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DOES MENTAL HEALTH MATTER  
FOR POOR, HIV-INFECTED WOMEN/  
MOTHERS IN THE ERA OF HAART?

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# Does Mental Health matter for Poor, HIV-Infected Women/Mothers in the Era of HAART?

## Abstract

*This paper reviews the available evidence regarding the relationship between HIV/AIDS, poverty, gender and mental health in order to address the question of whether mental health has any relevance for poor, HIV infected women and mothers in the era of HAART. Evidence points convincingly to the growing feminisation of the epidemic as well as the differential social and economic impact of HIV on women in general, and women in developing countries in particular. Further, HIV and poverty, both of which will be shown to be influenced by gender dynamics, independently contribute to elevated risk for poor mental health. It is argued that even with the advent of antiretroviral therapy, which has not been shown unequivocally to ameliorate poor psychological adjustment, mental health concerns remain relevant and significant for HIV infected women living in poverty. Further, this renders the relative neglect of mental health in the context of HIV/AIDS an important omission on the part of policymakers and service providers alike.*

## The feminisation of the epidemic

Some twenty-five years into the epidemic, several things have become clear, amongst these, the fact that HIV/AIDS is increasingly a disease of women living in poverty (Farmer, Connors & Simmons, 1996). While HIV was once viewed as a disease of homosexual men and intravenous drug users, the number of infected women has been increasing worldwide, particularly in areas where heterosexual sex is the dominant mode of HIV transmission (UNAIDS, 2004a). Further, in all communities and countries, including the richest nations, it is the economically and social disadvantaged who are most vulnerable to infection (Whiteside, 2002).

According to the latest (UNAIDS, 2005) figures, globally, 40.3 million people were infected with HIV in 2005, of which 17.5 million were adult women (aged

15-49 years). Women make up 46% of all infected adults, a number which rises to 57% in the epicentre of the pandemic – sub-Saharan Africa. Although home to only 10% of the world's population, 60% of people living with HIV/AIDS (PLWHA) reside in sub-Saharan Africa (UNAIDS, 2005) as well as eight out of every ten children orphaned by AIDS (UNICEF, 2003). Despite the fact that changes in incidence and rising AIDS mortality has caused global HIV prevalence to level off, the number of people living with the disease continues to rise due to population growth and the life-prolonging effects of antiretrovirals, and this is nowhere clearer than amongst poor women.

Seventy-seven percent of all HIV infected women live in sub-Saharan Africa, one of the poorest regions in the world and one of only two where women make up more than half of infected adults (the other being Oceania) (UNAIDS, 2005). A million more women were living with HIV in 2005 as compared with 2003, and among young women, the rate of incidence compared with young men is particularly telling. Globally, amongst 15 to 24 year olds, women are 1.5 times more likely than men to be infected (*ibid*), while young girls in southern Africa are 2.7 times more likely to test positive (UNAIDS, 2004c). In some countries in southern Africa, the gendering of the epidemic is even more pronounced, with girls and young women making up 80% of all infected youth in Zimbabwe and Zambia (*ibid*). HIV infection rates are also very high amongst pregnant women, reaching one in five or higher in six African countries (Botswana, Lesotho, South Africa, Swaziland and Zimbabwe) and 30% in two of these (Botswana and Zimbabwe) (UNAIDS, 2005). Given the prominence of the epidemic among youth and young adults, and the high rates amongst pregnant women, many infected women are also mothers or primary caregivers of children.

In South Africa, the country with the largest number of PLWHA, comparisons between different subgroups similarly reveal the prominence of the epidemic among poor women specifically as well as women in general. Five percent more women than men are infected with HIV in South Africa (13.3% versus 8.2%) (Shisana *et al.*, 2005) and women have a higher proportion of deaths due to AIDS than men (33.8 versus 29.8%) (Bradshaw *et al.*, 2003). Further, overall, one in five South African (adult) women are HIV infected (Shisana *et al.*, 2005), while figures based on attendance of antenatal clinics show that more than a quarter of pregnant women in six of the nine provinces are HIV positive (Department of Health, 2004), with the projected national prevalence rate for 2005 at 25.6%<sup>1</sup> (ASSA, 2002). The higher prevalence for African females (24.4%) compared with women in general (20.2%) also reflects the high representation of poor women given that the African population represents the poorest sector of South African society (Shisana *et al.*, 2005).

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<sup>1</sup> This figure is for the population ages 15 to 59 years.

# Gender inequality and HIV/AIDS

The increasing feminisation of the epidemic raises two particularly interesting and interconnected issues: one relates to the reasons for women's heightened vulnerability to infection and the other relates to the differential impact of HIV/AIDS on both affected and infected women. An attempt to address both questions, it will be shown, leads to the need to acknowledge the profoundly social nature of the disease and the fact that HIV is both fuelled by and fuels gender inequalities and the feminisation of poverty.

## Physiological, social and economic vulnerability to infection

In the first instance, it must be acknowledged that HIV is a disease process and that there are physiological reasons why women are more vulnerable to infection than men. Evidence shows that the rate of infection via unprotected sexual intercourse from woman to man is between 1 and 8%, while it is 20% from man to woman (Aberg, 2005). Several important reasons can be given for this difference (Africa Region Gender Team, 2000; Baingana, Thomas, & Comblain, 2005). First, a substantial proportion of the female genital tract is permeable to fluids, compared with male's anatomy. Second, semen contains a higher concentration of the virus than female secretions. Third, cervical ectopy<sup>2</sup> which facilitates HIV infection is common in young women (Baingana *et al.*, 2005). Fourth, pre-existing sexually transmitted diseases (STDs), which increase the likelihood of infection ten fold (*ibid*), are more likely in women given that STD symptoms are less apparent in women thereby delaying detection and diagnosis (Strebel, 1995).

Women's physiological vulnerability is, however, exacerbated by entrenched social and cultural norms regarding masculinity and femininity that render women disempowered and unequal members of their societies. While 'women' cannot and should not be treated as an homogenous group, this is the dominant cultural narrative and one that holds particularly for women living in poverty – those most affected by the epidemic and the focus of this paper. As Farmer (1996: 23/4) argues:

...women have been rendered vulnerable to AIDS through *social* processes ... economic, political and cultural forces that ... shape the dynamics of HIV transmission ... All sexually active women

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<sup>2</sup> This refers to the thinning of tissues on the surface of the cervix, thereby exposing delicate tissue that is more easily disrupted and vulnerable to the transmission of a virus such as HIV (Personal communication, Dr James Bull, 25 July 2006).

share to some extent biological risk, but it is clear that the AIDS pandemic among women is strikingly patterned along social, not biological lines.

Prevailing cultural norms, particularly at the epicentre of the pandemic, construct women as subordinate, dependant and passive, dictating silence regarding sexual matters, valuing virginity and chastity amongst women (but not men), and often treating women as legal minors, barring them from inheritance and independent financial decision-making (Africa Region Gender Team, 2000; Gupta, Whelan, & Allendorf, 2003; UNAIDS, 2004c). Further, as will be discussed in more detail later, women are valued for their ability to reproduce and for their role as mothers and carers.

Data from 35 of 48 countries in sub-Saharan Africa show that men are 20% more likely than women to have correct knowledge of HIV (UNAIDS, 2005), while globally 80% of young women have insufficient knowledge to protect themselves against infection (UNAIDS/UNFPA/UNIFEM, 2005). Further, this is more likely among the impoverished than at higher income levels (Gupta *et al.*, 2003). Also consequent to gendered social norms, women often have older male partners who are more likely to have a STD – a risk factor for infection (Baingana *et al.*, 2005). Gender-based violence also renders women vulnerable for a number of reasons. Fear of violence or abandonment often prevents women from discussing fidelity or negotiating condom use with their partner (Gupta *et al.*, 2003), and makes them more vulnerable to coerced sex, including rape and other sexual practices such as dry sex (Africa Region Gender Team, 2000). A study conducted in South Africa in the early 1990s reported that a large percentage of women believed that men had the right to multiple partners (62%), they did not have the right to refuse sex with their partners (49%), and their partner would get angry (51%), leave them (30%) or threaten violence (28%) if they requested condom use (Abdool-Karim, Abdool-Karim & Nkomokazi, 1991 in Outwater, Campbell, & Abrahams, 2005). Research in Africa on the link between intimate partner violence and HIV showed that infected women in Tanzania were two and a half times more likely than seronegatives to experience partner violence (UNAIDS/UNFPA/UNIFEM, 2005), while South African women beaten by their partners were 48% more likely to be infected (Outwater *et al.*, 2005).

Economic vulnerability also contributes significantly to gendered sexual practices that place women at risk of infection. Women have less command than men over assets, including productive resources, employment and education. Moreover, they experience the pressure to feed their children and families. This renders them vulnerable to abuse and exploitation, including being more likely to exchange sex for money, and less likely to be able to negotiate safe sex or to

leave a risky or abusive relationship (Africa Region Gender Team, 2000; UNAIDS, 2004c). Further, just as economic inequality drives HIV infection, HIV exacerbates inequality amongst women by forcing them to forego educational and economic opportunities in lieu of caring for the infected and affected (Baingana *et al.*, 2005). As Treichler and Warren (1998, p. 112) suggest, “[o]ne might even say that women contract HIV infection not only because of ‘what they do’, but because of ‘who they are’”.

## **Differential social and economic impact**

In addition to driving women’s vulnerability to infection, gender inequality is highlighted and exacerbated by the epidemic. Not only are women overrepresented by the numbers for all of the reasons discussed above, it is now widely recognised that the epidemic has a disproportionate social and economic impact on women (UNAIDS, 2004c). Here two main issues will be discussed: First, poverty is a significant risk factor for HIV and HIV has contributed to the increasing feminisation of poverty; and second, economic inequality and gendered social norms, as already mentioned, contribute to the burden of care experienced by women in the context of HIV/AIDS.

## **Poverty and HIV/AIDS**

Farmer and Kim (1996) have noted that poverty, alongside gender inequality, is the reason why the fastest growing epidemics are among women. Independent of gender, there is clear evidence that poverty contributes to the risk for, and transmission of, HIV/AIDS, as well as being an effect of the epidemic. While epidemiologists point to different subtypes of HIV and routes of transmission across the globe (Greenblatt & Hessol, 2000), the clearest pattern is that HIV is most prevalent and has increased most rapidly in the poorest communities. Poverty, and its associated stressors and characteristics, creates the “path of least resistance” in which the infection thrives (Lindegger & Wood, 1995: 7).

Whiteside (2002) provides an excellent discussion of this relationship, including some points that have already been raised. Only two important issues will be mentioned here. First, most infections occur via sexual transmission and economic (along with social and cultural) factors determine the nature of sexual activity (Baingana *et al.*, 2005; Whiteside, 2002). The poor, and poor women in particular as already noted, are more likely to have multiple partners, to trade sex, and to remain in risky relationships for economic protection, thereby making them vulnerable to HIV infection. Second, communicable diseases such as HIV thrive in poverty (Stillwaggon, 2002; Whiteside, 2002). Stillwaggon (2002) argues that two characteristics of people living in poverty, namely, high

rates of malnutrition and parasite infection, render them suitable hosts for the spread of an infectious disease such as HIV. Malnutrition and parasite infection undermine immune response, increasing susceptibility to HIV transmission and advancing disease progression. Consequently, Africa (along with other poverty-stricken regions) is “fertile terrain” for HIV/AIDS (*ibid*).

However, as Whiteside (2002) notes, there is a cycle between HIV/AIDS and poverty, with AIDS also causing poverty and increasing inequalities at every level, from individual and household to global. Amongst these impacts, food consumption in affected households has been found to fall by 15-30%; AIDS pushes household incomes down by up to 80% and increases household poverty; it undermines the attainment of gender equality by keeping young girls (rather than boys) out of school to care for sick relatives; and, at a more macro-level, undermines public and government efforts at poverty reduction (Loewenson & Whiteside, 2001 in Whiteside, 2002).

## **HIV/AIDS and the feminisation of poverty**

Without engaging in the debates about the technical correctness of the term (BRIDGE, 2001)<sup>3</sup>, it is clear that HIV/AIDS has contributed to the feminisation of poverty. By this is meant two things: First, there is a higher incidence of poverty among women relative to men, and second, that there is a trend toward greater poverty among women associated with a rise in the number of female-headed households (FHH; *ibid*). A third related point is that the poverty experienced by women is more severe than that of men (*ibid*).

Statistics cited by both the World Health Organization (2000) and the United Nations Development Programme (1995 in Budlender, 2004) indicate that 70% of people living in poverty are women or girls. Moreover, the increase in number of poor rural women in 41 developing countries over a 20-year period was 17% higher than the increase in poor men (World Health Organization, 2000). With respect to female headship, the numbers are high. On the African continent, one in five households with children in sub-Saharan Africa and one in three in southern Africa are female-headed (Monasch & Boerma, 2004; UNICEF, 2003). The proportion of female-headed households is higher in southern Africa than in any other part of sub-Saharan Africa, and almost double the rate in West and Central Africa (where the prevalence of HIV is also lower) (UNAIDS, 2004c; UNICEF, 2003). Of the southern African countries, the country with the largest epidemic, South Africa, has the third highest number of FHH's at 46% after Botswana at 52% and Namibia at 47% (Monasch *et al.*,

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<sup>3</sup> See BRIDGE (2001) for a detailed discussion of the limitations of data used to argue for the feminisation of poverty.

2004; UNICEF, 2003). There is some evidence of an upward trend (in parallel with the spread of the epidemic) in eight of the twelve countries in sub-Saharan Africa in which demographic surveys were available, and also evidence of a link between poverty and female-headed households (BRIDGE, 2001). Certainly an increase in the number of FHH's in the poorest and most affected region in the world is suggestive in this regard.

It is true that many households in South and southern Africa were female-headed even prior to the epidemic, and tended to experience more economic strain than those headed by men (UNAIDS, 2004c). However, HIV/AIDS has exacerbated this situation, leaving women in impoverished communities already under considerable strain, largely responsible for ensuring the viability of households. Recent survey data in South Africa suggest that only 12.5% of women who are household heads have a partner present in the home (Ziehl & Burns, 2004). Further, the differential experience of poverty in these households has been attributed to their lower earning capacity and competing domestic interests and expectations (BRIDGE, 2001). Poverty for women is more than simply income deficiency, it encompasses disadvantage with respect to other forms of impoverishment, including literacy and education, skills, and employment opportunities (World Health Organization, 2000). Many more women than men are employed in the informal sector where incomes tend to be lower or irregular and there is often a lack of protection through labour law (for example, work in unpaid subsistence agriculture, as street traders, or in low-paid domestic work) (Budlender, 2004). For the fourteen countries which fall under UNIFEM's regional office, female income is only a fraction of male income, the lowest being 39% in Swaziland (*ibid*). South African women earn 45% of the income of their male colleagues. Not only do these factors render women more vulnerable to poverty, it suggests that they have fewer opportunities to escape once poor.

## **The care burden on women in HIV affected households**

The second indication of the differential impact of HIV on women is the heightened burden of care they experience as a function of their gendered social and economic status. Reproduction and motherhood is a feminine ideal and a valued role in many cultures, but most especially in the African context (Tabi & Frimpong, 2003; Upton, 2003). Since children are viewed as a symbol of wealth, motherhood elevates women's social status (Were, 2000), affording them a social identity and in many cases guaranteed status in kinship groups (UNAIDS, 1999 in Gupta *et al.*, 2003). However, the construction of women's care role that is most salient in the context of the HIV epidemic is that this is a natural role (see Burman, 1994). Childbearing is seen as a woman's obligation (Were, 2000)

and by extension, although largely at an implicit level, so is the care of one's children and others.

Globally, women and girls provide up to 90% of care due to illness, in addition to many other tasks they already perform, including taking care of children and the elderly, cooking, cleaning and other domestic duties (UNAIDS, 2004c; UNAIDS/UNFPA/UNIFEM, 2005). In the context of HIV/AIDS, both sick men and women tend to be cared for by female relatives, and women are more likely than men to take in orphaned children (Evans, 2005; Monasch *et al.*, 2004; UNAIDS, 2004b; UNICEF, 2003; Upton, 2003). Throughout the sub-region, where mothers die, orphaned children are more likely to reside in female- than male-headed households. Evidence shows that female-headed households have, on average, two orphans per household, while men have 1.6 (Monasch *et al.*, 2004). Figures for the residence of double orphans in South Africa indicate a similar pattern (UNICEF, 2003). Further, a South African survey of AIDS-affected households showed that women or girls were the primary caregivers in two out of three households, and the only caregiver in one out of three of these households (Steinberg *et al.*, 2002).

The over-representation of women in childcare and other care roles within the family or household should, however, not be confused as meaning that only mothers care for children. Responsibility for childcare varies across countries and regions. For example, in sub-Saharan Africa, children, orphans and non-orphans are most likely to live with their parents in Eastern Africa and least likely to live with their parents in southern Africa, with patterns of residence for non-orphans a fairly good indicator of patterns for orphans (Monasch *et al.*, 2004). While 90% of non-orphans in Burundi live with both parents, 25% of children in South Africa, Botswana and Namibia live with neither mother nor father (*ibid*). Similarly, a diversity of alternative care arrangements were noted in a European study on childcare in the context of HIV/AIDS (Thorne, Newell, & Peckham, 1998). While extended family played the most important role in Italy and Spain, statutory care was more important in Northern Europe.

However, the fact that care in the context of HIV/AIDS is referred to as a burden to women, or as having reached crisis proportion (UNAIDS, 2004c), suggests that the construction of women's role as valued is overly simplistic. In fact, the assumption that this valued role is natural enables it simultaneously to be rendered invisible and undervalued. Where time-use surveys have been used to document household and domestic activities, childcare in particular is either not mentioned or listed as a secondary activity (Chobokoane & Budlender, 2001). Further, where childcare involves supervision (i.e. takes place while the carer is involved in another activity), it is not reported at all (*ibid*). In her study of child

labour in the Zambezi Valley, Reynolds (1991: 62) found that childcare was even omitted from people's own recall of their work:

No adult, whether male or female, includes infant or child care in his or her definition of work ... Infant and child care appeared neither under work nor leisure. It is invisible.

In addition to the practical and emotional responsibility women take for caring for people within their family and social settings, they are frequently carers in the formal HIV/AIDS sector, either as nurses or volunteers and community health workers (Strebel, 1995; Wilson, 1992). In the formal health sector (independent of HIV/AIDS), women make up 75% of the labour force, typically in positions that are either poorly paid or unpaid (Strebel, 1995). Occupations dominated by women have lower earnings because they are seen as less important and requiring less skill, and it is therefore unsurprising that this work tends to be similar to the unpaid care work that women undertake in their homes (e.g. childcare and housework) (UNAIDS, 2004b). In the context of HIV/AIDS, much of women's work is subsumed under the terms 'community care' or 'home-based care', thereby maintaining their social construction as 'natural' carers and denying them the support and recognition they deserve (Schiller, 1993; Skhosana, 2003).

Also important is the recognition that many women simultaneously adopt multiple roles in relation to the epidemic. In particular, the large majority of women continue to participate in the 'care economy', carrying out unpaid care and other domestic work in the household even if they themselves are HIV positive (Steinberg *et al.*, 2002; UNAIDS, 2004b). A large number of women, many of them with children, therefore negotiate the dual role of being HIV positive and being a caregiver, in addition to the economic demands placed on them by virtue of living in poor communities in which they are often responsible for meeting the survival needs of their households. Women's gendered position requires them to do domestic labour caring for the sick, often taking them away from other productive household tasks and preventing them from replacing the lost income associated with household providers unable to work due to illness (UNAIDS, 2004b; UNAIDS, 2004c). In so doing, women often neglect their own physical and emotional wellbeing, including the challenges posed by physical symptoms (Armistead, Klein, & Forehand, 1995), in the face of deepening household poverty and all its associated risks. Evidence to support this contention is the fact that some studies have found a low orientation to health status among HIV infected women where large numbers of children are a source of competing needs and interests (Karus, Siegel, & Raveis, 1999).

The point of this discussion is not to construct women as victims or to deny that a great many women demonstrate enormous resilience in the face of adversity,

for there certainly is evidence to suggest that this is the case (for example, see Brandt, 2005; Evans, 2005). Further, it is also important to recognise that the role of mother and carer is one that many women value themselves and derive self-esteem from (Kobayashi, 2000). Several studies conducted in developed and developing countries have found that HIV infected women have a particularly strong need to maintain their parental status, perhaps partly as a result of their internalisation of communal norms and values. Consequently, some women are reportedly reluctant to seek assistance or to give up their caregiving role despite their illness (Broun, 1996; Hackl, Somlai, Kelly, & Kalichman, 1997) for, as one woman explained, part of maintaining normalcy was being able to maintain the role of mother (Ciambrone, 2003). Being and remaining “normal”, something which was clearly desirable for many of the women, was therefore equated both with being a mother and maintaining an active caregiving role, as opposed to delegating a large number of typical caregiving responsibilities to others. Where women are less actively engaged in a caregiving role in relation to their children, or where caregiving is more shared as in some communities, it is possible that a different situation would pertain.

What this discussion has attempted to argue and shed light on is the interrelationship between gender, HIV/AIDS and poverty, and the extent to which this context places women, carers and mothers at particular risk. As several writers have noted, HIV/AIDS for poor women is a qualitatively different disease to that identified at the beginning of the epidemic (among homosexual men in the United States) (Ward, 1993). The social climate in which the disease is transmitted, diagnosed and treated, and the resources with which the disease is experienced, are strikingly different (*ibid*), but just as important, for poor women. HIV is a new disease that reveals, parallels and exacerbates old health and social problems (Farmer *et al.*, 1996; Ward, 1993). This is evident in the (limited) empirical evidence that shows that AIDS, in a country such as South Africa, is perceived as a part of a set of complex social problems and is not in fact singled out as the greatest or most immediate threat by either men or women living in endemic poverty (Kalichman & Simbayi, 2003). As Carol Bellamy, Executive Director of UNICEF, stated in the report of the Secretary-General's Task Force on Women, Girls and HIV/AIDS in southern Africa:

For some time now, it has been clear that women in Africa are buckling under the strain – besieged on one hand by high infection rates and on the other by the increased demands they face as caregivers and breadwinners (in UNAIDS, 2004c: 6)

Poor women and mothers infected with HIV experience poverty more acutely than before and face more responsibilities in their role as carers, both of which

are fueled by their gendered identity and both of which place them at risk. In the next section of this paper, a particular category of risk will be examined in more detail, namely, mental health.

## **Poverty, mental health and HIV/AIDS**

Once again, the interrelationships are complex but important in that they point to the most at-risk groups and hence to the key avenues for researchers, policymakers and practitioners alike. In this next section, evidence will be presented to demonstrate that both poverty and HIV/AIDS contribute independently to mental health, in addition to other social and health problems. Further, the implications of the advent of antiretroviral therapy (ART) for the psychological consequences of HIV will be considered.

## **The relationship between mental health and HIV/AIDS**

### **The neglect of mental health and the burden of disease in developing countries**

The neglect of mental health in developing countries is a long-standing phenomenon and one that has become more entrenched with every new public health challenge (Desjarlais, Eisenberg, Good, & Kleinman, 1995; Patel, 2005). The World Health Organization's (2001a) recent survey of mental health resources showed that 62% of low-income countries spend less than 1% of their national health budgets on mental health, and that beds per population and the number of mental health professionals are very low. Moreover, while private individuals are the primary source of mental health financing for 2.9% of high-income countries, they source 40% of low-income countries' financing (*ibid*). More recent evidence of this neglect is the almost complete omission of mental health (and non-communicable diseases in general) in the Millennium Development Goals despite the fact that health-related issues make up three out of the eight goals (Miranda & Patel, 2005).

The neglect of mental health is typically justified by the argument that developing countries are burdened with many more serious physical health problems that require the majority of scarce resources (Miranda *et al.*, 2005). However, there is clear evidence that mental health is an integral part of health and a significant contributor to disability and the burden of disease. In fact, a study conducted in 14 diverse World Health Organization country sites

demonstrated that mental illness is both an independent predictor of disability and functioning, and a stronger predictor than physical illness (Ormel *et al.*, 1994). Global estimates indicate that mental disorders contributed to 10.5% of the burden of disease in 1990 (Murray & Lopez, 1996) and 12% in 2000 (World Health Organization, 2001b). Further, three neuropsychiatric conditions rank in the top 20 causes of disability adjusted life years (DALYs) for all ages, and six in the age group 15-44, while depression is the leading cause of disability worldwide (Murray *et al.*, 1996). Although the prominence of disease, in particular communicable, perinatal and nutritional conditions, in developing countries means that the proportion of disability caused by mental illness is lower, neuropsychiatric conditions still account for 17.6% of all years lived with disability (YLD) in Africa (World Health Organization, 2001b). Globally, mental and neurological conditions account for 30.8% of all YLD (*ibid*). Mental and behavioural disorders therefore contribute significantly to both disability and morbidity in primary care settings (Patel & Kleinman, 2003). A wide range of figures have been reported, but it appears that between one in five and one in four people are affected by mental illness at some point in their lives, with the point prevalence for most disorders falling between 9 and 16% (Ormel *et al.*, 1994; Patel *et al.*, 2003; WHO World Mental Health Survey Consortium, 2004; World Health Organization, 2001b). Further, this finding has been corroborated in cross-cultural and socio-economically diverse primary care settings, with the most common diagnoses being depression, anxiety and substance abuse disorders (Ormel *et al.*, 1994; World Health Organization, 2001b). What is perhaps as concerning as the high rates of mental illness in developing countries and the serious role impairment with which they are often associated, is the fact that they frequently go untreated (WHO World Mental Health Survey Consortium, 2004).

## **Poverty, mental health and gender inequality**

In addition to the high prevalence and impact of mental illness in developing countries, there are several other associated features that are relevant to the present discussion, in particular gender inequality and poverty. With respect to the latter, there is considerable evidence that mental disorders are closely associated with poverty, in addition to potentially deepening poverty through the dysfunction, loss of employment and added medical expenses associated with severe psychiatric conditions. The evidence presented above has already demonstrated the considerable disability associated with mental illness in developing countries. However, poverty is also one of the factors that determines the prevalence, onset and course of many disorders (World Health Organization, 2001b).

According to Kohn *et al.* (1998 in World Health Organization, 2001b), the ratio for lifetime prevalence of mental disorder between the lowest and highest socio-economic status groups is 1.4:1. Further, in a review of community studies of mental illness since 1990, Patel and Kleinman (2003) report an association between poverty and common mental disorders in low- and middle-income countries. Only one study failed to find a significant relationship between mental health prevalence and several indicators of poverty, of which low education was most consistently associated. Other associated conditions include unemployment and income and material deprivation, as well as several factors that also present risks for poor physical health, namely, malnutrition, lack of access to clean water and inadequate housing (Patel *et al.*, 2003; World Health Organization, 2001b). It may be that the link between physical illness and common mental disorders partly accounts for the association between poverty and mental illness, and that the real risk factors for mental illness are poor physical health, insecure income and limited opportunities as a result of low education (Patel *et al.*, 2003). Poverty is therefore associated with a range of stressful life events which, in addition to personality, coping skills and genetic disposition, contribute to mental illness (World Health Organization, 2001b).

Given the link between mental health and poverty, and the evidence presented that women are most affected by poverty, it follows that some differences in mental health exist between men and women. With respect to severe mental illness, only depression is more prevalent amongst women (World Health Organization, 2001b). However, research on mental illness in general (and not only severe illness) in developed and developing countries shows that adult women have higher rates of depression and anxiety, and lower rates of substance use and antisocial personality disorders than men (*ibid*). Comorbidity (the presence of more than one disorder simultaneously) is also more common in women, with depression, anxiety and somatoform<sup>4</sup> disorders the most frequent presentation (*ibid*). Other gender factors discussed, for example, physical abuse from partners and fewer educational and job opportunities – all of which are also associated with poverty – are also likely to play a role in women’s heightened risk for mental illness (Patel *et al.*, 2003).

## **The relationship between mental health and HIV/AIDS**

An as yet unmentioned part of the above analysis of mental illness and poverty is that HIV/AIDS – most prevalent in the poorest regions of the world – has also been associated with mental health in several ways. To begin with, it may be

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<sup>4</sup> This is the presence of physical symptoms that cannot be accounted for by physical disease.

instructive to outline the substance of the bi-directional relationship between HIV/AIDS and mental health. With respect to the pathway from mental illness to HIV, three important points should be mentioned. First, the presence of psychiatric disorders increases the risk for HIV infection, particularly through their association with risky behaviours such as unprotected sex (Treisman, Angelino, & Hutton, 2001). Evidence marshalled to support this argument is the high lifetime rates of mental illness in people testing for HIV (Perry *et al.*, 1990), and the fact that many of the disorders presenting in PLWHA preceded seroconversion (Catalan, Burgess, & Klimes, 1995; Gallego, Gordillo, & Catalan, 2000). Second, research into psychosocial predictors of treatment adherence suggest that poor mental health is a risk factor for non-adherence to antiretroviral therapy which negatively impacts on HIV outcomes (see, for example, Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999; Mellins, Kang, Leu, Havens, & Chesney, 2003; Murphy, Marelich, Hoffman, & Steers, 2004; Starace *et al.*, 2002). Third, mental illness and psychological wellbeing can adversely influence disease progression by undermining immune functioning, a matter that is the subject of the field of psychoimmunology (see, for example, Panzer & Viljoen, 2002; Olley, 2003).

The focus of this discussion, however, is the pathway from HIV infection to mental illness. Here what is relevant is the psychological experience of testing HIV positive and living with the disease and its associated social sequelae at each stage of the illness. A critical, or cautionary, note must however first be made regarding the available research in this area. As Kalichman (1995) points out, there are several problems with the early research in particular, which limit the comparability of findings and undermine the emergence of a rigorous and scientifically sound body of evidence. Many of the studies are exploratory in nature and methodologically limited, failing, for example, to include control groups of seronegatives (Gallego *et al.*, 2000; Kalichman, 1995; Kalichman & Sikkema, 1994). Studies are also predominantly cross-sectional in design and do not always include participants at all stages of infection or a significant number of individuals with advanced infection (Gallego *et al.*, 2000). The majority of studies, predictably, come from the United States and United Kingdom, meaning that participants are often white males and bi/homosexuals with medium to high levels of education, while other studies focus exclusively on intravenous drug users, thereby limiting their applicability to large sections of the population living with HIV/AIDS in developing countries (*ibid*). A further difficulty is comparing studies that pre-date the HAART era or the changes to the definition of AIDS in 1993<sup>5</sup> (Kalichman, 1995; Kalichman *et al.*, 1994). Finally, self-

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<sup>5</sup> In 1993, the Centre for Disease Control (CDC) in the United States expanded the clinical definition of AIDS to include those with a CD4 cell count less than 200. Other changes were to include additional clinical conditions more common in women that were previously excluded (Stern, Perkins, & Evans, 2000)

report instruments in particular can present measurement problems as they tend to confound indicators of depression and anxiety with symptoms of HIV disease (for example, fatigue, weight loss and loss of *libido*) (*ibid*).

## **A disease stage model of the mental health impact of HIV infection**

However, despite these methodological limitations, there are several findings that contribute substantially to our understanding of the mental health impact of HIV infection. Generally, the large majority of people cope relatively well, both with receiving a positive diagnosis and living with the disease, with a minority experiencing psychological problems at some stage and an even smaller number severe psychiatric difficulties (Catalan *et al.*, 1995; Treisman *et al.*, 2001). For many, the response to the initial diagnosis is akin to an acute stress reaction (Kalichman, 1995). Intense and even severe distress is experienced, including feelings of shock, denial, guilt, self-pity and fear of imminent death, however, this distress is usually self-limited and of mild to moderate severity (Catalan, 1999; Gallego *et al.*, 2000; Treisman *et al.*, 2001). In many ways the reactions to this and other stages of the disease are similar to other life-threatening physical conditions, except that the associated stigma and discrimination is much greater and the social context is one of increased vulnerability to psychological problems – since these are often individuals who live in poverty and/or come from socially disadvantaged, at-risk groups (Catalan *et al.*, 1995; Kalichman, 1995; Treisman *et al.*, 2001). For those who previously used denial and avoidance and only test in the symptomatic phase (as is the case in many developing countries such as South Africa), the risk may be greater (Catalan, 1999; Kalichman, 1995).

For those who test during the asymptomatic stage, this is the time to come to terms with the diagnosis and its impact on their lives, including reassessing roles and priorities (Catalan *et al.*, 1995; Catalan, 1999). Distress is usually mild, with adjustment disorders, depression, substance misuse and sexual dysfunction the most common problems, but there is no clear evidence of differences compared with the general population (*ibid*). As the illness progresses, and individuals struggle increasingly with pain and disability (Treisman *et al.*, 2001), there is more consistent evidence of higher levels of psychological morbidity compared with both controls and asymptomatic individuals (Catalan *et al.*, 1995; Maj *et al.*, 1994). Some studies even suggest that the risk for mental illness may be greatest in this stage, more so than in AIDS patients who may in fact be less distressed than both asymptomatic individuals and those in the early symptomatic phase (Catalan, 1999; Kalichman, 1995). However, this does not negate the fact that anger and guilt, fear of how s/he may die, fear of loss of

control and dignity, and loss of hope are significant elements of the final stages of illness (Catalan *et al.*, 1995). While adjustment disorders, major depression and increased substance use are common in the symptomatic phase, organic brain syndromes (including delirium and dementia), psychotic illness and behavioural problems are most common in the final stage (*ibid*).

## **The course and prevalence of specific mental disorders**

Epidemiological research examining the course and prevalence of mental disorder in HIV infection has also been conducted. One review paper suggests that between 38 and 73% of PLWHA have at least one lifetime mental disorder, with most preceding seroconversion, as noted above (Gallego *et al.*, 2000). Nonetheless, a study on psychiatric morbidity on entering an HIV clinic found that one in two people reported significant levels of distress (Lyketsos, Hanson, Fishman, McHugh, & Treisman, 1994; Lyketsos, Hutton, & Fishman, 1996).

One category of mental disorder is the organic type that is aetiologically related to the impact of the virus on the brain. Neurological impairment, most commonly cognitive decline, occurs either due to the direct effect of the virus on the central nervous system (CNS) or due to AIDS-related opportunistic infections against which the immune system cannot defend (Baingana *et al.*, 2005). Significant cognitive decline is typically associated with advanced disease, with about 50% of AIDS patients experiencing some form of cognitive impairment (Baingana *et al.*, 2005; Kalichman, 1995; Stern *et al.*, 2000). However, the most severe form of impairment, AIDS-related dementia<sup>6</sup>, occurs in between 8 and 20% of AIDS patients (Baingana *et al.*, 2005; Maj, 1996b; WHO Consultative Meeting, 1990 in Catalan & Burgess, 1996), with cognitive slowing the most commonly observed symptom (Kalichman, 1995). AIDS dementia is also the first AIDS-defining illness for as many as 25% of patients, while another 15% develop it along with other features of AIDS (Stern *et al.*, 2000). Less severe cognitive deficits are more common, occurring in 30-60% of advanced cases, and are typically associated with minimal impairment in functioning (Kalichman, 1995; McDaniel, Purcell, & Farber, 1997).

CNS damage can also result in delirium, mania or psychosis, the most common sources of psychiatric referral and hospitalisation in critically ill AIDS patients. While delirium occurs in 43-65% of late-stage individuals, psychosis is much less common at 0.2-15% (Baingana *et al.*, 2005; Gallego *et al.*, 2000; McDaniel *et al.*, 1997; Stern *et al.*, 2000). New onset psychosis in the absence of personal or familial history is a poor prognostic indicator associated with slow cognitive

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<sup>6</sup> This condition is also referred to as AIDS Dementia Complex, HIV associated dementia or HIV associated cognitive motor complex (Stern *et al.*, 2000).

decline and reduced survival (Catalan *et al.*, 1995), as is mania which occurs in 8% of patients, also in the late stage (Baingana *et al.*, 2005; Gallego *et al.*, 2000). Both conditions tend to be more severe and chronic than mania or psychosis not associated with organicity (Fishman & Lyketsos, 1996). Other organic disorders are (rare) secondary mood syndromes, and medical conditions such as Kaposi's sarcoma and cerebral toxoplasmosis that manifest with psychological symptoms (McDaniel *et al.*, 1997).

Among the non-organic psychiatric disorders, adjustment disorders and major depression are the most commonly reported and diagnosed clinical syndromes, affecting as many as 60% of PLWHA at some point in the illness (Fishman *et al.*, 1996; Kalichman, 1995; Treisman *et al.*, 2001). It has been reported that PLWHA (at any point in time) present with rates of depression similar to those in other medical populations but higher than general primary care patients (4-14%) (Ciesla & Roberts, 2001; Rabkin, 1996), and that they are twice as likely to suffer from depression as the general population (Baingana *et al.*, 2005; Ciesla *et al.*, 2001). It may be that higher reported rates are a function of the high risk groups studied, particularly homosexual men who have been found to have elevated levels of depression regardless of their HIV status (Rabkin, 1996; Rabkin, Ferrando, Jacobsberg, & Fishman, 1997; Maj, 1996a; Perkins *et al.*, 1994; Rosenberger *et al.*, 1993). Moreover, Rabkin (1996) reported that 80% of those seeking treatment for depression had a history of depression predating seroconversion. Risk for suicide has also been reported to be elevated, as much as 7 to 36 times that in a matched population (Catalan *et al.*, 1995), and is likely to be predicted by HIV-specific factors as well as previous suicide attempts or serious psychiatric history (Kalichman, 1995).

Substance use disorders and sexual dysfunction are also amongst the most commonly reported psychiatric complaints in infected populations. The prevalence of substance use has been reported at 20-73% (Baingana *et al.*, 2005; Gallego *et al.*, 2000; Lyketsos *et al.*, 1996; Rabkin, 1996), although current rates are reported as much lower. Sexual dysfunction is particularly common in the symptomatic phase or when new treatment is started, but can also result from pre-existing difficulties or a psychological response to diagnosis and infection (for example, fear of infecting one's partner) at other stages of the disease (Catalan *et al.*, 1995; Gallego *et al.*, 2000). Uncertainty regarding the illness is a key contributor to anxiety, but levels average 5% and are not generally higher than in community samples (Kalichman, 1995; Rabkin, 1996). Personality disorders, somatisation and hypochondriasis have also been reported and can complicate the process of adapting to, and coping with, HIV (Baingana *et al.*, 2005; Kalichman, 1995).

## **General risk factors for psychological morbidity**

While it is possible to delineate mental health symptoms as a function of disease stage, and to state the prevalence of particular conditions, Kalichman's (1995: 156) observation is an important one, that "rather than a linear progression, psychological reactions to HIV infection represent cycles of emotions usually initiated by HIV/AIDS related events". Moreover, the particular pattern and nature of responses are determined by a range of factors, some of which have already been discussed. Medical events or HIV-related factors are one such risk category, and include receiving a diagnosis of HIV, the development or worsening of symptoms, being diagnosed with AIDS, and hospitalisation (Catalan *et al.*, 1995; Catalan, 1999; Gallego *et al.*, 2000; Kalichman, 1995; Lyketsos *et al.*, 1994). Related factors are the uncertainty regarding treatment efficacy, and dealing with the uncertain course of illness and constant reminders of the disease, including symptoms and daily medication regimens (Kalichman, 1995). Other factors that play a role in predicting morbidity are the nature and quality of social supports, personality traits and the choice of coping strategies (Catalan *et al.*, 1995; Catalan, 1999; Gallego *et al.*, 2000; Kalichman, 1995); perceived responsibility and cultural scripts regarding the expression of distress (Kalichman, 1995); and the experience of social losses (either partners, friends and employment or losses due to AIDS) (Gallego *et al.*, 2000; Kalichman, 1995). Past psychiatric history is a particularly strong predictor, partly since pre-existing mental health problems (including substance use) are present in many groups most affected by HIV, along with poor health resources, congested conditions, and care burden in the case of infected women and mothers (Kalichman, 1995; Lyketsos *et al.*, 1994; Lyketsos *et al.*, 1996; Perry & Fishman, 1993). The argument has already been made that these poverty and gender-related factors are in and of themselves risk factors for poor mental health, in addition to being associated with high HIV prevalence. The fact that these groups are also likely to be the target of HIV-related stigma and discrimination further complicates attempts at psychological adjustment by causing chronic stress, complicating disclosure, undermining coping and social support, and sometimes resulting in social withdrawal, all of which can contribute to persistent distress and mental health problems (Kalichman, 1995).

## **Mental health and poverty in the era of HAART**

With the advent of highly active antiretroviral therapy (HAART), available in the United States since 1996, it was fairly widely assumed that both the physical and mental health impact of HIV/AIDS would be significantly ameliorated (Siegel, Karus, & Dean, 2004). In 1999, Catalan stated that:

There is at present a feeling that the textbooks will have to be rewritten soon and that what was thought to be certain knowledge (of the adverse *psychological* and social consequences of HIV) will be shown to be less solid than expected (Catalan, 1999: 21 emphasis added).

Further, Rabkin and Ferrando (1997) used the term ‘second life agenda’ to refer to the renewed hope and optimism experienced as a result of HAART which, for the first time, signaled the possibility that HIV would be a treatable chronic illness rather than a disease that promised imminent death.

However, the prospect of extended survival presents significant psychosocial challenges – some old challenges in a different guise and some new ones associated with managing a chronic illness. With respect to treatment, antiretroviral therapy has side-effects and requires (sometimes) complicated regimens to be taken daily for life (Kalichman, Ramachandran, & Ostrow, 1998). Further, at least 95% adherence is needed to ensure sufficient viral suppression to avoid the development of treatment resistance. This is likely to be particularly important in developing countries where less treatment options are available in the event that resistance to firstline treatments develops. Despite the promise of new drug regimens, there was also considerable uncertainty regarding long-term treatment safety and efficacy, particularly at the time of their emergence (Catalan, Meadows, & Douzenis, 2000; Siegel & Lekas, 2002). Inadequate patient education may result in greater distress in the event of treatment failure (Kalichman *et al.*, 1998; Rabkin & Ferrando, 1997). Drug interactions are also likely, including psychotropic medication used to treat mental health problems, resulting in complex management issues and possible lessening of therapeutic effects (*ibid*). Some have also pointed to the implications of widespread availability of HAART for prevention efforts, suggesting that perceptions of reduced risk of transmission for those on treatment could result in an increase in high-risk sexual behaviour (Catalan *et al.*, 2000; Kalichman *et al.*, 1998)

Aside from treatment-related factors, people on HAART are faced with other challenges, key amongst them the need to reevaluate their life and renegotiate roles and relationships. This may involve returning to work, renewing old relationships, contemplating new intimate relationships, and negotiating shifts in role as result of improved health (Kalichman & Ramachandran, 1999; Siegel *et al.*, 2002). For women, treatment access may provide renewed hope regarding the prospect of parenthood. However, despite optimism, such changes can be associated with renewed anxiety regarding stigma and disclosure, and concerns regarding employability and the health implications of added stress on return to work. Further, sexual dysfunction is a possible side-effect of treatment, and can

greatly complicate an attempt to resume or begin new intimate relationships (Catalan *et al.*, 2000). These factors, together with the need to take daily medication, may be a constant reminder of the patient identity that challenges individuals in their attempt to positively reframe their concept of living with HIV (Siegel *et al.*, 2002).

## **Empirical evidence regarding the psychological impact of HAART**

While several published empirical studies (in developed countries) include participants on HAART, few have systematically explored the mental health and psychosocial implications of the availability of, and access to, treatment. Further, of this handful of studies, the majority have included only homosexuals and/or men. Two such studies, both of which followed a cohort for two years, found improvements in psychosocial wellbeing associated with HAART. While Rabkin *et al.* (Rabkin, Ferrando, Lin, Sewell, & McElhiney, 2000) found a modest reduction in distress in a cohort of bi/homosexual men with symptomatic illness, Judd *et al.* (2000) reported a decrease in depression and number of stressful life events in relatively asymptomatic adults (most of whom were intravenous drug users and/or homosexual). Further, Catalan and colleagues in a review of patients at a London psychiatric service for PLWHA, found a decrease in adjustment disorders, organic brain syndromes and mania throughout the 1990s, a period during which access to treatment became more common (Catalan *et al.*, 2000). Rates of depression and anxiety, however, increased, as did sexual dysfunction. Other qualitative studies with (mostly) homosexual men have also pointed to a range of difficulties associated with HAART, including uncertainty regarding negotiating social roles and interpersonal relations (Brashers *et al.*, 1999; Bogart *et al.*, 2000), uncertainty about returning to work (Brashers *et al.*, 1999; Lee, Solts, & Burns, 2002), and anxiety regarding treatment and the perceived intrusiveness of medication that serves as a daily, visible marker of illness (Lee *et al.*, 2002). Further, amongst a matched sample of women (75% of whom were mothers) in the pre- and post-HAART eras, women in the post-HAART era were more likely to report health-related stress and stress from stigma and disclosure, to view HIV as causing them harm, to report that their health is due to chance, and to use avoidant and emotion-focused coping (Siegel & Schrimshaw, 2005). They also exhibited generally poorer adjustment to their illness in the home environment (Siegel *et al.*, 2004). This difference is attributed to higher expectations amongst women in the HAART era (leading to more stress when problems arose), but also possibly to ongoing, chronic non-HIV related stressors in their lives.

While the results are not conclusive, taken together they suggest that treatment is more likely to change the nature of psychosocial and psychiatric problems than prevent them altogether or reduce their prevalence. Focus is likely to shift from anxieties regarding the short-term to concerns about the long-term. Further, difficulties might be particularly marked for PLWHA who have been very ill and dysfunctional prior to commencing treatment (as opposed to relatively asymptomatic). Such individuals may experience more real and perceived difficulties in managing their lives with the illness in the long-term (Personal communication, Desireé Michaels, July 2004).

## **Developing country access to HAART**

Of course a very important caveat to this discussion is the fact that, whether HAART improves or complicates mental health outcomes, not all PLWHA have access to treatment. While progress has been made through the vehicle of the World Health Organization's (WHO) '3x5' campaign<sup>7</sup>, only one in ten Africans and one in seven Asians in need of HAART were receiving it in mid-2005 (UNAIDS, 2005). Half of all people in developing countries receiving HAART live in sub-Saharan Africa, yet coverage in this region is still only at 11% (World Health Organization, 2005; UNAIDS, 2005). Further, progress has been uneven, thus while coverage in Botswana and Uganda is around 33%, 90% or more of those in need in Ethiopia, Ghana and Mozambique are still not receiving treatment (UNAIDS, 2005).

In South Africa, despite being home to one in four HAART recipients in sub-Saharan Africa, coverage remains low at 15% (UNAIDS, 2005). At the end of 2005, there were 193 579 people in South Africa on HAART, of which just more than half were in the public<sup>8</sup> sector (57.8%) (Nattrass, 2006). This was only 30% of the target set in government's Comprehensive Plan released in November 2003 to roll-out HAART in the public sector (Department of Health, 2003; Nattrass, 2006). Further, coverage is uneven, with successes in some provinces (for example, the Western Cape which reached its target in mid-2004) bringing up the national average while other provinces continue to lag behind targets considerably (Nattrass, 2006). However, for the purpose of the present discussion it must be noted that 70% of the patients at the country's first public sector HAART programme in Khayelitsha (Cape Town) were women (Coetzee *et al.*, 2004). For reasons that will be discussed below, women in Africa (and

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<sup>7</sup> This campaign aimed to provide access to treatment for three million people in need of HAART in developing countries by the end of 2005.

<sup>8</sup> The private health services' sector serves a minority of the South African population, thus the majority of, if not all, people living in poverty are reliant on the public sector to meet their health care needs.

South Africa) tend to have more access to HAART than men since many referrals continue to come through antenatal services (UNAIDS, 2004c).

## **The categorisation of women in HIV/AIDS discourse and practice**

Before considering the implications of the aforementioned discussion on women, HIV/AIDS, poverty and mental health, a brief discussion of the categorisation of women in HIV/AIDS discourse and practice is in order.

Two processes in particular seem to be at play simultaneously, what Squire (1993a) has referred to as overgendering and undergendering. Women are either ignored and marginalised, or pathologised in ways that mirror some of the dominant cultural definitions to which this paper has already referred. More specifically, where women are referred to it is as vectors of the disease, either the sex workers that infect men or the mothers that transmit the disease to their unborn children (Berer & Ray, 1993; Cohan & Atwood, 1994). The construction of women as pollutants and the incarnation of sexual danger and biological power are therefore reproduced despite the fact that men are permitted multiple partners (a risky sexual practice), without questioning how the sex worker herself became infected, and despite growing evidence of women's own vulnerability (Anastos & Marte, 1990 in Cohan *et al.*, 1994; Berer & Ray, 1993; Squire, 1993a; Upton, 2003). In a similar vein, debates regarding the reproductive choices of HIV infected women focus on women's behaviour while ignoring men's role or responsibility in decision making (Strebel, 1995). For women from socially disadvantaged groups (often those most affected by HIV/AIDS), these forms of marginalisation can be heightened as their gender intersects with ethnicity and class to create multiple vulnerabilities or avenues of risk (Gupta *et al.*, 2003; Worth, 1990).

There are several practical consequences of the construction of women in AIDS discourse, including a historical neglect of the effect of the illness on women themselves (Cohan *et al.*, 1994). Long after there was evidence that women were susceptible to HIV, it remained constructed as a gay man's disease and most research, including drug trials, were conducted either predominantly or exclusively with men, leading to implicitly male models of disease and non-specific, even clinically inappropriate treatment and therapeutic approaches for women (Cohan *et al.*, 1994; Hankins & Handley, 1992; O'Sullivan & Thomson, 1992; Squire, 1993a; Strebel, 1995). Even the definition of AIDS was derived from research with men, with conditions that tended to affect or were unique to women, such as invasive cervical cancer, recurrent pneumonia and pulmonary tuberculosis, only added to the definition of AIDS just more than ten years into

the epidemic in 1993 (Cohan *et al.*, 1994; O'Sullivan & Thomson, 1992). Consequently, cases in women were underreported and tended to be diagnosed later, and women frequently started treatment later when they were more ill (Strebel, 1995). Given that the manifestations of the disease were less well understood in women, as was the effectiveness of drugs and their potential side-effects, clinical management of women on treatment was also undermined (Cohan *et al.*, 1994)

The marginalisation of women in AIDS discourse has also been evident in at least three other related ways. First, women's issues received limited coverage at international AIDS forums, with the first coverage occurring at the seventh international AIDS conference in 1991 (Long, 1996). Where women were included in international agendas they continued to be treated only as those who passed on the infection as mentioned above (*ibid*). Second, women-centred or gender-specific issues were slow to become the focus of global research, policy and service organisations. Despite the fact that the United Nations Development Fund for Women (UNIFEM) and the International Centre for Research on Women (ICRW) had already been formed in 1976, and a regional community-based organisation on women and AIDS in Africa (The Society for Women and AIDS in Africa - SWAA) was formed in 1988, it was only in 2004 that the UNAIDS formed the Global Coalition on Women and AIDS. Twenty years into the epidemic, this was a recognition of the need to respond to "the increasing feminisation of the AIDS epidemic and a growing concern that existing AIDS strategies did not adequately address women's needs" (<http://womenandaids/unaid.org>). Third, and perhaps surprising, is the fact that even feminist leaders and activists were slow to focus attention on women and HIV/AIDS, having failed to do so for much of the first decade of the epidemic (Treichler & Warren, 1998: 119).

More recently, however, increasing global attention has been focused on women and HIV/AIDS and a growing academic literature is also available. By way of example, since the first well-documented book on women and AIDS, Diane Richardson's 'Women and the AIDS crisis', was published in 1987, at least 25 books have been published by social scientists and women living with HIV/AIDS focusing specifically on women and gender issues. These have covered a range of topics including the invisibility of women in the epidemic (Corea, 1992), the experiences of infected mothers (Walker, 1998), the psychological concerns of Western women affected by HIV (Squire, 1993b), the need for feminist theory and practice (Doyal, Naidoo & Wilton, 1995) and gender-sensitive interventions and policies for women (Long & Ankrah, 1996), and, most recently, women's everyday experiences of the impact of the disease on their lives, including how they work to 'mend their fractured selves' (Ciambrone, 2003). It is perhaps significant that a large number of these edited

and single-authored volumes were published in the mid-1990s, following the change in the definition of AIDS to include women-centred syndromes.

While it is certainly not accurate to characterise the research, policy and service arena as having completely failed to address women's issues until very recently, the point to be made is that there is clear evidence of the marginalisation of women's issues, particularly in the first ten to twelve years of the epidemic (1981-1991/3), and the problematic representation of their roles and experiences in general. Further, there has been a growing historical shift subsequently toward not only more attention, but more appropriate attention, to matters concerning women. Nonetheless, in relative terms, the gaps and omissions very clearly remain. Just as Reynolds (1991: 159) stated that children are "all too often ... lumped in that amorphous category 'women and children'", the corollary is true that women have been "lumped" in that category and not often treated as analytically separate. Women continue to be emphasised in terms of what they are to other people, in particular mothers and wives/partners (Hogan, 1998), and thus the lens seldom falls on their experience per se.

## **The relevance of mental health for HIV infected women and mothers living in poverty**

For the purpose of the present discussion, two particularities of this failure are relevant: first, poor women and AIDS are still largely neglected, despite the growing number of publications (Farmer, Connors, Fox, & Furin, 1996), and second, the wellbeing and mental health of women, including but not exclusively those living in poverty, are especially neglected. Issues of class, social context and poverty are either absent or glossed over in the few psychological theories of the impact of HIV/AIDS, activist literature and much feminist literature (*ibid*). Moreover, mental health, including that of women, remains low on the agenda of developing countries even in the era of HIV/AIDS.

Given the arguments presented in this paper, the answer to the question posed in the title is that the mental health of HIV infected women and mothers living in poverty, including those with access to HAART, does matter and does merit addressing. Living in such circumstances, and dealing with the multiple stressors associated with poverty, HIV and childcare, quite clearly places these women at increased risk for mental health problems for all of the reasons already discussed. In addition to the challenges which living with HIV and being a caregiver places on women in middle-class societies, women living in developing world settings must negotiate these challenges against the backdrop of adverse social and environmental conditions.

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