

**Need Analysis for AIDS - related
Bereavement Counselling Programmes to Assist
Women Affected by HIV/AIDS
- An Indonesian Perspective**

by

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Acknowledgments

People around me could not fathom why I decided to specialise in a field of studies that has little to do with my education or experience. Indeed, I majored in French Literature as a college student, although I also took a particular interest in Public Health issues. Then I held several jobs where my knowledge of the French language came in handy, before I decided to go into business and set up my own company.

I first became interested in HIV/AIDS when I realised the serious challenges faced by developing countries in trying to contain such a devastating epidemic made notorious by the strong stigma attached to it, for which no cure is yet available. Then I became aware of the threat the epidemic presents to my country, Indonesia, considering that knowledge of HIV/AIDS among its large and diverse population is limited and resources for prevention programmes are lacking. It struck me that a low HIV prevalence may actually mean that a large number of people are affected by the disease. This prompted me to specialise in social behaviour in HIV/AIDS, with the anticipation that my knowledge will eventually allow me to *make a difference where I can*

I would like first of all to thank my supervisors and all the staff in USBAH at the University of South Africa. My special thanks go to Dr. Du Plessis who has so patiently guided me through this research endeavour, for sharing with me her valuable knowledge and for offering me critical reviews. I believe she has contributed a great deal to opening up a whole new horizon for me – not a fuzzy one with vague ideas but one where I can see exactly what I can do in my effort to help people living with HIV in Indonesia.

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Last but not least, I would like to dedicate this dissertation to all the women living with HIV in Indonesia. I am totally, wholeheartedly and unwaveringly determined to make their voices heard.

Declaration

I declare that “Need Analysis for AIDS-related Bereavement Counselling Programmes to Assist Women Affected by HIV/AIDS – An Indonesian Perspective” is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

Jakarta, September 30, 2008

Alita P. Damar

Summary

The aim of this study was to determine whether there is a need for specific bereavement counselling programmes for women affected by HIV/AIDS in Indonesia, where death is believed to be fated.

Six AIDS-bereaved women were recruited. Data analysis was conducted based on the women's interview transcripts and journal entries.

The women experienced at least three traumatic life events. The most challenging experience was learning that they have contracted a disease they knew to be mostly associated with prostitution. Given the short lapse of time between their husbands' deaths and learning about their seropositivity, biographical disruption appeared to have acted as an "*analgesic*", while concerns to protect their children seemed to have triggered biographical reinforcement. This phenomenon may have brought about a positive bereavement outcome.

Specific counselling programmes for women affected by HIV/AIDS are needed, but emphasis should first be placed on improving their wellbeing and their perception of stigma.

Keywords: Bereavement counselling, Indonesia, HIV/AIDS, widows of HIV-positive men, biographical disruption, biographical reinforcement, AIDS-related stigma, death-accepting attitude, positive bereavement outcome, psychological needs of HIV-positive women.

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List of Acronyms and Abbreviations

AIDS	-	Acquired Immunodeficiency Syndrome
ART	-	Antiretroviral Therapy
ARV	-	Antiretroviral
BPS	-	Badan Pusat Statistik (Statistics Indonesia)
CBT	-	Cognitive Behavioural Therapy
CD-4	-	Cluster of Differentiation 4
CFAH	-	Center for the Advancement of Health
CIA	-	Central Intelligence Agency
DHHS	-	Department of Health and Human Services
EAPI	-	East Asian Pastoral Institute
EOT	-	Explicit Observation Technique
EWD	-	Emotional Writing Disclosure
HIV	-	Human Immunodeficiency Virus
IDU	-	Intravenous Drug User
IPT	-	Interpersonal Psychotherapy
KAPETA	-	Karya Peduli Kita (Our Work of Care)
MRI	-	Magnetic Resonance Imaging
NAC	-	National AIDS Committee
NGO	-	Non-Governmental Organization
Rp.	-	Rupiah, the Indonesian currency
STI	-	Sexually Transmitted Infection
TB	-	Tuberculosis
TV	-	Television
UNAIDS	-	Joint United Nations Programme on HIV/AIDS
UNDESA	-	United Nations Department of Economic & Social Affairs
UNICEF	-	United Nation's Children Funds
UNISA	-	University of South Africa

CHAPTER 1: SITUATING THE RESEARCH PROBLEM

1.1 INTRODUCTION

*“No misfortune can happen
On earth or in your souls
But is recorded in
A decree before We bring
It into existence:
That Is truly easy for Allah:*

*In order that ye may
Not despair over matters
That pass you by,
Nor exult over favours
He bestowed upon you,
For Allah loveth not
Any vainglorious boaster”*

(Surah Al Hadid verses 22 & 23)

Indonesia is a developing country with currently the fastest spreading HIV epidemic in South-East Asia (UNAIDS 2008). With over 200 million inhabitants (BPS 2005), almost 90 per cent of which are Muslim (Dean 1999), the majority of the population consists of young people in their most productive ages (BPS 2005). While an abundant workforce certainly constitutes a great asset for a developing country with ample natural resources, it can also be a liability considering that young people are particularly vulnerable to HIV-infection. So far, the total reported HIV/AIDS cases nationally are still below 18 000 (Ministry of Health 2008), but UNAIDS (2006) estimates that approximately 170 000 Indonesians were already living with the virus at the end of 2005. More worrisome yet is the possibility that the real figure actually far exceeds estimates, considering that knowledge about HIV/AIDS is limited and few of those considered at risk are aware of their HIV status (NAC 2007-2010). Moreover, because awareness about HIV is still limited, even health professionals are not always clinically competent to suspect HIV when patients come in with various symptoms, so

deaths resulting from opportunistic infections are not necessarily diagnosed as AIDS-related when they actually might be¹.

More cases of HIV generally mean more AIDS-related deaths, especially in developing countries with limited access to antiretroviral therapy (ART). According to Sikkema *et al* (2000), these deaths can cause great distress in people whose loved ones have died of an AIDS-related illness. As stated by Stroebe *et al* (2005), death and bereavement are closely associated with depression. Hence, depression can seriously impair a person's ability to work or to function. It is thus important to investigate what the impacts of AIDS-related bereavement may be on the young Indonesian people. The aim of this study, therefore, was to focus on young women in Indonesia who had recently lost their husbands to AIDS-related mortality to see if specific counselling services were needed.

The above quote from the Koran (Surah Al Hadid verses 22 & 23) reflects the basic Islam teaching that no bad or good shall happen unless it was preordained by Allah, in strict accordance with His will or plan. Therefore, people in Indonesia tend to normalise death as it is believed to be fated, hence unavoidable. For many, however, HIV/AIDS is associated with "immoral behaviour" (Riono & Jazant 2004), which may imply that death caused by an AIDS-related illness *can* be avoided. It was thus fascinating to examine the dynamics between AIDS-related stigma and the "death-accepting" attitude of the Indonesian people and how they impact bereavement outcomes in a country where no bereavement counselling programmes currently exist².

Through this qualitative study, I analysed the women's experiences, beliefs, circumstances, coping mechanisms and social support, taking into account my own observations and experiences. The research study focussed on women because besides

¹ I have no written evidence to support this statement but the problem of late diagnosis or undiagnosed HIV regularly comes up in the national AIDS discussion forum (www.aids-ina.org) which includes physicians, NGOs and private individuals throughout the country concerned with HIV/AIDS, which I am also part of.

² I have no written evidence to support this statement but it was confirmed after discussions with academic professionals and clinical psychologists.

the multiple social issues they are often already burdened with, namely gender inequality, poverty and violations of women's rights (Arivia 2006), very little research has been done to understand the impact of AIDS-related bereavement on women. I believe the face-to-face interviews with these women and the use of diaries/journals in the approach I employed has allowed me to get a close look of their day-to-day lives. Such methods have also allowed me to gain a better understanding of what women in their situation go through, in a society where a "death-accepting" attitude prevails but where HIV/AIDS is highly stigmatised.

1.2 PROBLEM STATEMENT

Most work on the subject of bereavement during the first three quarters of the twentieth century was written from the point of view of Western psychiatrists, mainly to identify risks to mental health and to prevent psychiatric problems (Parkes 2003:1). Only in recent years have social work contributions to the bereavement literature been significant, especially as they relate to psychosocial issues pertaining to life-threatening illnesses such as cancer and AIDS (see, for example, Addington-Hall *et al* 1991; Rosengard & Folkman 1997; Stez & Brown 2004). The increasing interest from behavioural and social scientists in the bereavement field has been accompanied by the fading influence of psychiatric and clinical perspectives on this research (CFAH 2003). It is however interesting to note that, although an increasing number of studies has been conducted in non-Western settings during the last ten years, most research in this field are still based on studies of a predominantly middle-class, white population (DeSpelder & Strickland 2005:536), and based on a "Western perspective". Consequently, while social and behavioural scientists write about people in Western countries who generally have a notion of life that focuses on the "here-and-now" and commonly embrace a "death-avoiding" attitude, little remains known about how people in poorer settings in non-Western countries view death, grieve, and cope with loss. In the shantytown of Alto de Cruzeiro, Brazil, in the 1960s, for example, mothers had come to face child death with "*stoicism and equanimity*", as seventy per cent of all child deaths there occurred in the first six months of life (Scheper-Hughes 1993). In KwaZulu-Natal, South Africa, Demmer (2007) found that the constant struggle to

survive took priority over grief for many AIDS-bereaved individuals. Therefore grief, in this part of the world, is considered a “luxury” as far as the poor are concerned.

Increasingly, researchers have recognised the necessity of exploring whether specific aspects of bereavement as they apply to different groups of populations in the West also apply to non-Western people living in non-Western countries such as India, Sri Lanka, Turkey, etc. Bhugra and Becker (2005), for example, suggest that Western constructs of bereavement may provide only partial or limited explanations of expressions of grief when applied to people from other cultures. Depression, for example, can mean different things to different people in different cultures. In Zimbabwe, depression is almost exclusively associated with illnesses, without any emotional symptoms (Patel *et al* 1997). On the other hand, people in certain countries may suffer from depression but not know it or not pay any attention to it, probably because mental illness is associated with madness, as is the case in India (Raney & Cinarbas 2005). Thus, I believe Bhugra and Becker (2005) are referring to cultural relativism, meaning there are *many* truths - not just one - to be uncovered in a research situation. In other words, Western constructs of bereavement, according to them, would constitute just one such perspective among many in the world. In support of this view, Goodkin and Blaney (1996) emphasise the necessity to extend bereavement studies in HIV/AIDS to other cultures worldwide. In the case of Indonesia, it appears that the absence of such research is attributed not only to lack of resources, but also to the fact that grief and bereavement have never seemed to be major concerns in this South-east Asian country where death is “part of life”. It was thus interesting to investigate whether people, particularly women, affected by HIV/AIDS in this country had a way of their own to cope with loss, whether there were circumstances surrounding their husbands’ deaths that might have prompted them to recover quickly from their grief or, conversely, to aggravate their situation. The fact that there are no grief counsellors in Indonesia did seem to indicate, indeed, that the issue of bereavement might be considered irrelevant by many.

I intended to examine whether such a situation might be changing, particularly as far as AIDS-related bereavement is concerned. Indeed, Indonesia is now facing the prospect of a serious HIV epidemic due to the overlapping risk of contaminated needles and unsafe sex. For example, HIV prevalence has increased significantly

among injecting drug users surveyed at rehabilitation centres in the capital city of Jakarta, i.e. from 0 per cent in 1998 to more than 40 per cent by 2002 (UNAIDS 2006). Commercial sex work is also widespread in this country, and although condom use may be improving in some places, Jakarta is not among these. In fact, three quarters of sex workers operating out of massage parlours and clubs and 85 per cent of those working out of brothels in the capital city said they had not used condoms with any of their clients in the previous week (UNAIDS 2006). Currently, with a national adult HIV prevalence of 0.16 per cent, HIV is still concentrated within the high-risk groups in most parts of the country, but the virus has already spread to the general population in the eastern provinces of Papua and Irian Jaya Barat (NAC 2004-2005), where HIV prevalence is 2.4 per cent and AIDS cumulative rate is more than 15 times the national rate. Further, taking into account the low percentage of most at-risk populations who have received HIV testing and those reached by prevention programmes (NAC 2004-2005), the threat of an exploding epidemic is clearly there. Indeed, it is estimated that by 2010, 110 000 people will be suffering or will have died of AIDS-related mortality, while another million will be infected with the virus (UNICEF 2006). Approximately 170 000 Indonesians were estimated to be living with the virus at the end of 2005 while approximately 5 500 AIDS deaths occurred during that year (UNAIDS 2006). Currently, the majority of HIV cases (54.07 per cent) are in the age group of 20-29; almost half of them (48.9 per cent) have been transmitted through injection drug use, while heterosexual transmission accounts for most of the rest (39.4 per cent) (UNICEF 2006). Thus, considering that those living with HIV are in the productive age group and their number is increasing rapidly, I felt it was important to see whether bereavement might turn into a serious psychosocial problem for the young Indonesian people, many of whom are likely to become infected or affected by HIV/AIDS.

Obviously, with more infections and more deaths expected to occur in the coming years, there will also be a greater number of people grieving the loss of loved ones to AIDS-related deaths. Nieuwmeyer *et al* (2006:251) state that “*many of the risk factors that can lead to complicated mourning apply to AIDS-related deaths*”. Indeed, while most bereaved individuals experience normal, uncomplicated grief reactions (Zhang *et al* 2006), some may need professional help to avoid complicated grief. As further asserted by Sikkema *et al* (2004:188), “*bereavement is a severe life stressor*” – which

means that it causes high levels of distress - and is common among people living with HIV. The authors thus strongly recommend the development and evaluation of psychological treatments for bereavement especially among those who are living with HIV, considering that many spouses of men living with HIV do become themselves infected with the virus. In line with this finding, Goldblum and Erickson (1999) suggest that the level of AIDS bereavement distress can range from uncomplicated mourning without risk factors to complicated mourning with clinical disorder, but that effective bereavement education and support can assist mourners in coping with their grief and preventing bereavement-related problems. As mentioned earlier, the field of bereavement is still evolving despite great progress in bereavement studies in the past twenty years. Today, no one really knows how to best cope with loss, but perhaps there is no such thing as “the best way to cope with loss”, as grief may be as varied and as individual as life itself (Kübler-Ross & Kessler 2005:7). In light of this, findings from this study are simply meant to *enrich* our knowledge on bereavement and the circumstances surrounding death.

This study corresponds to calls by various social scientists for research on bereavement using non-Western samples, such as Eisenbruch (1984), Goodkin and Blaney (1996), who stress the need to clarify how effective mourning practices of various ethnic groups are in preventing “bad grief”³ and whether some of these practices may be beneficial if taken up by other ethnic groups. This research, therefore, is meant to contribute in terms of methods, substantive knowledge, insight or theoretical enlightenment, its overall objective being to gain a better understanding of the experiences of women affected by HIV/AIDS in a poorer, non-Western setting where a “death-accepting” attitude prevails. As stated by Bhugra and Becker (2005:20), “*all human beings get bereaved, but the cultural norms are essential in dealing with bereavement*”.

In this qualitative research, I am the insider telling the story to the outsiders, without imposing my own conceptual frameworks, with the hope that my findings may assist

³ This refers to complicated and prolonged grief - see definition of key terms in this chapter, Section 1.4.2.

decision-makers to understand better the situation of women affected by HIV/AIDS in Indonesia.

For this study, I worked closely with the KAPETA Foundation (this name is an acronym of Indonesian words meaning “*our work of care*”), a non-profit organisation established in 2002 by parents of children with drug addiction problems, psychologists and academic professionals concerned with drug abuse issues. This NGO initially focused its activities on drug addiction issues, but later included HIV/AIDS workshops and counselling. As is the case with most NGOs, KAPETA enjoys a wide co-operation network that includes other NGOs and peer support groups. The women I recruited for this study are connected with the KAPETA Foundation through this extensive network, although they do not necessarily participate directly in KAPETA’s activities. Like all other AIDS organisations in this country, the policy of this organisation is based on the national AIDS strategy which was established in 1994 by the National AIDS Commission (NAC) and reviewed periodically thereafter. In light of this, my recommendations based on the results of this study will be duly forwarded to the NAC, for information.

1.3 PURPOSE AND OBJECTIVES OF THE STUDY

The main purpose of this qualitative study was to investigate the need for a specific bereavement counselling programme for women affected by HIV/AIDS due to the loss of their husbands to AIDS-related deaths and to gain insight and understanding as to what types of services need to be rendered. The over-arching aim of this study was to uncover how women bereaved due to the AIDS-related death of a spouse in Indonesia experience their loss and what needs there are in terms of targeted counselling for such women.

In order to fulfil the above research aim, my objectives were as follows:

- 1) To investigate psychosocial and socioeconomic problems experienced by women as a direct result of their husbands/partners’ AIDS-related deaths.

- 2) To investigate circumstances surrounding their husbands' deaths that might impact their bereavement outcomes.
- 3) To explore the coping mechanisms of women who have lost a husband to an AIDS-related death in the last 12 months.
- 4) To find out whether social support networks exist for women who are coping with the loss of a male partner due to an AIDS-related death.
- 5) To investigate the need for specific AIDS-related bereavement services to assist these women.

For the first objective, my main research questions were: In what way, according to the research participants, is a loss due to an AIDS-related death different from other kinds of deaths that they may have experienced or know of? Did the death of their husband/partner make a difference in their day-to-day life? What became different?

The second objective led to the following research question: Were there particular circumstances at the time of their husbands' deaths that either aggravated or alleviated their grief, or distracted them from thinking about their husbands' death?

The third objective led to the questions: Was there anything in particular that the women did to make them feel better? Did they find some kind of support that they found helpful?

For the fourth objective, my questions were: Did the research participants know of support groups and/or religious leaders and were they able to talk to them?

This led to the final research questions, namely: Did the women think that talking to a counsellor who specialises in AIDS-related bereavement would have helped them? How so? Did they have suggestions? What did they think such counselling sessions should cover?

In the section below, key terms used in the dissertation listed in alphabetical order will be described.

1.4 DEFINITION OF KEY TERMS

1.4.1 AIDS-related deaths:

This refers to deaths that are a consequence of AIDS, meaning those that are brought about by opportunistic infections such as tuberculosis, pneumonia, etc. which are common among people living with HIV. AIDS-related deaths in this study refer mostly to the drug addicted husbands of the research participants, whose deaths were confirmed as AIDS-related either by self-definition or by a medical diagnosis.

1.4.2 Complicated and prolonged grief:

Often referred to as “bad grief”, complicated grief is a debilitating disorder associated with important negative health consequences, and a source of significant distress and impairment (Shear *et al* 2005). Most studies assessing the Complicated Grief model conceptualise caregiving as a stressor, and typically focus on the presence, absence, or intensity of this purported stressor (Carr, Wortman & Wolff 2006)

1.4.3 Death-accepting attitude:

As opposed to people in Western countries who in general have adopted a death-avoiding attitude (DeSpelder & Strickland 2005), people in Indonesia tend to normalise - hence to accept - death because they believe that death is fated, as taught by the Islam religion - nearly 90 per cent of Indonesians are Muslim.

1.4.4 Delayed grief:

Delayed grief reaction has been considered problematic from the *Grief Work* perspective (CFAH 2003) which stresses the necessity to work through the emotional meanings of a loss.

1.4.5 Grief and bereavement:

Grief and bereavement are used in their simplest definitions in this dissertation, i.e. “bereavement” refers to the loss of a loved one by death and “grief” refers to the distress resulting from bereavement (CFAH 2003). However, seeing that the distinction between the terms has been inconsistently maintained in research, this

dissertation uses both words interchangeably, separately or together, when referring to research in this field in general.

1.4.6 Indonesian perspective:

This study offers a view on how Indonesian women grieve and cope with loss following the death of their male partners due to AIDS-related deaths and thus provides a bereavement construct from this particular culture.

1.4.7 Intravenous/Injecting drug use:

The vast majority of HIV and AIDS cases in Indonesia is attributed to injecting drug use, i.e. through the use of shared, contaminated syringes and needles (e.g. NAC 2007-2010). Drug use is a criminal offence in this country (Riono & Jazant 2004).

1.4.8 Need:

The word “need” in this study refers to a requirement or a call for a specific bereavement counselling programme identified through the interviews, specifically for women who have lost a male partner due to an AIDS-related death.

1.4.9 Need Analysis:

This study is descriptive aiming at understanding the grief experience of women who have lost their male partners to an AIDS-related mortality. I examined the data collected from the interviews and journal entries, more particularly those relating to needs for bereavement counselling programmes, summarised them, analysed them, and made a conclusion whether there was a need for a specific bereavement counselling programme in respect of HIV/AIDS.

1.4.10 Stigma:

Stigma related to HIV/AIDS refers to prejudice, discounting, and discrimination against people perceived to be living with HIV or affected by HIV/AIDS, and the individuals or groups they are associated with (Cogan & Herek 1998). Although HIV/AIDS stigma is universal, the specific groups targeted for HIV/AIDS stigma vary from one country to another. Generally, though, people who contract HIV are assigned blame for their infection, whether they actually belong to so-called “risk-groups” or

not – stigma is therefore considered a major obstacle in the fight against the pandemic, mostly because it prevents people from testing for HIV or disclosing their seropositive status (e.g. Serovich & Mosack 2003).

1.4.11 Women affected by HIV/AIDS:

This refers to women who have lost their husbands to AIDS-related deaths. For this study, I only recruited women whose husbands died within 12 months prior to the study, in order that they still remembered relevant details and important aspects related to their grief, that might have made them feel the need for a special care or service.

1.5 CONCLUSION

Despite great advancement in the last ten years, most research in the field of bereavement are still based on studies of white populations, mostly middle-class, known as the “Western perspective”. As little remains known about how people in poorer settings in non-Western countries view death, grieve and cope with loss, social scientists have called for studies on bereavement using non-Western samples in order to examine how effective mourning practices of various ethnic groups are in preventing “bad grief”³ and whether other ethnic groups may benefit from some of these mourning practices (e.g. Goodkin & Blaney 1996).

With the advent of HIV/AIDS almost three decades ago, researchers began to explore psychosocial aspects associated with HIV/AIDS-related bereavement to shed light on this new phenomenon and to identify the different factors that seem to make AIDS-related bereavement *atypical*. As Indonesia is currently experiencing the fastest growing HIV epidemic in South-East Asia, it was important to examine what the impacts of AIDS-related bereavement might be on the young Indonesian people who make up the majority of the population in this middle-income country of over 200 million inhabitants, where a “death-accepting” attitude prevails, where HIV/AIDS is highly stigmatised.

Through this qualitative study based on in-depth interviews with six young women who have recently lost their husbands to AIDS-related deaths and using data entered in

a journal by the women, I was able to look closely at their experiences, beliefs, thoughts, worries and wishes, which allowed me to gain a better understanding of what women in their situation went through, and the circumstances surrounding their husbands' death that might have affected their bereavement outcomes.

In Chapter 2, the readers will find a review of some of the available literature upon which this study was based, followed in Chapter 3 by a description of the methods used to answer the main research questions detailed above. In Chapter 4, the findings of the present study will be described, which will lead to a conclusion and recommendations detailed in Chapter 5.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

Almost three decades into the AIDS epidemic, no cure is yet available for the Human Immunodeficiency Virus. In 2007, 33.2 million people were living with HIV worldwide, with annual deaths reaching 2.1 million that same year (Kaiser Family Foundation 2007). Sub-Saharan Africa, home to two-thirds of people living with HIV (68 per cent), is the most affected region, where more women than men are now living with HIV. In many countries, women are today bearing a heavier burden than men when it comes to HIV-infection.

Little is known, however, about bereavement experiences of women who have lost their husbands to AIDS-related causes, even in countries badly stricken by the epidemic. In Demmer's (2007) study, which was conducted among bereaved individuals in KwaZulu-Natal, South Africa, one of the four themes that emerged was the burden placed on women to care for the sick and to deal with loss. This has indeed become common scenery in many sub-Saharan African countries where many households are now led by women after they lost their male partners due to AIDS-related deaths (e.g. Foster 2007; Kanyamurwa & Ampek 2007). But Demmer's study highlights that the constant struggle to survive took priority over grief for many of these people. This is a profound conclusion which supports earlier findings by Scheper-Hughes (1993) who claims that mourning the loss of a child is indeed an unattainable luxury for impoverished women. As far as HIV/AIDS is concerned, poverty is indeed a key factor leading to behaviours that expose people to the risk of HIV infection, and poverty aggravates the impact of HIV/AIDS. On the other hand, HIV/AIDS tends to lead to an intensification of poverty or cause poverty to those affected by the disease (UNDESA 2005). Therefore, poverty is not only a cause but also a consequence of HIV/AIDS. Moreover, poverty and unequal access to resources are problems for many women who are also noted to experience social disruption (Kanyamurwa & Ampek 2007), while the extended family unit, often considered the backbone of society in developing countries, is being overburdened by HIV/AIDS (e.g. Anarfi & Appiah 2004).

The low economic status of women often makes them dependent on men for their livelihood, and when men become very ill and unable to work or when they die of AIDS-related causes, the women are left on their own, struggling to earn a living and make ends meet, not only for themselves but for their children as well. Therefore, after the death of their husbands, many women are forced to exchange sex for survival, sometimes resorting to sex work with no possibility to negotiate safer sex (Gysels *et al* 2002).

Studies have shown that female-headed households are indeed poorer than male-headed households (see, for example, Foster 2007). Foster's study also shows that women who lived for many years in their community or moved into their spouse's community after they were married developed stronger social networks. But younger women who were divorced, never married or widowed were likely to have migrated into communities recently in search of livelihoods, and been shunned because of breach of local mores or were "outsiders" with less access to community structures. Other studies have compared male and female-headed households' access to natural and physical resources, to social networks and to finance capital for production (e.g. Kanyamurwa & Ampek 2007) and demonstrated that AIDS affects women's remarriage opportunities more than men's, again because widows are often blamed for the deaths of their husbands.

Indonesia is currently at a crossroad in its HIV/AIDS epidemic. With an income per capita of nearly US\$ 1,500 (World Bank 2007), Indonesia is considered a middle-income country. But as the fourth most populous nation in the world with over 200 million inhabitants (BPS 2005), it has now become "*the new frontline of an AIDS epidemic*". Indeed, like a number of its Asian neighbours, Indonesia had low HIV prevalence until the late 1990s but the situation changed rapidly at the turn of the century (USAID 2003), with the rise of illegal drug trafficking. At the end of 1997, known cases of HIV and AIDS were 486 and 153 respectively but in 2002, 2 552 cases of HIV-infection were reported, while 1 016 people have died of AIDS (NAC 2007-2010). However, these 2002 figures are still far lower than estimates by the Indonesian Ministry of Health which put the number of HIV-positive people between 90 000 and 120 000 for that year (NAC 2007-2010).

Women in Indonesia make up roughly half of the total population. This is true across all age groups (BPS 2005). It is moreover important to keep in mind the implications of the spread of HIV amongst women in low economic and social position in Indonesia. Indeed, according to the Central Statistics Agency (BPS) 2005 data, out of the 15.6 million illiterate people in Indonesia, 10.6 million are women. While illiteracy has declined and school enrolment has risen, boys outnumber girls by 51.58 per cent to 48.32 per cent at the elementary level (Arivia 2006). According to this author, the gender gap in education is most pronounced in relatively poor provinces like Maluku, East Java, and Lampung, but also in the capital city, Jakarta. In general, women are discriminated against in almost all areas of life, while deep-rooted cultural beliefs render them more vulnerable to human rights abuses than men. For example, women do not enjoy equal rights to speech, participation, ownership and inheritance of land and housing (Arivia 2006). Social norms dictate that women, rather than men, are to abstain from sex before marriage and when married, to have sex only with their husbands. As women are taught to obey their husbands, social, cultural and religious norms often prevent them from insisting on prevention methods such as the use of condoms in their relations with their spouses (Mboi & Smith 2006). It is thus also understandable that young women typically have limited access to reproductive health services unless they are married, and therefore are less informed on health-related issues, including HIV prevention methods.

Today, there are approximately four times as many men as women living with HIV in Indonesia (Ministry of Health 2007), but the number of women living with HIV will most likely be increasing fast as new HIV cases resulting from heterosexual contacts are rapidly catching up with those resulting from injecting drug use (NAC 2007-2010). It is therefore expected that in the coming years, not only will there be more women affected by HIV/AIDS following the loss of their male partners due to AIDS-related deaths, but more and more women will themselves become infected with HIV.

2.2 INDONESIA

2.2.1 Background

It should be stated, first of all, that there is a dearth of published literature in

international journals regarding a great number of topics relating to Indonesia, including HIV/AIDS as a psychosocial issue. I suspect that this is due to a lack of financial resources and, most importantly, to a problem of language. Indeed, quite a number of studies on various topics have actually been written by Indonesians, either as research studies or as Masters' dissertations or PhD theses, but most findings have not been published in international academic journals as they were not written in English. For example, research in medical science was conducted by Sudoyo (2004); research in economics was carried out by Mubiyarto (2004). This section will therefore review some of the available literature relating to Indonesia, particularly those addressing HIV/AIDS as a physiological health issue, while background information on Indonesian culture and religion from available literature will be discussed.

To a certain extent, it may well be that Indonesia's apparent lack of interest in understanding grief and bereavement is associated with the generally prevailing "death-accepting" attitude of the people. But considering the fast spreading epidemic, it is certainly understandable that the Ministry of Health may be more interested to contain the disease due to the geographical complexities of this country which stretches some 5 000 km along the equator and comprises more than 17 000 islands (Walhi 2004). The diversity and wide distribution of the population have indeed been identified as major obstacles hindering efforts to generate valid, quantitative projections about how the epidemic will develop in the short-term as a national phenomenon (Mboi & Smith 2006). But the fact that the disease is already generalised in certain parts of the country certainly constitutes a serious cause for concern, given Indonesia's large population. Indeed, a relatively low HIV prevalence can mean that a great number of people are actually infected with the virus.

Indonesians have gone through a great many natural disasters. In 1883, for example, more than 36 000 people died as a result of Krakatoa volcano eruption in West Java. Recently, there has been a string of national disasters, including the 2004 devastating tsunami off the coast of Aceh in Western Indonesia, the 2006 powerful earthquake that shook the island of Java, the 2007 floods paralysing the capital city of Jakarta and the more recent ferry accident off Sulawesi island, which caused more than 170 000

deaths overall (www.voanews.com). Although some Indonesians blame the series of natural disasters on a host of supernatural influences, and although the media seem more keen on addressing this mystical aspect rather than how Indonesians deal with grief and bereavement following such disasters, it is clear that there exists some kind of bereavement processes – individually, socially and institutionalised. But considering the *atypical* characteristic of AIDS-related bereavement (Sikkema *et al* 2000), it remained to be seen whether the same processes would also apply to such bereavement, considering that stigma may prevent bereaved people from seeking effective support from others (Sikkema *et al* 2004). This is why I believed my attempt at gaining a better understanding of how women grieve the loss of a male partner due to AIDS-related deaths was important and timely.

2.2.2 HIV/AIDS

Behavioural problems such as sharing needles and unsafe sex practices seem to be underlying the quick spread of HIV in Indonesia. The Health Ministry estimates that at least 60 per cent of Indonesian drug users share syringes (NAC 2007-2010). Although most drug injectors know where to get sterile needles, they continue to use non-sterile equipment for fear that if they are caught in possession of needles, the police might use this as evidence in court as proof that they are injecting drug users, as drug use in Indonesia is a criminal offence (Riono & Jazant 2004). Between 1999 and 2002, HIV prevalence among injecting drug users has increased three-fold from 14-16 per cent to 45-48 per cent (Riono & Jazant 2004).

Similarly, condom use in Indonesia is low. Pisani *et al* (2004) for example found that only 10 per cent of condom use was reported by injecting drug users in three cities in Indonesia. According to most studies examining this issue, part of the reason why most sex workers reported that they had not used a condom with any client the previous week was, again, fear of being caught by the police in possession of a condom, which may be used as proof of prostitution, which is illegal. Other reasons include perceived less pleasure, the belief that clients who are acquainted with the sex workers do not need protection against STIs, including HIV, and taking antibiotics (Basuki *et al* 2002) which is believed by some will protect them against HIV-infection. A number of religious leaders advocate against condom use which is considered as “*encouraging promiscuous behaviour*” and national leaders tend to

discredit condom use (Riono & Jazant 2004). In other words, if Indonesia's leaders may have positively contributed to national prevention efforts by advocating sex among married people only, they may on the other hand also have exacerbated the problem by stating that condom use encourages "*immoral behaviour*", thereby promoting unsafe sex practices among many young people.

Although notifications of HIV-infection were increasing, there were fewer data on other sexually transmitted infections, especially in the eastern part of Indonesia. Worth noting among these few is the research conducted in 1999 by Davies *et al* (2003) who, interestingly, detected no case of HIV among the female sex workers surveyed in the eastern city of Kupang. On the other hand, the same study found high levels of N gonorrhoea infection (31 per cent), C trachomatis infection (24 per cent) and syphilis (13 per cent) among them, with few of the women having symptoms of STI. In 2003, high rates of gonorrhoea (42 per cent) were found among sex workers in seven Indonesian cities while HIV prevalence already reached 17 per cent among sex workers in Sorong, Papua (UNAIDS 2006). Indeed, as mentioned earlier, although the HIV epidemic currently remains concentrated within the high-risk groups, the virus has recently spread to the general population in the eastern provinces of Papua and Irian Jaya Barat, where multiple sexual partnerships are common (NAC 2004-2005; UNAIDS, 2006). Thus, in addition to the problem of contaminated needles, the high levels of unprotected sex coupled with large numbers of sexually transmitted infections among most-at-risk populations suggest that the epidemic could spread rapidly between injecting drug users and their sexual partners and between the clients of sex workers and their sexual partners.

As far as AIDS-related stigma in Indonesia is concerned, it is interesting to note that, while it entails consequences for those who are directly affected by the disease as well as those who deal with the epidemic such as health professionals or volunteers (Snyder, Omoto & Crain 1999), the Indonesian National AIDS Commission report that 30 per cent of the discrimination practices in Indonesia are actually being performed by the health providers themselves (doctors, medical assistants, nurses). Discrimination practices by service providers in the health care have furthermore been confirmed by Merati *et al* (2005) who suggest that serious instances of discrimination occur such as denial of health services, delay in treatment and the arbitrary imposition

of additional fees and charges. Although underreporting has been identified as one of the main reasons for the significant discrepancy between estimates and recorded cases of HIV/AIDS in Indonesia, it is clear that underreporting is mostly attributed to the stigma attached to the disease. This was supported by Ford *et al* (2004) who conducted in-depth interviews with a sample of 40 drug users in Bali, Indonesia.

2.2.3 The Javanese Culture and the Influence of Islam

One reason why Indonesian people themselves do not talk about their “death-accepting” attitude could be because it is a philosophy they have taken for granted. For example, I myself was unaware of it until I took “Death and Dying”, an online course organised by the Health Department at Lehman College in New York, based on DeSpelder and Strickland’s (2005) textbook entitled *“The last dance – encountering death and dying.”* To illustrate what is meant by a “death-accepting” attitude, below is part of a letter addressed to the editor of the leading English language newspaper in Indonesia (The Jakarta Post 29/7/06). The letter was written by an American who came to Java three days after the powerful earthquake of May 2007 which took the life of more than 6 000 people. He wrote:

“The spirit of the Indonesians continued to amaze me as victims came to our medical facility with hope in their eyes. Not only were they smiling, but they seemed sincerely happy. How could they be so happy after a disaster?”

The original religion of Java was animistic, with beliefs in nature-spirits, ancestral spirits and guardian-spirits of holy places. Java is one of the main five islands of Indonesia, accounting for more than half of the country’s population (Wikipedia sa). This probably explains why the Javanese culture is predominant in this archipelago and has strong influence on the whole country that comprises around 300 ethnic groups. Maintaining harmony and avoiding conflicts are very important to the Javanese. Therefore, in the Javanese culture, respect and loyalty towards superiors and elderly people are commonly observed, as well as an attitude of disinterestedness and acceptance (EAPI sa). However, although acceptance or surrender is a basic idea of Javanese philosophy, it is not considered a passive resignation or an absence of determination or assertiveness, which have negative connotations in Western culture

where people are conditioned to be *in charge* (Haisten 2005). Acceptance is *wisdom* to the Javanese.

Traditionally, children in Indonesia learn early in life about death, as they are generally involved in the funeral preparations and rituals for their deceased families and neighbours⁴. Indeed, while people in Western populations are characterised as individual and autonomous, Indonesians consider themselves as part of an interdependent collective, where the concept of “extended families” still prevails even in today’s society, often including close friends and neighbours⁵. Almost 90 per cent of Indonesians are Muslim, at least statistically (Dean 1999). Considering that death is a prominent theme in the Koran and within the Islamic ethos, one can say that life is regarded as a long preparation for the Day of Judgment, which is an extremely important feature in this religion (e.g. Al-Din Zarabozo 2007). As all things are “predestined” according to the Koran (Surah Al-Hadid, verse 22), which naturally also implies death itself, it is not difficult to understand why the concept of “surrender” plays such an important role in the way people face death in this country and why a “death-accepting” attitude has been widely adopted. But it seems evident that the reason the Islam concept of surrender has been so readily embraced by Indonesians is not independent of the fact that Indonesians are mostly Javanese, and considering that surrender or acceptance is also a prevailing theme in the Javanese culture (Koentjaraningrat 1985). Open displays of “bad grief”³ would therefore not be regarded favourably, as they would be interpreted as “challenging the will of the Almighty” or defying the concept of surrender⁵. It thus seems logical that the psychosocial issues related to grief and bereavement have not raised concern in Indonesia, considering the prevailing assumption that everyone must and will cope successfully with the loss of a loved one and will get over their grief in due time. Exploring the psychological impact of a culture that tends to ignore and suppress “bad grief”³ certainly proved to be very interesting.

⁴ I have no written document to support this statement, but this is based on my personal experience as an Indonesian who has spent most of her life in this country. As a child, I sometimes took part in funeral preparation and rituals for my deceased relatives.

⁵ This is also derived from my own experience as an Indonesian.

Indonesia is a country with the largest Muslim population in the world (CIA 2007). And yet, although the vast majority of Indonesians are Muslim, religious tolerance is seen as the cornerstone of relations between different faiths (Duff 2002), thus reflecting the fact that most Indonesian Muslims are traditionally moderate. But the advent of democracy after the downfall of General Suharto coupled with the financial crisis in South-East Asia in 1997, and the arrival of more radical, purist Islamic preachers from the Middle East, started to challenge Indonesia's traditionally moderate Islam (Duff 2002). The rise of Islamic extremist terrorism has led to the emergence of an increasingly conservative Muslim mainstream (Vatikiotis 2003). So far, Indonesia's national leaders have succeeded in maintaining the country's secular status, but there has been a definite shift in Indonesian politics towards conservative Islam, and moderates fear that Indonesia's leaders will not uphold pluralism in order to secure political support (Vatikiotis 2003).

Though the subordination of Islam to the Javanese culture by the regime of Indonesia's first President, Sukarno, and his successor, General Suharto, may have caused resentment among Indonesians (Kimura 2002), it is clear that Islam in Indonesia has taken on a different and distinctive identity as it has been influenced by many aspects of the Javanese culture. This is especially apparent as far as death rituals are concerned which have maintained certain aspects of the ancient animistic religion, therefore have little in common with those in other Muslim countries. But with regard to death itself, as mentioned earlier, both the Islam religion and the Javanese culture strongly advocate the philosophical concept of "surrender", which appears to explain greatly the strong "death-accepting" attitude of Indonesian people.

The above data on the current HIV situation in Indonesia certainly show that the threat of a widespread epidemic is there, and that prevention and intervention efforts may quickly find themselves outpaced by the rapidly expanding disease which is now deemed the fastest spreading in South-East Asia (UNAIDS 2008). This means that without effective prevention programmes, many more people may become infected and die, and problems associated with AIDS-related bereavement may become as widespread as the disease itself. Particular attention need to be paid to women living with HIV and women whose husbands are infected with HIV because they experience more discrimination and stigmatisation. Indeed, HIV-positive women are often

labelled promiscuous or accused of violating religious values or societal norms which teach them to stay faithful to their husbands (AWID 2007). Thus, women living with HIV as well as those whose husbands are infected by HIV often have to hide the truth even from their own extended families due to the “shameful” nature of the disease.

2.3 THE WESTERN PERSPECTIVE

2.3.1 Bereavement Studies and HIV/AIDS

Thanatology or the *study of death* is a relatively new field of science that started over five decades ago and has flourished especially during the last 20 years, with the publication of scores of research reports and reviews on bereavement and grief (CFAH 2003; DeSpelder & Strickland 2005). With the growing interest in bereavement studies from social and behavioural scientists and as further findings provide additional insight into psychosocial issues related to grief and bereavement, mainstream thoughts are continuously being challenged. Bonnano and Field (2001) and Field, Gal-Oz and Bonnano (2003), for example, called into question the *Grief Work* theory which emphasises the necessity to work through the emotional meanings of a loss and that failure to do so will typically result in “delayed grief” symptoms. Indeed, in their study examining the *Delayed Grief Hypothesis* across 5 years of bereavement, Bonanno and Field (2001) found no evidence that minimal emotional processing of the loss would lead to delayed grief. For her part, Lindstrom (2002) suggests it may be wise to stop recommending grief work, depressive reactions and too much social disclosure, and tell people to accept their emotional and cognitive reactions and let them pass.

To date, theories that continue to influence bereavement and grief studies include *Attachment Theory* which proposes the maintenance of “affectional bonds” between the primary caregivers and their loved ones after the death of the latter (CFAH 2003). *Meaning-making* which refers to the bereaved striving to make sense of troubling events (also referred to as “*meaning reconstruction*”) has also emerged as a theoretical perspective that has great influence in bereavement (CFAH 2003). During the last decade, there has been an increasing recognition that mourners may also develop debilitating grief-specific symptoms that do not match existing diagnostic

categories (Boelen *et al* 2006). As far as Complicated Grief is concerned, for example, despite its growing recognition and acceptance in the literature, there is no agreement on whether it should be included in a future version of the Diagnostic and Statistical Manual of Mental Disorders (DSM) (Boelen *et al* 2006). This may be explained by the fact that many different terms have been used to describe the same phenomenon, i.e. pathologic grief, abnormal grief, atypical grief, pathologic mourning and traumatic grief (Zhang *et al* 2006).

Among the theories and models developed in the field of grief and loss, stage models are predominant (Shernoff 1998). Based on her work with terminal cancer patients, psychiatrist Elisabeth Kübler-Ross (1969) introduced what was later known as the “*five stages of grief*” which are denial, anger, bargaining, depression and acceptance, while Bowlby described four phases of mourning which includes numbing, yearning and anger, disorganisation and despair, and reorganisation (Bhugra & Becker 2005). However, the stage approach has also been questioned. The available data in the study by Wortman *et al* (1993), for example, did not support and at times even contradicted this theory. In line with this finding, the development as widowers of most gay men in Shernoff’s (1998) study did not necessarily proceed in a linear fashion as the subjects frequently experienced aspects of more than one stage at the same time and often moved back and forth between the different stages. But, as later conceded by Kübler-Ross in the last book she wrote before she died (Kubler-Ross & Kessler 2005:7), “[*the five stages*] were never meant to help tuck messy emotions into neat packages”. She added that those stages were responses to loss but that there is no typical response to loss, as there is no typical loss. In her own words: “*Our grief is as individual as our lives*” (Kübler-Ross & Kessler 2005:7).

With the advent of HIV/AIDS in the early 1980s, researchers began to explore psychosocial aspects associated with HIV/AIDS-related bereavement to gain a better understanding of this new phenomenon and to identify the different factors that seemed to make AIDS-related bereavement *unique*. For example - and most particularly - stigma, bereavement overload, lack of disclosure, and religious beliefs and practices have been identified as among the key factors influencing AIDS-related bereavement (e.g. Nieuwmeyer *et al* 2006; Rogers *et al* 2005) As stated by Sikkema *et al* (2000), AIDS influences the psychological coping of the persons living with HIV

and also the people around them, especially those with close relationships with the individuals. Pirraglia *et al* (2005) found that high caregiver burden was strongly associated with depression among informal caregivers of HIV-infected individuals who themselves had difficult life circumstances. Caregiving burdens and lack of social support were even associated with suicidal ideation (Rosengard & Folkman 1997). It seems therefore reasonable to say that coping may be more challenging for grieving individuals who were caregivers and who are themselves HIV-positive, as they also have to deal with their own deteriorating health.

2.3.2 Stigma

Stigma has been found to discourage HIV testing in the United States (Hutchinson *et al* 2004). The stigma attached to a transferable disease can also affect how the members of society understand its transmission. Already stigmatised groups may face heightened stigma even while society underestimates the likelihood of transmission among people who do not belong to risk groups (Herek & Glunt 1988). For their part, Herek *et al* (2002) who assessed the prevalence of AIDS stigma and misinformation about HIV transmission in 1997 and 1999 found that AIDS remained a stigmatised condition in the United States although support for extremely punitive policies toward people living with HIV has declined. This certainly underscores the fact that not only effective prevention programmes but also efforts to inform the public about HIV/AIDS, particularly how it is and is not transmitted, still have a long way to go, even in an advanced country such as the United States. More worrisome, as asserted by Serovich and Mosack (2003), those who feel more ashamed about their HIV status are less likely to disclose to casual sexual partners. The role of stigma is thus an important consideration because it influences disclosure (Omarzu 2000) and therefore seems to explain the frequent discrepancies between estimates and reported HIV/AIDS cases.

Further, because HIV/AIDS is a stigmatised disease and associated with stigmatised risk conditions such as homosexuality, promiscuity and injection drug use, stigma has also been widely acknowledged as a key stressor in AIDS-related bereavement (Sikkema *et al* 2004). Such stigma, according to the authors, may prevent bereaved people from seeking effective support from others. This view is shared by Kain (1996) who states that AIDS-related bereavement is different from other types of grief

because the stigma associated with HIV/AIDS may prevent those who survive from freely mourning or acknowledging the cause of a friend or a loved one's death. Indeed, Goldblum and Erickson (1999) report that AIDS-bereaved subjects were more likely to hide the cause of death from others and received more support from friends rather than from family. Some of them reported greater levels of rejection when the cause of death is known.

2.3.3 Multiple-loss

Distress increases directly with the number of bereavements, which suggests that the effect of bereavement overload or multiple-loss is not attenuated but cumulative (Sikkema *et al* 1995). These authors emphasised the prevalence and adverse mental health consequences of AIDS-related bereavement among gay men and injecting drug users who often experience multiple losses of friends and lovers. However, although bereavement may be particularly severe when the loss is multiple, the review of literature by Springer and Lease (2000) suggests there is ambiguity about the effect that multiple AIDS-related losses is having on the gay male population, given that a number of studies have failed to find an association between number of losses and psychological distress. The main question arising from this, according to the authors, is whether it is healthy in the long-term to accept AIDS-related loss as a normative experience. They suggest that after several years of the epidemic, adaptation to multiple-loss and bereavement may be occurring, meaning gay men may have become habituated to AIDS depressive symptoms. Whether this is true for other risk groups susceptible to experiencing multiple-loss such as injecting drug users remains of course to be seen. In any case, the question remains as to how individuals experiencing multiple bereavements are coping with loss and if the coping strategies will be productive in the short as well as in the long run.

2.3.4 Suicidal Ideation

Bereavement is associated with suicidal ideation in the general population (Stroebe & Stroebe 1993). When Stroebe *et al* (2005) examined a group of 60 recently bereaved widows and widowers compared to 60 individually matched married comparison subjects, they found that suicidal ideation was higher among widowed people than among married people and was most excessive for widows. They also found that heightened suicidal ideation in bereavement is associated with extreme emotional

loneliness as well as severe depressive symptoms. As regards AIDS-related bereavement, Rogers *et al* (2005) assert that this particular type of bereavement is a severe stressor, particularly for people who are at risk of HIV-infection. However, little has been reported on characteristics and consequences of bereavement in *women* who are at high risk of HIV-infection (Summers *et al* 2004), or who are themselves HIV-positive. Indeed, most such research has focused primarily on gay men, mainly because the AIDS epidemic has historically most affected this population in particular (Rogers *et al* 2005). Among the few authors who have examined women in this situation are Summers *et al* (2004), who compared the bereavement experience, psychiatric morbidity and suicidality among bereaved men and women living with HIV. They suggest that gender distinction in AIDS-related bereavement does exist, as demonstrated by HIV-positive women in the sample who exhibited more distress on several grief aspects when compared with men living with HIV. They also suggest that bereaved women living with HIV are more likely to have unresolved grief and more intensified mourning responses during the study as well as at the time of learning of their loved one's death, and exhibit a higher prevalence of current thoughts and gestures of suicide when compared with HIV-positive bereaved men. The authors, however, remain uncertain as to whether or not gender places a person at risk for adverse bereavement outcomes and under what circumstances this may occur.

On the other hand, a good number of scientists examined whether HIV seropositivity is associated with suicidal thoughts and feelings. Depression and thoughts of suicide have been found to be common among people who are HIV-positive, especially among those who have recently found out about their seropositive status. Chandra *et al* (1998), for example, who examined factors related to anxiety, depression and suicidal ideation among HIV-positive heterosexuals soon after being tested for their HIV status for the first time, found that depression was present in 40 per cent, anxiety in 36 per cent and suicidal ideation in 14 per cent of the sample consisting of 51 HIV-seropositive heterosexual men and women with various stages of HIV infection. These findings are supported by Gielen *et al* (in Mental Health AIDS 2005) who, based on interview with 611 women in an urban setting, half of whom were living with HIV, report that thought about suicide was mentioned by 31 per cent of the sample and 16 per cent reported having attempted suicide. Among HIV-positive women, thoughts of suicide occurred more often among those who were recently tested. In a study by

Cooperman and Simoni (in *Mental Health AIDS* 2005) of a sample of 207 consisting largely of Hispanic and black women living with HIV in New York City, as many as 78 per cent experienced suicidal ideation. Interestingly, when Carrico *et al* (2007) conducted a large study involving a diverse population of 2 909 HIV-positive patients in four large US cities, they found that few people living with HIV actually plan suicide or would kill themselves given the opportunity. These authors suggest that certain factors seem to be associated with lower risk of suicidal thoughts, such as being Hispanic, which they believe may be explained by cultural norms such as a moral objection to suicide.

2.3.5 Religious Beliefs or Spirituality

Religious beliefs or spirituality has been widely recognised as a positive factor in the coping process. The study by Tarakeshwar *et al* (2005) shows that addressing spirituality within mental health interventions is valuable and feasible and can be effective in enhancing the mental health of adults living with HIV. A crisis often can cause a person to come to grips with issues of spirituality, even when one had never really been religious. Such a crisis can be in the form a life-threatening illness either menacing one's own life or that of a loved one, or the death of a significant other. Reflecting the potentially important role of spirituality in coping, Pargament *et al* (2004) stress the need to evaluate and extend spiritually integrated forms of intervention to people facing HIV which, of course, may also benefit individuals who have lost a loved one to AIDS-related illnesses. However, as noted in the recent review by Becker *et al* (2007), Johnston and co-workers reported in 1999 conflicting evidence on the role of religion in the process of coping with loss. They point out that while some studies have either failed to observe a relationship between religion/spirituality and a sense of coping, others have detected negative effects. As a result of their review of literature, Becker *et al* (2007) conclude that the question of whether religious or spiritual beliefs influence bereavement is a matter of interest in different domains of science. Furthermore, although most studies report positive effects, the authors note a weakness in design and methodological flaws which seem to explain why no statistically significant findings could be reported in the studies reviewed. Hence, they suggest that comparison of adjustment over time be made between those holding religious or spiritual beliefs and those who do not.

2.3.6 Biographical Disruption

The concept of biographical disruption was introduced to the sociology of health and illness in 1982 by Michael Bury, who notes that a chronic illness represented a discontinuance of one's ongoing life, hence a disruption (Faircloth *et al* 2004). This conceptual framework has been widely used in studies into the everyday experience of chronic illness, the sudden onset of which is said to create an aura of uncertainty for the sick persons, leading them to question their taken-for-granted assumptions about the world. As explained by Thomas and Bosch (2005), activities which were once completed as part of a daily routine may then become difficult and there may be a disruption between the individual's definition of themselves with regard to the past, present and future. Because biographical disruption brings up issues relating to identity, Corbin and Strauss (1987, 1988) state that significant psychological work may be required to sort through the losses of identity and aspects of identity which have changed as a result of the illness. But the notion that the illness constitutes an intense crisis to the ill person has been challenged. Faircloth *et al* (2004), for example, argue that the lives of people who have a particular illness that is notably highlighted by a sudden onset are not inevitably disrupted; that once certain social indicators such as age or other health concerns are taken into account, there is a biographical flow rather than a biographical disruption to specific chronic illnesses. Put differently, these authors argue that the lives of people who have a stroke, for example, are not inevitably disturbed because while some people do find their lives disrupted by the stroke, others may have braced themselves against the impact of the stroke, and be able to maintain a sense of a coherent pre- and post-stroke self. Thus, although the concept of biographical disruption has been predominant in the stroke recovery literature, the authors express concern that some important aspects of the survival experience may be dismissed if all survivor experiences were treated universally. In other words, not all physiological changes resulting from a chronic condition have the same impact on peoples' lives. This argument corresponds with the findings by Carricaburu and Pierret (1995) who, after examining the everyday life contingencies of asymptomatic HIV-positive men, argue that instead of disrupting the men's biographies, HIV reinforced specific aspects of biography. For example, someone with a pre-existing illness might feel that the diagnosis of an HIV-infection provided a sense of continuation of their biography considering that they were accustomed to a life built around illness – such as the case with haemophiliacs. In line with this

finding, when Wilson (2007) examined the inter-relationship between HIV-infection and motherhood, she discovered that the emphasis on the need to survive and to protect their children represented a fundamental re-formulation of their identities as mothers and hence a kind of biographical disruption which, paradoxically, also contained aspects of biographical reinforcement. Faircloth *et al* (2004) thus call for periodical “*conceptual stock taking*” by scientists in order to avoid treating concepts like biographical disruption as “*mechanistic truisms*”, considering that this concept is, after all, not irreversible.

2.3.7 Bereavement Counselling and Interventions

While a good number of bereaved people can cope reasonably well with their distress, the distress of loss is substantial for many (Gillies & Neimeyer 2006). Caring for terminally ill loved ones and the death of those persons are extremely stressful experiences (Herbert *et al* 2006). According to findings by Haley *et al* as mentioned in the study on death preparedness by Herbert *et al* (2006), the stress involved can cause serious morbidity. According to these authors, a substantial number of caregivers are unprepared for the death of their loved ones, which may explain why 50-60 per cent of caregivers of the terminally ill experience depressive symptoms. However, they draw attention to the necessity to develop a reliable, valid and multidimensional measure of preparedness before clinical interventions targeting preparedness can be developed and tested. Such interventions, in their opinion, are expected to have an impact on the mental health of the caregivers not only during the illness but also after the death of their loved ones.

In bereavement research, the effectiveness of bereavement interventions and counselling and the question of who benefits from these interventions are central issues (Wagner *et al* 2006). According to these authors, research has shown that interventions for normal grievers have modest effects on outcome variables, while interventions aimed at patients suffering complicated grief or at high risk for poor bereavement outcomes show reliable positive effects. Supporting this view, the study by Zhang *et al* (2006) has led to the conclusion that resilient bereaved individuals are not likely to benefit much from bereavement services. Furthermore, although bereaved persons are generally at elevated risk for a variety of adverse consequences, the authors stress the importance for clinicians to understand not only how to treat persons

with complicated bereavement but also how to identify them, given that during the first months after the loss, signs and symptoms of normal grief are very similar to those of complicated grief. However, whether it is true that bereavement interventions and counselling only benefit those at risk for poor bereavement outcomes is not clear, as suggested by findings by Goodkin *et al* (1999). In their survey using 166 respondents (97 HIV-positive and 69 HIV-negative), the authors conclude that a brief group intervention can significantly reduce overall distress and speed up the process of grief reduction, even in a sample of bereaved people who are unselected for psychopathology or at high risk for subsequent maladjustment. The question remains whether it would be recommendable to suggest AIDS bereavement interventions for *anyone* experiencing the loss of a loved one to an AIDS-related illness, despite the merits of such interventions and in light of the contradictory findings.

Because family members and friends may experience atypical bereavement following an AIDS-related death, Sikkema *et al* (2000) call for interventions for AIDS-related bereavement that reduce distress and maladaptive ways of coping. A more recent study by Sikkema *et al* (2004) examining the impact of a group coping intervention for HIV-positive men and women found that both men and women participating in the group intervention showed significantly more reduction in psychiatric distress than controls. In addition, such group interventions were also beneficial to the physical health of the participants, as shown in a subsequent study by Sikkema *et al* (2005). In this study, participants in the group intervention demonstrated improvements in general health-related and HIV-specific quality of life, while those in the control group remained the same or deteriorated. These findings therefore suggest that cognitive-behavioural interventions may indeed have a broad impact not only on emotional but also physiological health of the participants.

Indeed, bereavement has been found to affect immune parameters. In a study designed to examine the association between depressive symptoms and mortality among women living with HIV, for example, Ickovics *et al* (2001) found that HIV-positive women with chronic depressive symptoms were twice as likely to die compared with those with limited or no depressive symptoms. Those with the lowest CD-4 T-cell count and highest viral load were most vulnerable to adverse consequences of depressive symptoms. Reed *et al* (1999) found that the interaction of negative HIV-specific

expectancies and bereavement was a significant predictor of symptom onset. In other words, negative HIV-specific expectancies predicted the subsequent development of symptoms among bereaved men.

Research has shown that for bereaved people suffering complicated grief, responses to cognitive-behavioural treatment are more favourable and faster than responses to interpersonal psychotherapy (IPT) (Wagner *et al* 2006). Cognitive-behavioural therapy (CBT) is a form of psychotherapy based on the theory that people's thoughts influence how they feel and what they do, while IPT is another short-term therapy based on the theory that depression can be caused or precipitated by disturbed social and personal relationships (www.umm.edu). My search in various databases for AIDS-related bereavement studies evaluating the efficacy of CBT in comparison with IPT has not been successful, however. But a meta-analysis conducted by Feijo de Mello *et al* (2005) based on thirteen studies assessing the effectiveness of IPT for major depression found that IPT was in fact superior in efficacy not only to placebo but also to CBT. It goes without saying that no assumption on the generalisability of the above finding to AIDS-related bereavement should be made.

Finally, no less important is the question of who seeks professional help with bereavement. Marshall (2007) suggests that those who request bereavement counselling may well be people who also need help with other psychological issues because the bereavement acts both as catalyst and an entry point to those psychological issues. Although, in her opinion, the limitations of bereavement counselling can be counterproductive given that counsellors are expected to confine their attentions to the client's grief when they are actually doing general counselling, the author believes that bereavement counselling has to be acknowledged as worthwhile and valuable. Further, a research on online behaviour of bereaved people by Vanderwerker and Prigerson (in Wagner *et al* 2006), established that 60 per cent of bereaved individuals use the Internet and 50 per cent communicate by e-mail in order to receive social support. Only around 30 per cent, however, was found to have used bereavement services in the year after the death of the patient and particularly during the first 6 months post-loss, in a recent study by Cherlin *et al* (2007) examining family caregivers of patients with cancer. Although research suggests that AIDS caregivers and cancer caregivers experience similar levels of distress (Stez & Brown 2004), it is

not clear whether comparable results would be found among AIDS bereaved caregivers who experience a range of other adverse factors such as stigma and a lower social support (Stez & Brown 2004). Nevertheless, it is worth noting that the reason most frequently cited in the above mentioned study by Cherlin *et al* (2007) for not using bereavement services is the perception that they were not needed or would not help.

2.3.8 Counselling/Interventions to Improve the Wellbeing of HIV-Positive People

As mentioned earlier, the consequences of stigma are devastating. As asserted by Chesney and Smith (1999), HIV/AIDS-related stigma not only causes delays in testing, which in turn lead to further transmissions of the virus, it also affects individuals' responses to testing positive. In fact, Gray (1999) found that the fear of HIV-related stigma was more of a concern than the fear of dying among women living with HIV. Therefore HIV-related stigma strongly compromises the well-being of people living with the disease. A review of literature conducted by Brimlow, Cook & Seaton (2003) shows that stigma can be reduced through a variety of intervention methods such as information (advertisement, brochures, lecture presentations) and counselling (support groups for people living with HIV). Although counselling in primary care has become increasingly prevalent in recent years (see, for example, Thomas 1993), the effectiveness of counselling in such settings has been difficult to establish empirically owing to the fact that the research evidence is limited and often of poor quality (Harvey *et al* 1998). For example, few scientists have actually addressed the need for specific counselling services and/or interventions to help people, especially women, to come to terms with their new positive status and to improve their wellbeing. Among these few is Abel (2007) who claims that HIV-positive women participating in an emotional writing disclosure (EWD) intervention would demonstrate an improved perception of HIV-related stigma compared to women in a control group. As it turned out, the experimental group did report greater cognitive reorganisation compared with the control one, and significantly improved perceived HIV-related stigma scores over the course of the study. Given the positive influence of EWD on the perception of stigma among HIV-positive women shown by the study, the author suggests that this inexpensive and convenient intervention is a promising finding that may advance the health of women, and calls for further studies using a larger sample. Coming to terms with one's seropositivity would corroborate

Frankl's concept of *self-transcendence* which means accepting the reality that certain circumstances cannot be changed (Mellors *et al* 2001).

2.4 SUMMARY

A review of literature on bereavement, including AIDS-related bereavement, confirms the dynamic image of a young field of science in evolution, characterised by scores of contradicting views. The fact that much progress in the bereavement field has been achieved especially during the last two decade demonstrates that grief studies correspond to a modern society's growing need for a better understanding of death and the various aspects surrounding it, particularly the influence of social and cultural contexts on the grief process.

A number of risk factors have been identified as having the potential to adversely affect bereavement outcomes in individuals who have lost a loved one to AIDS-related illnesses, particularly multiple-loss and stigma (see, for example, Sikkema *et al* 2004; Wagner *et al* 2006). Indeed, people grieving the loss of a loved one to an AIDS-related illness may find themselves having to deal with the death of another person close to them, while society may turn away from AIDS-related deaths because of the strong stigma attached to the disease. This in turn may lead to intensification of certain emotions associated with normal grief.

It is clear, however, that everyone has a different way of coping with loss, and that most bereaved individuals may improve without the help of bereavement interventions. While bereavement is closely associated with suicidal ideation, little is known of the impact of AIDS-related bereavement and psychosocial factors related to HIV-infection on heterosexual individuals, and whether gender plays a role in the bereavement outcomes. Interestingly, Bonanno and Field (2001) found no evidence that minimal emotional processing of the loss would lead to delayed grief, thus questioning the *Grief Work* theory which stresses the necessity to work through the emotional meanings of a loss and that failure to do so will typically result in "delayed grief" symptoms. Furthermore, a growing body of empirical evidence shows that religiousness and spirituality play an important role in the health and well-being of

HIV-positive people (Pargament *et al* 2004). In this regard, however, contradictory views have been noted (Becker *et al* 2007).

Moreover, Bury's concept of "biographical disruption" has been widely used in studies examining the everyday experience of chronic illness, the sudden onset of which is said to drastically disrupt the ill person's life (Faircloth *et al* 2004). Recent findings suggest however that physiological changes resulting from a chronic condition do not always have the same impact on peoples' lives; that, therefore, the concept of biographical disruption is not immutable. For example, although the emphasis on the need to survive and to protect their children constituted a type of biographical disruption for the HIV-positive mothers in Wilson's (2007) study, it also contained elements of a biographical reinforcement for the women. Faircloth *et al* (2004) thus recommend a periodical review of concepts by scientists.

Finally, the great advancement in bereavement research during the last two decades was also accompanied by a growing body of literature on mental health interventions for people experiencing AIDS-related bereavement. Contradictory findings of studies assessing the efficacy of cognitive-behavioural therapy (CBT) in comparison to interpersonal therapy (IPT) have joined other controversies in the field of bereavement (Feijo de Mello *et al* 2005). The need for interventions for people with HIV, particularly to improve their perception of stigma, has also been identified, but few scientists have looked into this matter closely, particularly as far as women are concerned. Among these few is Abel (2007), who suggests that emotional writing disclosure (EWD) interventions may help to advance the health of women living with HIV.

I believe the present study has filled some of the gaps in our understanding of Indonesia's cultural perspectives, and answered calls made earlier by various researchers (see, for example, Eisenbruch 1984; Lindstrom 2002) to investigate and take into consideration cultural norms as well as religious, spiritual and philosophical convictions which are all part of the intricate field of bereavement. As different societies and nationalities have different views on death and different ways of mourning and coping with loss, it was certainly interesting to explore whether death due to a highly stigmatised disease would be openly acknowledged and publicly

mourned in a society with a “death-accepting” attitude, which seems to have resulted from the interplay between cultural and religious influences. It was particularly interesting to observe how learning about their HIV status within a relatively short time before or after their husbands’ deaths impacted the women’s bereavement outcomes.

Seeing in particular that no study has ever examined this unique “death-accepting” attitude in the past, especially as it relates to AIDS-related deaths and the psychosocial and socioeconomic impacts of AIDS-related death on women, and also considering that AIDS-related bereavement may develop into a serious problem with long-term socioeconomic impacts on the development of Indonesia, I was most interested to find out how stigma versus a “death-accepting” attitude would impact bereavement outcomes, and how AIDS-bereaved women coped with loss in the absence of formal bereavement services. The main purpose of this study, therefore, was to investigate the need for a specific bereavement counselling programme for women affected by HIV/AIDS due to the loss of their husbands to AIDS-related deaths, and to gain insight and understanding as to what types of services need to be rendered.

Personal Relevance: I am a woman - an Indonesian, a Javanese and a Muslim. I have lived most of my life here, but I have also spent six years living in the United States. Therefore, I have noticed the markedly different manner in which people in the two countries react to death, and have often wondered about it. However, only after taking an online course in “Death and Dying” last summer did I realise how much there was to learn about death and, in particular, the various ways peoples or nationalities grieve. As an Indonesian, I was struck by what the textbook (DeSpelder & Strickland 2005) said concerning modern societies’ death-avoidance attitude and its implications for current psychosocial issues relating to grief and bereavement. For example, I found it interesting that a good number of people in America actually have jobs that specialise in helping grieving people to cope with loss. I found this profession “Grief Counselling” curious because in my country there seemed to be no need for it. This is one example of how radically different Indonesians and Americans experience death and bereavement and it is this disparity between peoples’ and nationalities’ attitudes towards death and its surrounding issues that I find personally and intellectually engaging. However, keeping in mind the *atypical* characteristic of AIDS-related

bereavement (Sikkema *et al* 2000), I suspected that death resulting from an AIDS-related illness may have different implications on the way people grieve and cope with loss, even in a country with a “death-accepting” attitude such as Indonesia. For this reason, I examined what those implications were and investigated the needs for bereavement counselling programmes for women who have lost their male partners to the highly stigmatised disease.

In the following chapter, the qualitative methods used to answer the research questions as detailed in Chapter 1 will be discussed.

CHAPTER 3: METHODOLOGY

3.1 INTRODUCTION

Strauss and Corbin (1998) note that one reason for choosing qualitative methods is the preference of the researcher and the other is the nature of the research problem. But I came to realise that a researcher rarely actually “chooses” to use qualitative methods over quantitative ones - or vice versa - simply because of his/her preference of certain methods of inquiry. Why particular methods are decided upon generally depends on the nature of the research objective that has been identified and which the researcher seeks to fulfil in the most efficient manner. Therefore, studies that involve both qualitative and quantitative methods are not uncommon (e.g. Deo *et al* 2004).

Trochim (2006) suggests that one of the major reasons for undertaking qualitative research is to become more experienced with the phenomenon one is interested in, while Denzin and Lincoln (2003:28) emphasise the emic, idiographic, case-based position qualitative researchers are committed to, which directs their attention to the specifics of particular cases. As I wondered what the impact of an AIDS-related death might be on people from this “death-accepting” society where “bad grief”³ tends to be suppressed, I thought that qualitative methods would provide me with a better understanding of the lived experiences of women whose husbands died of AIDS-related illnesses within the previous year. I believed, therefore, that the choice of qualitative methods for this study was justified.

Although I have lived most of my life in Indonesia, I have also spent a few years in the United States and noted that people from the two countries react differently to death. But I did not realise how much there was actually to learn about death and the way people from different nationalities grieve and cope with loss until I took an online course in “Death and Dying”. This was certainly an enlightening experience as I realised that I had in fact taken the “death-accepting” attitude of my people for granted, as perhaps millions of other Indonesians have.

Furthermore, having developed a particular interest in HIV/AIDS and thus having been studying about this “still incurable disease” at the University of South Africa, I became involved in outreach activities organised by the KAPETA Foundation - an Indonesian NGO specialising in drug addiction and HIV/AIDS - and became more perceptive to the various issues individuals affected by the disease are faced with in this country. Taking into account the *atypical* nature of AIDS-related bereavement (Sikkema *et al* 2000), I wondered how stigma vs. this “death-accepting” attitude might impact the bereavement outcome of Indonesian women who have lost their husbands to AIDS-related illnesses.

My aim in undertaking this research, therefore, was to gain a better understanding of how Indonesian women who have lost their husbands to AIDS-related causes grieve and cope with loss. As virtually no research has been done to document the bereavement experiences of people from this “death-accepting” society, this study enables the assessment of whether specific bereavement counselling programmes are needed. The main research question of this study, therefore, was whether specific AIDS-related bereavement counselling programmes to assist women affected by HIV/AIDS are needed in Indonesia where, currently, even general bereavement counselling programmes are non-existent.

Grounded Theory was chosen as the best approach to achieve the stated research objectives and the Strauss and Corbin model was primarily used, as this made data analysis simpler. In order to answer the above research question, I gathered data that reflect the experiences, hopes, feelings and worries of women who have recently lost their husbands to AIDS-related illnesses. To this end, in-depth interviews and journaling were used to collect the necessary data.

This chapter describes the research design used in the study, the sampling design and procedures involved, and the data collection procedures and analysis. It also includes a discussion on the sampling process, how trustworthiness was ensured and how ethical issues were addressed.

3.2 RESEARCH DESIGN

Denzin and Lincoln (2003) note that qualitative methods imply an emphasis on the qualities of entities and meanings that are not experimentally examined or measured in terms of quantity, amount, intensity, or frequency. As qualitative researchers seek answers to questions that stress how social experience is created and given meaning, a qualitative research is therefore *value-laden* because it highlights the *process* (Denzin & Lincoln 2003) - in contrast with quantitative studies which emphasise the measurement and analysis of causal relationship between variables. Qualitative methods have therefore been used for this study, given that the aim was to gain a better understanding of the experiences of women who have recently lost their husbands to AIDS-related illnesses.

3.2.1 In-depth Interviews

One of the most common methods used in qualitative research is in-depth interviewing (e.g. Faircloth *et al* 2004; Van den Hoonaard 2004; Wilson 2007). In this study, in-depth interviewing had the potential to yield rich data because it gave the respondents the opportunity to tell their own life stories and reflect on their experiences. As stated by Guion (sa), in-depth interviewing is an important data-gathering tool characterised mainly by open-ended questions, semi-structured format in the discussion (which almost resembles a natural conversation), seeking understanding and interpretation, and recording responses, observations and reflections. Open-ended questions are questions that cannot be answered by a simple “yes” or “no” and therefore encourage the respondents to elaborate on their responses. Bearing in mind the emphasis of qualitative research on quality and meanings, the role of open-ended questions are thus essential in making the respondents expand on the topics discussed (Guion sa). As suggested by the author, I prepared the questions in advance but I allowed them to flow naturally, based on information conveyed by the participants. In other words, the order of the questions followed the flow of the conversation. Hence, the term “semi-structured format”.

Guion (sa) further stresses that in-depth interviews involve not only asking questions,

but also recording and documenting systematically the respondents' response, coupled with intense probing, in order to obtain deeper meaning and understanding of the responses. Repeated interview sessions with the participants of this study were therefore necessary to clarify certain answers and to obtain immersion into their life-worlds. Indeed, as the in-depth interviews were conducted on a one-on-one basis, I was able to focus entirely on one respondent at a time, observing and noting each woman's expressions and body language while they were responding to the questions I asked, based on the list I had prepared in advance.

Kvale (in Guion sa) proposes seven stages of conducting in-depth interviews which includes thematising, designing, interviewing, transcribing, analysing, verifying, and reporting. Before starting the interviewing process, I kept thinking about what Vidich and Lyman (in Denzin & Lincoln 2003) said about qualitative research being born out of concern to understand the "other". But this "other" was described as a primitive, non-white person from a foreign culture judged to be less civilised than that of the researcher. Strangely enough, although both the respondents and I were non-white people from the same culture, I dreaded being thought of as superior, intimidating or judgmental by the women. I was not sure if they knew what research was about or why a research is conducted. I had somewhat expected coming face-to-face with women who would be awkward and confused at having an opportunity to discussing issues they probably never talked about openly with other people, although I was convinced that the exercise would do them good. But my worries turned out to be unfounded. I was happy to acknowledge that awkwardness, if any, only lasted a few fleeting minutes and dissipated as soon as I explained that although I was doing the research as part of my degree requirements, I was genuinely concerned about HIV/AIDS in Indonesia and wanted to help women in their situation. I made it clear that if the results of my study did indicate the need for specific bereavement counselling programmes for women like them, I would endeavour to make such programmes available at the KAPETA Foundation (this was previously agreed by the Directors of the NGO) to assist other women in their situation in the future. I could not agree more with Van den Hoonard (2004) about the importance of establishing rapport with the participants, because it was absolutely necessary that they felt comfortable when speaking to me.

I began the interview by introducing myself and explaining what my study was about, emphasising on the importance of the data that they would give me by answering the questions I asked. I made it clear that I was not there to judge them but simply to understand them, so that I can interpret what their needs were based on what they would tell me, and make recommendations for other women in their situation in the future. Then I gave them the informed consent form to read (the English translation of which is available in the Appendix section) specifying that I would be happy to answer any question they may have relating to the written text. There is no equivalent expression for “Informed Consent” in the Indonesian language; therefore, it was left in English. As four of the women had never participated in any research before, I took care to describe thoroughly to them what the basic concept behind this expression was. In essence, I informed them that their signing the consent form was tantamount to testifying to not having been forced into participating in my study, that their participation was therefore totally voluntary and that they may withdraw at any time.

Kvale (in Guion sa) suggests that the researcher must guide the respondent through a conversation until all of the important issues on the interview guide are explored. For this, the author recommends the following strategies:

- Active listening. The researcher should listen and rephrase what was said in order to avoid any misunderstanding.
- Patience. The researcher must not rush the respondent and allow him/her to speak freely, while guiding the conversation to cover important issues.
- Flexibility. Slight deviations from the topic should be allowed, which may require rearranging the questions or coming up with new questions.
- Audio recording. To increase accuracy, audio taping the interview is recommended whenever possible.

I did listen attentively to what each of the respondents had to say. As they tended to jump from one event to another, considering that all the women had experienced a series of traumatic life events within a relatively short period of time, I often had to clarify which particular event they were referring to when they made a certain comment. I was also patient as I wanted to let the women say as much as possible

about any particular theme I was trying to probe. In so doing, I did not get to the end of my list quickly, as each question often led to more questions. Some of the interview sessions lasted up to two hours, but I was glad to note that the women were not unhappy to tell their stories. In fact, when I asked for second interviews, most seemed happy to have another opportunity to tell an outsider their experiences and opinions. Being flexible, as recommended by Kvale (in Guion sa) and stressed upon by Guion (sa), was of course a necessary strategy in the interviewing process, since the answers provided by the women did not necessarily fit the order of questions on the list I had prepared. My task was therefore to ensure that all the questions were covered, in whichever order they were answered. Finally, I used audio recording in all the interviews, which the women did not object to, as they understood how important utmost accuracy was for the credibility of my study. But when certain conversations were deemed “totally confidential”, I was sometimes requested to not record on tapes those particular parts.

The first interview with the first respondent took place in her home, as she declined to meet me at the KAPETA Foundation which, she said, was too far away from where she lived. The woman stayed in a small, rented two-room house in a modest neighbourhood in the outskirts of Jakarta with her parents, her autistic younger sister and her two-year old daughter, Angky. When I arrived, it was past lunch time. Angky was sleeping on the bed near the entrance. The woman’s mother and younger sister were watching television (TV) in the next room, while her father was out, working, but came home during the interview which lasted until late afternoon. I was duly introduced to everyone, was offered drinks, and we held the interview on the traditional mat, by the small bed where Angky was sleeping. I learned that the woman had prior experience participating in a research, so she seemed to know what was expected of her.

Interviews with four of the other five women took place in my office, as the women also preferred not to meet me at the KAPETA Foundation which according to them was a long distance from where they lived. Only one of the women who came to my office also had experience participating in another study. But even if the rest of the participants did not, they did not project any feeling of insecurity while answering my questions and I found what they had to say to be informative. Two of the women came

together to my office, bringing with them two children they were baby-sitting. They both were working for the woman-head of an NGO, taking care of orphans who lived in her house. So while I was interviewing one woman, the other waited outside with the two children. I did the best I could to make all encounters as informal as possible. I also played the hostess by offering them drinks and cookies before starting the interviews, which was customary in Indonesia.

One of the participants asked to meet me in a shopping mall for the interview, which she said was close to where she lived. We toured the mall looking for a quiet coffee shop where we could talk, but as we could not find any, we ended up doing the interview in my car. This woman was particularly happy to receive the notebook because her current diary was full and she had not had time to buy another one. She asked me specifically to give the notebook back to her once I was through analysing her entries.

Sometimes, though, even open-ended questions were not sufficient to yield information on a specific theme. But considering that an in-depth interview is conducted on a face-to-face basis, this offered me the opportunities to obtain more data with a technique called the EOT (Explicit Observation Technique). Mischler, (in Brown 2006), asserts that accounting for human factors allows for a potentially richer data yield than using traditional structured or semi-structured interview method. Harowitz and Brown (also in Brown 2006), consequently suggest that one way to accomplish such accountability is by “making explicit those elements implicit” during the interview. To accomplish this, they propose to train the interviewer to be more self-conscious during the interview by learning how to systematically consider human factor cues in real time. This has led to a data collection model designed to incorporate human factors and enhance data richness in qualitative and evaluation research called the EOT, which I found to be helpful. When I asked whether spirituality played an important role in their daily life, for example, a participant offered a short answer, took a deep breath and then stayed silent. When I remarked about taking a deep breath, she smiled and explained that she did not always pray five times a day, which in this country could be interpreted - by some circles at least - as not fully complying with the Islam teachings, thus making her a “non-devout Muslim”. As I explained that I also do not always pray five times a day despite being a Muslim, she relaxed and talked more

freely, convinced that I was not there to judge her on her religiousness. My experience corresponds with the findings in Brown's (2006) methodological study which show that the EOT yielded richer data when compared with traditional semi-structured interview. The EOT is defined as "*the interviewer explicitly and systematically noting with respondents' observations of nonverbal cues (such as shaking one's head, smiling, laughing, etc.) as a strategic adjunctive probe to schedule interview questions during a qualitative interview*".

3.2.2 Use of Journaling

In order to enrich the data collected through the in-depth interviews, I also asked the participants to make entries in a personal journal. I used this approach to complement the in-depth interviews transcripts, with the idea that during their leisure time, the women could record their daily experiences, thoughts, emotions, hopes and worries, and provide me with pieces of information they may not have mentioned during the encounters. Journaling is also a way for people to express certain thoughts that might otherwise not be mentioned in interviews with someone they hardly know. In a culture where open displays of "bad grief"³ are not regarded favourably, considering that death "has" to be accepted, I thought the journals may be considered "diaries" where the women could confide their "secrets". I was convinced the experience would prove cathartic for them, as I myself keep a diary so I know that writing can provide one with some sense of relief, especially when one has to deal with painful emotional problems that they must keep to themselves. Some of the participants provided straight-forward answers to the questions I asked during the first interviews, others addressed issues they were emotionally dealing with, such as falling in love at a time when they thought they were supposed to be still mourning the recent deaths of their husbands. Others yet did both. Some journals had significantly more entries than others.

My objective in using more than one method was to allow triangulation of my collection of data, keeping in mind that "*qualitative research is inherently multi-method in focus*" but that "*triangulation is not a tool or a strategy of validation, but an alternative to validation*" (Flick in Denzin & Lincoln 2003:20). As stated by Denzin and Lincoln (2003:20), triangulation reflects an attempt to secure an in-depth

understanding of the phenomenon being studied. Because reality can never be captured, a thing can only be known through its representations.

It was challenging, I found out, to have the women actually make entries in the journals despite the reminders I sent them in the form of short messages through their cell phones. Some said they were busy working and did not have time to write yet, others did not respond. I found out later that these women had changed their cell phone numbers, but I was able to trace them back thanks to the KAPETA Foundation's staff who then contacted the NGOs to which the women were connected and I was able to get their new cell phone numbers. One woman said she changed her number to avoid being contacted by an aspiring lover, the other decided to change her cellular provider in order to benefit cheaper rates.

In the end, although the process took much longer than anticipated, I was able to collect all the journals from the women. At the beginning of the study, I did not specifically request participants who were able to write, as I was not even sure whether I would have enough respondents who fit the criteria of "having lost their husbands to AIDS-related illnesses within 12 months prior to the study". My strategy was to have a first meeting with all the candidates during which I would determine their literacy. If it turned out that some of them were not able to write, I would place them on a hold list until I knew for certain whether or not I was able to recruit sufficient literate participants. In case I was not, I planned to use them despite their illiteracy. But I soon found out that none of the participants was illiterate because they were all high school graduates. They all readily agreed to write when I mentioned during the first encounter that journaling was part of the data collection methods of my study.

The journals served to complement the information I collected during the in-depth interviews and were also useful when I needed to check certain data in the transcripts. Although they were by far inferior in terms of quantity, they provided me with insights in terms of how some of the women felt, that were not available in the transcripts. But because the in-depth interviews yielded a wider scope of data than the journals, I purposely spent more time with the women for the second interviews, not only to elaborate on the emergent themes which generated other sets of questions, but also to

enrich further the data collected during the first interviews and those recorded in the journals. I even had to see one of the women for a third interview to further clarify the data collected during the second encounter. Each interview lasted between one and two hours.

In sum, as far as this study was concerned, the role of in-depth interviewing proved to be critical in the data collection process, while the personal journals served to complete them - which was exactly what I expected. Both methods were therefore equally necessary to obtain the data needed to answer the main research question.

3.3 SAMPLING DESIGN AND PROCEDURES

One important reason behind my choice of working with women in this study was that in general, women report greater emotional distress, admit to feeling helpless and express more significant changes in identity and social role (Allen & Hayslip 2000). But I also chose women as respondents because of the social issues they are often burdened with, namely gender inequality, poverty and violation of women's rights, and because little research has been done to gain a better understanding of AIDS-bereaved women.

I used a non-probability sample of six women in this study. A non-probability sampling means that it does not involve random selection, as opposed to probability sampling (Trochim 2006). Probability sampling requires a sampling frame and naturally no list of women who have lost their husbands to AIDS-related illnesses exist for such a purpose. The participants were recruited from around the capital city of Jakarta, using a purposive sampling technique. Purposive sampling means grouping participants according to pre-selected criteria which are relevant to a particular research question. In other words, the participants were recruited with a purpose in mind (Trochim 2006). For this study, therefore, the target population was Indonesian women who have lost their male partners to AIDS-related mortality within 12 months prior to the start of the study.

I intended to recruit the participants through one of KAPETA's staff members who

was married to an HIV-positive woman whose previous husband died of an AIDS-related illness over a year earlier. This woman worked for another Non-Governmental Organisation (NGO) but often conducted activities in conjunction with KAPETA. She was in contact with other women who have lost their husbands to AIDS-related illnesses and had agreed to help me to recruit participants for my study. But when the time came for me to actually recruit participants, the woman had moved to another job and was unavailable. Her husband then offered to connect me with the target population.

Having understood the criteria for the participants I needed to recruit for my study, the staff at the KAPETA foundation – his name is Irfan - contacted his colleagues in other NGOs connected with his organisation. My name and contact number were given to the women and then I also received from Irfan the names and cell phone numbers of the women who were willing to participate in the study. I did not get the names all at once. In fact I was given one or two at a time. I proceeded by sending the women a short text message to their cell phones explaining what the study was about and the criteria which were applicable. Then they responded by saying that they were willing to participate and asked when I wanted to see them. When some of the women whose names were given to me did not respond to my messages, I called them. By talking to them, I learned for example that one woman wanted to participate but she was not allowed to do so by her sister in whose house she was staying. I explained to her that if she really wanted to take part in the study she did not have to tell anybody because we did not have to meet at her house, so her family would not have to know about it. I always suggested a couple of possible meeting places, i.e. the KAPETA Foundation's venue and my office, the objective being to conduct the interviews in a place where the women could feel free to talk openly to me and quiet enough so I could concentrate and audiotape the conversation. As mentioned earlier, not one participant agreed to meet me at the KAPETA foundation's address, citing long distance therefore time consuming.

Qualitative studies consist mainly of in-depth interviews with the participants; therefore, samples are typically small. As I transcribed the data from the in-depth interviews shortly after each encounter, I soon realised how much data I was able to collect from just one interview session. When I felt that I had sufficient contextually

rich narratives to deepen my understanding of experiences of AIDS-bereaved women following in-depth interviews with six women, I stopped recruiting. At the time, I still had one name left that I had not contacted so I called the woman to explain that I seemed to have gathered enough data and therefore was not in need for another respondent. But I also told her that it was not unlikely I would call her at a later stage if for some reason the data I had collected proved to be insufficient.

3.4 DATA COLLECTION PROCEDURES

As mentioned earlier, the two qualitative methods used for this study are in-depth interviews and journaling. But the transcribed recordings of interviews and the journal entries were not the only sources of data used in this research, as I also had available field notes made during the interviews and reflective notes written mostly while I was transcribing the data.

As noted by Pope *et al* (2000), the analytical process starts during data collection because the ongoing data collection is shaped by the data already gathered and analysed. This “sequential analysis” or “interim analysis” (Pope *et al* 2000:114), allowed me indeed to go back and refine questions and pursue emerging themes during the following interviews. It also allowed me to look for negative cases in the form of transcript extracts that ran counter to the emerging themes I had identified. For example, when little awareness of HIV/AIDS among the medical professionals was emerging as a sub-theme, I realised that on one of the transcripts, a husband who went to the hospital to get an infection treated was immediately suggested to take an HIV test, which seemed to indicate that the physician was not at all ignorant of HIV/AIDS. As it turned out, the husband went to the same hospital where his wife, a few months earlier, tested positive for HIV. This therefore made the health care providers in that particular hospital more perceptive to the possibility of an HIV-infection. Thus, a continuous analysis is an integral part of qualitative research because it is impossible for a researcher who is out there collecting the data, to not start thinking about what is being heard and seen (Pope *et al* 2000).

All the interviews were conducted in the Indonesian language and recorded on tapes.

The transcripts were therefore also in Indonesian, but this was not a problem since I am Indonesian and speak fluently the language. Transcription of the tape recorded interviews took place almost immediately after each encounter. I listened to the tapes again after transcription to proofread the texts and inserted in parenthesis observations of the respondents (for example crying, laughing). Each text is then segmented into its most basic meaningful components. This was meant to facilitate the coding process, which began after the first interview. After each interview, I compared the transcribed data to the previous ones, always searching for similarities and differences.

When I gave each of the women a small notebook after the first interviews, I asked them if they were still willing to make entries in them as they said they would at the beginning of the interviews. When they said yes – and they all did - I asked them when they thought they would have time to write. Some said they could write when their children were in school, others said at night before going to bed. They all agreed to let me know when I could pick up the notebooks. Again I explained that I needed to truly understand their experiences after losing their husbands to AIDS-related illnesses, that the journal entries would therefore help me a great deal to interpret their needs based on what they would have written. In other words, the more entries they made, the more data I had upon which to make interpretations of what their needs were. I asked them to describe their daily activities, their thoughts, feelings and emotions. I also gave them a copy of the list of questions I asked during the in-depth interviews, with the idea that if they felt they wanted to complete some of their answers they may do so by writing in the notebooks. This list of questions was prepared before the interview, so I had it printed out and inserted in the notebooks to be handed over to them after the interviews. The list only contained the main questions as more questions emerged during the interviews in response to the main questions, which therefore were not part of the list. But I believed the list was sufficient to guide the women when making entries, namely to remind them what the main questions were so they could elaborate their responses based on them. I suggested that writing may also prove to be cathartic to them. We agreed to allocate between 3 weeks to one month for them to make entries in the journals, after which I would pick the notebooks up. At the end of the meeting, I also explained to the women that data analysis requires utmost accuracy on the part of the researcher in interpreting the data available. Therefore, I asked the women if they were willing to come for a second or even a third interview, if

necessary, to clarify what they may have said or written in the notebooks which may appear ambiguous to me. Everyone agreed.

Once I managed to collect the notebooks, I read and analysed the contents and compared them to the transcripts, again searching for similarities and differences. Some statements sounded contradictory or ambiguous and needed clarification. For example, one woman said during the interview that she did not think that bereavement counselling was necessary as one eventually gets over one husband's death, but that counselling that addresses seropositivity was important to have. In the journal, however, she wrote that a bereavement counselling programme was needed to help overcome desperate feelings, sadness and anger. When I called her, she explained that the desperate feelings, sadness and anger actually related to her infection and not her husband's death. Generally, though, the women's statements were complementary. But there were also other things that needed extensive clarification, especially after I identified emergent themes. So, second interviews with all the participants were necessary. I was able to interview them again within one month after they gave me back the journals, except for one woman who was constantly travelling inside and outside of the country, with whom I had a second interview much later. A third interview was necessary with one of the women because when I analysed the transcript of her second interview, I was left with a number of ambiguities.

At the closing of each interview, I gave the women an envelope containing Rp. 100.000,- which is the equivalent of approximately US\$ 12.00 to compensate for their loss of time and real or potential loss of income. I understood of course that any incentive that may be considered an inducement was unethical in social research.

When data analysis was concluded, all identifying information were removed from the transcripts and pseudonyms were assigned to the participants as well as the significant others mentioned during the interviews.

3.5 DATA ANALYSIS

The focus of the analysis was first directed to the identification of themes to describe

what the women went through after they found out that their husbands were infected and after the death of their husbands; and then, after they discovered that they themselves were HIV-positive.

Data were analysed using the principles of grounded theory (Glaser & Strauss 1967), which means discovering or generating theory from data. Shortly after each interview, I transcribed the tape recordings while handwritten notes or analytic memos were often added to the transcriptions. These notes were intended to record my emotional responses to the interviews, including my thoughts, feelings and biases, to help the analytical process. Then I studied all the interview transcripts, journal entries and my field notes and reflective notes. The data were analysed using a constant comparative process within the context of the experiences and emotions described by each participant as they related to the death itself and the circumstances surrounding such death, as recommended by Strauss and Corbin (1998). I became familiar with the data by listening to the audio tapes a few times, reading the transcripts, the journals, reading the field notes and the reflective notes, and by listening to the audio tapes and reading the transcripts simultaneously, watching for patterns and themes emerging from the data. A word or phrase that captured the meaning within a section of the text was written in the margin of the transcripts. Then each sentence or paragraph was labelled with numbers according to its “meaning” units. This “coding” process is meant to categorise qualitative data and describe the implications and details of these categories. In the beginning, I proceeded with open coding, meaning I considered the available data in detail while developing some initial categories. Later, as I proceeded with the subsequent interviews and obtained more data transcribed in addition to the journal entries, I did a more selective coding where I systematically coded with respect to a core concept.

The coding process was done as follows: First I assigned numbers to the materials according to the broad discussion topics they related to and then established a list of topics. I highlighted remarks that were particularly illustrative. But after topics were numbered and emergent themes were identified, differentiation was often necessary. For example, after awareness of HIV/AIDS emerged as a new theme, it appeared necessary to distinguish according to the different settings in which it occurred, i.e.

among the health providers, the families, the husbands and the women themselves. Therefore, I defined the sub-topics in the margins. Then, the responses from the participants were organised under these sub-topics in compilation sheets. Furthermore, in the discussions about stigma, distinction also had to be made between the stigmatising attitude of the family or self-stigmatisation (for example a participant said she did not want to put her friends at risk of contracting HIV by not sharing any food with them). In short, the numbers in the margin designated the different topics of the extracts, which corresponded with my list of topics and sub-topics. Little awareness of HIV/AIDS, for example, was topic (14) in the list, so I marked everything related to this topic with a (14) in the margin, and added key words such as health providers, family, husband, wife, as well as details such as *no symptom so can't be HIV* or *stopped using drugs so can't be HIV* to indicate the extent of ignorance.

After ordering the data, I summarised them per interview or per journal on separate compilation sheets. The compilation sheets contained columns with the different topics of the study as headings. Sometimes the headings were further sub-divided into smaller themes that I identified and coded when ordering the data. Then the data from each compilation sheet were sorted out and put in other compilation sheets which were organised according to the themes. Besides the compilation sheets, I also used matrices so I could easily compare the information given by each participant. The matrix looked like a cross-table with words. One matrix included basic information relating to the participants, such as name, age, education, religion, number of children, etc., as well as basic information pertaining to the deceased, including the date of death. The second matrix contained information such as when the women found out that their husbands were HIV-positive, when they discovered that they themselves were infected, when their husbands died, etc., so it was easy for me to make interpretations. Interpretation of the data allowed me, for example, to understand differences in the lack of awareness of HIV/AIDS, why the husbands were shocked to find out that they were HIV-positive despite the fact that they were IDUs, etc. As suggested by Strauss and Corbin (1998), I was continuously collecting data, comparing incident to incident as I moved further along the way, looking for similarities and differences, also comparing the data to my own experiences and observations. As described by Strauss and Corbin (1998:42), "*analysis begins with the first interview and observation, which leads to the next interview or observation,*

followed by more analysis, more interviews or fieldwork, and so on. It is the analysis that drives the data collection". According to these authors, alternating data collection with analysis enables validation of concepts and hypotheses as these are being developed.

I always recorded my thoughts and ideas as they evolved throughout the study. Early in the process, these notes tended to be very open while later on they tended to increasingly focus in on the core concept, i.e. the emerging themes I had identified. I became the inner person of the research - or the insider telling the story to the outsiders - as I was the research instrument in this qualitative study. Finally, I made a summary of all the conclusions that appeared after having linked the findings obtained in the research to the theories obtained from the literature review and watched to see if a new theory would emerge from the analysed data. According to Strauss and Corbin (1998), theories are always traceable to the data that gave rise to them. Theories can be explained in words and is usually presented with much of the contextually relevant detail collected. Drawing and verifying conclusions is not an isolated activity because it is the core of data analysis. In fact, when I started to summarise data in compilation sheets or matrices, I was continuously drawing conclusions and modified or crossed out some of them as I proceeded. The analytic process took as long as I felt necessary, at the end of which I felt I had a well thought-out explanation for the phenomena of interest, i.e. the grounded theory. At this stage, therefore, I had an answer to the main research question.

Quantitative researchers view validity and reliability as the main methods of establishing rigour in social science research (Lietz *et al* 2006). But defining "rigour" as validity in research contradicts philosophical positions regarding social construction and the acknowledgment of multiple realities. Gamlil (in Lietz *et al* 2006) therefore suggests that rigour in qualitative inquiry does not have to be an inflexible set of standards and procedures as in quantitative inquiry. Instead, it involves engaging in efforts that increase confidence that findings represent the meanings presented by the participants. Considering social work's mission to raise awareness of the needs of underprivileged populations, Lietz *et al* (2006) assert that qualitative research should reflect as closely as possible the thoughts, feelings and experiences of the people who participate in the research. Thus, the concept of trustworthiness was introduced to

qualitative research. In order to manage the threats to trustworthiness, a variety of strategies were recommended to describe research findings in a way that authentically represents the meanings as described by the participants. These strategies include prolonged engagement, triangulation, peer debriefing, member checking, negative case analysis, audit trail and reflexivity (e.g. Lietz *et al* 2006).

Thus, although triangulation was intended to ensure the deep understanding of the phenomena being studied, as suggested by Denzin and Lincoln (2003), I also used triangulation as part of my efforts to ensure trustworthiness and veracity of my findings. To further warrant trustworthiness, I also used member checking. At times, I described to the participants what I thought I was finding and asked them whether I interpreted their experiences or opinions correctly. My perception or perspective was of course important, especially during the analytical process, but I also realised that the way the participants interpreted what they had gone through mattered most.

Horsburgh (in Lietz *et al* 2006) defines reflexivity as “*active acknowledgment by the researcher that her/his own actions and decision will inevitably impact upon the meaning and context of the experience under investigation*”. This process involves deconstructing who we are and the ways in which our beliefs, experiences and identity intersect with that of the participants (Lietz *et al* 2006). Being from the same culture as the participants, where death is considered “fated”, I expected to be able to uncover hidden meanings in each narrative. But I have been living in this particular society for so long, so that perhaps, instead of problematising things, I have taken them for granted, such as the Indonesian people’s “death-accepting” attitude. Thus, I agree with Lietz *et al* (2006) that reflecting on the feelings of being an outsider was also important, because emotional reactions that stem from our own experiences may hamper our ability to hear what the participants are trying to tell us. Asking questions, engaging in reflection on both differences and similarities, therefore sensitised me to ways in which varying perspectives can both support and hinder this process at the same time.

Being exposed to emotional and potentially demoralising materials and processes, I understood what Malacrida (2007) said about how engaging in intense research can pose risks to student researchers’ senses of well-being and their ambitions as

researchers. Listening to what the participants had to say in response to my questions clearly did not entail just a passive listening. I was emotionally involved in the narratives of the women, experiencing their pain - and sometimes their joy – and, at times, also, feeling revolted by a sense of injustice, just like they were. Of course, our perspectives often differed. For example, as far as most participants were concerned, their sense of injustice stemmed mainly from the fact they had contracted a disease that “faithful, married women do not generally get”. For me, this injustice was attributed to the painful realisation that the government’s programmes truly had a long way to go to get the message across to the average citizen that no one, in fact, is safe from the threat of an HIV-infection.

Finally, being Indonesian and fluently speaking the Indonesian language, I had no difficulty conducting the interviews and transcribing the data collected. But when it came to translating some parts of the transcripts in English, namely the parts where I was quoting the participants, I sometimes hesitated over the use of certain words because I realised that the English vocabulary was in fact much richer than the Indonesian one. Also, as a measure of veracity when it occurred, I called the participants concerned to clarify the exact meaning of their narratives in order to determine which English words more precisely describe their emotions or opinions. This meticulous verification process was necessary in order to avoid misunderstanding or ambiguity.

3.6 ETHICAL CONSIDERATIONS

Considering the sensitive nature of the research questions as well as the probing nature of the inquiry methods used in this study, ethical concerns were carefully addressed to ensure that the needs and rights of the participants were not violated. All the ethical considerations listed below are included in the consent form, the English version of which is attached in the Appendix section.

3.6.1 Voluntary Informed Consent:

“Respect for Persons” is one of the basic principles in research ethics. One of the main ethical convictions incorporated in this principle is Voluntary Informed Consent,

which stipulates that individuals should be treated as autonomous agents (DHHS sa). This means that the person involved should have legal capacity to consent, able to exercise free power of choice and have sufficient knowledge and comprehension of the research he/she will be participating in, so as to be able to make an informed decision. In light of this, the purpose of the study was clearly explained to the participants before starting the first interview. I made sure that they fully understood the procedures as well as the risks and benefits involved, i.e. that they may feel a benefit from participating in the study from having an opportunity to share their thoughts and describe their experiences, but that talking about their grief could cause them to feel some discomfort, therefore they can stop the discussions any time. They were informed that they would be reimbursed for potential or real costs, and that completing the whole set of interviews was important in order to enable me, the researcher in this study, to adequately understand their experiences based on their narratives. They were also informed that they were fully entitled to decide whether to participate or not or to withdraw at any time, and that they would be entitled to a copy of the final study.

Two of the participants knew what “informed consent” was, as they had participated in other studies before. But for the other four who had never even heard of this expression, I had to explain that it was basically meant to ensure that the participants did not participate in the research against their will. The women were thus advised that the information collected was confidential and that their name would not appear anywhere on the typewritten pages; that pseudonyms would be used. Not one participant raised any question while reading or after reading the consent forms, and these were duly signed before starting the interviewing process.

3.6.2 Protection from Harm:

This ethical conviction is contained in the principle of “Beneficence” which stipulates that benefits and risks must be "balanced" and shown to be "in a favorable ratio" (DHHS sa). The first step is to identify and understand the factors creating the potential for harm. In my case, I was aware that the participants may experience some discomfort or pain when talking about the traumatic events they went through recently. It should be pointed out that my concern for the emotional well-being of the participants took priority over my curiosity as a researcher. When a participant seemed

to be breaking down while recounting a particularly stressful event, for example, I stopped the interview and suggested we take a break. I was certainly not a therapist nor did I ever pretend to have such capacity, but I was after all a human being so when someone before me was clearly in a great deal of emotional pain, I could not help but to react as such, by trying to comfort them and suggesting that we talk about what just happened. As much as I knew how important it was to just let the moment pass, I could not just sit there quietly and wait. Generally though, the women insisted on resuming the interview after taking a small break. At the end of each interview, we always held a debriefing session so we could talk about what happened during the interviews that seemed particularly difficult for the participants. I was thus continuously trying to balance my curiosity with compassion, my role as inquisitive observer with empathic human being.

But listening to the women and transcribing the tape recordings certainly made me realise that being exposed to depressing materials can take a great psychological toll on me as well. At times, I felt I needed the debriefing sessions as much as the participants did, which seemed to correspond with Malacrida's (2007) argument that an ethics of emotional care and support for research team members was called for. But I agree with her that, although engaging in emotional and difficult research topics has the potential to unsettle the researcher's self-understandings and values, emotional research is necessary to ethical research.

Furthermore, as stated earlier, there are currently no NGOs in Indonesia that offer services in bereavement counselling to which the participants can be referred to – which is precisely why this study was so important, as its main objective was to investigate whether a need for such services exists. Upon recommendation by the University of South Africa's (UNISA) Ethics Committee after reviewing my research proposal, I had specifically asked one of the Directors of the KAPETA Foundation, who was a clinical psychologist, to give counselling to my participants in the event that such counselling emerged as a necessity, considering the potential emotional strain they may experience. I made sure that the participants were debriefed at the end of each interview and made sure they did not go home heavy hearted. Not one woman changed her mind about participating in the study or decided not to complete the set of interviews.

3.6.3 Confidentiality:

Confidentiality is part of the “Protection from Harm” principle, which relates to the right of individuals to protection of their data during storage, transfer, and use, in order to prevent unauthorised disclosure of that information to third parties, the breach of which may cause harm to the individuals (UNAIDS 2007). Researchers must keep the identities of the people and organisations they work with confidential. It is by maintaining the privacy of research study participants that social scientists can ensure that they do them no harm. I understood that I must not even share information in my research study with family or friends in any way that could identify the study participants. I was aware that women affected by HIV/AIDS may have hesitations to participate in this study because of at least two reasons. First, they have lost someone to a highly stigmatised disease. Second, they may themselves be seropositive – which turned out to be the case with all the participants in this study. They were therefore given the assurance that no one besides me would listen to the tape recordings and that whatever they said would be kept confidential and would not be traced to them in any way. All the working documents and recordings were locked in a safe place until they can be destroyed, and only a secure computer was used.

This study was conducted as part of the requirements for the degree of Master of Arts in the subject of Social Behaviour Studies in HIV/AIDS, at the University of South Africa. It has been approved for protection of human subjects by the Ethics Committee of the University. I have also received permission from the KAPETA Foundation to recruit women who have lost their husbands to AIDS-related illnesses, who were connected to its network.

3.8. CONCLUSION

The aim of this study was to determine whether there was a need for specific bereavement counselling programmes for women who have lost their male partners to AIDS-related illnesses within 12 months prior to the study.

I decided to use qualitative methods considering that my aim was to gain a better understanding of the phenomenon I was interested in, and not in analysing causal relationships between variables. Data analysis was conducted based on the in-depth interview transcripts, personal journal records, my field notes and reflective notes, based on the principles of grounded theory, while trustworthiness was ensured by triangulation, member checking and reflexivity. This multi-method approach has led to the identification of emergent themes which then allowed me not only to answer the main research question, but also to propose new theories and to make recommendations for future research, which are detailed in Chapter 5.

CHAPTER 4: FINDINGS

4.1 INTRODUCTION

HIV/AIDS is still a major public health concern and a major cause of morbidity and mortality, especially in developing countries where more and more women are contracting the disease; where, ironically, a growing number of new infections is expected to occur in marriages (Mishra *et al* 2007). This phenomenon is due in great part to the fact that globally, despite almost thirty years of the pandemic, close to 95% of the people considered to be most at risk of contracting HIV do not know that they are infected (UCLA 2008). More aggressive prevention programmes and scaling-up of HIV testing have thus been implemented in response to this challenge, including moves by several countries to impose controversial mandatory HIV testing for people who wish to apply for a marriage license, such as in Saudi Arabia and Malaysia (Kamali sa; The Body 2007). In the meantime, the stigma attached to HIV/AIDS continues to prevail in most parts of the world.

An increasing number of HIV cases, especially undiagnosed ones, generally leads to more AIDS-related deaths, especially in countries with a high HIV prevalence or a fast spreading epidemic where awareness of HIV/AIDS is low, such as Indonesia (NAC 2007-2010; UNAIDS 2008). Researchers agree that AIDS-related bereavement is atypical (Sikkema *et al* 2000) mainly because HIV/AIDS is a highly stigmatised disease associated with stigmatised conditions such as homosexuality, promiscuity and injection drug use. However, if the bereavement literature has seen a growing number of research looking into AIDS-related grief and bereavement experiences of HIV-positive individuals in the last two decades (see, for example, Shernoff 1998; Sikkema *et al* 2000, Sikkema *et al* 2004), few studies were done in respect of the bereavement experiences of non-Western heterosexuals living with HIV, more particularly women.

In the body of literature on chronic illness, Bury's (1982) theoretical model of biographical disruption plays an important role to explain why the sudden onset of illness can potentially create a crisis in a person's life, hence cause a disruption. But few authors have addressed this concept as it relates to HIV-infection, especially as far

as *women* living with HIV are concerned (see, for example, Cambrione 2003; Wilson 2007). Thus, little remains known of the impact of a biographical disruption on HIV-positive women who are coping with the death of their male partners, and the role of motherhood in the bereavement process of women in their situation.

The goal of this study was to explore whether specific bereavement counselling services are needed for women who have recently lost a husband to AIDS-related mortality. During my journey of discovery, however, I learned that all the research participants have been infected with HIV. The narratives of the women suggest that biographical disruption may have played a critical role in the bereavement outcome.

Analysis of the tape recording transcripts of the women's in-depth interviews and their personal journals led to the following emergent themes:

- Limited knowledge of HIV/AIDS
- Coming to terms with being a widow, also with living with HIV
- The "new" role as a single parent, i.e. mothering, for the widow of a spouse who died of an AIDS-related illness.
- The need for counselling addressing seropositivity

4.2 CHARACTERISTICS OF THE SAMPLE

I have interviewed a total of six women between the age of 22 and 31 who have lost a husband to an AIDS-related illness within 12 months prior to the start of this study. All the women were high school graduates – this places them on the lower side within the large, complex mosaic of middle class groups in Indonesia, consisting mainly of working people who live in sprawling urban centres. Defining this country's social classes never has been a straightforward job for a good number of reasons, however, namely the lack of a clear identity of the current "upper class", the questionable existence of a bourgeoisie in any traditional sense, the divisions between the indigenous and later Chinese and Arab immigrants, the experiences of population mobility in the archipelago, and the overall developing national culture, which underscore the continuing importance of social stratification in Indonesia (Frederick & Worden 1993). Indeed, scholars and policy analysts do not seem to agree on the

degree to which social classes could be defined in ethnic, economic, religious or political terms. But while it is clear that the research participants were not from the upper class, it is also evident that they did not belong to the lower class groups which are mainly characterised by illiteracy, poverty and dwellings in villages or remote areas.

My research did not require determining the HIV status of the research participants, but I discovered during the in-depth interviews that all the women have contracted the virus, most likely from their husbands, all of whom were or had been intravenous drug users (IDUs). So, in addition to having to deal with the death of their husbands due to AIDS-related causes, the women also carry the psychological burden of being a person living with HIV and, for most of them, the responsibility to raise their children as a single parent. Finding themselves in a new, vulnerable, position and bracing themselves against anticipated stigma, clearly constitute a new traumatic experience for the women, considering that even as the wife of an IDU, they did not have to worry about stigma (wives of IDUs are not known to be socially stigmatised in Indonesia although IDUs are⁶).

Below is a biographical sketch of the research participants. I believe background information on each of the respondents will give additional insight to the readers that I hope will allow them to have a better understanding of the experiences, thoughts, beliefs, hopes and worries of HIV-positive women who have recently lost their husbands to AIDS-related illnesses.

4.2.1 Ita

Ita, 22 years old, is the youngest of the participants. After completing her high school degree, she took up several jobs doing administrative and accounting work. When she met her second husband Roy who was working for an NGO involved in HIV/AIDS prevention, she was a widow with a one-year old daughter. Besides being the only interviewee who has been twice a widow, Ita is the only participant who came from a

⁶ This was confirmed after discussions with sociologists.

non-Muslim family. Raised as a Protestant, she had plans to convert into Islam, which was Roy's religion, but this did not materialise.

Ita's relationship with Roy did not receive the blessings of her family because they knew all along that he was an IDU. But Ita went ahead and married him anyway. Unfortunately, her marriage only lasted three months.

Ita is also the only participant whose husband knew he was HIV-positive before marrying her but did not disclose his status to her. Tragically, Ita learnt that her husband was HIV-positive the day after the wedding and found out shortly afterwards that Roy's infection had already progressed to a very advanced stage. In fact, the couple only had two weeks of honeymoon, after which Roy began to be seriously ill and died. Ita found out that she was living with HIV the very day before Roy died.

4.2.2 Liana

Liana is two years older than Ita. As with Ita, she held several jobs after graduating from high school, including administrative work and sales promotion. Against her parents' wish, she chose not to pursue higher education, by rationalising that she was going to be the wife of an executive with a promising career. Therefore, a college degree would have been useless, as she was going to be a housewife anyway. Reynold was indeed a successful executive in a food manufacturing company.

Liana and Reynold dated since high school but they did not become seriously involved until much later. At first, Liana was not aware that Reynold was using IV-drugs. All she knew was that he had frequent bouts of ill health. Liana later found out that when he appeared to be ill, he was in fact craving drugs. One day while they were together, he had to inject drug in front of her, apparently because he could no longer control his craving. Reynold then decided to go through a drug rehabilitation programme in a nearby city and came back to Jakarta three months later. But then he met up with his IDU friends and started using drugs again. Liana kept pressing him to quit and threatened to leave him if he continued, but to no avail. Then one day one of Reynold's IDU friends died of an overdose. The incident seemed to have scared him and apparently made him quit drugs for good, without even going through another

drug rehabilitation programme. Liana and Roy were married for seven years, and were blessed with three sons.

Liana's case is interesting because her husband still appeared to be in very good health and continued to work normally as she began to develop symptoms of HIV-infection. In other words, while it seems safe to assume that Liana contracted the virus from her husband, it was she who found out first that she was living with HIV. Two of her three sons were found to be HIV-positive as well, while the middle one is HIV-negative which, according to Liana, is because he refused to be breastfed, unlike his two brothers.

4.2.3 Ana

Ana is 25 years old. She was a mountain climber and met her husband Herman while on a mountain climbing trip. Herman was several years older and was a salesman in a food manufacturing company. After graduating from high school, Ana worked as a store attendant and kept her job for a while after they were married. She had a baby-girl about a year later but the baby died following a severe episode of diarrhoea.

Unlike most of the other research participants, Ana had no idea that Herman had a history of injecting drug use and only found out about it after he started to show symptoms of ill health. Herman admitted having experimented with such drugs when he was younger, but did not see any relevance in mentioning it to her as he was no longer using drugs when they met and fell in love.

Ana is the only participant with currently no children, having lost her only child at the age of 9 months. Ana suspects that her baby-girl also died of an AIDS-related illness, although this was never confirmed. In fact, the possibility of an HIV-infection seemed quite remote at the time as both parents were still perfectly healthy.

4.2.4 Amelia

Amelia is 29 years old. She was working as a salesperson in a department store when she met her husband, Yanto, who was a factory worker in a food manufacturing

company. Amelia continued to work after her marriage, doing different jobs, but quit working when her husband's health started to deteriorate.

As with Ana, Amelia had no idea that her husband used IV-drugs. But while Ana's husband used injecting drugs and quit *before* he met her, Amelia's husband experimented with IV-drug *after* he was married to her. Fortunately, both their children are HIV-negative.

Particularly striking in Amelia's case is the little awareness of HIV/AIDS among the medical professionals who treated her husband. This has led to a series of diagnoses over a period of many months, resulting in the delay of HIV treatment.

4.2.5 Mamiek

Mamiek, 29 years old, is the only research participant who was herself an injecting drug user. Although by definition she was herself at risk of HIV-infection, it was most likely that she contracted the disease from her husband, as she still tested negative at the beginning of her pregnancy. Mamiek and Igor were married in 2005 and have a son who is now one and a half years old.

Mamiek has always known that her husband Igor was an IDU, as they met through the IDU network. Mamiek held several jobs after graduating from high school, mainly as a waitress in various coffee shops, but her husband on the other hand had never worked in his life. She and her husband continued to use drugs after they were married and were totally dependent financially upon their parents.

Mamiek stopped using IV-drugs when she was seven months pregnant. She believed that she had been using drugs for a longer period than her husband, but stressed that she had never shared needles with anyone else, not even with her husband. Igor eventually also stopped injecting drugs before he developed symptoms of HIV-infection. Unfortunately, he fell sick shortly after knowing his status and died a few months later of toxoplasmosis. Their son was still HIV-negative when he last tested at the age of 16 months.

4.2.6 Ika

Ika, 31 years old, is the eldest of the research participants. She met her husband Anto when she was working as a salesperson in a clothing store in the north of Jakarta. Anto was a painter who had a studio in the same neighbourhood.

Ika and Anto were married following an unintended pregnancy. But the baby-boy died at the age of 7 months as a result of severe diarrhoea. A couple of years later, when Ika was pregnant with her second child, Anto's health started to deteriorate. But as with their first child, the medical professionals also did not suspect an HIV-infection, which again emphasises that the medical professionals in Indonesia lack awareness of HIV/AIDS. In fact, her husband died without knowing he was HIV-positive. Ika began to have symptoms of HIV-infection about a month later, and later found out that she as well as her son were living with HIV.

4.3 FINDINGS

Within a brief space of time, all of the women in the study underwent three traumatic life experiences in a row: they learned that their husbands were living with HIV; they found out that they were themselves seropositive, and they lost their husbands to AIDS-related illnesses. However, for some of them, the trauma extended even further: their child/children were found to be infected as well. And for one of these women, this included losing a baby to an AIDS-related mortality.

4.3.1 The String of Traumatic Life Events

As mentioned above, the women experienced at least three traumatic life events in a row, one as devastating as the other. Considering there was in general a relatively short lapse of time in between, it seems understandable that it may not be easy for the women to remember how they felt precisely about each of the event they have gone through. Shock and coping took place repeatedly one after another and the series of events have culminated into one major conclusion, which is that they are now widows, also living with HIV.

In general, the women held the view that other pressing things of living with HIV overshadowed the death of their husbands or distracted them from “simply” mourning their loved ones’ deaths. Amelia and Liana, for example, were consumed by their anger and vengeful feelings towards their husbands who “gave” them the virus. While Amelia lamented the “injustice of things” because she contracted a disease mostly associated with prostitution, Liana was zealously resisting the idea that her children were also living with HIV. Mamiiek kept reflecting back with frustration on the fact that her husband waited so long to be tested for HIV when he had in fact been suspecting his infection for quite some time (as he so admitted to her when he came home with his positive result). And Ana, who had to find a job right after her husband died, had to endure stigmatising talks about HIV in her new working environment, while pretending they did not concern her at all. When asked to talk about the death of their husbands, it was therefore not uncommon that the women addressed the subject only briefly and went on to discuss another topic that seemed to weigh more heavily on their conscience or which they appeared to feel more strongly about. Ika and Ita, for example, said respectively:

“I wanted to die, I wanted to kill myself. But I said to myself, *Let go of Anto. His death is fated. It was written that you’d be a widow. Accept it.* I thought about the future, I thought who would support my son? But the most difficult part was when I found out that I was living with HIV. Of course, I was also sad when my first child died, which is normal, but it hurt so much to know that I was positive. I was so afraid to be shunned. When I was sick none of my neighbours came to visit. Apparently somebody in the neighbourhood said *Don’t get near Ika, she’s got HIV. It’s contagious.* I cried. My mother also cried” (Ika).

“I thought, he’s dead, so who do I talk to? What’s gonna happen to my daughter? My thoughts were focused on my seropositivity. Even if my husband died a year later, my thoughts would still be focused on the fact that I’m HIV-positive. I don’t think the death of a husband has such a great impact on a woman, especially if she already has children. My concern was that I was now

living with HIV, so what should I do to live longer? What's important to me is how to feed my daughter, how to keep my status secret in order to protect her” (Ita).

4.3.1.1 Circumstances Leading to the Husbands Being Tested for HIV

While delay in HIV diagnoses has contributed to accelerating the husbands' death, such delay was mainly attributed to a limited awareness of HIV/AIDS generally as well as among the medical staff who attended to the husbands prior to their deaths. Most husbands were surprised when they received their positive test results.

The question relating to the circumstances that led to the husbands being tested for HIV is examined from the stories told by the research participants. It shows that there was limited awareness of HIV/AIDS among the husbands, the women, the families, and even the healthcare providers. Indeed, while the husbands did not perceive themselves as being at risk of contracting HIV despite being IDUs, the healthcare providers in general did not readily suspect an HIV infection despite the men displaying symptoms of opportunistic infections. It is therefore not surprising that the husbands had already reached an advanced stage of the infection when they were finally diagnosed with HIV and that in most cases, death was imminent.

Ana's husband, Herman, had been suffering from terrible headaches as well as from diarrhoea, which were treated on a case-by-case basis, mainly at a nearby clinic. When he was finally taken to the hospital because his illness seemed to get worse, the physician ran tests on him and gave him medication. Herman stayed at the hospital for a few days, felt better, and was sent home. But a few weeks later he suffered again from diarrhoea and went back to the hospital. The doctors finally convinced him take an HIV test after diagnosing him with toxoplasmosis. Ana said:

“When the test result came back positive, Herman was stunned. He couldn't believe it. Eventually he blamed himself for the infection, but I told him there was no use for regrets. Things have already happened”.

Liana's husband Reynold had been suffering from severe headaches but instead of taking him to the hospital, his parents opted to get him treated by traditional healers. One day Reynold collapsed and was finally taken to the hospital where Liana, a short time earlier, was tested for HIV and found positive. This seems to explain why the healthcare providers immediately suggested to Reynold to take an HIV test.

Reynold was also taken aback when he received his positive test result, and so were his parents who knew that he was an IDU. Liana explained:

“When he received his positive test result, his parents were convinced that it was a mistake. They said he could not have been infected because he was not losing weight. They also believed that the ARV pills he was consuming were in fact prescription drugs to prevent him from contracting HIV from me. They said, *If he really is HIV-positive, why didn't he get sick long ago? He's been injecting drugs for a long time, hasn't he?*”

Amelia is one of the two women in my study who were not aware that their husbands had, at one time, been IDUs. They only found out about it after their husbands were diagnosed with HIV. Amelia's husband Yanto eventually admitted that he was on and off IV-drugs 4 years prior to his HIV diagnosis. As far as her husband was concerned, experimenting with IV-drug for a short while was not associated with any risk of HIV-infection. Amelia explained:

“My husband didn't believe he was infected because he said he was *not really* an injecting drug user. He just happened to run into an old friend who was a drug user and decided to try some. But he never told me about it before he became sick He was the kind [of guy] who didn't go out much. He was working at the factory and I was also working, so I didn't know what he was up to. As far as I knew, he never did bad things. He prayed regularly, he was also good at chanting prayers, but he liked to drink ... I stayed at my mother's house after I gave birth to my second child, so maybe during that time he met up with his IDU friends.... But he told me he had never used drugs before. When I asked him he always said he never used them. So I never knew what he did until he fell sick”.

But the women who knew that their husbands were using IV-drugs never seriously thought that their life partners might become infected with HIV, although some of them may have been vaguely aware that the use of injecting drug is associated with HIV-infection. The prevailing idea was that an infection would immediately produce telltale symptoms; in other words, if one has stopped injecting drugs and remains asymptomatic, then one must be free of HIV. Liana, for example, explained:

“I had no idea that you can get HIV from injecting drugs. If I knew, I would not have agreed to marry Reynold. If I knew that injecting drugs can cause HIV, I would have gotten him tested. In 2004 I read an article in a magazine about a woman who was infected with HIV. I thought, what if I’ve got HIV? But I didn’t know where to get such a test. I said to my husband, *What if we both got HIV?* But my husband said, *No way, I’ve been through a rehabilitation programme. I stopped injecting drugs a long time ago*”.

She added:

“When I found out that my husband was positive, I felt really disgusted. I told him, *When you get better, and I get better, I don’t want you to touch me ever again. I’d prefer we get a divorce. I don’t ever want to have sex with you again.* It was so disgusting. There was a virus there. There was *HIV* there. So every time we would have sex, there would be more viruses going into my body”.

This repugnance for sexual contacts with their husbands - whom they considered to be the source of their own infection - was also experienced by Mamiiek. She said:

”Ever since I found out that I was positive, I always refused when my husband wanted to have sex. So when he wanted it, I just had to come up with a means [to satisfy him] as long as it did not require sexual contacts, as long as he didn’t touch me. Was I mean? What mattered was that he was sated”.

Besides the lack of knowledge or little awareness about HIV/AIDS, denial on the part of the husbands appeared to have also played a role in delaying their HIV diagnosis. Ika's husband, Anto, died without even knowing he had HIV. This occurred a few years after Ika's first child died, also without having been diagnosed with an HIV-related illness. She said:

“I only knew he used to shoot drugs. I thought he stopped. But I found out after we were married that he kept doing it behind my back. I'd find a syringe hidden in the bathroom, between his books And then we'd fight. *If you continue doing it you'll catch HIV*, I often said to him. *Impossible, I use sterile needles*, he would say. I guess I knew a little about HIV, I just never thought my own husband would be infected I never suspected it although I knew he was an IDU We wanted to have another kid. I kept telling him to behave. He promised he would not shoot drugs again, but he did, because everybody in the neighbourhood was doing it. My friends used to say to me, *Your boyfriend shoots drugs, what if you catch HIV from him?*”

Ita's husband Roy's denial took another form. He knew since 2005 that he was HIV-positive, but apparently never checked his CD-4 cell count. He would tell the physician that he was fine, just tired. When he finally took ARV, it was probably too late. In fact, he died the day after he started ART. Ita found out that he was living with HIV the day after their wedding, when she accompanied him to the clinic for his monthly check-up. She said:

“The doctor asked why I agreed to marry him. Maybe she thought I already knew his status. She then asked if I was ready to be tested, but I wasn't. I was shocked to find out that Roy was living with HIV”.

Little awareness about HIV/AIDS is certainly unfortunate but more worrisome is the lack of such awareness among the medical professionals because in a country with a burgeoning but fast spreading epidemic such as Indonesia, a great number of people are expected to seek medical treatments for symptoms of various opportunistic infections, and delays in diagnosing HIV are bound to cause serious consequences for the patients' lives.

Amelia's husband, Yanto, displayed a series of symptoms over several months, which in turn led to a series of diagnosed illnesses that were treated on a case-by-case basis to a varying degree of success. But when HIV was finally suspected and confirmed, many months had already passed. Amelia said:

“My husband never admitted he had used IV-drugs. I asked him a few times but he said, *God forbid*. So I had no idea until he fell sick. He alternated between high fever and chills. When I brought him to the clinic, they said he had typhoid. Another time, they said he had dengue fever. He was given medication for two weeks, but he didn't get better. His father finally took him to the hospital where the physician also said he had dengue fever. He was hospitalised for 2 weeks, got better, went home and 2 weeks later he started to have chills and fevers again. So I took him to another hospital. They said he had typhoid. He was hospitalised there for a week, got better, went home, went back to work and then he collapsed. For a whole month after that he had fever, sometimes very high, sometimes just mild. So I took him back to the old hospital because that's where he could get medical reimbursements from his workplace Finally the doctor asked me to come to his office to talk. He asked me if my husband used IV-drugs. I said no, although I was kind of suspicious that he did, but I insisted that he didn't use any of that stuff”.

For some of the women at least, their husbands' drug use and HIV-positive statuses were a betrayal of what they expected from the marital relationship. From their narratives it can be seen that they immediately assumed the care-giver roles when the husbands became ill.

4.3.1.2 The Husbands' Deaths

The question relating to their husbands' deaths and how the women felt were examined from the women's narratives and journal entries. It shows that all the husbands were or had been IDUs and died after experiencing serious symptoms of AIDS-related illnesses. One of them passed away without even knowing he was HIV infected. Although their period of illness varied from several months to a couple of

years, there was in most cases a short lapse of time between finding out their serostatus and their death, which shows that there was in general a long delay in diagnosing HIV. As explained by the women, HIV remained unsuspected for a long time, even after the appearance of severe, often recurring, opportunistic infections. Precious time has therefore been lost in trying to treat the various infections while missing the core problem, and when HIV was finally diagnosed, more time was often required to cure the various infections before the patients could start taking antiretroviral drugs.

As discussed earlier, Amelia's husband had been going back and forth to a number of hospitals and was treated for various infections, including typhoid and dengue fever, before he was finally diagnosed with HIV. At a late stage of his illness, Yanto contracted tuberculosis (TB) and had heart problems, but it was vertigo that brought him back to the hospital for the last time. Amelia took him to the same hospital where he received his HIV diagnosis a few weeks earlier.

At the hospital, the physicians ran a series of tests including magnetic resonance imaging (MRI); it did not reveal toxoplasmosis, which was suspected to cause his dizziness. Amelia was told that her husband's symptoms could be explained by the TB. Yanto was then advised to go for physiotherapy because he was unable to walk. A few days later he felt better and stronger, his vertigo was gone and he was able to sit up, lie back and even go to the bathroom on his own. Amelia thought he was on his way to recovery and that they would be going home shortly. One night, Yanto said to Amelia that he did not want to sleep because he wanted to watch a soccer game on television (TV). Amelia wanted to stay awake and watch TV with him but she fell asleep on the traditional mat next to him, completely exhausted. Yanto immediately woke her up, insisted that she stay awake and watch TV with him, but again Amelia fell asleep. At around 2 am, she woke up because she felt water dripping on her. She realised that Yanto had pulled off the IV-plug. She asked him what was wrong but he could not speak coherently. Amelia went out to look for the nurse but when she came back to the room Yanto was having seizures. He then lost consciousness and remained unconscious for almost two weeks before he died. Amelia said:

“When I realised Yanto was dead, I didn’t feel anything. I just didn’t want to live, I wanted to die with him. I was hysterical. I didn’t want him to be wrapped in *kafan*⁷. I didn’t want him to be covered up. I still could not believe [that he died] because he promised me that he would never leave me. I was only able to face reality when his parents and my parents came. Then they took away his body to be cleansed, and put him in a coffin. They didn’t allow anybody to reopen the coffin. They were afraid I would go hysterical again”.

Ita’s husband Roy had been diagnosed with toxoplasmosis and started to have difficulties walking a few weeks after the wedding. During the last weeks of his life, Roy was completely unable to walk and was mostly unaware of his surrounding, but the day he died, Ita was still able to talk to him. She asked him if he loved her and her daughter Angky and he responded by whispering that he did. So Ita urged him to keep on fighting and reminded him that she needed him to be with her and Angky. That day, Ita was able to make him eat some porridge, which was unusual since Roy had been unable to eat lately. Then Roy asked her to hug him. A little later he started to have difficulties breathing. Ita had the feeling she was losing him and started to recite prayers. Then Roy was dead.

“I didn’t want to let go, but in the end I did Roy’s friend who was a psychic said that Roy didn’t want to leave me, but that his body could not take it anymore. Roy said to me once that I must be strong for my daughter if he had to die. He loved her very much. He didn’t want to have a kid of his own because he didn’t want to have a child who is living with HIV”.

Two of the women participants did not attend the burial of their husbands. This sounded odd, especially in a society where women are taught to be subservient to their husbands and to always be there to attend to their every need, and considering that the burial was a once-in-a-life-time event which formally marked the end of their togetherness. While the real reason may be as explained by the women, it is also

⁷ White sheets used to wrap the body of the deceased, in accordance with the Muslim faith which does not recommend the use of a casket for burial unless there is a need for it. Caskets are only used to transport the bodies to the cemetery.

possible that the gesture implied other meanings, such as an unresolved anger or a strong protest, or even a “rebellion” against the above mentioned socio-culturally imposed norms, which may have been triggered by the recent disruption of their taken-for-granted assumptions about the world. The women’s stated reasons for not attending the burial were quite “matter-of-fact”. Liana simply said that she did not go to the cemetery because she felt “she was not strong enough to go”, adding that she lost consciousness several times after her husband died, but managed to gather her strength when Reynold was already wrapped in *kafan*⁷ and ready to be taken to the cemetery, as it was customary in Islam that the last good byes are said during this time, during which no tear shall be shed.

Ika said she did not attend her husband’s burial because he died shortly after she gave birth to her second child and was still confined to her bed after having had problems with the baby’s delivery. Interestingly, until the time of the interview, Ika still had not gone to the cemetery to send flowers to her husband, citing the same reason as Liana, i.e. that she was not strong enough to do it.

As for Amelia, she did attend her husband’s burial, but it appears that she still has not let go of her hatred for him, which seemed to have kept her from going back to the burial site, as we will see in her next quote. Her next quote also reveals that her mother-in-law had a change of heart about her, as she invited her to go to the cemetery with her, despite the fact that she had been ignoring her and her children since her son died.

“I still remember everything: when he was happy, when he was laughing, when he was angry. But I hate him for lying to me. What I feel mainly now, when I think of him, is hatred. Until today I have not been back to the cemetery. I hate him for lying to me and I hate him for leaving me on my own. Later, maybe, I will want to go to the cemetery, but yesterday when my mother in-law asked me to come with her to visit the grave, I still didn’t want to go. I pray for him though” (Amelia).

“When I think of him, I miss him. I want to be with him again. We used to go out together every Saturday and Sunday. I used to make tea for him in the

morning. But I thought, why should I keep thinking about him? He's not around anymore, and he's probably happy up there anyway. So I just have to live my life" (Ana).

"When I think of him, the first thing that comes to my mind is that I'm positive. I don't really blame him but when I think of him I think about HIV/AIDS. That's the most important legacy he left me with" (Ita).

"When I think of him, sometimes I feel sorry for him, sometimes I hate him, sometimes I feel vengeful. I feel sorry for him because when he was sick, I didn't get him hospitalised. I was pregnant so we needed the money for the delivery of the baby, just in case I had to get a C-section., so I let his mother take care of him. So I feel kind of guilty that he didn't get proper medical treatment" (Ika).

"When I think of my husband, I remember the time we were still dating, when we were still in school, so sometimes I miss him. But when I think about my sons, damn, because of him my children are sick. Sometimes when I'm angry at my children, I thought, why wasn't it me who died? Why did it have to be him? If I was the one who died I would be free, let him be busy taking care of the children. But then I thought this was probably how God wanted my life to be. I shouldn't be so narrow-minded" (Liana).

Clearly, the women in general still felt sad about the death of their husbands and still missed them occasionally, but they appeared to have come to accept it. The above quotes also show that sorrow was mixed with feelings of great anger and betrayal. Moreover, the narratives of the women suggest that for most of them, it was the economic impact of their husbands' death that preoccupied them most once they were able to get past their initial shock of losing their life partners, considering that most of them were not working then. But by the time of the interviews, half of the participants were already earning money, mainly through the different NGOs they joined after their husband's death.

Roy left Ita some money which was only sufficient to support her and her daughter for a month. This meant mainly that she no longer could afford to buy formula milk for her daughter and instead had to buy canned concentrated milk that she diluted with water. Ita was determined to find a job as soon as possible and when I interviewed her for the second time she was already working in sales promotion and seemed happy about her new job.

For Liana, whose two children are infected, her main concern was the fact that they would need medication all their life, which certainly has important financial implications, considering that children do not benefit from free ARVs in Indonesia. Unfortunately, Liana was still unable to overcome the fact that she was a person living with HIV, which made it difficult for her to go out and look for jobs. She now lives with her parents who took her back into their home after her husband's death. She said:

“I never experienced relief about his death. On the contrary, I felt it was a burden that he died because even if he was sick, at least he would still be able to give me money if he had continued to live”.

Unlike the other women, Ika was still working when her husband died but had to quit when she in turn started to suffer from poor health a few months later. But even so, she was concerned about how to cover her living cost after her husband's death, because she had to take care of herself and her child who is also HIV-positive. Fortunately, she received a small loan from the NGO she joined after her husband died and was able to earn money by producing and selling cassava chips regularly. She said she was still trying to find a job to earn extra money, as her mother was perfectly capable of handling the chips production on her own. In the next section, the circumstances that drove the women to obtain an HIV test are described.

4.3.1.3 Circumstances Leading to the Women Being Tested for HIV

As with their husbands, the women were also little aware of HIV/AIDS. None of them proactively sought diagnosis and treatment for HIV-infection. The lack of perceived susceptibility as regards HIV-infection seemed particularly glaring in Liana's case.

She fell sick and tested positive for HIV before her husband had any symptoms of an AIDS-related illness. But even after knowing that she was infected, the idea did not occur to her to ask her husband to get tested for HIV.

Liana and Reynold were married in 2000 after Reynold quit using drugs. As far as Liana knew, her husband never experienced relapse. Trouble began when their 6-year old son started to cough endlessly and broke up in sweat frequently. Liana gave him various cough syrups but none seemed to help. He was finally diagnosed with lung problems and given various medications but the symptoms persisted, even after he commenced with his treatment regime for TB. Liana in turn became seriously ill while her husband continued to be asymptomatic. Her symptoms included diarrhoea and feeling constantly nauseated. She lost weight very quickly and was down to less than half her original weight when she was finally admitted to the hospital.

“I felt so weak. I thought maybe I was exhausted because I was taking care of three small children, maybe because I had one child after another within a short time. I went to the Doctor and he said the same thing, until I got worse. My husband said maybe I got TB from our son, but I never coughed. I just felt tired, I had no appetite. I thought maybe I was pregnant. I even bought a test kit but it was negative. So my husband finally got me admitted to the hospital”.

The above excerpt tells us that ordinary people do not suspect that they have HIV. Liana’s own explanations for her ill health is closely related to her own interpretation of “women’s troubles” – she ascribes her fatigue to too many closely spaced pregnancies, perhaps another pregnancy or to taking care of a child with TB. In fact, in the very next quote, her strong identification with being “a housewife” and therefore being not at risk is reiterated. The category “housewife” is therefore narrated as a group signalling low risk for HIV-infection.

At the hospital, Liana went through a number of tests. Nothing was found wrong with her, including her lungs, although her thrombocytes and her haemoglobin levels were low. After a few days, the physician finally suggested an HIV test. Liana explained:

“The doctor said, *Sorry to ask, but where have you worked? Have you been abroad?* I said, *Doctor, I’m a housewife. I had jobs before, regular jobs. I worked in sales promotion. Yes, I’ve been out of town, but I’ve never done any bad thing....* He asked, *Have you had sex with more than one man?* Of course not. I’m a housewife. I have a husband”.

Liana was tested without receiving any counselling and received her test result from the nurse who handed it to her without giving any explanation. This casual manner in handing over test result to a patient certainly is worrisome but unfortunately it seems to be widely practiced in busy healthcare settings as we will see in the following sections of this chapter. Not receiving counselling primarily means that the patients are not informed of the implications of a positive result and may not know what to do or where to go. In Liana’s case, she did not even know that “reactive” actually meant “positive”. After receiving her test result, Liana was allowed to go home as she was able to eat normally again. She said she remembered seeing the word “reactive” written on the test sheet but she dismissed it as “unimportant”. When her mother later asked her what “reactive” meant, Liana convinced her to just ignore it, stressing that she was obviously fine since the doctor allowed her to go home.

But a month later Liana fell sick again and this time collapsed. When she regained consciousness, she found herself lying in a hospital bed. That was about a week after she lost consciousness at home. She finally inquired what “reactive” meant when the physician came to examine her. She explained:

“The doctor said, *Well it’s positive. What? You mean I’m HIV-positive? ... That’s not possible. How did I get it? No, I never used drugs. Yes, my husband did, but he’s healthy. If he’s got HIV, he would have fallen sick before I did. Why would I get sick when he’s the one using drugs in the first place?”*

Shock and disbelief were experienced by all the women in the study, some of whom also expressed elements of denial, such as Liana, as discussed above. Also in denial was Amelia who finally agreed to be tested about 3 months after her husband was found to be HIV-positive, although her physician had kept urging her to find out about

her status as soon as possible. She went to the same hospital where her husband was tested. She said:

“After I was tested, I didn’t want to look at the results. The nurse said, *You’re positive*. I said, *Positive of what?* She said, *Like your husband*. I was so shocked. I cried until I passed out. I was so afraid because what I’m most afraid of in this world is to be sick”.

The above excerpt tells us that Amelia, like Liana, did not receive any counselling relating to her HIV testing. This seems indeed to be common practice in some hospitals, where patients simply give an oral consent to the physician’s suggestion for an HIV test, receive no pre-test counselling and the test results are handed casually to them by the nurse on duty. While Liana was left guessing about what the word “reactive” meant, Amelia was told point blank that she was living with HIV, with seemingly no effort on the part of the nurse to prepare her to receive the bad news.

Ita’s husband Roy became seriously ill two weeks after they were married. Ita realised the urgency of finding out about her own status but delayed getting tested until two months later. When she went to the VCT clinic to pick up her test result, Roy came along in a wheelchair, as he was already unable to walk due to the toxoplasmosis he was diagnosed with, and was hardly aware of what was going on around him. The fact that Ita, unlike most participants, went to get tested for HIV in a VCT clinic instead of a hospital tells us that she has been made aware of the importance of receiving a pre- and post-test counselling. This seems logical since Roy was working for an NGO involved in HIV/AIDS prevention and since she had been to such a clinic with him for his monthly check-ups. Naturally, Ita was still healthy at the time, therefore she had no business to be in a hospital where she might also have been tested without any counselling. She said:

“The counsellor handed me the test result. He didn’t say I was positive. I was looking at the plus signs wondering what they meant. I didn’t know what to ask. The Counsellor said, *Do you understand?* No. He said, *It means that you’ve got some virus in your body*”. Some virus in my body? What do you mean? *It means that you’re positive*, he said. What?? ... That was my first

reaction. I was stunned. Around 10 minutes must have passed, I couldn't say a word. Then I started to cry. I told my husband that I was positive. He must have heard me, he seemed upset to see me cry, he cried too. I was so confused. I felt like I lost half of my soul. I was only twenty and I got *that* kind of disease”.

Ita's own perception was that HIV-infection is a stigmatised disease as she referred to it as “that kind of disease”. This perception is also evident in Ika's narration. While Ita internalised her shock and described it as a “loss of half her soul”, Ika saw this as Divine punishment for falling pregnant before marriage.

Ika found out about her status *after* she had lost both her 9-month old baby-boy and her husband Anto. The baby died following a severe episode of recurring diarrhoea, while Anto died of toxoplasmosis. Ika's symptoms started to develop around the time her husband died. She often felt weak, had recurring headaches and developed lesions on her ears. After she was sick on and off for several months, she finally took an HIV test upon the urging of her sister who suspected that Ika's husband might have died of an AIDS-related illness, as she knew that he was an IDU. Ika says:

“I waited for three hours for the test result to come back. It said “reactive”. When I realized that I was positive, I thought it was the end of the world. My sister hugged me tightly and I cried as hard as I could. I asked God if I was cursed for letting myself get pregnant before I was marriedI was devastated. Completely devastated and Well, I just wanted to die, I wanted to kill myself. Life seems pointless when you have this kind of infection. Like people say, it's a curse. Very shameful. I was terrified that people might think I was no better than a prostitute, although I got the disease from my husband. That's all I could think about when I found out about my status”.

The above narratives highlight the compounded aggravated nature of the trauma in the women's lives. They were the wives of addicts who turned out to be living with HIV, they were widows and they were diagnosed as HIV-positives. The narratives also point out how the popularisation of so-called most-at-risk populations (IV-drug users,

prostitutes) makes people unaware of their own vulnerability to HIV, especially as far as the wives of IV-drug users, married women, etc. are concerned.

4.3.1.4 Coming to Terms with Being a Widow, also with Living with HIV

As we have seen in the above narratives, the women in the study never thought that they would one day be living with HIV. They were married and were faithful to their husbands and as far as they knew, only sex workers were at risk of contracting HIV. They were in general vaguely aware that injecting drug use was associated with HIV. Although it occurred to some of the women who knew that their husbands had a background of injecting drug use that the men might be at risk, they never thought that they themselves were vulnerable to the infection.

Thus, as far as the participants of the study were concerned, being HIV-positive implied not only the loss of a former self that was HIV-negative but also the loss of a sense of security that was part of the taken-for-granted assumption about marriage and heterosexual relationships (Du Plessis 2007). As mentioned earlier, all the women were exposed to a series of traumatic life events that occurred within a relatively short period of time, but discovering their own seropositivity seemed to be the most difficult experience they had to deal with. Ika, for example, said:

“Many times I said to my husband *Stop using IV-drugs, you’ll get HIV*. But I never thought that *I* would get the virus. Never thought that. I thought only he was at risk of being infected. If I knew, I would not have agreed to have sex with him”.

Among the most prominent feelings expressed by the women in relation to their serostatus was anger, although in most cases such an emotion remained unexpressed. In a society where women are told to obey their husbands, where they are duty-bound to immediately step in as care-givers when they fall ill, it is certainly understandable that the women may not have felt it appropriate to vent their anger at their husbands, especially when the men were clearly, helplessly sick. Demonstrating servitude at a time like this is widely believed to be part of being a good Muslim and is therefore expected to reflect one’s devoutness. As we will see further down in Amelia’s, Ita’s

and Ana's narrations, this awareness to remain subservient appeared to act as a powerful anger management tool. Anger, in most cases, was mixed with elements of acceptance. For example, Amelia stressed that she was a "victim" of her husband's actions. She took an HIV test six months after he tested positive. She felt betrayed because he had never told her about experimenting with IV-drugs and confessed about it only after he became very sick. But she was also overwhelmed by a deep sense of regret because she had not found out earlier that he was a drug user. She said:

"I felt like I was struck by lightning when he confessed I have never done anything improper. I have never smoked, never drunk, never done anything *wrong*, so how could it be that *I* ended up with the wrong disease? I was angry and I felt vengeful. I wanted to yell at my husband but how could I? He couldn't even stand on his feet. So all I could do was cry I was even angry at God because this is *unfair*".

Amelia was also angry at her in-laws who did not seem to care that she had contracted the disease. In fact, they threw her and her children out of the house shortly after Yanto died. This action seems to reflect their wish for closure - their desire to put a rather "embarrassing" past behind them and hence to do away with what still connected them with such a past. They never even bothered to call Amelia to inquire how she and her children were doing.

Ita, whose marriage to Roy only lasted three months, also felt angry when she found out about her status but was not able to express her anger at her husband, as he was already on a wheelchair, unable to walk. Roy was indeed experiencing severe symptoms of toxoplasmosis, indicating a late stage in his disease trajectory. She said:

"Part of my life was gone. I couldn't do anything. I couldn't even cry because it had already happened I wanted to get angry at my husband, but he was so sick already God is not fair. Why? Why me? I have never engaged in risky behaviour. I have sex only with my husband So for women who never do bad things, contracting the virus is an act of unfairness from God".

The fact that Amelia and Ita could not express their anger towards their husbands who were seriously ill may have led them to turn their resentment to God. Showing one's anger at God to an outsider certainly is indicative of a very strong emotion. This may seem rather surprising, considering the prevailing philosophy of acceptance, widely considered here as the philosophy of "wisdom". But perhaps the women were merely expressing their frustration towards the widespread cultural and gendered perception that a woman must always be subservient to her husband, no matter what the circumstances were.

Ana was the only respondent who was not surprised that she tested positive. But despite her wish to lash out at her husband, she preferred to stay quiet. In fact, she did not even dare to cry, for fear of upsetting him. She explained:

"I knew my test would come back positive because my husband already tested positive. I already had a child from him so I thought there was no way I would still be HIV-negative. I'm a woman so I'm more vulnerable. Well, if this is my destiny, I accept it. When I found out about my status, my husband was lying weakly on the hospital bed. He couldn't do much, so how could I have gotten angry at him? I wanted to cry but I didn't want to burden him".

Only Liana was able to express her anger and even demanded divorce, although this never materialised, considering that Reynold died shortly after his diagnosis. As mentioned earlier, Liana was sick first and found out that she was positive a month after she received her reactive test result. This happened after she experienced a severe case of diarrhoea, collapsed, and was brought back to the hospital where she was tested for HIV.

"My husband was tested for HIV the day I found out what reactive meant. When his test came back positive 3 days later, I was very angry. It finally dawned on me that *I* was living with HIV. I thought, my children need to be tested right away. My husband said, *Just accept reality*. I said, *It's easy for you to say that. No, I don't want to accept that I'm positive*". He said, *But what can you do? You can't turn back the time*. I finally said, *Ok, I will let go on one condition. If the kids are found positive, I will file for a divorce*. He agreed".

Here, the gender dynamics come to the fore. Reynold's offhand reaction indicated his desire to show that he was still in charge, that despite the crisis they were going through, he was still the head of the family. But Liana's outrage as a result of her infection and the possibility that her children might also be living with HIV probably caused her to not care any longer to play the subservient wife, especially considering that Reynold had not developed any symptoms of ill health at the time.

Interestingly, although the women were angry, most of them said they did not really think that their infection was a kind of betrayal on the part of their husband. This may seem contradictory to what Amelia said earlier, that "she felt betrayed because her husband never told her about experimenting with IV-drugs and confessed about it only after he became very ill". But as we will see in Ita's and also in Ana's quotes below, although they said they were not betrayed, they actually expected truthfulness and kindness from a husband and from a romantic love, but received the opposite.

"I don't think I was betrayed, but of course I was disappointed in him. I didn't feel vengeful, just angry. I figured he probably didn't disclose his status because he was afraid I would leave him. I said, *Why didn't you tell me? Why did you let me find out only after we spent our first night together, after we did all those things together? How could you be so mean?* He defended himself by saying that he did give me hints, but stressed that if he did tell me frankly about it, I would have left him and that would have destroyed him. So I let go. We really cared for each other, we loved each other. He loved me for what I was, so how could I not love him for what he was?"

The above excerpt tells us that despite the betrayal - which Ita refused to call as such - she found it in her heart to *forgive* her husband although she was among those who were most taken aback when learning that they were infected. She said she had no vengeful feelings for him although he did not disclose his status to her. Ironically, her husband feared abandonment but in the end *he* abandoned her through death.

Ana put forward the finality of death to absolve her husband's lack of truthfulness. She said:

“I don’t think it was betrayal. Maybe if he experimented with drugs behind my back after we were married, I would think it was betrayal. But it happened before he even knew me, when he was still single and going to high school. So I accept it. Anyway, what could I have done? Sue him? He’s already dead, so forget it. Let’s not even discuss it anymore”.

Thus, despite her husband’s lie, it appeared that Ana still felt duty-bound to defend him. She even internalised a reason (it happened before he even knew me) to absolve his “sin” of not being truthful about his past which has led to his death and their only child’s and caused her own infection as well.

Another common reaction one generally has besides being angry when faced with bad news is to blame others. Ana, for example, believed that the government was mostly responsible for not providing enough information to the people regarding the danger of HIV/AIDS. But she also blamed her husband for not telling her that he used to be an IDU. Looking back, she was certain that had she been aware of the connection between IDUs and HIV/AIDS, she could have prevented her own infection, and both her husband and her baby would probably still be alive today.

Liana also blamed the government for not providing sufficient information to the people about the danger of HIV/AIDS. She believed that information and education programmes should be organised in every neighbourhood so that people can take precautions and the stigma attached to the disease can be minimised. But while she blamed her husband and held him responsible for her infection and her two children’s, her parents and her in-laws blamed *her* for her infection. She explains:

“I’ve always been a good girl. How could *I* have AIDS? I’m a victim of what my husband has done But my parents said it’s all my fault because I married Reynold against their wish. My parents wanted me to get a higher education but I chose to marry Reynold and become a housewife instead. Reynold already had a good job with a promising career, so why would I have wanted to go to college? Reynold’s parents also blamed me. They think I was the one doing bad things”.

Ana also firmly stressed that she had no way of preventing her infection. When asked whether she felt, in a way, that she had let herself down by not taking safety measures to prevent the infection, she said:

“How could you say that I failed to protect myself? I didn’t know what was at stake. You can’t see HIV, you can’t touch it, but you can get it from having sex, from injecting drugs. If I knew Herman was an IDU, if I knew he was positive and if I knew how HIV was transmitted, I don’t think I would have agreed to marry him although he was Mr. Perfect”.

Liana’s and Ana’s narrations tell us that they do not want to position themselves as irresponsible in their choice of life partners. This may be a reaction to their internalised stigma as being the widows of HIV-positive addicts, but clearly also another attempt to emphasise that they were not responsible for their own infection.

Ita, on the other hand, tended to blame herself for her infection. Her narrative put forward the guilt feeling she experienced for failing to protect herself from the infection. She said:

“Why was I so stupid? Roy already gave me hints about his infection but why didn’t I insist on using condoms? I could have said that I didn’t want to get pregnant because my daughter was still a baby So I deserve this I have made a huge mistake by letting myself become infected. I gave my parents the biggest shock of their life I thought I was a good girl but I got infected anyway, so what can I say? ... If my friends knew, I’m sure they will shun me. And people will shun my family because I’ve got HIV and I live with my parents”.

It is interesting to note that despite their infection, the sense of being duty-bound is still very strong in most women. They were thus angry about their infection, and yet they refused to blame it on their husbands although, paradoxically, they held them responsible for it.

4.3.2 Thoughts of Death and the Meaning of Children

Most women in the study had thoughts about dying or suicidal ideation after finding out about their serostatus and/or when their husband died. One of them even attempted suicide. But such thoughts were generally fleeting. Again, elements of acceptance were present in the women's narratives, which coincided with a re-evaluation of their roles as primary care-takers of children and other people living with HIV.

Amelia started to develop candidiasis of the mouth and could not eat while her husband was sick. She wanted to die before he did, as she was afraid of being left alone. She lost her will to live after her husband died. She was hoping that God would take her life too, as she felt she was not strong enough to stand on her own two feet, until it dawned on her that her life still had a purpose after all. She said:

“I was sad thinking that no one would be willing to take me in, but then I thought that our life is fated I finally realised that God still loved me. He still gave me the strength to go on. Then I did all I could to take charge of my life because I realised that I was still needed. So, no matter what, I have to get over my anguish for the sake of my beloved children because I have faith in God. I know that God doesn't make mistakes. No matter how difficult, I have to get up and earn a living for my children”.

Ika's suicidal ideation also disappeared when she realized her presence was crucial to keep her HIV-positive son alive. She was determined to stay healthy, namely by adhering strictly to her regimen, so that she can continue to earn money for his sake. She said:

“I did want to die. I wanted to kill myself, but when I saw my son, I felt sorry for him. How is he going to live without his mother? He would have lost both parents. Poor thing The most important thing in my life now is to stay healthy, and to make sure that my son is also healthy, so I can continue to work and earn money to buy medication and milk for him. I want to see him grow up to be a good person, someone I can be proud of, because even with HIV he can still achieve great things in life. I pray that he will perform really well in school

so that he can get scholarships all the way through college. But that would only be possible if he stays healthy, hopefully until he gets married. That is my dearest wish”.

Ana too wanted to die. She explained:

“When I got the test result I felt like I was struck by lightning. I felt like I couldn’t breathe. I was angry; I was frustrated; I was sad; just like when somebody just stabbed you over and over again. I thought I’d better die, but then I remembered what my husband said. He said, *We must always look forward, we must never look back, we must keep going, we will die when God says it’s time to die. So while we’re still alive, we must keep going.* I have been doing that until now ... When I feel sad, I go over in my mind what my husband said I realised that people living with HIV who become very sick can still survive.

Ana was referring to AIDS patients she had visited at the hospital as part of her current job at one of the NGOs. She said that those patients were lying helplessly on the bed, skeleton thin, with deep sunken eyes, and yet they were able to recover and get on with their lives. She realised that being HIV-positive does not necessarily mean that death was imminent. As regards her baby who died at seven months following a severe episode of diarrhoea, Ana remembered how often the baby actually had diarrhoea, but no one, including the physician, suspected that it might be HIV-related, as both she and her husband were still very healthy then. Her comments suggested she had feelings of guilt about the baby’s death, for not taking her to the hospital like the previous times, because of financial reasons.

When Ita was informed of her status by the counsellor, the first thing that occurred to her was that she probably wouldn’t have that much time left to live. She once actually attempted suicide by swallowing all the pills she could find in her bedroom (mostly cold remedies), but decided she did not want to die when her daughter suddenly walked into the bedroom. She was horrified by what she did and ran to the kitchen where she gulped down milk to neutralise the medication.

Being a widow living with HIV with the responsibility to raise children certainly is a difficult task. But the burden is even heavier for mothers whose children are HIV-positive, considering that the Indonesian government does not provide free ARVs for children. It was thus enlightening to discover that although having children and bringing them up imply additional expenses, these children were also the women's main reason to live, which stopped them from having suicidal ideation and gave them the encouragement to go on.

Mamiiek did not experience suicidal ideation but when she thought about her infection, she still wondered whether she would live long enough to watch her son grow up. She still missed her husband sometimes but lately when she thought of him, such thoughts were mainly in relation with the new man in her life, which made her feel guilty. Recently she got a job in Kalimantan, one of Indonesia's main five islands, working as a dancer in a discotheque. This job often takes her away a few weeks at a time from home. Unfortunately, she still had not checked her CD4 level. But Mamiiek was committed to keep her spirit up because she now has a very important objective in life, which was to protect her son. She said she had great hopes that he has not contracted the virus, although she was not ready to confront reality. She said:

“Yasril is HIV-negative. I've got him tested only once I also tested negative the first time but then later I tested positive Yeah, I know The reason I work, although the job takes me away from him, is that I don't know how long I will live, so while I'm still alive - and thank God I have a job - whatever he needs hopefully I can fulfil. I do this only for him. He's the only one who gives me encouragement to live. If he wasn't there, I don't know ... I was so shocked when I learnt that I was positive. What to do? ...”

Mamiiek's narrative shows that she has not fully come to terms with her own infection and implies that she was not ready to deal with the possibility that her son might be infected. The fact that she first tested negative and then positive appears to have been particularly traumatising to her, and she is obviously afraid that the same thing might also happen to her son. The above excerpt also tells us the extent to which Mamiiek lacks knowledge of HIV/AIDS, in particular with regard to post-diagnosis care and the importance of finding out or confirming one's HIV status as early as possible.

The perception of “the good mother”, however, takes on greater significance for the women in the study. It is a powerful counter-narrative in their lives as widows of drug addicted HIV-positive men. Indeed, it almost becomes redemption for “picking the wrong husband”. In her journal, Mamiek wrote:

“Day by day my life becomes more beautiful thanks to my son. Day by day I love him more and more”.

“I will always take care of you, Yasril. When you’re awake, when you’re asleep, in dreams and in reality, my dear son. I will always take care of you in life and in death. I don’t ever want to be away from you. I want you to be a good person to all those who love you. I want you to always remember your father. I want you to grow to be self-reliant. I love you”.

For Liana, her children meant everything. She said:

“My children mean more than the world to me because they can make me forget my problems, my sadness. They can be my friends and they can make me forget that I’m lonely”.

Accepting that two of her three children were also living with HIV was most challenging for Liana. She explained:

“I’m an adult. I’ve been married. I have already lived a good part of my life, but my children are so young, they still have a long way to go. But if they do live a long life, what should I tell them? What should I say they are suffering from? Even now the eldest already starts asking questions, *Why do I have to take medicines everyday, twice a day? Why only me and Andy? Why not Amir?* He also said, *You also take medicine. What’s wrong with you?*”

The above narratives highlight the research participants’ profound love for their children and demonstrate their deep concerns for their sons’ good health and wellbeing, which constitute strong motivations for the women to come to terms rapidly with their own infection.

4.3.3 Stigma

It was most interesting to note that most women seemed to be more concerned about being a person living with HIV rather than mourning the death of their husbands. But this concern about seropositivity is certainly understandable, considering that HIV/AIDS remains a highly stigmatised disease in Indonesia.

The narratives of the women reveal that they have experienced stigma within their own family. But they were mostly afraid of being shunned by other people, as this was seen as a dreadful barrier to carry out their role as a single parent. One of their top priorities, therefore, was to make sure that no one would ever find out about their serostatus. Ita, who until now still endured stigma at home, said:

“My father is the one who shuns me most. I had to use my own dishes, silverware, glasses, and keep my dirty clothes apart. Now he still watches me closely when I’m with Angky. He forbids me to kiss my own daughter. Sometimes, when he catches me kissing her, he would say, *You really want to infect her, don’t you? You really want Angky to die!* It hurt so much He keeps saying that even with a small amount of saliva, HIV can be transmitted I’m most terrified by the idea that people might find out that I’m living with HIV. That would be disastrous, especially for my daughter and also for my extended family. But my parents would also be shunned because they live with me. That is what I fear most. Only my main family knows Roy’s death was AIDS-related. As far as other people are concerned, he died of a kidney failure”.

She added:

“A man living with HIV will not be blamed, but when you’re a woman living with HIV, people automatically assume that you’re promiscuous. But as a widow, you’ve got to live with the legacy... a virus”.

Liana, as mentioned earlier, was blamed for her infection by her in-laws who accused her of being a bad girl and of transmitting the virus to her husband although they knew

that he was an IDU. After her husband's death, Liana went back to her parents' home with her three children. She explained:

“Sometimes my in-laws want to see my children, so I bring them over to their house. But they don't want to see me.... When my children are at their house, people are told to stay away from them because my in-laws think that my children are contagious. I told them that HIV is not that easily transmitted but they don't believe me. They continue to think that HIV is dangerous and contagious. I don't mind that people discriminate against me and my children but I do mind that my own family does it to us. It really hurts”.

Liana was also afraid that other people might know that she was HIV-positive. It is the main reason why she still wasn't ready to go back to work. Referring to the antiretroviral drugs she was taking, she said:

“I'm scared that my co-workers might ask what pills I was taking, although I would have gotten rid of the wrap. After learning my status, I didn't even dare go out on my own. I kept wondering if just by looking at me, people would know that I was HIV-positive”.

Mamiek expressed regret that prevention programmes were still limited. She was terribly hurt by her neighbours' stigmatising attitude when her husband died and felt somewhat vengeful. In Islam, it is a tradition to give a last bath to the deceased in order to prepare him/her for the afterlife. Normally, when a man dies he is given a last bath by male relatives and neighbours and when a woman dies, she is given a last bath by female relatives and neighbours. She said:

“We were going to give Igor his last bath at home but our neighbours said no, they said that the water will be made contagious. So I said to them, *Who died of AIDS? My husband died of toxoplasmosis!* Of course I had to hide the truth. But they knew. Maybe because they saw how Igor looked. He had lost so much weight. So his remains were brought back to the hospital where he can have his last bath and then brought back home in a coffin ... I really felt vengeful towards my neighbours”.

When Ika came back from the hospital with her test result, she told her mother right away about it. The latter broke down and cried hysterically. She told Ika to leave the house and to go live with her in-laws in Bogor, a city about an hour drive away from Jakarta. Ika said:

“My mother said I should go away and live with my in-laws, and I should bring my child with me so that people don’t shun me She said that in Bogor nobody knows that I’ve got the virus. Oh God ... are people really that naïve about this disease?”

Curiously, Amelia did not experience stigma but was actually, unconsciously, self-stigmatising. She said:

“I have not been discriminated against by my friends because I didn’t tell any of them that I was HIV-positive, but I took care not to put my friends at risk by not sharing any food with them”.

The above narratives tell us that stigma has indeed become part of their new life as widows living with HIV. While the women resented being stigmatised by their own family and, to a lesser extent, their neighbours, they were determined to keep their serostatus hidden from outsiders, so they can lead a “normal” life and continue to earn a living for their families.

4.3.4 The Need for Counselling

The question whether a specific bereavement counselling programme was needed for women who have lost their husbands to AIDS-related causes and what kind of topics should be addressed in such counselling were examined from the narratives and journal entries of the women. It shows that there was a need for counselling but not the kind that is specifically intended to address grief and bereavement issues. Although the respondents generally agreed that bereavement counselling services can help women who have just lost their husbands to AIDS-related illnesses, it is clear that there is a stronger need for programmes that would deal more particularly with their

infection, namely to give them “a sense of direction” after finding out that they were infected. In other words, the research participants confirmed the need for programmes for women who recently lost their husbands to AIDS-related illnesses and are themselves HIV-positive, to help them to come to terms with their new status as a widow living with HIV.

As mentioned earlier, all the women were in general sad that their husbands had died. But learning that they were themselves HIV-positive was a particularly devastating experience mainly because they had never thought they would ever contract HIV and because HIV remains a highly stigmatised disease in Indonesia. A growing number of NGOs do provide services that are intended to give support to people who have just found out about their serostatus, particularly peer support groups, but the women were not aware of the existence of such services at the time they found out about their status.

In Ana’s opinion, one important topic to be discussed in counselling is health issues. She mentioned meeting another person living with HIV whom four years post-diagnosis still did not know what opportunistic infections meant. She said that women in her situation needed especially to feel that they were not alone. They need to know where to meet other people like them; therefore it is important that information about peer support groups is conveyed during the counselling sessions. As she pointed out, finding out that one lives with HIV is a terrifying experience because “*you don’t know where you go from here*”. She still remembered how confused her husband looked when he came out of the post-counselling session. She said:

“There’s a need for a programme that when you come out of it, you have an objective, you have hope, you don’t feel alone, you don’t feel down and out. A programme that makes you feel that living with HIV is just like having a cold, that you can get well, that you can still have plans”.

Liana, who now has the responsibility to raise three young children on her own, believes that a counselling programme should address what to do when you are discriminated against by people around you, especially by your own extended family.

She stresses that a woman in her situation dearly needs to regain self-confidence and thought that 4 to 5 months of counselling would be necessary. She said:

“You need this kind of counselling: You’re infected. Where do you go from here? How do you tell your children that they’re infected? How to have a decent life despite your status? You don’t need bereavement counselling. Of course, you’re sad when your husband dies, but your sadness goes away with time and surrendering also helps - even if you get angry you can’t undo what’s already done. As for your status, you’re stuck with it for life. You have to keep taking medication. So how do you tell your children that they are HIV infected when they’re old enough to understand?”

Ita said:

“There’s a need for counselling for women living with HIV because women are more vulnerable, they are shunned more than men are. If you’re a man living with HIV, people don’t really care what you do. But if you’re a woman, people automatically think that you’re a “bad girl”. People around me have said bad things to me. I need a programme where I can say what’s in my heart. It’s not good to be left on your own [after finding out your status]. If you’re alone, you’re alone with the devil”.

As for Mamiek, she believes that counselling services were especially needed to give hope to women in her situation that they can and will fall in love again, as this will provide them with a strong motivation to go on with their lives.

It is clear that for the women, being shunned, being sick and therefore not being able to take charge of their children, are serious concerns that are closely associated with being a person living with HIV. The women are thus of the opinion that counselling services are needed, but mainly to help them to come to terms with their infection. Indeed, none of them alluded to the need for bereavement counselling programmes.

4.3.5 Other Matters of Living with HIV

Below are other issues of living with HIV that transpired from the women’s narratives,

namely the prospect of a new relationship, the meaning of an AIDS-related death, and the role of family support and religious beliefs in the lives of women who have to hide the cause of their husbands' deaths and their own seropositivity from outsiders.

4.3.5.1 The Prospect of a New Relationship

The prospect of a new relationship appeared to present a dilemma to the women. On the one hand they needed someone close to them to replace their husbands but, on the other hand, they were reluctant to make commitments, especially because of their serostatus.

Mamiek, for example, was reunited with an old boyfriend, Arman, shortly after her husband died. Although she reciprocated his feelings, she had doubts about getting into a serious relationship with him. She kept wondering whether a romantic involvement between an HIV- positive woman and an HIV- negative man could have a happy ending. Her hope of finding happiness with another man was therefore tainted with constant confusion and hesitation. In the journal, she wrote:

“Why do I have doubts now? Tonight I really miss Arman but I’m scared I also miss my husband”.

Ika specifically mentioned that she would not want to have a relationship with an HIV- positive man. She said:

“I’ll be careful to engage in a new relationship. If somebody is willing to take me as I am, I’ll make sure that he can support me and my son, that he can accept that I’m positive. But I have never wanted to have sex again. I’m afraid to pass the virus to other people. I’m willing to get married again but not if that would make my life more complicated”.

Liana said:

“Sometimes when I’m alone, I think about having a new relationship. Not that I want to have sex, I just need someone to talk to. I need someone who cares. If

I have a boyfriend, he'll take care of me when I'm sick, he'll remind me to take my pills. But I keep thinking, what happens if he finds out that I'm positive? If I have a boyfriend who is also living with HIV, that would be too complicated. It can lead to resistance to the drugs, that's what I've learned. So it's best if I don't get married again".

Ita was determined to never marry another person living with HIV. She strongly believed that a couple should not be both HIV-positive, since no one would be there to care for them if they both happened to be sick at the same time. She also did not want to have a relationship with another former drug addict. She said:

"Most ex-junkies die faster than other people living with HIV. I want someone who can protect me and my daughter. I don't want to have to hide my status because you cannot start a new life with a lie. If no one would take me because of my status, well, so be it. I don't want what happened to me to happen to other people. It hurts so much to be lied to".

Ana, on the other hand, stressed that she only felt comfortable when she was among people who were living with HIV, but has hesitations about getting into a serious relationship. She said:

"I have never thought of having a relationship with someone who is not living with HIV Since my husband died, I have only been with this one, but I don't know if I want to have a more serious relationship. Now we're just dating. I don't want to hope too much. In the past I wanted to have a happy family, but look what it got me into. And now I'm HIV-positive. If I have that kind of hope again, I can find myself in deeper trouble".

Amelia said she was not looking for a new life partner. She said:

"I don't want to have a relationship with someone who is not HIV-positive. I don't want to make his life difficult. But if I meet somebody who is also HIV-positive, what can two sick people expect to have together? I'm sure we will go through what Yanto had gone through so as long as I can still keep my eyes

open, as long as I can still breathe, I'd rather try to earn money for my children".

It was interesting to note that the women sounded very "matter-of-fact" about their serostatus when it concerned the prospect of a new, consensual relationship. They have concluded, realistically, that having another husband may not be worth the trouble, as they needed to concentrate on earning a living for their children, which was more important than anything else.

4.3.5.2 AIDS-related Death

Some of the women believed that AIDS-related death can be prevented, while others did not. Ita said that Roy could have been saved if he was brought sooner to the hospital and received proper medical care. Having been diagnosed with toxoplasmosis, Roy started to have difficulty walking shortly after the wedding. His legs hurt when he put his full weight down, therefore he needed support when standing up. But instead of giving him the medical care he needed, his parents took him to a traditional healer, who made him walk on shreds of glass and take cold baths in drums, which were part of the healing process - or so they were told.

Ana also believed that her husband's death could have been avoided if she knew the association between IDUs and HIV/AIDS. She was certain she also would have been able to prevent her own infection and her child's death had she had a better knowledge about how HIV was transmitted.

Ito believed that an AIDS-related death is different from other deaths because it can be prevented, while other deaths are fated. She said:

"One gets AIDS because of his own behaviour, so one must bear the consequences of his actions".

Mamiek on the other hand believed that death is fated, no matter what the cause of death may be. She assumed that Igor died quickly because God loved him, therefore He did not want to prolong his suffering.

As with Mamiek, Liana also believed that death is predestined and unavoidable. She said:

“As a Muslim I believe that death is fated. Death due to an AIDS-related illness is no different than any other death, it also cannot be prevented. God decides how we die, whether from an AIDS-related illness or from any other cause and we never know when we will die. I accept death because it’s fated”.

It was moreover interesting to observe that when asked whether an AIDS-related death was different from other kinds of death, the women stressed heavily on the physiological characteristics of people who are dying of AIDS-related illnesses. AIDS-related stigma, which was clearly among their top concerns, was not mentioned.

In Ita’s opinion, for example, loss of memory was a telltale sign of an impending AIDS-related death. Also, the fact that her husband Roy lost so much weight so quickly made AIDS-related deaths different from other kinds of deaths. She remembered that over a period of only two weeks, Roy’s body shrunk dozens of kilograms.

Extreme weight loss was also cited by Amelia who moreover emphasised on her husband’s deep sunken eyes. She pointed out that her husband also had high fever and experienced convulsions, whereas someone who dies a “normal” death would simply stop breathing without going through all those symptoms.

For Liana, the main characteristic that set AIDS-related deaths apart from other deaths is the presence of opportunistic infections that are often difficult to treat or recurring in accordance with one’s CD-4 cell count’s fluctuations.

None of the women has thus mentioned stigma as regards AIDS-related death, although it is clear that their new life as a widow living with HIV revolves around the fear of anticipated stigma. This is an interesting phenomenon, considering that they have experienced and resented stigmatisation by their own family and, to a certain

extent, their neighbours, and have identified stigma as the most dreadful threat to being able to work and earn money for their children.

4.3.5.3 Family Support

In the absence of bereavement counselling services for people who have just lost their partners to AIDS-related illnesses or for people who have just found out about their serostatus – and considering that many people who have just found out about their serostatus are not aware of the existence of peer support groups, the role of family support is evidently crucial. The importance of such support transpired from the narratives of the research participants, which is certainly understandable considering that the women could not rely on social support as they were afraid to be shunned, and therefore did not disclose the cause of death of their husbands or the fact that they themselves were seropositive.

As mentioned earlier, some of the women faced discrimination and stigmatisation by their own family when they first found out that they were living with HIV. But the situation generally changed to the better once the family understood that HIV was not that easily transmitted.

After the death of her husband, for example, Ika was invited to stay at her elder sister's house where she lived with her husband and her parents. At the time, she did not know that her husband's death was AIDS-related and was not aware that she herself had contracted the virus. She fell ill a few months later and was diagnosed with HIV. She then found out that her son was also infected. She said:

“I wanted to kill myself and my son. But my sister gave me strength, she convinced me that I can still live like I used to, that I shouldn't care about what other people say. What's important is that I got the virus from my husband, not because I was a prostitute”.

But she was devastated that her own parents shunned her when they found out that she was HIV-positive. She was particularly hurt when her mother told her that she and her son should live in isolation - in “quarantine”. The situation changed after Ika from

time to time asked her mother to come along to the NGO where she was working, so she could understand how HIV can and cannot be transmitted. During the second interview she said happily:

“My family can now accept me for what I am. They are willing to drink from the same glass I use, share meals with me, even share the same pillow with me... They never did that before. They were afraid”.

Fearing stigma, Ana initially wanted to keep her status hidden from her parents. But as she thought that they would end up knowing anyway, she finally decided to tell them the truth. She was relieved to find out that her family was able to accept her infection and in fact reached out to her by inviting her to come back to live with them in her hometown, Cirebon.

As for Ita, although she still had to endure being shunned by her own father who continues to forbid her to kiss her own daughter, she was happy that her parents finally allowed her to come back to live with them after Roy died.

Thus, family support played a crucial role in the women’s lives post-diagnosis and post-loss. In fact, as in Ana’s case, such support proved potent even when long-distance. In short, knowing that their own family still cared for them despite their serostatus provided the women with the necessary confidence to go on, and a platform to start a new life as a person living with HIV.

4.3.5.4 Spirituality or Religious Beliefs

Although spiritual support was not the first thing that came to their minds when asked how they tried to cope after the series of traumatic life events, and although none of the women confided in religious leaders owing to the nature of their husbands’ deaths and the stigmatised disease they were now living with, it is clear that, for some of the women at least, religious beliefs also played an important role in their lives, especially during the most difficult times they were going through.

Mamiek, for example, mentioned that when her husband was sick, she prayed diligently, asking for his recovery. She admitted however that after his death, she did not observe the 5-time-daily praying ritual commonly observed by people of Muslim faith. There were several entries evoking God in her journal. Mainly, she asked the Almighty to show her what to do with regard to her newfound love, more precisely what to say next time he brought the subject of marriage up again during their conversations, which emphasised the dilemma of getting into a new consensual relationship for women in her situation.

Ana did not have friends she could trust and could not talk to her parents because they lived in another town. For some time after her husband's death, which occurred after she knew she had contracted the virus, she kept to herself, refused to go out or talk to people. But she was able to find relief by crying while doing her prayers whenever she was missing her husband.

Ika prayed mostly for a long, healthy life despite her status, reminding herself that she had to be strong after her husband died as her son needed her to be there for him.

Amelia is one of the women who blamed God for her infection. Her journal entries revealed an ongoing conversation with God in which she was giving Him a chance to right the "wrong" He had done to her, stressing her conviction that He was "just" as she had grown up to believe that He was. She wrote:

"Dear God, I still cannot accept my destiny. I feel lonely and confused every time I think about my status. Will I be able to live longer than I expect? Please give me a chance so that I can see my children grow up and become good people. Please God give me a chance. I know you are just and wise. I am a victim of injustice Let me live longer so I can earn a living and not become an encumbrance to the people who are close to me. Show me that you are fair".

If family support was crucial in the lives of the women at a time when they had no one to turn to or when they could not expect moral support even from close friends for fear of anticipated stigma, it is evident that religious beliefs also can play a positive role in

the coping process of the women. Such beliefs seemed to have contributed in enhancing their mental health while they were trying to cross over and enter a new life where they have come to terms with being a widow and also with living with HIV.

4.4 DISCUSSION: SUMMARY AND INTERPRETATION

This section will present a summary of the findings and an interpretation of those findings. Each finding will be linked to the available literature detailed in Chapter 2, based on which conclusions will be drawn and recommendations for future research and for policy and practice will be made. A new theory will also be proposed.

4.4.1 Summary

The women in the study experienced not one but at least three traumatic life events over a relatively short span of time: they found out that their husbands were living with HIV; they discovered that they themselves have been infected; and they lost their husbands to AIDS-related illnesses. While each event was certainly as devastating as the other, it appeared that it was most difficult for the women to come to terms with being a person living with HIV. It seemed indeed most challenging for them to accept that they had contracted a disease that was closely associated with prostitution, while they were in a heterosexual marriage and faithful to their husbands. The infection was therefore seen as an act of injustice, utterly unexpected. Even the women who knew that their husbands were IDUs seemed shocked when they found out that their husbands tested positive and that they themselves have been infected.

The death of the husbands occurred in general a short time after the men were diagnosed with HIV. Although there were a number of reasons explaining the late HIV diagnosis, most prominent is the fact that there was little awareness of HIV/AIDS not only among the husbands, the wives and the families, but also among the medical professionals who failed to suspect HIV early enough, sometimes despite the glaring opportunistic infections they were treating.

The women believed that death is fated, but some thought that death due to an AIDS-related illness can be avoided because it is attributed to one's behaviour, not God's will. In general, they expressed sadness over the death of their husbands but they also felt anger and sometimes even hatred towards them, as they held the men responsible for passing the virus to them. It was thus little surprising that the women did not appear to be mourning the deceased - at least not anymore - despite the relatively short period of time since their husbands died. Considering that learning about their seropositivity took place within a relatively short time before or after their husbands' deaths, the women's biographical disruption may have acted as an "analgesic" in the aftermath of their husbands' deaths and may have accelerated their grief recovery process. It was indeed interesting to discover that the new responsibility as single parents and their concerns to protect the well-being of the children seem to have prompted the women to come to terms with being a widow and with living with HIV. Thus, as far as the research participants were concerned, their biographical disruption also contained elements of biographical reinforcement. In sum, while biographical disruption appeared to have distracted them from mourning the death of their husbands, biographical reinforcement seems to have strengthened the women's identity as mothers and this experience may have brought about a positive impact on the bereavement outcome.

But perhaps, also, the women's positive bereavement outcome was not totally independent of the prevailing philosophy of surrender, which underlies the "death-accepting" attitude of the Indonesian people. In fact, such philosophy transpired from the narratives and the journal entries of the research participants, not only when they were coping with the death of their husband, but the whole series of traumatic life events they had gone through in a brief space of time. Although thoughts of death and even suicidal ideation appeared, it was clear that such ideas were short-lived and that the women have been able to pick up the pieces of their shattered life and move on. Coming to terms with being a widow and with living with HIV also seemed to coincide with a re-evaluation of their role as primary care-takers of children and other people living with HIV.

Most women have faced stigma and discrimination essentially from their own families but also from their neighbours. One of their main concerns and priorities as a single

parent living with HIV, therefore, was to keep their status hidden from outsiders and to stay healthy as long as possible so they can continue to work and support themselves and their children.

As for the prospect of a romantic involvement, the women were not sure whether they were ready to engage in a new, consensual relationship, although they admitted that they needed someone close to them. For them, being with an HIV-negative person implied disclosure and the possibility of being rejected, while being with another person living with HIV presented more possibility of developing resistance to ARV drugs. The women were therefore more inclined to be self-reliant and concentrate on earning a living for their children.

Family support appeared to play an important role in the women's life, especially during their coping period. For women who had to hide the cause of their husband's death as well as their own seropositivity due to the strong stigma attached to HIV/AIDS, it was indeed rather inconceivable to expect social support during difficult times; therefore the role of family support was crucial. Furthermore, although religious beliefs did not appear prominently in their discussions, it was clear that these had a dear place in the women's life.

Finally, the need for counselling did emerge, but not for a programme that addresses AIDS-related grief and bereavement as initially expected. Indeed, the women conveyed the need for a specific counselling programme that is designed to give them "a sense of direction" after finding out about their serostatus, so they can regain their self-confidence and face the world. In other words, there is a need for a counselling programme that is purposely designed to help them to come to terms with being a widow, also with living with HIV.

4.4.2 Interpretation

Data analysis based on the in-depth interview transcripts, the women's personal journals, my field notes and reflective notes using the principles of grounded theory has led to the following interpretations:

One of the most important themes that emerged from this study is the lack of knowledge of HIV/AIDS among the general population and the healthcare providers, which has led to a delay in HIV diagnosis and even to undiagnosed HIV – hence resulting in “premature” AIDS-related deaths that might have been prevented if the patients had received treatment early enough during the course of their illnesses. This finding supports statements by the NAC (2007-2010) that, despite numerous prevention and intervention programmes which have been conducted for many years, knowledge of HIV/AIDS remains limited in this country and few of those considered at risk are aware of their HIV status. This finding also stresses the fact that limited awareness of HIV/AIDS is prevalent among the medical professionals, which is of course worrisome, considering that Indonesia is a developing country with currently the fastest spreading HIV epidemic in South-East Asia (UNAIDS 2008). More delay in HIV diagnoses simply means that more AIDS-related deaths are to be expected in the coming years. The fact that all the women appeared to have contracted the virus from their husbands also confirms claims that more and more women will become infected in the coming years and that a growing number of new infections are expected to occur in marriages (Mishra *et al* 2007).

Thoughts of death were experienced by the research participants, which support claims that bereavement and HIV seropositivity are associated with suicidal ideation (Chandra *et al* 1998; Stroebe & Stroebe 1993). But such thoughts were found to be momentary as far as the participants of this study were concerned, and only one of the women actually attempted suicide. Taking into account Cooperman and Simoni’s (in Mental Health AIDS 2005) claim that cultural norms, such as a moral objection to suicide, may be associated with lower risks of suicidal thoughts, it is not unlikely that the women’s thoughts of death were short-lived because of the widespread Muslim belief in Indonesia that death is fated. In fact, the only participant who did attempt suicide came from a non-Muslim family.

Another important finding of this study was the apparent lack of grief among the research participants. The narratives of the women suggest that while they still felt sad over their recent loss, they have come to accept such loss and were no longer mourning the death of their husbands. One may be tempted to say that failure to work through the emotional meanings of a loss will typically result in “delayed grief”

symptoms, but one would be wise to remember that the *Grief Work theory* has been challenged (see, for example, Field, Gal-Oz & Bonnano 2003) and no evidence was found that minimal emotional processing of the loss would lead to delayed grief (Bonnano & Field 2001). I suggest that the lack of mourning exhibited by the participants may also be attributed to the concept of surrender which underlies the “death accepting” attitude of the Indonesian people.

Furthermore, supporting the widely recognised positive role of religious beliefs or spirituality in the coping process (Tarakeshwar *et al* 2005), the women in this study also relied on their religious beliefs to keep them strong. But I will agree with Becker *et al* (2007) that the question of whether religious or spiritual beliefs influence bereavement is a matter of interest in different domains of science. As for family support, the narratives of the women stressed the significant role it has played in their life, particularly at a time when it seemed unthinkable for them to seek or expect social support. Indeed, AIDS-related stigma may prevent bereaved people from seeking effective support from others and may prevent those who survive from freely mourning or acknowledging the cause of a loved one’s death (Kain 1996; Sikkema *et al* 2004).

Moreover, it is important to keep in mind that the women have gone through at least three traumatic life events in a row within a brief space of time. Discovering that they were living with HIV has emerged as the most distressing experience for the women, as it implies the loss of a sense of security that was part of the taken-for-granted assumption about marriage and faithfulness to their husbands (Du Plessis 2007). This finding corresponds with Michael Bury’s concept of biographical disruption which explains why the onset of a chronic illness represents a discontinuance of one’s ongoing life, hence creates a disruption (Faircloth *et al* 2004). But considering the short lapse of time between discovering their seropositivity and their husband’s death, it does not seem unlikely that biographical disruption may also have acted as an “*analgesic*” in the aftermath of their husband’s death and contributed positively to the grief recovery process of the women. Moreover, as proposed by Carricaburu and Pierret (1995), an illness can also reinforce specific aspects of biography. My findings suggest that taking up a new responsibility as a single parent reinforced the women’s identity as mothers and prompted them to come to terms with their own infection.

Thus, as far as the women in this study were concerned, biographical disruption also contained elements of biographical reinforcement, which corresponds with Wilson's (2007) findings when she examined the inter-relationship between HIV-infection and motherhood. I suggest therefore that the above phenomenon may have brought about a positive impact on the bereavement outcome of the women.

Finally, I also discovered that the research participants were able to cope reasonably well with their distress, although the distress of loss is substantial for many (Gillies & Neimeyer 2006). Referring to the study by Zhang *et al* (2006) who suggest that resilient bereaved individuals are not likely to benefit much from bereavement services, I do not, at this stage, recommend any specific bereavement counselling programmes for women who have lost their husbands to AIDS-related illnesses.

On the other hand, the narratives of the women put forward the strong need for counselling programmes that are specifically designed to help women in their situation to come to terms with being a widow, also with living with HIV, considering that the stigma attached to the disease can strongly compromise the well-being of HIV-positive people (Gray 1999). This programme should be aimed, in particular, at giving a "sense of direction" to women who have just found out about their seropositivity, in order to help them regain their pre-test self-confidence and self-esteem.

Indeed, the narratives of the women suggest that stigma still highly prevails in this country, confirming findings of earlier studies (see, for example, Ford *et al* 2004; Merati *et al* 2005). Although the respondents reported discrimination and stigmatisation mainly from their own family, such as instruction to use their own cutlery, dishes and glasses and to not kiss their own children who were HIV-negative, they insisted that keeping their status hidden from outsiders was a priority, since they viewed disclosure as a potential threat to their ability to continue to work and earn a living for their children. Gray (1999) found that the fear of HIV-related stigma was indeed more of a concern than the fear of dying among women living with HIV. This seems to corroborate my discovery that the women's thoughts of death and suicidal ideation were momentary, as discussed above, although, once again, the unknown influence of this society's "death-accepting" attitude must also be taken into account.

Clearly, the consequences of stigma are devastating, especially for women who have recently discovered that they were living with HIV. As asserted by Chesney and Smith (1999), HIV/AIDS-related stigma not only causes delays in testing, which in turn lead to further transmissions of the virus, it also affects individual's responses to testing positive. Unfortunately, few scientists have addressed the need for specific counselling services and/or interventions to help individuals, particularly women, to come to terms with their new positive status and to improve their well-being. Among these few is Abel (2007) who found that HIV-positive women participating in an emotional writing disclosure (EWD) intervention demonstrated an improved perception of HIV-related stigma compared to women in a control group. Given the positive influence of such an intervention as shown in Abel's study and taking into account the promising potentials of this inexpensive and convenient method, its inclusion in the specific counselling programmes for women affected by HIV/AIDS mentioned above should be taken into consideration. Eventually, coming to terms with their seropositivity should coincide with a re-evaluation of their role as primary care-takers of children, which also corresponds with Frankl's theory of *self-transcendence*, which means accepting the reality that some situations are unchangeable (Mellors *et al* 2001).

In conclusion, the findings of this study highlight the urgent need for aggressive, widespread dissemination of HIV information, education, communication (IEC) materials and prevention programmes which should include specialised training courses for medical students and physicians in order to encourage a better awareness of HIV/AIDS among the health providers. Furthermore, considering that the psychological needs of people living with HIV have so far received little attention owing to the fact that most financial resources have been allocated for prevention efforts, I recommend specific counselling programmes that are designed to help women who have lost their husbands to AIDS-related illnesses and are themselves HIV-positive, to come to terms with being a widow, also with living with HIV. This programme, mainly designed to enhance the well-being of the women, should include an intervention to improve their perception of stigma, such as the emotional writing disclosure (EWD) technique suggested by Abel (2007).

CHAPTER 5: CONCLUSION

5.1 INTRODUCTION

As explained in Chapter 1, the purpose of this study was to determine whether specific bereavement counselling programmes for women affected by HIV/AIDS are needed in Indonesia, where no general bereavement counselling programmes currently exist. In order to answer the above research question, I used concepts as discussed in the literature review in Chapter 2 and followed the qualitative methods as described in Chapter 3.

Six young women who had lost their husbands to AIDS-related illnesses within the previous 12 months were thus recruited for this study. My in-depth interviews with the participants revealed that the women had in fact experienced not one but at least three traumatic life events within a short period of time: They learned that their husbands were living with HIV, they discovered that they themselves were HIV-positive, and they lost their husbands to AIDS-related illnesses – all of which have culminated in the unfortunate end result that they were now not only widows but also living with HIV.

The four main themes that emerged from data analysis based on the principles of grounded theory as described in Chapter 4 are as follows:

- Limited knowledge of HIV/AIDS
- Coming to terms with being a widow, also with living with HIV
- The “new” role as a single parent, i.e. mothering, for the widow of a spouse who died of an AIDS-related illness
- The need for counselling addressing seropositivity

What was mostly unexpected from this study was the discovery that all the participants were also HIV-positive. This experience changed the women’s bereavement from “simply” mourning the loss of their loved one to a complex grief that was mainly highlighted by concerns about their new, irreversible status, in addition to having to cope financially with the loss of a bread winning partner.

The results of this study demonstrate that undiagnosed or late diagnosis of HIV-infection was fatal for the IV-drug users, and this has led to the infection of the wives and in some cases their children as well. It shows that stigma pervades the lives of these women affected by the death of a man who was living with HIV, who did not perceive himself to be at risk despite being or having been an injecting drug user (IDU), who did not know about his serostatus (or was not “open” about it), and who was not diagnosed until it was too late. The stigmatisation of the husbands spilled over into the stigmatisation of the women, some of whom were even blamed by their in-laws as being the vectors for the infection. Thus, stigma was perceived by the women as the most frightening threat that was “part of the package” of being a person living with HIV. This fear for anticipated stigma, in turn, may hinder their efforts to ensure the welfare of their children. This perception is certainly understandable and consistent with this study’s other findings that highlight the limited knowledge of HIV/AIDS among the research participants and their deceased partners as well as the medical professionals who attended to them. As elaborated in Chapter 2, AIDS-related stigma is associated with misinformation about HIV, and this also transpired from the narratives of the women which suggest that the most challenging experience they had to deal with was that they have contracted a disease they knew to be mainly associated with prostitution.

The women in the study learned about their seropositivity within a brief time either before or after their husbands’ deaths. The biographical disruption they experienced appeared to have numbed their anguish resulting from the loss of a husband to an AIDS-related illness and, surprisingly, may have accelerated their grief recovery process. Indeed, the results of this study show that biographical disruption had elements of biographical reinforcement which stemmed mainly from the women’s concern to protect their children, which was then viewed as their primary responsibility as single parents. Thus, earning a living suddenly became an urgent priority for the women. This biographical reinforcement appeared to have set off the women into coming to terms with being a widow and, most importantly, with living with HIV. In other words, while biographical disruption appeared to have repressed the women’s grief over the death of their husbands, concerns about the well-being of

their children may have triggered biographical reinforcement, and this phenomenon seemed to have brought about a positive bereavement outcome.

In light of the above, the answer to the main research question is yes, specific counselling programmes for women affected by HIV/AIDS are indeed needed in Indonesia, but when developing such programmes, there are priorities that need to be taken into account. First and foremost, emphasis should be placed on how women who lost a husband to an AIDS-related illness and are themselves HIV-positive can deal with their seropositivity and improve their perception of stigma. In other words, the counselling programmes should first be directed at improving the well-being of such women, as this is essential before they can tackle other complex psychosocial and socioeconomic needs which are looming ahead of them, such as earning a living to support their family or getting into a new, consensual relationship.

Moreover, as discussed in Chapter 2, it is important to bear in mind that bereavement intervention or counselling for normal grievors have modest effects on outcome variables (Wagner *et al* 2006) and to take into account Zhang *et al*'s (2006) findings that resilient bereaved individuals are not likely to benefit much from bereavement services. Furthermore, I would like to remind the readers that there has been no evidence to support the *grief work theory* which highlights the necessity to work through the emotional meanings of a loss, or that minimal emotional processing of the loss would lead to delayed grief (Bonanno & Field 2001). In my opinion, based on the findings of this study, the research participants were normal grievors; therefore they may not benefit much from so-called bereavement counselling programmes.

In conclusion, I found the concept of biographical disruption and biographical reinforcement, as well as the grief work theory and the delayed grief hypothesis as described in Chapter 2 to be particularly useful as heuristic devices to help me analyse my findings, and the qualitative methods based on the principles of grounded theory as elaborated in Chapter 3 to facilitate the goal of understanding the lived experiences of women who have recently lost a husband to an AIDS-related mortality and are themselves HIV-positive.

5.2 LIMITATIONS OF THE STUDY

Low recruitment rates are well-reported disadvantages of qualitative research. The fact that the study utilised a small, non-probability sample consisting exclusively of women who all turned out to be HIV-positive limits the generalisability of the findings.

Furthermore, participants in qualitative research are generally either very happy or very unhappy with the theme that is the object of the study – in this case, it was bereavement counselling programmes for women who have lost a husband due to an AIDS-related illness. Although no polarised views of their experiences were given by the participants, perhaps because all the women in the study were HIV-positive, and they all highlighted their difficulties to come to terms with their own seropositivity rather than with the death of their husbands, it is nonetheless important to appreciate that the objective of qualitative research is to identify not only the full range of issues the participants are faced with, but also the nuances within each issue that transpire from their narratives. All these issues and nuances are meant to be incorporated into a measure which can later be used to survey a larger and more representative sample.

As I was working with an NGO which delivers services for addicts, this probably caused me to find that injecting drug use was the major transmission route of HIV-infection for the participants' deceased husbands. But by working through this NGO, I was able to get access to the participants and they were then also offered support after my research encounter via this structure. Because all the women in the study were married to men who were or had been injecting drug users, the generalisability of the findings to cases in which the husbands were not associated with IV-drug use is also not known.

Furthermore, my own subjectivity or biases may also limit reliability and objectivity when analysing the data collected. Hence, I was careful not to allow my personal values, beliefs and biasness such as gender, age, education and own socio-cultural background, to influence the process of data collection (De Vos 1998:244). Personal contact with the participants was limited and standardised except for the delivery of

questionnaires and the administration of interview schedules. Also, interaction with the participants was as far as possible equal in the sample, to ensure that the research process was formalised and controlled more explicitly (De Vos 1998:243). However, all research is interpretive; it is guided by a set of beliefs and feelings about the world and how it should be understood and studied. Each interpretive paradigm makes particular demands on the researcher, including the questions he/she asks and the interpretations he/she brings to them (Denzin & Lincoln 2003).

Finally, the study participants live in and around a capital city which happens to have one of the highest HIV prevalence rates among injecting drug users in the country. Jakarta is also a modern city with widely available public transportation means, entertainment choices, internet connection, medical services, etc., which are not always easily obtainable in rural areas. Therefore, the generalisability of the findings to other parts of the country is not known.

5.3 SUGGESTIONS FOR FURTHER RESEARCH

As mentioned earlier, this study was conducted using a small, non-probability sample of young women affected by HIV/AIDS. In the absence of a sampling frame, the recruitment of a random sample based on a list of women who have lost their husbands to AIDS-related illnesses was not possible. Most unexpected was the discovery that all the women in this study were also HIV-positive. To see whether the findings of this study will be replicated in other Indonesian cities, I recommend a similar study to be conducted in three other Indonesian cities simultaneously. However, this endeavour should not include the two eastern provinces where HIV has already spread to the general population (NAC 2004-2005; UNAIDS 2006), considering the specific characteristics and dynamics of those territories, e.g. the Papua population are black and are noted for a local tradition of non-commercial sex with multiple partners (Butt *et al* 2002), but at the same time also taking into account that each Indonesian region has its own particular characteristics and dynamics.

Furthermore, owing to the fact that all the women in this study were HIV-positive besides being single parents (one of them lost her only child), I believe that the studies

proposed below would add depth to our current understanding of the experiences of women who have recently lost their life partners to AIDS-related illnesses:

- 1) A similar study using a non-probability sample consisting exclusively of HIV-negative women with and/or without children, or
- 2) A similar study using a non-probability sample comprising both HIV-negative women with and without children, and HIV-positive women with and without children.

However, given the generally limited awareness of HIV/AIDS and the small number of people who know their HIV status in Indonesia (NAC 2007-2010), I believe recruiting a sufficient number of HIV-negative women who have lost their husbands to AIDS-related illnesses may be difficult. Indeed, the results of this study show that the IV-drug users were diagnosed with HIV very late during the course of their illnesses, not only due to the limited awareness of HIV/AIDS among the men, their wives and their family, but generally also among the health providers who were treating their various opportunistic infections. As a result, considering that HIV in the IV-drug users remained undetected for a long time, the women found out about their husbands' infection only after it was too late – too late to save their husbands from an imminent death and too late to protect themselves (and in some cases their unborn children) against the infection.

One possibility where the women might remain HIV-negative despite being married to an HIV-positive husband is if they knew the status of the men they were going to marry and took measures to prevent their infection. But this implies willingness on the part of the women presumed to be HIV-negative to be romantically involved with men they knew to be living with HIV. This appears unlikely in a country where knowledge about HIV/AIDS is limited, and considering the strong stigma attached to HIV/AIDS, which make it unfavourable for a person to disclose his/her, seropositive status to their permanent sex partners. Naturally, while the findings of this study confirmed that the men who were aware of their HIV-infection preferred not to disclose their status to their partners for fear of rejection, and highlighted the women's assertion that they would not have married their husbands had they known the men were living with HIV, such findings cannot be generalised owing to the small sample used in this research.

That being said, if indeed it was possible to conduct the above proposed studies, I believe it would be fascinating to examine whether HIV-negative women who have lost their life partners to an AIDS-related illness would be more freely mourning the death of their husbands or more openly displaying their grief over their recent loss compared with HIV-positive respondents, as those women would have to deal with only part of a new hierarchy of needs that presents itself. Such needs, in a way, kept the women in this study distracted from mourning the death of a husband due to an AIDS-related illness, of which coming to terms with their seropositivity and dealing with the fear of anticipated stigma seemed most pressing. The above proposed research would also allow us to discover whether motherhood also impacts the bereavement experiences of HIV-negative women who have lost their husbands to AIDS-related mortality, and to make recommendations on whether or not specific bereavement counselling programmes for such women are needed.

Finally, taking into account the “death-accepting” attitude of Indonesian people, which may also have played a significant role in the positive bereavement outcome of the women in this study, it would certainly be interesting to conduct a similar research in a society with a “death-avoiding” attitude. Although there are some indications that bereaved women living with HIV in this kind of society are more likely than HIV-positive men to have unresolved grief and more intensified mourning responses (e.g. Summers *et al* 2004), such a study would undoubtedly help us to gain a better understanding of the bereavement experiences of HIV-positive women who have recently lost their husbands to AIDS-related illnesses in that kind of cultural environment. I believe the results of such a study would be very useful for comparative purposes.

5.4 RECOMMENDATIONS FOR POLICY AND PRACTICE

Although the Indonesian National AIDS Committee (NAC) may not have the necessary resources to follow-up on the findings of this study, I will send a copy of this research to those in charge at the institution. It is indeed public knowledge that this country is in dire need of financial resources to support its HIV/AIDS-related

activities (NAC 2006-2007:11). With less than 30 per cent of Indonesia's national programmes financed by the government, the country remains heavily dependent on international support. And even with increased regional budgets, available resources are still not sufficient. During these past two years, it has been difficult for the Health Department to ensure the continuous supply of ARVs, and this condition naturally entails serious implications for the national HIV prevention programmes. But considering that the NAC is responsible for HIV/AIDS policy and practice in this country, the results of this study clearly need to be communicated to the institution, particularly because they confirmed the limited knowledge of HIV/AIDS among the risk groups, the general population and the health providers, and highlighted the necessity to pay attention to the psychological needs of people living with HIV in this country.

The NAC should therefore be reminded of the urgent need for a wider, more intensive, dissemination of HIV/AIDS information, communication and education materials, and for organizing specific training programs for medical professionals in order to make them more perceptive to the possibility of an HIV-infection when treating patients with various opportunistic infections.

Although, as discussed earlier, Indonesia has limited resources to finance its HIV/AIDS-related activities, the NAC should also be reminded of the importance of paying heed to the psychological needs of people living with HIV in this country. Taking into account the increasing number of people affected by HIV/AIDS in Indonesia, most of whom are young people in their most productive ages, it is clear that their psychological needs cannot be ignored much longer despite the lack of financial resources. The NAC should therefore also be informed of the need for specific counselling programmes for women who have lost their husbands to AIDS-related illnesses within the previous year and who are themselves HIV-positive, which are mainly intended to help them to come to terms with being a person living with HIV and to improve their perception of stigma.

Finally, as part of my personal commitment to the HIV/AIDS cause in Indonesia, I will follow up on my intention to offer counselling services for women who have just lost their husbands to AIDS-related causes and are themselves HIV-positive at the

KAPETA Foundation. What I have in mind is once the counsellor has the idea that the women have made progress towards acceptance of their seropositivity after a few sessions of private counselling, they will be advised to join a support group consisting of people living with HIV, also to be organised by the KAPETA Foundation. However, in the absence of funding from the Government, and taking into account the limited financial resources available from foreign funding agencies, these programmes may have to be financed exclusively by Corporate Social Responsibilities funds.

5.5 CONCLUSION

I set out defining the key notions listed alphabetically below, and uncovered the following about these key notions during my research, thereby adding to the existing body of knowledge:

5.5.1 AIDS-related deaths:

Late diagnosis or undiagnosed HIV led to the premature deaths of the participants' husbands, which were not necessarily reported as AIDS-related. This, to a certain extent, may explain the existing gaps between estimates and reported HIV/AIDS cases in Indonesia.

5.5.2 Complicated and prolonged grief:

I did not come across any cases of "bad grief", i.e. complicated and prolonged grief during this study, although the participants may be part of a group of people considered to be particularly susceptible to experiencing such a condition.

5.5.3 Death-accepting attitude:

The possibility that this society's prevailing "death-accepting" attitude may have contributed to the research participants not experiencing complicated and prolonged grief should not be overruled.

5.5.4 Delayed grief:

There was no indication that the lack of mourning among the research participants may lead to delayed grief.

5.5.5 Grief and bereavement:

No modification.

5.5.6 Indonesian perspective

This research uncovered that the participants did not need bereavement counselling programmes but required programmes to help them to come to terms with their seropositivity.

5.5.7 Intravenous/Injecting drug use:

This research confirmed the lack of knowledge of HIV/AIDS among the drug addicted husbands of the research participants, despite the fact that the majority of HIV cases in Indonesia is attributed to injecting drug use.

5.5.8 Need:

This study did not identify the need for bereavement counselling programmes among the research participants.

5.5.9 Need analysis:

Data analysis led to the conclusion that bereavement counselling services were not needed, but that counselling programmes to enhance the women's well-being and to improve their perception of stigma was necessary.

5.5.10 Stigma:

As far as the participants of this study were concerned, anticipated stigma associated with being a person living with HIV was more of a concern than the death of their husbands.

5.5.11 Women affected by HIV/AIDS:

The most unexpected discovery made during this study was that all the participants were also HIV-positive; therefore, they had to come to terms not only with being a widow, but also with living with HIV.

In conclusion, the policy makers of this country need to be reminded of the urgency of addressing the limited knowledge of HIV/AIDS among the general population and in particular among the health providers, through more aggressive prevention efforts and a wider dissemination of information, education and communication materials. While awareness programmes for medical professionals are imperative to prevent further “premature” AIDS-related deaths, I recognise that the implementation of HIV prevention programmes aiming at the general population can be rather dilemmatic for a country with a wide distribution of the population and limited financial resources, such as Indonesia. As a result, arguments are generally in favour of prevention efforts that focus on so-called “most-at-risk” population groups which, in my opinion, is unfortunate for the following reasons: 1) They leave the general population highly vulnerable, as ordinary people tend to be unaware of their own susceptibility to HIV-infection and, 2) Prevention programmes exclusively targeting “most-at-risk” population groups tend to amplify the strong stigma already associated with them, and are likely to scare individuals from within as well as from outside these groups even further away from finding out about their HIV status. The question that needs to be addressed immediately by the NAC, therefore, is how to implement HIV prevention programmes targeting the general population that are *cost-effective*.

Furthermore, I strongly believe that the NAC should also be reminded of the importance of taking into consideration the psychological needs of people living with HIV in this country. The results of this study show that women who have lost their husbands to AIDS-related illnesses and are themselves HIV-positive do need counselling programmes that are directed to help them to come to grips with the reality of being a person living with HIV and to improve their perception of stigma. While the death of their husbands was generally imminent - the men died shortly after receiving their positive results - the women need to realise that it does not have to be that way for them as they have become aware of their status, so they can take proper care of themselves and stay healthy for many years to come. Finding out that they were HIV-positive may have been a disruption of previously held assumptions, but such an infection is manageable once one realises that HIV-infection is not necessarily fatal and “simply” requires a reorientation to living with a chronic condition. Thus, the aim of such programmes is to make them see that HIV does not have to be fatal if diagnosed early enough during the course of one’s illness, and that people living with

the infection can continue to live “normally” for a long time. Although this may sound rather ironic, the women need to understand that they were in fact “fortunate enough” to find out about their status before it was too late, so they can still expect to have a long healthy life like any other person living with a controlled chronic illness, despite being infected with HIV.

On a personal note, I would like to add that such counselling programmes may provide the women with a “shortcut” to achieving the fundamental Muslim-Javanese philosophical state of “acceptance”, widely recognised here as a state of “wisdom”, which people from this culture will naturally strive to achieve. While death is generally believed to be fated, therefore “easily” accepted, that is clearly not the case with being HIV-positive. I do think therefore that women who have been widowed due to the AIDS-related death of a husband and are themselves HIV-positive should be provided with a means to allow them to reach acceptance of their seropositivity as quickly as possible, so they can move on and tackle other complex psychosocial and socioeconomic issues. Ultimately, reaching such a state of acceptance would mean accepting the reality that some situations cannot be changed, which should also coincide with a re-evaluation of their role as primary care-takers of children and other people living with HIV.

Finally, I would like to end this dissertation with a quote of hope addressed to all the women living with HIV in the world and to all of those who are involved in the fight against HIV/AIDS and its related stigma – each in their own way, each in their own capacity.

“Courage, it would seem, is nothing less than the power to overcome danger, misfortune, fear, injustice, while continuing to affirm inwardly that life with all its sorrows is good; that everything is meaningful even if in a sense beyond our understanding; and that there is always tomorrow” (Dorothy Thompson, 1893-1961).

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AIDS-related Bereavement Study Consent Form

Appendix A

If you have any questions about this study or if you would like a summary of the results, you may contact Ms. Alita Damar, Researcher, at her office: P.T. Calcosol Unggul Medika, Jl. Mampang Prapatan VII no. 21, Jakarta, 12790, Indonesia, Phone: (6221) 7992365, Fax (6221) 7901020.

Purpose of the Study: To understand the experiences, beliefs, circumstances, coping mechanisms, social support networks, feelings, attitudes and concerns of women who have lost a male partner due to AIDS-related deaths within the last 12 months. The data will then be analysed to determine the need for bereavement counselling programs, particularly whether they should be part of the services offered by AIDS organisations in Indonesia.

Your participation: You must be at least 18 years old to participate in this study. Taking part is totally voluntary. You are free to change your mind at any time, and you can choose to drop out of the study at any time. You will be contacted to schedule an appointment whenever it is most convenient for you. Together, you will decide the length of the conversations, and how often you would like the researcher to contact you. The researcher will guide the conversations with some questions. You are free not to answer any questions that you do not want to answer. The researcher will make an audio tape recording of her conversations with you, to ensure that she can remember the exact words you say. No-one besides the researcher will listen to these recordings, and whatever you say to the researcher will be kept confidential, and will not be traced to you in any way.

Some considerations: You may feel a benefit from participating in the study from having an opportunity to share your thoughts and describing your experiences. However, talking about your grief could at times cause you some discomfort as you discuss matters. You may stop these conversations at any time. In the event that you need counselling as a result of participating in this study, you may contact Ms. Betty K. Taruc at the KAPETA Foundation. Phone: (6221) 7392338.

Confidentiality: The tape recordings will not be played for anyone else. The researcher will transcribe the conversations onto paper, some of which will be translated into English and these will also remain confidential and will not be shared with other people. Your name will not appear anywhere on the typewritten pages. Pseudonyms will be assigned to you and other people you will mention. Transcription will be performed using a secure computer. The transcripts will be used for analysis only, and will be kept safely locked in the researcher's office until they can be destroyed. The consent form will also be retained separately for five years, and then destroyed. You will not be identified by personal characteristics in any presentations or in any publications that might come from the analyzed information.

Date: _____

(Researcher)

I have read the consent form and I agree by signing this form.

Date: _____

(Participant)

Questions for Conversations with Participants

Appendix B

When did your male partner die?
Tell me about yourself (age, family, religion, occupation, interests)
Does your family know that your male partner died of AIDS?
What does your family think of it? Your friends?
Tell me about your family and the way they reacted to the death. Your friends?
How long were you caregiving?
What was the experience like before your loved one died?
How long before his death did you know that he was living with HIV?
Does your family know?
Did you know about HIV/AIDS then?
What has come as a surprise to you?
Do you know how your male partner became infected?
How did you learn about HIV/AIDS?
Were you prepared for the death? Could you have prepared yourself better? How so?
How long did you know he was dying before his actual death?
What were your concerns before the death? After the death?
What happened after his death?
What were your feelings at the time of death/immediately afterwards?
Are there things you regret?
Do you experience guilt? In what way?
Do you think that the death was in some way preventable?
What does death mean to you?
What are your feelings about your own mortality?
Have you lost someone else you loved dearly due to non-AIDS-related deaths?
Who was it? Tell me about it.
Do you think that AIDS-related deaths are different from other kinds of deaths? How so?
What was most helpful to you at the time of your male partner's death and in subsequent months?
When was the time you found most difficult? What was/has been most difficult and why?
What has been disappointing to you?
What have you learned from this experience?
Have you talked to anyone about your feelings/experience before and after the death?
What has that been like?
What are your worries now?
What are your goals and priorities now? In the next few months?
What is going well right now? What brings you relief/joy at this point in your life?
Tell me about your spiritual/religious beliefs
Do you observe your religion strictly? How does your belief provide you comfort?
How do you apply your belief in your daily life? How does this belief relate to HIV?
How has it helped you? Or not?
How do you qualify your general health status today? (poor, average, good)
Have you made any plans regarding your health?
How do you see your future?
Have you sought assistance from support groups/social support networks that can help you cope with your AIDS-related loss?

If so, has it been helpful?

Do you know other women who have also lost their husbands to AIDS?

Did/do you talk to them? If so, did/does talking with them help? How so?

Have you sought assistance from third parties to help you cope with grief?

If so, has it been helpful?

What do you think should be done to help people who are going through AIDS related bereavement?

Tell me about your job-reactions of co-workers/boss relating to your male partner's death (do they know your male partner died of AIDS?)

Do others treat you differently/avoid you?

Do people understand what you are going through and what you need?

How can you let people know? Have you done this?

Do you have friends or relatives who have died of AIDS? How many?

When did they die?

What have you learned from the experience?

What are your suggestions relating to AIDS-bereavement?