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Men and care in the context of HIV and AIDS: Structure, political will and greater male involvement

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Men and care in the context of HIV and AIDS: Structure, political will and greater male involvement

Dean Peacock and Mark Weston[1]

Introduction: The problem

Over 33 million people worldwide are living with HIV/AIDS. In low and middle-income countries, nearly 10 million are in immediate need of treatment yet only 3 million are receiving it. This leaves 7 million people sick with AIDS and in need of intensive and long-term care.[1]

AIDS is a long and debilitating illness that renders patients unable to fend for themselves and often unable to cope with the mental stress of knowing that death, in the absence of treatment, is inevitable. Caring for those with the virus therefore involves both physical care – feeding, cleaning and providing medicine to cure opportunistic infections – and emotional support. Many of those caring for AIDS patients

caring for people with such AIDS related opportunistic infections is extremely tiring. Fatigue renders carers more vulnerable to illness themselves, including to the opportunistic infections that plague those with HIV themselves. The stress of caring for someone who is dying increases susceptibility to psychological problems; carers of those sick with AIDS in Botswana, for example, report being emotionally drained by their roles.[5] Because caring for AIDS patients is a full-time occupation, moreover, women can become disconnected from their communities (and the stigma associated with the infection can exacerbate this), which heightens the risks to their health. Putnam (2000) has found that social capital helps people fight off illnesses; those who have close links to their families and communities have half the risk of dying from any cause compared to those who are so

Global economic policies, the erosion of the public sector and the displacement of care into the household and onto women and girls.

In wealthy countries, governments, aided by civil society, have taken on much of the responsibility of HIV prevention, treatment and care. Their capacity for doing so is, of course, greater than that of poorer countries as they generally have quite well-functioning health systems and the money to expand those systems to address new threats. Many developing country governments lack this capacity.

Over the last two to three decades, most developing countries have been pressured by the World Bank, the International Monetary Fund and other financial institutions to pursue neoliberal development policies characterized by a reduction in public spending, privatisation of public services, flexible labour laws, and an emphasis on attracting foreign investment.[22]

The strictures of international financial institutions led to steep declines in spending on vital public services such as education and health and were often accompanied by the imposition of user fees aimed at "cost recovery" in the areas of education, health services, electricity, water and sanitation. With clinics and hospital infrastructure crumbling, patient loads increasing and salaries decreasing, large numbers of doctors and nurses emigrated for better pay and working conditions. The legacy of these policies is made clear in a recent report from Medecins Sans Frontieres. The report compares the number of health care providers per 100,000 inhabitants in Southern Africa against the US, the UK and WHO minimum standards and reveals that whereas the US and the UK have 247 and 222 doctors per 100,000 inhabitants respectively, South Africa has on average 74 doctors per 100 000 inhabitants whereas Lesotho has only five. Malawi and Mozambique have only two. The World Health Organisation's minimum standard is 20. The number of nurses per 100 000 in the UK is 1,170, in the US 901, in South Africa 393, and 62 in Lesotho. The WHO's minimum standards for nurses is 228[23]

Hein Marais makes clear what this gutting of the health sector has meant for women. He writes, "Patients and their care-givers must subsidise many aspects of care provision, and bear the costs of not receiving the levels of care and support they require … Although thrust into the roles of mediators, counsellors and saviours, care-givers often are unable to -provide things as basic as pain-killers or a meal…This form of value extraction subsidises the economy at every level from the household outward, yet remains invisible in political and economic discourse."

Government inaction and the burden of AIDS care

The second reason for government inaction is that governments failed to invest sufficiently in health care in general and AIDS care in particular. Even when prevalence rates had become shockingly high, many authorities delayed – still delay - in making antiretroviral treatment available. Globally, millions of adults with advanced AIDS are dying or posing a heavy burden on their families and, later on in the illness trajectory, often to public health systems because they are not receiving antiretroviral drugs.[24] Few pregnant women infected with HIV in Africa, moreover, receivir,jvco1sr7they/TTu(ent a-1.1591 Tw 19.495ng antire.15 tor govern

Two: What strategies might reduce the burden on women?

Reduce the overall AIDS burden

The best way for states to relieve the burden of AIDS care is by reducing the overall level of HIV in a population. Governments and civil society must take urgent action to roll-out effective prevention approaches such as comprehensive sexuality

poverty. Psychological counselling to both carers and their sick family members and advice for carers on how to deal with their relatives' emotional difficulties are also important in relieving the strain of caring.

Carers of those sick with AIDS generally need adequate supplies of water for cleaning and laundry as well as sanitation facilities. In communities affected by the virus, governments can help ease the burden by halting and rolling back the privatisation of electricity, water and sanitation services.

Government interventions not directly related to health can also make carers' lives easier and redress gender inequalities and women's vulnerabilities. Legislative and policy change strengthens women's rights to own property and land and allows them to inherit possessions increases women's ability to absorb the burden of care and support. Empowering women economically can render them and their families less vulnerable to HIV infection as well as helping them if they have to care for the sick and mitigating the impact on them of the death of a husband.

Broader workplace measures can also help address the gender imbalance in care. Rules that prohibit gender discrimination in recruitment, pay and promotion can open up economic opportunities to women and thereby strengthen their position within households. Economic clout can give women more control over family affairs and more leverage to insist that men participate in caring duties. Governments' own employment policies should also proscribe such discrimination.

Governments, then, can take steps to improve gender equality among those caring for patients with AIDS, and they can also alleviate many of the difficulties facing carers of both sexes. These steps involve health ministries as well as other parts of government. In countries where HIV/AIDS is already crippling societies and in those where it still poses a potential future threat, a multi-sectoral response is required. Greater government action on HIV/AIDS not only helps mitigate the problem – by relieving the heavy burden on women

review of 57 male involvement programmes published by the World Health Organisation found evidence that at least a quarter were effective in transforming harmful gender attitudes and behaviour, and many of the others were regarded as promising. [39] Similarly, an intervention implemented in South Africa's Eastern Cape province showed significant changes in men's attitudes and practices including significant reductions in intimate partner violence and other practices that are high risk for HIV transmission.[40,41] In Brazil, *Instituto Promundo*'s intervention with young men on promoting healthy relationships and HIV/STI prevention, showed significant shifts in gender norms at six months and twelve months.[42]

To date, however, most interventions with men have been limited in size, impact and sustainability. To make a real difference in reducing the burden of care carried by women, interventions with men will need to be taken to scale to ensure far greater impact than has been the case to date. We propose a number of ways to do this. These include: recognising the positive contributions some men already make as a way of shifting social norms and prompting other men to do the same; training men and boys to provide care and support; building on existing civil society models and innovative initiatives aimed at engaging men; integrating a focus on engaging men and boys into existing AIDS plans and policies, including especially national AIDS plans; improving the health systems capacity to reach men with HIV prevention and treatment services so as to reduce the burden of care; and by taking gender transformative work with men to scale by integrating a focus on men and gender equality into national programmes and policies that can reach large numbers of men and boys.

Move beyond stereotypes and recognise the positive contributions men can make: It is important that we alter the terms of the discussion about men and AIDS in some significant ways. Governments and civil society organisations working to reduce gender inequality in AIDS care should start by approaching men differently - as potential partners and not just probable perpetrators of violence or inevitable obstacles to women's health and wellbeing.

Experience shows that is possible to change men's care related attitudes and practices. As we have seen, men often know that they should be involved but lack a sense of permission to act on their convictions. The experiences of a group of men in Goromonzi, Zimbabwe are instructive in this regard. Luckson Murungweni describes the process whereby he and other men in Goromonzi became involved in home based care, saying "For years we watched with bleeding hearts as our daughters and sons came home from the towns and cities to die after having contracted HIV. Those who lived in the towns were also passing on the virus to the young in the area, and the burden of caring for the ill was left to women…As men, we never viewed ourselves as crucial in providing care to those being claimed by the AIDS pandemic, choosing instead to spend most of our time drinking beer. But things changed last year when councillors … approached us and urged us to become involved." As a result of the intervention of the councilors, men like Murungweni became active in "bathing, feeding and doing chores for patients, … fetching firewood and food (and providing) financial assistance for buying drugs, or when patients need to be taken to clinics or hospital to have opportunistic infections treated".[43]

Reuben Mokae's story is also instructive. Reuben was a Soweto based gender activist with the Men as Partners Network until the time of his death from AIDS in 2005. Reuben often spoke publicly about his experiences as an HIV positive father. At a community event held in Soweto on Father's Day in 2004, he said, "Last October my wife passed on due to AIDS. It has been one of the most difficult times for my three boys and me. Now, though, life is starting to get back to normal. We often talk about her with the boys as a healing process. Sometimes we cry together holding hands when we do this".

There are lots of men like Reuben Mokae and Luckson Murungweni across southern Africa. However, instead of recognising and affirming them and in so doing encouraging other men to emulate them, the current discourse about men and AIDS too often trades in stereotypes and contributes to the self reinforcing notion that men are unwilling to care for people they often love deeply.

A study by Montgomery et al in KwaZulu-Natal provides useful insights into the disjuncture between what men do and how men are described. In their field work in rural KwaZulu-Natal, usually considered a bastion of patriarchal attitudes and practices, they found that some men were indeed involved in caring for their families but that this often went unacknowledged. They argue that whilst there is a "linguistic and conceptual locus for the discussion of 'deficient' men, no such language appears to exist to talk about men who are positively involved in their families". They point out, though, that their study revealed that men were involved in care giving activities, and that they "care for patients and children, financially support immediate and extended family members and are present at home, thereby enabling women to work or support other households". However, they write that these activities were seldom acknowledged by community members or by the field workers conducting research who continue to hold the perception that "men are not caring for their families because they are irresponsible and profligate". They conclude by calling for more research on men's roles in the family and argue that this has the potential to "inform the development of new programmatic approaches that might feasibly engage men's concerns and needs, and more effectively involve men as actors in community coping strategies"[44]. Similarly, a study on the impact on caring provided by teachers to their students due to AIDS indicates that "teachers in schools with the least resources are frequently those required to provide the most demanding forms of support and care to learners" and points out that in the schools they studies, "the work of caring does not seem to be confined to women teachers. Male teachers, in our study, do emotional work". They argue, "…the state provides neither adequate staff to deal with the challenge of care, nor the training necessary to support teachers who find themselves at the frontline". The authors insist that "much more recognition must be given to teachers for providing care…in schools" and call for "professional counsellors to be employed in each school"[45]. We reiterate this call; publicising the stories of men involved in care work is likely to strengthen the resolve of those men and it also increases the likelihood that other men will find the courage to challenge restrictive gender norms and act on their conviction that they have an important role to play.

Build on existing models and strategies: Many models exist that indicate that men can be supported to play a more active role in meeting the care needs of children made vulnerable by HIV and AIDS. Sonke Gender Justice, the organisation for which the authors work, has developed a model for working with men to increase their involvement in meeting the needs of orphans and children affected by HIV and AIDS. The One Man Can Campaign's Fatherhood and Child Security Initiative has two primary objectives. The first objective is to increase men's involvement, not only in the lives of their own children, but also in ensuring that children in general, and orphans and vulnerable children in particular, have access to essential social services. As such, men of all walks of life—traditional and religious leaders, representatives of local government, teachers and coaches, fathers and social fathers--are supported to play an active role in making sure that children are able to access child grants, attend school, benefit from school feeding schemes and have their psycho-social and educational needs met. The second objective is to develop men's capacity to be advocates and activists in efforts to eliminate violence against women and children, prevent the spread of HIV and AIDS and promote health, care and support for orphans and vulnerable children. As a result of the project, local government in

has now integrated a focus on reaching men and boys for gender equality into their annual integrated development process, an outcome that may lead to a sustained focus on involving men and boys in achieving gender equality.

The success of the project is then measured against very concrete impact indicators that determine whether men are in fact playing a more active role in meeting the care related needs of orphans and vulnerable children. These indicators include: men spend more time actively parenting their children; men assist their children with homework; men decrease their use of physical punishment of children and report increased understanding of alternatives to corporal punishment; men decrease their use of violence against children and their mothers; men demonstrate improved understanding of their children's nutritional needs and report doing more to ensure that children's nutritional needs are me and men become more actively involved in local childcare forums. This in turn should lead to an increased number of orphans and vulnerable children accessing social grants, attending school, and demonstrating improved nutrition.

Build the capacity of health systems to reach and engage men: To achieve further involvement by men in the care economy, states can take steps to improve health systems to make them more friendly to men who either want to or are already involved in care and support activities. Nurses and clinics that provide care to the sick are not always set up to deal with male carers – like society as a whole, health systems expect women to do care work and are therefore sometimes unfriendly to men who wish to become involved[46].
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off work. Over seventy per cent of fathers in both countries now use this month.[51] Smith (2001) has shown that the Scandinavian measures have helped increase the time spent by fathers performing caring duties,[52] while Aldous and co-authors (1998) found that fathers' early engagement in child care makes them more likely to continue to provide care later.[53]Similar interventions are possible in poorer countries, and they could help ease the burden on women. For instance, in Brazil, a number of states

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