

The Care Economy: Gender and the Silent AIDS Crisis in Southern Africa

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This article considers the impact of AIDS on women's roles and responsibilities within the household 'care economy'. In particular, it emphasizes that all interventions aimed at reversing the AIDS epidemic need to take into account the excessive work-load that members of the household, usually women, shoulder in responding to the needs of sick family members. Most notably, gender equality and care economy issues need to be identified by development programmes. There is also a need to implement policies that focus on issues such as treatment, prevention, education, economic empowerment and violence against women. The article argues that unless the care economy and the relations of gender inequality within the household are included in the design, implementation, monitoring and evaluation of such interventions, results will be compromised.

Introduction

When AIDS enters the household, it devastates the family, drains assets, plays havoc with education, escalates domestic violence, and pushes families into a downward spiral towards greater poverty. Unlike most other epidemics or pervasive diseases, AIDS tends not to target the very young and the very old. It attacks young adults and those in the prime of their life, those who are healthiest and generally strongest.

The figures tell the story of the feminisation of the epidemic. Annually revised statistics prepared by UNAIDS, show that the percentage of women living with HIV/AIDS has grown steadily over the past decade and that, on a global scale, women have reached parity with men. In sub-Saharan Africa, women now comprise 57 per cent of the estimated 25.8 million people living with HIV and AIDS.¹ In Africa there are now twice as many young women living with HIV as young men (between the ages of fifteen and 24). In the hardest hit countries of southern Africa, there may be six times as many young women as men who are HIV-positive. In parts of these regions, more than one-third of teenage girls are HIV-positive.²

Women are both physiologically and socially more vulnerable to infection than men. In recent years, there has been a growing understanding that social factors – a mix of gender inequality, poverty and stigma – fuel the AIDS epidemic. Cultural norms and societal expectations circumscribe the ability of women, young women and girls to take charge of their bodies and exercise their reproductive and sexual rights. Too many women do not have the power to negotiate safe sex, or find it difficult to say no to unwanted sex. When poverty is endemic, it can mean that women may have little option but to engage in risky sexual practices in order to ensure their survival as well as that of their family.

An additional gender dimension exists in this scenario: when AIDS enters the household it is women who overwhelmingly provide the care. Women are therefore not only

1 UNAIDS/WHO, *AIDS Epidemic Update, December 2005* (Geneva, UNAIDS, 2005), p. 17.

2 UNAIDS, *Report on the Global AIDS Epidemic* (Geneva, UNAIDS, 2004), p. 94.

disproportionately *infected* with HIV in southern Africa; women are also disproportionately *affected*. In 2005 alone, 4.9 million people became infected and 3.1 million died from the disease. Who took care of those 3.1 million during the last days of their lives? It is not unreasonable to assume that nearly every one of them, whether male or female, was cared for by a woman – a mother, a grandmother, a sister, a daughter, the female neighbour, a female homecare attendant – regardless of where they lived. While there have been some advances in dealing with HIV/AIDS, the epidemic is not yet being tackled on the kind of scale necessary to reverse it. Certainly more funds have been allocated to HIV/AIDS in the last few of years than ever before with donors such as the Global Fund for AIDS, TB and Malaria, as well as bi-lateral and multi-lateral donors providing new funding. But, even as political will increases in some countries, the funding continues to fall far short of the need. Current funding is insufficient to cover the provision of drugs (including anti-retrovirals as well as other drugs such as antibiotics and even aspirin), basic items (such as disinfectant or gloves), information and training, and critical resources (such as accessible, clean water) and, notably, state subsidies and social protection measures. When these needs continue to be unmet, it is the care economy that fills the gaps with the result that an already heavy workload becomes untenable.

For example, the task of water collection illustrates the extent to which women are affected by the HIV/AIDS crisis. In households where one person is seriously ill with AIDS the amount of water needed daily increases substantially – those infected with HIV may experience five, six, or sometimes continuous episodes of diarrhoea each day. Bedclothes need to be washed. The patient needs to be washed. Clothes need to be washed. Clean drinking water is essential for re-hydration. In the remoter parts of Africa, collecting water can mean walking long distances, and it can take as long as one or two hours to head-carry a heavy load back home.

Women, for the most part, perform this work, which is done alongside the day-to-day roles and responsibilities within the household. Such labour is reflected in terms such as ‘care economy’ or ‘unpaid care work’,³ and involves a wide range of caring roles and responsibilities that are performed in the household and community. These include all the tasks associated with maintaining a household and family, including food preparation, water collection, cleaning, washing clothes, child-bearing and rearing, caring for the elderly and the sick, providing emotional support, passing on social values, as well as providing informal education. These roles and responsibilities are intertwined with inequitable gender relations, which serve to prescribe who undertakes this work, and under what conditions.

As economist Diane Elson indicates:

There is the risk that the use of the term ‘care’ will mystify the relationship between the provider and the receiver. It must be recognised that care may be given unwillingly, extracted by psychological and social pressure or even physical violence, from women who can see no alternative but to provide care, even to those who oppress them. The lack of support for such care creates pressures on those who give it; thus caregivers may also visit their frustrations upon those in their charge, who are even more vulnerable to abuse. The advantage of the term is that it signals the fundamental importance of interpersonal attention to other people’s needs in the maintenance of human societies.⁴

3 For the purpose of this article, I will use the term ‘care economy’, cognisant of the fact that it can be a confusing term in the context of AIDS where the word ‘care’ brings to mind caring for people who are ill rather than the many tasks associated with women in their roles as caring for the household as a whole.

4 D. Elson (ed.), *Progress of the World’s Women 2002* (New York, UNIFEM, 2003), p. 23 (available at www.unifem.org). See also, D. Elson (ed.), *Male Bias in the Development Process* (Manchester, Manchester University Press, 1995); *World Development*, Special Issue on Gender, Adjustment and Macroeconomics, (1995); D. Elson, ‘Social Policy and Macroeconomic Performance: Integrating “the Economic” and “the Social”’, in T. Mkandawire (ed.), *Social Policy in a Development Context* (London, Palgrave Macmillan, 2005).

Categorising care as the natural work of women thus obfuscates the psychological and physical violence that can make women engage in that work. Too often HIV/AIDS programmes are organised around the assumption that nurturing is women's role and thus implicitly support patterns of female exploitation, even abuse.

Care giving is essential for human survival. As Elson also points out, 'in the long term it is these services that sustain a supply of labour to the economy, and make human societies possible, weaving the social fabric and keeping it in good repair. Taking these services for granted may have unforeseen costs in terms of deterioration of both human capabilities and the social fabric'.⁵ The deterioration of both human capabilities and the social fabric is now a crisis. It's a crisis beyond measure; it's a crisis that cries out for a global response such as that which provided for victims of the tsunami in Asia. However, this is a crisis that continues to be ignored, and one which the world continues to dismiss. The costs, still unforeseen in the era of the AIDS epidemic, now have to be tallied as does the cost of *not* responding to the crisis.

The role of primary care giver is an undertow that pulls women out of regular employment (whether formal or informal), extracts girls from school to assist in the care-giving, prevents women from seeking medical treatment when they have no one to care for children and their homes in their absence, escalates household tension into violence when women cannot provide food on time or adequately perform other aspects of their expected domestic roles. The burden on women and girls to look after the ill can create a time poverty so severe that households implode under the strain. Although this reality undermines virtually every step taken to stem a pandemic of global proportions, most governments – quintessential patriarchal structures – do not, or believe they cannot, provide the social protection measures needed to deflect a crisis that is rapidly spinning out of control. In southern Africa, where the epidemic is at its most intense, the impact of AIDS on women's work in the household is most acute and is threatening the survival of family, household and community in dire and multi-faceted ways.

The gendered relations of power and understandings of femininity and masculinity help structure the care economy. While care may be given unwillingly, it is often given willingly out of love and genuine concern for family members. Many women who are taking care of members of their families with AIDS resent the inference that this work should be paid because they feel it is performed out of love. To offer payment would be considered an insult by many. For others, the emotions are mixed and care may be a source of resentment but is regarded as a duty. As economist Nalini Burn points out, there is an issue of agency, choice and freedom.

Some [unpaid care work] activities – which are costly in terms of resources – can be valued in themselves and women can prefer to exercise choice to look after their own sick husbands . . . [and] their sick adult children rather than delegate this task to others. They may abandon work, fields, [or] trade off personal maintenance to do so. Or they may just have to save lives.⁶

While women might argue that the choice – their agency – is theirs, it comes with heavy costs, and those costs reverberate back to women because of inequitable gender relations and assumptions about care-giving.

There are, then, two facets to consider when addressing the impact of AIDS on the care economy. The first relates to the tasks and responsibilities associated with the care economy, which are regarded as the domain of women. The second relates to the locus of the power

5 Elson (ed.), *Progress of the World's Women 2002*, p. 23.

6 N. Burn, 'Coping with HIV/AIDS: Unsustainable Care, Unattainable Policy Targets: Pathway for Action' (unpublished paper, prepared for UNIFEM, New York, 2004).

relations between men and women at the intimate level, which serves to reinforce the gender division of labour and place those who perform care in a subordinate position. Inherent in these power relations are men's perceptions of their 'masculinity', which includes the expectations of their roles *vis-à-vis* those of the women in their family. Both care responsibilities and power imbalances within the family must be taken into account in order to analyse and understand the impact of AIDS on the care economy and the impact of an overstretched care economy on the HIV/AIDS epidemic.

This article highlights the way in which women's work must be calculated into every aspect of the HIV/AIDS crisis. I will examine how the care economy links to five particularly critical areas, namely treatment, prevention, education, economic empowerment and violence against women. To some extent this division is an artificial one, as the sectors themselves are closely interlinked. Prevention initiatives include education as a key measure; economic empowerment is related to the perceptions of society of men as breadwinners, while women are more likely to be able to remove themselves from violent relationships if they are financially independent. Examining each of these areas separately will illustrate how the care economy and inequitable gender relations are at the core of the HIV/AIDS crisis. Only when the dynamics of the care economy are taken into account, can effective responses to the epidemic be fully conceptualised.

Interconnected Interventions

The impact of AIDS on the care economy is getting some attention through an emerging body of academic and development literature, studies and press coverage. Estimating the cost of the care economy in the context of AIDS, a necessary step in order to bring evidence to policy makers, has also begun. However, when we look at the global response to the epidemic there is limited acknowledgement of how the care economy is robbing women of their time and energy, placing an unbearable and increasingly untenable load on their work within the home, and how this work within the care economy is subsidising governments who are able, as a result, to limit expenditure on social protection. It is becoming increasingly clear that programmes and policies have limited effectiveness if the relationship between the care economy and issues such as treatment, prevention, education, violence against women, condom use and economic empowerment, is ignored. The time and energy women expend on tasks and responsibilities within the care economy prevents them from accessing treatment, benefiting from prevention messages and critical information about transmission. Consequences include the withdrawal of girls from school, increased violence against women, as well as making it difficult for women to be active and productive in both the formal and informal sectors of the economy.

At present, the care economy in the context of AIDS tends to be regarded as its own sector. While it is absolutely necessary for any socio-economic and gender analysis to show the untenable load of this work on women, it is also essential to link the care economy to the other sectors. Donors – whether these are multi-lateral, bi-lateral, large foundations or international non-governmental organisations (NGOs) – tend to focus on providing resources for one particular sector or a multi-sectoral initiative, but fail to take the overlap with the care economy into account. There is a tendency to treat each aspect as if it stands alone, ignoring the links between the various aspects of the epidemic. This seriously hampers the attainment of targets and goals such as the Millennium Development Goals for 2015 or the WHO campaign, which has set a target of treating 3 million people in low- and middle-income countries with ARV therapy by 2005. However, by following the thread of the care economy through all sectors a far more effective response to the AIDS crisis can be achieved.

Treatment

In 2004, less than one out of ten people who urgently needed HIV treatment globally were on ARV treatment.⁷ A recent report by the WHO on the '3 by 5' campaign states that nearly six out of ten adults on treatment are women, which reflects an equitable distribution because more women are infected than men. The number of people on anti-retroviral therapy is still very small, although it has grown from 150,000 to 500,000 since 2004 as a result of the campaign.⁸ Nonetheless, this is still a small proportion of those who need ARV therapy. In South Africa alone, over 6 million people are living with HIV or AIDS. The figure for the sub-Saharan region is an estimated 25.8 million. Most of the 6 million people estimated to be in need of ARV treatment live in sub-Saharan Africa and there are considerable obstacles in the way of reaching those people who urgently need treatment. Small studies and considerable anecdotal evidence persistently point to a major constraint being gender inequality and women's responsibilities within the care economy.

If many more of those who are sick with AIDS were able to access the necessary drugs and adhere to the drug regimen, then the crisis around care giving would be reduced. If those women who are both carers and living with AIDS had increased access, then they would be in a better position to provide the care. It is not surprising, therefore, that one of the most persistent demands from people living with AIDS relates to the need for affordable drugs. With free ARVs, household members and household assets would not have to be rallied to respond to sick and dying family members. Girls and boys could return to school. Time would be freed to work the fields, engage in informal or formal market activities, and energies could be focused on prevention.

As the UNAIDS 2004 AIDS Epidemic Update points out, there is a likelihood that as treatment programmes expand women may miss out because of their fear that their partners will become aware of their HIV status. While it is not possible to over-emphasise the urgency of providing anti-retroviral drugs to everyone who needs them, it is important to add to the equation the day-to-day gendered realities that confront women – and men – living with AIDS that prevent them from being tested, or from being consistently adherent once they are on ARV treatment.

The following examples speak to some of these realities:

In Brazil, which is held up as an example of a country that has forcefully addressed the epidemic including the provision of free drugs, a UNIFEM colleague found on her visit to Bahia that there are definite constraints. People living in rural areas of Bahia where the rate of infection is growing, travel up to fifteen or sixteen hours to the nearest clinic. While men are likely to be able to make this journey without offering any particular explanation, women do not have the mobility nor the money for bus fare. And they cannot explain to their family or neighbours why they have to be away from home for days and need to have someone look after their family. In addition, this journey would have to be made a few times a year. Thus, travelling to the clinic, when it pulls them away from their responsibilities in the household, is therefore not an option for these women.⁹

Rwanda is one of the countries in Africa that has recently received support from the Global Fund for AIDS, TB and Malaria to provide free drugs to those who need them. African Rights, an NGO currently setting up a programme to support women who were raped during the genocide and now have AIDS, has found in their initial assessment that a myriad of constraints prevent women from

7 UNAIDS, 'Report on the Global AIDS Epidemic' (UNAIDS, Geneva, 2004), p. 101.

8 UNAIDS/WHO, Progress on Global Access to HIV Antiretroviral Therapy: An Update on 3 by 5 (Geneva, WHO, June 2005).

9 UNAIDS/UNFPA/UNIFEM, 'Women and HIV/AIDS: Confronting the Crisis' (July 2004), p. 25 (available at www.genderandaids.org).

seeking treatment and taking the drugs regularly even when they technically have access to them.¹⁰ Some of the constraints relate directly to their roles within the care economy. For instance, take Catherine whose sister Denise is living with AIDS and is totally dependent on her. Both women are genocide widows and live in poverty. Denise does not have money for transport to the hospital and so gets increasingly ill, which means that the care that Catherine gives her will be more and more time consuming and costly and the chance of getting the drugs further and further removed. It becomes a vicious cycle. If Denise could access the drugs, the care provided by Catherine would lessen and both women might be in a better position to generate some income, and the dependency could be broken. In a different scenario, Celeste was generously providing drugs for several women as well as basic food provisions. However, many of those she supports are looking after others' children as well as their own. Celeste found that the women would share their rations among the children. Without proper nutrition, the drugs were not effective.

In Zambia, the intersection between women's gender roles and lack of treatment was highly evident at a local hospital in Petauke, a small rural town. Of the 40 patients on ARV therapy, three were women. Alyce Banda, a midwife, said that in her ten years at the clinic she had seen women bringing their husbands in on wheelbarrows, bicycles and even on their backs, like babies. But she has yet to see a man even offer the support of his arm and bring his wife in for treatment. And so it was the men and not the women who got treatment. One of the patients at the clinic, Agnes Zulu, asked: 'How would I feel if there is no food in the house to feed the children because the money has been spent on medication which is only for me?' Holder Chama, a single mother of five, said food was also an issue in her home. 'On most occasions we go without food . . . as women, we eat last and there usually is not enough to go around. So how can we go on the medication? We need food to go with it. I tried to take the medication on a stomach full of water and I vomited everything.'¹¹

In contrast, some studies conducted in South African urban areas where clinics are reasonably widespread, found that it is the men who are reluctant to get tested. Of the 1,500 men and women currently enrolled on ARV therapy at the Chris Hani Baragwanath Adult HIV clinic in Soweto, Johannesburg, only about one-third are men. The figures are similar at the Helen Joseph AIDS clinic, where men also make up less than one-third of the 2,000 patients.¹² Testing for HIV/AIDS has a similar gender imbalance. Another study conducted in Soweto surveyed over 2,500 people and found that men are half as likely as women to have been tested for HIV.¹³ The study argues that part of the problem is the socialisation of gender roles. Men are supposed to be the head of the household and do not want to admit their own weakness.¹⁴ 'From personal experience I have seen men die in numbers because they didn't want to know their status', Treatment Action Campaign (TAC) representative, Gordon Mthembu said. It may be as hard for those wielding power to show vulnerability, as it is for women to refuse to submit to that power.

These examples demonstrate that even when drugs are free, and where treatment and care are free, *access* continues to be limited by the time and energy women need to spend on caring responsibilities, on lack of money for transportation (particularly severe for the women who are financially dependent on men) and by the power imbalances in the household. Treatment can ameliorate the drain on women's caring roles, but it cannot be effective if the serious obstacles raised by gender inequality are ignored.

10 Interview during visit to the African Rights Gift for Life Project, Kigali, Cyangu and Butare, April 2005.

11 United Nations, Integrated Regional Information Network (IRIN), Nairobi, 5 March 2004.

12 'Stubborn, Scared Men Less Likely To Go For an HIV Test', *New City Press*, 17 April 2005.

13 The study was conducted by EngenderHealth, Hope Worldwide and the FRONTIERS programme of the Population Council.

14 'Stubborn, Scared Men', quoting Gordon Mthembu, provincial Chairperson for the Treatment Action Campaign, South Africa.

Prevention

The gender roles prescribed by society and taken up within the context of the care economy do not only shape individuals' willingness and ability to seek treatment. Unequal power relations are a major factor in the inability to practice safer sex. Men's inability to show vulnerability or to appear weak to their partners and society leave them equally unable to practise prevention. Men who are expected to be experienced and knowledgeable about sexual matters are unlikely to seek enlightenment. In many societies where a woman's 'innocence' is regarded as synonymous with virginity, seeking information about her reproductive health and rights is considered suspect: to have or to want such knowledge means that she is a 'loose' woman. The 'ABC' message – Abstain, Be faithful, use a Condom – is an ideal that is hard to adhere to. Yet, how can a woman abstain in a society where sexual violence is rife? Condoms are irrelevant when a woman is being raped, or where the fear of violence means that women do not demand their use.

Prevention efforts intersect with gender inequality in the home and women's roles and responsibilities in the care economy. The first is graphically illustrated by a husband's response to his wife when she asked him to use a condom: 'If you want me to have sex with a condom, I won't give you money for food.'¹⁵ Even when women are fully aware that their husbands are having a sexual relationship outside of the marriage they are often unable to demand condom use because of the fear of a violent or punitive response. Unlike the wife quoted above, many do not even try. Trapped in their inequitable gender roles and dogged by gender inequality, both are vulnerable to infection.

Where poverty and gender inequality converge, many women are unable to provide for their families, and seeing their children hungry night after night, they have little option but to engage in survival or transactional sex work. Today they need to feed their families. They can pay no attention to the possibility of getting sick years down the line, at some indeterminate date. There is no choice, no option in these circumstances, and when men offer to pay more for sex without a condom that can only be welcomed.

Access to education and information is key for young women and girls to be able to implement prevention messages and to experience the empowerment needed in order to refuse unwanted sex and unsafe sex. But one of the major obstacles to entering school and staying there, as discussed below, is the need for their labour within the household to support the care work performed by women.

Education

In recent years, in southern Africa, the enrolment of children in school was increasing, albeit slowly and in favour of boys. A reversal of this trend, which is a cause for serious concern, is now evident. In countries with high rates of AIDS, girls are twice as likely as boys to be kept out of school to care for sick relatives, or to work to contribute to household income. For example, studies in countries such as Botswana, Lesotho and Zambia, give weight to anecdotal information that suggests that girls are pulled out of school to care for the sick or because of the economic impact of HIV/AIDS on families. In Swaziland, it is estimated that school enrolment has dropped 36 per cent because of AIDS, with girls the most affected.¹⁶

Another care-related factor that is keeping children – both girls and boys – out of school is the reality that grandmothers have to take up the roles involved in care-giving once again,

15 Cited in a joint report by UNAIDS/UNFPA/UNIFEM, 'Women and HIV/AIDS: Confronting the Crisis' (July 2004), p. 13; available at www.genderandaids.org.

16 Global Coalition on Women and AIDS, 'Media backgrounder: Care, Women and AIDS' (Geneva, UNAIDS, 2004); available at www.womenandaids.unaids.org.

this time for the children of their children who have died of AIDS. They are doing so without economic support, and simply cannot afford to pay for school fees and school uniforms. Jackeline, aged 14, from Juba, Sudan, spoke of this reality:

Our grandma is really caring for and supporting us. She is doing her best to provide what we need, but I am in third grade, my brother in the first, and my youngest brother in pre-school. I am not sure my grandmother will be able to pay our school fees when we go to higher class.¹⁷

Grandmothers fill this role rather than grandfathers for obvious reasons: that they were the carers for their children, and now take on the care of their grandchildren – but also because women tend to outlive men.

Lack of education has dire consequences for prevention strategies. Education has been referred to as the vaccine against HIV transmission. Studies indicate that girls who have been able to go to school are more likely to know about how HIV is transmitted and how to prevent it, to delay sexual activity and to take measures to protect themselves. According to the Global Campaign for Education,

research shows that a primary education is the minimum threshold needed to benefit from [health information] programs. Not only is a basic education essential to be able to process and evaluate information, it also gives the most marginalised groups in society – notably young women – the status and confidence needed to *act* on information and refuse unsafe sex.¹⁸

Evidence from across the world shows that, although women everywhere continue to be constrained by unequal power relations, increased education helps women to gain status and to secure greater decision-making power in the family and the wider community.¹⁹ Other studies have similarly shown that the more educated and skilled young people are, the more likely they are to protect themselves and the less likely they are to engage in risky sexual behaviour. In situations where more boys than girls attend school, higher infection rates are found among both men and women. A study in 72 capital cities found significantly higher infection rates where the literacy gap between women and men was large.²⁰ These studies show the close relationship between prevention and education, and how far-reaching the consequences are for girls and young women who are unable to attend or complete their education, and ultimately for the national economy and the country as a whole.

Economic Empowerment

Women's ability fully to enjoy human rights, and to demand such rights, is integrally linked to their economic empowerment. To make decisions about their reproductive and sexual rights and health requires a sense of autonomy, which develops in tandem with the knowledge that women can provide for themselves and their children and that they have the skills to do so. When, as Petchesky and Judd point out, women have paid jobs or a small business and money they can call their own, economic empowerment conveys the right to imagine a different future. With it comes the courage to stand up against husbands and partners, parents and in-laws, to assert their rights to decide whether and when to have sex, or bear children,

17 HelpAge International/International HIV/AIDS Alliance, 'Forgotten Families: Older People as Carers of Orphans and Vulnerable Children' (policy paper, HelpAge International, London, 2003); available at www.helpage.org

18 Global Campaign for Education, *Learning to Survive: How Education for ALL would Save Millions of Young People from HIV/AIDS* (GCE, Johannesburg, 2004), p. 2; available at www.campaignforeducation.org.

19 *Ibid.*

20 M. Over, 'The Effects of Society Variable on Urban Rates of HIV Infection in Developing Countries: An Exploratory Analysis', in M. Ainsworth, L. Fransen and M. Over, *Confronting AIDS: Evidence from the Developing World* (Brussels and Washington DC, European Commission and World Bank, 1998).

to resist violence, to make household decisions.²¹ This is a goal that, in the era of AIDS, becomes less and less possible to attain.

Women in formal or informal employment have to take increasing amounts of time out to care for sick relatives (because they are the primary caregivers), or to attend clinics for themselves. Attendance rates decrease. Jobs are lost. A labour force crisis of huge proportions is looming. According to the ILO, the yearly increase in the social burden of AIDS illness and death on surviving women of working age is projected to rise by a multiple of eight between 1995 and 2005, and then double by 2014. In 1995 the number of females lost to the labour force due to death and care responsibilities was just shy of one million. By 2000 it was just over 3.5 million. Projections for 2005 and 2010 respectively are 15.325 million, and 22.745 million.

Southern Africa already has a very high proportion of female-headed households; these are among the poorest families. It has been estimated that 34 per cent of households with children in this sub-region are female-headed. The ability of the poorest, female-headed households to cope is compounded by another sobering estimate – that 90 per cent of AIDS care in sub-Saharan Africa is home based, and women are disproportionately responsible for this care. One study reported that families that have to cope with AIDS-related illness on average experience a two-thirds loss in household income.²²

Survival, transactional and intergenerational sex are key drivers of the epidemic, and there is anecdotal evidence of girls and young women exchanging sex for money, for food or school fees. This puts girls at risk on the one hand, but also becomes an increasing necessity when AIDS-affected households spiral downward into deeper poverty. In Lesotho, for example, absentee rates among garment factory workers – most of whom are women – have been rising dramatically. An ILO/UNIFEM delegation to Lesotho to review the connection between the care economy and formal employment in the context of HIV/AIDS found that:

Employers are recognising that productivity and profit levels have been affected by HIV/AIDS. In an interview with a manager from a garment factory employing 6,500 workers (virtually all women), it was revealed that a rapidly increasing number of workers visit the factory health clinic every month. There is a daily absenteeism rate of 3–5 people, with approximately 5–7 workers dying every month. For each worker lost in the factory, replacement costs are rather high. This is because newly recruited workers receive one week's training, 3–4 weeks' orientation and familiarisation with their work tasks on the factory floor, and it takes 3–4 months before the worker is fully integrated and is functioning at full levels of productivity.

At the same time, employers are beginning to cut back on benefits to workers infected with or affected by HIV/AIDS, arguing that these costs have become untenable and would threaten the viability of the enterprise if these rising costs were to be met. One employer of a factory of 5,000 workers used to provide free transport to burials of employees or their family members a few years ago when there was usually only one funeral per month. However, this ceased as they could no longer afford to provide this support when funerals took place as frequently as once a week.²³

The absentee rates, referred to above, are not only for those that are sick themselves but also include those caring for sick members at home or attending funerals (which, as noted earlier, has become a major task and expense). In southern Africa, it is the women who tend to be responsible for organising funerals. These caring roles do not only affect women in the formal sector, but are evident in the informal sector as well. Dependence on informal

21 R. Petchesky and K. Judd (eds), *Negotiating Reproductive Rights: Women's Perspectives Across Countries and Cultures* (London, Zed Books, 1998).

22 M. Steinberg, S. Johnson, G. Schierhout and D. Ndegwa, *Hitting Home: How Households Cope with the Impact of the HIV/AIDS Epidemic* (Cape Town, Kaiser Family Foundation, 2002).

23 ILO/UNIFEM, 'Lesotho Mission Report' (unpublished report, 19 April 2002).

employment, such as trading in the market for example, is jeopardised, and already fragile household incomes plummet. In discussion with trade union officials in Lesotho, it became clear that many of the workers who were no longer able to hold on to jobs in the formal sector were increasingly setting up informal sector activities, only to have these affected by the pull of both the care economy and ill health.²⁴

Economic independence is one of the most crucial factors in the transformation of gender inequality and the achievement of women's empowerment in general. But when the ability to seek employment and income is corroded by the epidemic, the fall-out is vicious. This affects not only income and women's capacity to feed their families. It robs the caregiver of the education needed to gain employment in the first place, increases dependence on men, and prevents women from leaving violent relationships.

Violence against Women

Domestic violence is a graphic manifestation of the social construction of gender roles and relations. At the most basic level, the social construction of gender means that women undertake the caring roles, and men are expected to be the decision-makers. The ultimate expression of this male power is through violence. Laws prohibiting violence against women have been passed in many countries in Africa and Latin America in recent years to respond to this reality. There is growing anecdotal evidence that violence against women increases in situations where women are unable to prepare the food in a timely manner, or to complete the household chores to the man's satisfaction. Or, in response to a wife's request that condoms be used, money for food is withheld as punishment, making it difficult for the women to fulfil their food preparation activities.

One recent study in South Africa showed that women who are beaten or dominated by their partners are much more likely to become infected with HIV than women who live in non-violent households. A study on the link between violence and HIV transmission in South Africa concluded that women who were emotionally or financially dominated by their partner were 52 per cent more likely to be infected than those who were not.²⁵ A growing body of anecdotal evidence suggests that women who are financially dependent on their partners find it harder to negotiate safe sex, refuse sex, or leave a marriage. It can also be assumed that violent male partners exert their masculinity both inside and outside the home, and that for women within these relationships the fear of being abandoned and destitute means they continue to carry out their household responsibilities and tasks whatever the cost.

The ability to bring about behavioural change lies in the need to shift power relations, persuading men to forgo that power and showing them that relinquishing that power can be empowering. This realisation is more critical than changing who does what within the home. That can become a more technical and practical negotiation of equals, if the relations are balanced and in harmony. However, it is often difficult for men who wish to share caring roles with their partners to do so. In pointing out the obstacles to getting more men involved in sharing roles within the household, Dean Peacock in writing about the Men as Partners (MAP) experience, noted:

Dominant social norms create the expectation that women will assume the burden of responsibility for taking care of family and community members weakened or made ill by HIV/AIDS while simultaneously discouraging men from playing the critical support and care

²⁴ *Ibid.*

²⁵ K. Dunkle, R.K. Jewkes, H.C. Brown, G.E. Gray, J.A. McIntyre and S. Harlow, 'Gender-based Violence, Relationship Power, and Risk of HIV Infection in Women Attending Antenatal Clinics in South Africa', *The Lancet*, 363, 9419 (2004), p. 1,415.

roles needed of them by equating male involvement in such activities as indicative of weakness and 'unmanliness'.²⁶

A UNAIDS study, in 1998, revealed that in Kyela, Tanzania, on occasion 'male heads of households would wish to do more when their partners fall ill, but were curtailed by cultural definitions of maleness and the roles defined which determine masculinity'.²⁷ These findings have been supported in MAP workshops and focus groups where men frequently describe the fear of being ostracised and ridiculed by other men in the community as a major reason for their reluctance to be more actively involved in domestic activities, including care and support. At the same time, men find that it is their partners who fear that their neighbours might interpret these role changes as a sign that the women are lazy, incompetent or even that they have been bewitched by their partners.²⁸

Fear of not being a 'good' wife or partner runs deep. A peer counsellor for MAP related how he had been transformed by the first MAP workshop he had attended. One of the workshop exercises required participants to perform tasks at home that they had never done before, and relate their experience to the group the following day. Eager to comply, he told his partner that she could relax that evening, as he would do all the housework and prepare the dinner. The next day when he returned home, the house was spotless; every inch had been cleaned. His partner interpreted this uncustomary behaviour on his part as a slight on her abilities. He had failed to appreciate that communication was as important as sharing of roles; that he had imposed his actions on her, and had not discussed them. In order to shift roles, relations of power need to be transformed. Asked how it was going now that he was a peer counsellor and months had passed since the workshop, he responded: 'We're still working on it.' Another peer counsellor related how he was trying to avoid being the one to make all the family decisions. Initially, this did not go down well with his wife. When he suggested that she make the decision about a specific issue they were confronting, she responded with, 'Aren't you man enough to make decisions any more?'

Violence against women is tied to men's perceptions of what it means to be a man. Changing these perceptions, attitudes and behaviours on the part of men and women is critical to decreasing violence and reversing the AIDS epidemic. It means changing a culture of violence in which women have been heard to comment: 'But if he doesn't hit me, it means he doesn't love me.' Addressing the inequalities in the household can reduce violence and thus the infection rate of HIV/AIDS.

Valuing the Care Economy

There is growing awareness of the gender dimensions of the epidemic, and many inspiring and successful programmes exist, from the community level to large government and internationally funded interventions.²⁹ At the same time, gender equality and women's empowerment have been emphasized consistently, if at times blithely, to be an essential ingredient to reversing the epidemic. For example, the 2001 Declaration on Commitment signed at a UN General Assembly Special Session on HIV/AIDS by some 187 nations, states

26 D. Peacock, 'Men as Partners: Promoting Men's Involvement in Care and Support Activities for People Living with HIV/AIDS and in Preventing Mother-to-Child Transmission of HIV/AIDS' (unpublished report from UNDAW Expert Group Meeting on 'The Role of Men and Boys in Achieving Gender Equality', Brazil, October 2003); available at www.un.org/womenwatch/daw/

27 See, for instance, P. Aggleton and I. Warwick, 'A Comparative Analysis of Findings from Multi-Site Studies of Household and Community Responses to HIV and AIDS in Developing Countries' (Geneva, UNAIDS, 1998).

28 Peacock, 'Men as Partners'.

29 Many of these are captured in the report published for the Bangkok Aids Conference 2004, 'Women and AIDS: Confronting the Crisis' (New York, UNAIDS/UNFPA/UNIFEM, 2005).

that 'gender equality and the empowerment of women are fundamental elements in the reduction of the vulnerability of women and girls to HIV/AIDS'. If all, or even some of the countries, truly implemented this declaration, we would be witnessing a process of total social transformation. The long-term implications of this statement were no doubt lost to most of the signatories to this declaration, but it is an important one, giving legitimacy to the urgent need to address gender and women's issues. Since the early 1970s, and perhaps for more than a century earlier, feminists have stressed that the roles and relations within the family and society have been a lock that keeps gender inequality in place, and prevents the empowerment of women across communities and societies. Now, in the context of the extreme emergency that the AIDS epidemic presents, this can be seen and quantified in concrete and obvious ways by tracking the impact on household labour.

What remains puzzling to those of us who recognise the true emergency resulting from the care economy overload, is the continued resistance to ensuring that this work is valued and costed. It is equally perplexing why policy makers, donors, the United Nations' agencies continue to resist developing, funding and implementing programmes and policies aimed at addressing this aspect of the growing AIDS crisis. Nonetheless, there are encouraging signs in some, if not sufficient, quarters, that the cost of *not* paying attention to it is being acknowledged and calculated. We can hope that this will translate into a real difference to women's lives by supporting and transforming their efforts to protect themselves from infection, to living with HIV and AIDS for many years longer than the death sentence now hovering above their heads, to leading productive lives governed by their ability to be independent agents able to make their own choices.

Conclusion

Ongoing campaigns as well as programmes being funded to the tune of millions of dollars risk failure if they continue to take unpaid care work for granted. Social protection policies such as income security, employment opportunities and access to health care are a critical first step towards solving the care economy crisis. Youth stipends, old age pensions and family grants already exist in some southern African countries. The Government of Swaziland and the Global Fund for AIDS, TB and Malaria (GFATM) have already begun to build on these foundations. Through a recent grant from GFATM the Government of Swaziland is able to provide stipends of \$30 per month to 10,000 women caregivers who take care of orphans. Information, training and kits that include such basics as gloves, disinfectant, soap, bandages and over-the-counter painkillers can also make a difference.

Unprecedented funding has been allocated to HIV/AIDS work over the past few years. While this funding is far from sufficient, it is more than we have seen previously. Yet we must ask how much of this is allocated to gender sensitive programmes that address women's roles and responsibilities? How much is going to programmes that specifically promote women's empowerment? How much is going to the community and the community-based organisations that are the bricks holding up the whole AIDS response structure?³⁰ Urgent analysis that exposes the gaps is necessary, so that resources can be distributed accordingly. But along with this, political will is needed on the part of the region's leaders to ensure that these gaps are addressed.

Campaigns cannot succeed unless driven from below, by those organising in communities and those experiencing the crisis, thus it is essential that the voices of women, their stories, their realities and their demands are brought to the attention of national and international

30 *Ibid.*

policymakers and donors so that the care economy is recognised as the critical thread linking the elements of the AIDS epidemic.

These are some measures that can be taken that will certainly impact on the epidemic and make a difference to those living with HIV/AIDS. However, in order to achieve this, unpaid care work must be given value. This, as is often pointed out, is a question of justice. Valuation of unpaid care work would show how many more hours women spend working in contrast to the hours put in by those considered to be the 'main' breadwinners.³¹ When this work is valued, understood and counted, it will no longer be possible to ignore or to take for granted one of the most critical and urgent issues underpinning the AIDS crisis. Only then will the appreciation of this common thread generate more effective, comprehensive and long-term solutions. Long-term solutions will be possible once governments whole-heartedly integrate support for work within the care economy in all the mechanisms they use for addressing the national economy. By continuing to ignore or take this work for granted, maintaining its invisibility in the national system of accounts, governments will simply continue to allow this work to subsidise the national economy. They will continue to download their responsibilities on to the backs and into the hands of women, and increasingly men who, as a result of the growing crisis, are taking on these roles and responsibilities. Already the strain on households can be witnessed, as AIDS continues to dismantle the very fabric of family and society. The costs are becoming more and more obvious, as girls, and increasingly boys, lose out on education, and cannot adhere to prevention messages; as violence against women increases and any gains in terms of women's economic empowerment continue to be whittled away. Policies and programmes can provide long-term solutions. But those policies must challenge patriarchal structures at all levels – from the state to the community to the family. Only then will we be able to see with clarity that while the *disease* is a health issue, the *epidemic* is a gender issue, and that only a serious commitment to transforming gender roles and relations will enable us to stem the epidemic and treat the disease.

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31 D. Budlender, *Why Should We Care About Unpaid Care Work?* (Harare, UNIFEM, 2002); available at www.genderandaids.org.