previously acted inappropriately, in this particular case by not adhering to the 'rules' of HIV, the suffering can be explained in terms of an undesirable consequence following undesirable actions. The person is no longer perceived as innocent and the suffering becomes understandable. Furthermore, others can find comfort in the knowledge that they are safe from the anguish of HIV/AIDS as long as they adhere to the 'rules' of HIV.

Although the above reasoning can be applied on situations involving HIV+ adults, the situation of the HIV+ child is more complex. According to the Just World hypothesis, suffering can be explained either through a person's poor conduct or poor character (Lerner & Miller, 1978). In participants' discourses, however, children were constructed as lacking agency and could therefore not be held

accountable for their hardships. As such, their suffering cannot be explained through their poor conduct. Poor character, on the other hand, requires a history of poor conduct; as such, children's suffering cannot be explained through poor character either. An enquiry of interest, then, is whether the Just World hypothesis cannot be applied to children because children are perceived as lacking agency, or whether children are not attributed agency in order to prevent the Just World hypothesis from being applicable to them. Yet, the thought of an innocent child suffering for no reason seems unbearable and in this study the children's suffering was explained through the poor conduct of adults, that is, the children's caregivers who failed to properly care for the children. Previous research, for example, found that parents of terminally ill children would blame themselves and that this blaming in fact alleviated anxiety because the alternative, the idea that no one was responsible for the suffering, was unbearable (Chodoff, Friedman, & Hamburg, 1964). Although holding adults accountable for children's suffering may explain the suffering, it does not explain why innocent children *deserve* to suffer. What it does do, however, is rebut the frightening thought that suffering is entirely arbitrary, which brings some comfort regarding one's own fate and risk of suffering.

8.2.2. Cognitive Dissonance

Cognitive dissonance (Festinger, 1957) is the uncomfortable state an individual experiences when holding two or more inconsistent cognitions; for example, the knowledge that one has behaved in a way which one in fact does not approve of would most likely produce dissonance because the behaviour and the opinion are dissonant. The higher the importance of the cognitions to the individual, the stronger dissonance will be experienced. Individuals who hold such conflicting cognitions will act to reduce, or if possible eliminate, the dissonance in order to reduce the discomfort. In the case of a behaviour being dissonant with a value, the individual can either change the behaviour or change the value. Where the individual is unable to change past behaviour, addressing the value in order to

reduce dissonance is a more probable solution. The dissonance can be reduced, for example, by altering the importance of the value or even by adding another cognition which 'reconciles' (Festinger, 1957, p. 23) and makes consonant the previously dissonant cognitions and reduces dissonance and discomfort.

Cognitive dissonance can arise as a result of cultural norms when an individual behaves in a manner dissonant with acceptable behaviour as defined by prevailing cultural norms, with norms varying across cultures; in other words, cognitions that are dissonant in one culture need not necessarily be dissonant in another culture (Festinger, 1957). As such, the theory of cognitive dissonance is useful for explaining the reappraisal processes which participants engaged in. For example, Extract 7.14 in Chapter 7 illustrates a staff member describing how bringing her own young children to Cotlands has affected her. In the account, the participant demonstrates an awareness of potentially having put her children at risk by bringing them into an HIV environment. In a context of a prescriptive caregiver identity whereby 'proper' caregivers are expected to not put children at risk, the participant's behaviour is dissonant with this value. In order to reduce this state of discomfort, she can either alter the behaviour or the value. As the act of bringing her children to Cotlands cannot be undone, she is then left with the option to alter the value. In doing so, she, first, adds another value which to some extent 'reconciles' the previously dissonant cognitions: she highlights the *benefits* to her children of having experienced the Cotlands environment. Thus, the act of having brought her children to Cotlands is no longer as dissonant with the value of not putting children at risk because the experience has also been beneficial to the children. Second, by stating that the benefits outweigh the risks, she attaches higher importance to this value than to the value of not putting children at risk; consequently, she reduces the dissonance even further. Conclusively, the participant can justify bringing her children to Cotlands without compromising herself as a 'proper' caregiver. Reappraisal of meaning, then, has the potential to reduce discomfort produced by cognitive dissonance.

8.2.3. Identity Control Theory and Self-Categorization Theory

There are a number of social psychology theories addressing the self and identity, ranging from those with an interpersonal focus to those with an intergroup focus (Turner & Onorato, 1999). Two of these theories, Identity Control Theory (ICT) and Self-Categorization Theory (SCT), will be discussed here as these are particularly relevant to this thesis in terms of understanding the identity-related findings. (I do acknowledge that some may perceive a theoretical tension between these theories and theories of DA and social constructionism; however, I also believe there to be value in approaching the findings of this study from a number of different perspectives.) While SCT addresses questions of self-categorisation – that is, ‘the cognitive grouping of the self as identical to some class of stimuli in contrast to some other class of stimuli’ (Turner & Onorato, 1999, p. 21) – ICT ‘focuses on the nature of persons [*sic*] identities (who they are) and the relationship between the persons identities and their behavior within the context of the social structure within which the identities are embedded’ (Burke, 2007, p. 2202) – that is, the identity verification processes that take place within social interaction. These social identity theories maintain that when people categorise themselves as members of a particular social group, they subsequently wish to emphasise similarities with other in-group members, and differences with out-group members, as this produces a sense of belonging and acceptance (Stets & Burke, 2005; Turner & Onorato, 1999). Consequently, people consciously behave in a manner that meets the social expectations of the meaning of any given group membership, or identity (Burke, 2007; Stets & Burke, 2005). Thus, identities, and their meanings, become socially defined, prescriptive, internalised, and maintained (Burke, 2007; Turner & Onorato, 1999). If during social interaction, the identity-relevant feedback people receive is congruent with the identity meanings they hold, the social situation is unfolding as expected and people continue to behave accordingly; however, if the identity-relevant feedback is incongruent with the identity meanings they hold, people experience a range of negative emotions that generate a change in their behaviour in order to reduce any discrepancy (Burke, 2007). Any behaviour change produces

new feedback which is re-assessed in order to achieve congruence between the identity-relevant feedback from the social interaction and the identity meanings held. This ongoing process is known, in ICT, as the identity verification process (Burke, 2007). While high discrepancy may lead to rejection by a social group, successful identity verification that meets expectations can result in an individual being perceived as competent, authentic, and worthy (Stets & Burke, 2005).

The prescriptive nature of the caregiver identity can thus be better understood in light of these social identity theories; for example, the process whereby HIV/AIDS aid workers are socialised and expected to behave in certain ways in order to demonstrate their authenticity as 'proper' and 'genuine' caregivers, as well as how these expectations become internalised and maintained, and ultimately prescriptive (as demonstrated, for example, by participants' use of imperatives). The identity verification process is particularly useful for explaining participants' need for discursively conveying their authenticity as HIV/AIDS caregivers (for example, by framing their caregiving as beneficial to others, or in contrast to monetary incentives). Such discursive endeavours suggest, first, that participants are highly aware of what meanings are attached to the identity of an HIV/AIDS aid worker, and second, that they, as HIV/AIDS aid workers, are required to socially behave in a manner that is congruent with these meanings; a requirement that, in the case of HIV/AIDS aid workers, can eventually become too taxing.

8.3. Implications of This Study and the Findings Therein

The control-related findings of this study arguably have the greatest implications. This study highlighted, as previously also suggested (e.g., Demmer, 2004), that the challenges that contemporary HIV/AIDS aid workers mainly face are control-related: knowing that HIV treatment, and prevention, or at least

deceleration, of AIDS-related death, is possible but being unable to exercise control over such issues due to patients' lack of compliance and non-adherence with medication. In order to address the helplessness HIV/AIDS aid workers subsequently experience as a result of being unable to exercise such control, solutions to non-compliance, and other barriers to control, need to be identified. In this regard, studies of social interaction and communication, involving techniques such as discourse and conversation analysis, may prove particularly useful. Indeed, previous work has stressed the significance of communication training for health professionals (de Kok, Laurier, & Widdicombe, 2012). Examples of such training are those being developed at the University of the Witwatersrand in Johannesburg, South Africa: training that is based on analysis of instances of real interactions between health professionals and clients (Watermeyer & Penn, 2009a, 2009b), addressing issues such as adherence (or, rather, non-adherence) to ART (Penn, Watermeyer, & Evans, 2011; Watermeyer & Penn, 2012) and informed consent (Watermeyer & Penn, 2008). Such training is undoubtedly already of relevance to HIV/AIDS aid workers at Cotlands, but there is reason to believe that it may become even more important in the future. In a Cotlands context, the abovementioned issues of control were predominantly an aspect of the outreach and community care; Cotlands residential care centre was found to be a high-control environment. In Chapter 3, however, it was briefly mentioned that Cotlands is undergoing a major organisational change whereby the residential care is progressively being phased out and focus is shifting towards outreach and community care. Consequently, there is even greater potential for HIV/AIDS aid workers at Cotlands to experience control-related helplessness, and, therefore, communication training based on findings from communication and interaction research has an important role to play in the work, and psychological well-being, of Cotlands staff and volunteers.

The psychological wellbeing of HIV/AIDS aid workers can further be enhanced by the identification of the nature of their caregiving identity as well as their belief systems as these increase our understanding of what challenges HIV/AIDS aid workers may face and why. The development of support systems for

HIV/AIDS aid workers should therefore take these issues into consideration as support that is tailored to these needs is not only likely to be more effective (Reynolds & Alonzo, 1998) but also less resource consuming. On this note, it should be noted that HIV/AIDS training for international volunteers may simply be – not entirely but to a large extent – a matter of managing expectations. Because HIV/AIDS and TB are much more widespread in South Africa, in comparison to, for example, northern Europe, there was a sense that international volunteers expected knowledge on these topics to be more extensive in South Africa. Consequently, international volunteers arriving at Cotlands appeared to be expecting management to offer them HIV/AIDS training that involved more obscure knowledge, that is, more than the ‘obvious’ knowledge of what the HIV virus does and how it is spread. When this expectation was not met, simply because such imagined obscure information is non-existent, international volunteers were concerned that they were not being offered adequate training on a serious topic such as HIV/AIDS. Managers of HIV/AIDS aid workers should, therefore, consider addressing the issue of training expectations and ensure curricula are agreed on before executing training programmes.

8.4. Limitations of This Study and Suggestions for Future Research

As stated previously, however, AIDS-related death rates at Cotlands are currently very low, and this brought about a number of limitations for the present study. First, it is possible that the findings of this study, in relation to the needs of HIV/AIDS aid workers, may not be applicable to HIV/AIDS aid workers in contexts of higher death rates. It would, for example, be of interest to further assess the findings of this present study in Kwa-Zulu Natal, the South African province with the world’s highest HIV and AIDS-related death rates (Horwood et al., 2012). Second, the study was unable to address the issue of multiple losses and the dose-

effect relationship between trauma and its effects (as discussed in Chapter 2). Finally, due to the lack of occurrence of AIDS-related deaths during the fieldwork for this study, many participants completed the IES-R based on a death occurring many years previously. Because time since trauma often has an effect on trauma symptoms (Weiss, 2007), it is unclear whether the results of the participants' IES-R scores would look different if death rates at Cotlands were higher.

The decision regarding which organisations to contact during the recruitment stage of this study was by and large based on a subjective appraisal of the organisation's relevance to this study. This appraisal was in turn based on information available on the Internet or sometimes through word of mouth. Future studies of this kind should consider a two-stage recruitment process, where the first stage is dedicated to finding presumably relevant organisations, providing them with general information about the study, and, if the organisation expresses an interest in participating, obtain information about the operation of the organisation and statistics (such as, death rates). The second stage would then be dedicated to identifying the most suitable organisation based on the information available. Arguably, this kind of recruitment would more accurately depict what organisations are available and which would be best suited.

Another challenge for this study was in terms of language. First, despite efforts to avoid such challenges, it appeared the language on the consent form and the IES-R was sometimes too difficult for non-English native speaking individuals to comfortably understand. Given the high number of official languages in South Africa (11 of them), which was also reflected among Cotlands' staff and volunteers (not least the international volunteers), it would not have been feasible for this study to provide every participant with documents in their native language. The potential effect of this issue on the IES-R results is unclear, and the suitability of using the IES-R in this kind of research needs to be evaluated. It should, however, be noted that the IES-R has previously been utilised in various non-English native speaking countries and cultures, some employing the English (original) version of the scale

(e.g., Bachar, Hadar, & Shalev, 2005) whereas others have employed translated versions (e.g., Bunzel, Laederach-Hofmann, Wieselthaler, Roethy, & Drees, 2005; Godeau et al., 2005; Ohtani et al., 2004). Despite differences in symptom category, the international studies show robust psychometric properties that suggest the IES-R can legitimately be employed in studies using non-English participants.

Second, the analysis of the interviews was sometimes complicated by the non-English native speaking participants' (including locals) use of the English language. Because words and phrases would sometimes be literally translated from their native language into English, these words and phrases were subsequently not always suitable or comprehensible in English. This matter was mitigated by the insight gained through having lived, worked, and socialised with the participants, which consequently facilitated the interpretation of their language and responses. Thus, a further strength of this study, in addition to the use of discourse analysis, was the use of ethnography, not least due to its pragmatic benefits.

8.5. Conclusion

In Chapter 2 it was speculated that, after decades with the HIV/AIDS pandemic, expectations may have changed and that HIV/AIDS aid workers are now accustomed to the (psychological) effects of their work, but also that this could be a hazardous assumption to make as aid workers' needs, particularly with regard to bereavement, could lead to negative health outcomes if not identified and met. This study, then, has highlighted that despite decades of the HIV/AIDS pandemic and despite AIDS-related death no longer being the prominent issue it once was, the care of HIV/AIDS aid workers should not be overlooked; trauma-related research on HIV/AIDS aid workers needs to continue being carried out. The new era HIV work simply involves new challenges, and possibly new traumas. It is, therefore,

important to continue regular assessments of the needs of HIV/AIDS aid workers in order to identify new needs that develop in response to these new challenges.

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Appendix A. Request for Participation in Research Project Letter



THE UNIVERSITY *of* EDINBURGH

Vania Ranjbar
Department of Psychology
The University of Edinburgh
F23, 7 George Square
Edinburgh
EH8 9JZ
Scotland

[Organisation address]

[Date]

Dear [name],

Request for participation in research project

My name is Vania Ranjbar and I am a PhD psychology student at the University of Edinburgh, Scotland. My research aims to explore the effects of bereavement due to HIV/AIDS and tuberculosis on staff and volunteers in aid organisations in Africa.

I am writing to ask for your organisation's assistance in conducting this study. This assistance would involve two elements. First, I would like on a volunteer basis to visit the organisation's project located within [place] for approximately six to nine months, starting October 2010, and in the course of that visit to participate in and observe the ongoing activities of the project. If you accept me as a volunteer for that period, I will be happy to carry out such duties as are required for the duration of the study. Second, I seek your agreement that during my visit I be allowed to approach individual staff and volunteers within the organisation to take part in my research. This participation would involve staff and volunteers being asked to take part in audio-recorded one-to-one interviews and to complete a research instrument: the "Impact of Event Scale". This instrument aims to measure a person's response to trauma. In addition, I would also like to gather data by audio-recording naturally occurring conversations between staff/volunteers, with their consent. Whether or not individual members of staff or volunteers agree to take part in the research would of course be entirely a matter of choice and no data would be collected from anyone without his or her fully informed consent to take part. All data collection would be conducted sensitively and in ways intended to minimise any impact upon the work of the organization.

Being able to observe first-hand the work of the organisation and to gain insights into the experiences of those working directly on the ground would be of enormous benefit to my research. I am interested in how staff and volunteers perceive their experiences of working with terminally ill individuals, the experiences of the subsequent bereavement, and how they deal and cope with this. I envisage that the outcomes of such research will also be of considerable benefit to organisations such as yours in making available staff and volunteer experiences of such matters and potentially being able to inform future practice and/or training. I will therefore be pleased to provide you on the conclusion of the project with a summary of the key findings that are produced.

Please find attached a copy of my CV as well as a Participant Information Sheet and a Consent Form to provide you with further details about myself and the study. Please do not hesitate to contact myself (v.ranjbar@sms.ed.ac.uk), or my supervisors Dr Andrew McKinlay (a.mckinlay@ed.ac.uk) and Dr Chris McVittie (cmcvittie@gmu.ac.uk), if you require any further information.

This project has been approved by the
University of Edinburgh Psychology Research Ethics Committee (Ref 82-0910)

I hope, therefore, that your organisation will feel able to assist me in conducting this study. I thank you for your time and look forward to hearing from you.

Sincerely,

A handwritten signature in black ink, appearing to read 'Vania Ranjbar', is written over a light grey rectangular background.

Vania Ranjbar

**This project has been approved by the
University of Edinburgh Psychology Research Ethics Committee (Ref 82-0910)**

Appendix B. Participant Information Sheet



THE UNIVERSITY of EDINBURGH

Participant Information Sheet

PROJECT TITLE

Losing someone to HIV/AIDS and tuberculosis; exploring the effects on staff and volunteers in aid organisations in Africa.

INTRODUCTION

You are being asked to participate in a research study conducted by Vania Ranjbar, a PhD psychology student at the University of Edinburgh, Scotland. The study aims to investigate the effects of bereavement due to HIV/AIDS and/or tuberculosis on staff and volunteers in aid organisations. The study will explore if and to what extent such experiences are perceived as traumatic, as well as how individuals deal and cope with them.

WHAT WILL I BE ASKED TO DO IF I TAKE PART?

In this study, you will be asked to participate in audio-recorded interviews with the researcher to discuss your experiences; complete the IES (Impact of Event Scale), a measure of response to trauma; and if suitable, you may also be asked to consent to my audio-recording naturally occurring conversations.

*Please note that this is **not** a clinical study and there will be **no** clinical diagnoses. The purpose of the IES is merely to gain a general idea of people's responses to trauma.*

TIME COMMITMENT

The one-to-one interviews will last up to 60 minutes per session. The IES takes approximately 5-15 minutes to complete. The audio-recording of naturally occurring conversations requires no extra time on your behalf. The number of interviews and IESs may vary across individuals.

PARTICIPANTS' RIGHTS

You may decide to withdraw from the research study at any time without explanation and without any detriment to you. You have the right to ask that any data you have supplied to that point be withdrawn/destroyed.

Please note that you are only required to discuss what you are comfortable discussing and you are not required to answer questions you wish not to answer.

You have the right to have your questions about the procedures answered (unless answering these questions would interfere with the study's outcome). If you have any questions as a result of reading this information sheet, please ask the researcher before the study begins.

BENEFITS AND RISKS

The findings of this study could potentially contribute to future improvements of work and health situations for other aid workers in similar situations.

**This project has been approved by the
University of Edinburgh Psychology Research Ethics Committee (Ref 82-0910)**

There is a small possibility that, in processing memories, you may experience some discomfort or distress. If you are upset or concerned by any of the issues raised in this study, please discuss these with the researcher or contact any of the support services which will be provided.

CONFIDENTIALITY/ANONYMITY

The link between the data you provide and the identifying information you supply will only be known to the researcher. No potentially identifying information will be shared or given to any researcher or agency or will be published or presented in any educational or research forum. Pseudonyms will be used where quotations are published.

Any information that is obtained in connection with this study will be disclosed only as agreed to by you on the consent form, with your permission. All electronic data will be kept encrypted and hard copies will be securely stored under the responsibility of the researcher.

Please note that the British Data Protection Act 1998 requires that 'personal data shall not be transferred to a country or territory outside the European Economic Area, unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data' (Data Protection Act 1998, Schedule 1, Part I, Principle 8). Since the data will be 'held' by the University of Edinburgh, you are asked on the consent form to give permission for your data to be transferred outside of the European Economic Area.

FOR FURTHER INFORMATION

If you require further information regarding this study, please feel free to contact Vania in person or at: v.ranjbar@sms.ed.ac.uk

or the study supervisors:

Dr Andrew McKinlay: a.mckinlay@ed.ac.uk

Dr Chris McVittie: cmcvittie@qmu.ac.uk

**This project has been approved by the
University of Edinburgh Psychology Research Ethics Committee (Ref 82-0910)**

Appendix C. Impact of Event Scale – Revised

PID: _____

IMPACT OF EVENT SCALE – REVISED (IES-R)					
<i>INSTRUCTIONS: Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you during the past seven days with respect to _____, which occurred _____ weeks ago. How much were you distressed or bothered by these difficulties?</i>					
	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. Any reminder brought back feelings about it.	0	1	2	3	4
2. I had trouble staying asleep.	0	1	2	3	4
3. Other things kept making me think about it.	0	1	2	3	4
4. I felt irritable and angry.	0	1	2	3	4
5. I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	2	3	4
6. I thought about it when I didn't mean to.	0	1	2	3	4
7. I felt as if it hadn't happened or wasn't real.	0	1	2	3	4
8. I stayed away from reminders of it.	0	1	2	3	4
9. Pictures about it popped into my mind.	0	1	2	3	4
10. I was jumpy and easily startled.	0	1	2	3	4
11. I tried not to think about it.	0	1	2	3	4
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.	0	1	2	3	4
13. My feelings about it were kind of numb.	0	1	2	3	4
14. I found myself acting or feeling like I was back at that time.	0	1	2	3	4
15. I had trouble falling asleep.	0	1	2	3	4
16. I had waves of strong feelings about it.	0	1	2	3	4
17. I tried to remove it from my memory.	0	1	2	3	4
18. I had trouble concentrating.	0	1	2	3	4
19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.	0	1	2	3	4
20. I had dreams about it.	0	1	2	3	4
21. I felt watchful and on-guard.	0	1	2	3	4
22. I tried not to talk about it.	0	1	2	3	4

Appendix D. Interview Schedule

1. Could you please tell me a bit about yourself?
2. What is your role here?
3. Why are you here? Why do you want to do this?
4. Did you come here on your own or through an organisation?¹⁰
5. Did you receive any training or particular information before coming here?
6. What did you know about HIV, AIDS, or TB before you came here?
7. Have you learned anything new about HIV, AIDS, or TB since coming here?
8. How do you feel about working with HIV+ individuals, or those who have AIDS or TB?
9. What aspect of working with individuals who are HIV+, or who have AIDS or TB, do you find most difficult?
10. When you first came here, did you feel prepared enough?
11. Were you offered any additional training or information once you arrived here?
12. Do you feel that Cotlands gives you enough support to cope with your work?
13. Have you had an experience that was particularly negative?
14. Have you had an experience that was particularly positive?
15. If you could change anything with regard to your experiences, would you change something, and if so, what?
16. What recommendations do you have for those who want to come and do this kind of work? What advice would you give them?

¹⁰ Question was only posed to international volunteers as only relevant to them.

Appendix E. Support Contact Details



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Support contact details

Lifeline Southern Africa

SA National Counselling Line

24 hour service, 7 days a week. Anonymous and confidential. Entry point to various services.

Telephone: 0861 322 322

Website: www.lifeline.org.za

Lifeline Southern Africa

National AIDS Helpline

24 hour service. Anonymous and confidential. Information, counselling, referrals to HIV-infected and affected individuals.

Telephone: 0800 012 322

Website: www.aids helpline.org.za

South African Depression & Anxiety Group (SADAG)

Mental health support and advocacy group

Monday to Sunday, 8 am – 8 pm. Referrals to psychologists, psychiatrists, support groups.

Telephone: 011 262 6396

Website: www.sadag.co.za

Appendix F. Participants Descriptive Statistics

Table F.1

Descriptive statistics for participants and interviews

	Gender		Average age (years) [SD]	Average time at Cotlands (months) [SD]	Average interview length (minutes) [SD]
	F	M			
Administration	3		42 [9]	131 [75]	47 [13]
Hospital Counsellor	1		33	73	25
Education	1		35	169	24
Ex-staff	3		45 [13]	100 [43]	49 [14]
Fund Development	2	1	32 [7]	52 [78]	35 [12]
HBC	12		41 [7]	52 [34]	33 [14]
Health	1		54	137	63
Hospice	9		46 [6]	95 [52]	25 [8]
Psychosocial	3		35 [7]	40 [28]	37 [9]
Sanctuary	7		46 [8]	185 [88]	30 [11]
Services	1		36	153	35
Local Volunteers	2	1	51 [23]	N/A	34 [11]
International Volunteers	11	5	23 [6]	4 [4]	28 [13]
Totals and averages [SD]	56	7	40 [9]	99 [57]	36 [11]

Table F.2
Nationality statistics for participants

	Nationality										
	White African	Black African	Coloured African	North American	Australian	British	Dutch	German	German / Turkish	Irish	Swiss
Administration	3										
Hospital Counsellor		1									
Education	1										
Ex-staff	2	1									
Fund Development	1		1	1							
HBC		12									
Health		1									
Hospice		9									
Psychosocial	1	2									
Sanctuary		7									
Services	1										
Local Volunteers	3										
International Volunteers				1	2	3	1	5	1	1	2
Totals	12	33	1	2	2	3	1	5	1	1	2

Appendix G. Transcript Notations

(.)	A pause shorter than 0.2 of a second
(0.5)	Timed pause (for example, half a second)
↑word, ↓word	Pitch rise or fall
wo(h)rd	Laughter within a word
wor-	Sharp cut-off
wo::rd	Stretched sound, the more colons the longer sound
(word)	Uncertainty if the word is correct
()	Unclear talk, the more space the more syllables
<u>Word</u>	Emphasised/louder word
°word°	Talk delivered more quietly
>word<	Talk delivered faster
<word>	Talk delivered slower
A: word [word] B: [word]	Overlapping talk (that is, simultaneous speech)
A: word= B: =word	Latching talk (that is, no discernible pause between two speakers)
((chuckles))	Non-speech acts