

## FROM PMTCT TO A MORE COMPREHENSIVE AIDS RESPONSE FOR WOMEN: A MUCH-NEEDED SHIFT

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### ABSTRACT

*Half of the 33.2 million people living with HIV today are women. Yet, responses to the epidemic are not adequately meeting the needs of women. This article critically evaluates how prevention of mother-to-child transmission (PMTCT) programs, the principal framework under which women's health is currently addressed in the global response to AIDS, have tended to focus on the prevention of HIV transmission from HIV-positive women to their infants. This paper concludes that more than ten years after their inception, PMTCT programs still do not successfully ensure the adequate treatment, care and support of HIV-infected women. Of particular concern is the continued widespread use of single-dose nevirapine despite World Health Organization recommendations to employ more effective combination therapies that do not potentially jeopardize women's future treatment outcomes. In response, the article calls for a more comprehensive approach that places women's health needs at the centre of AIDS responses. This is critical in settings where the pandemic is generalized and there is a push to greatly expand PMTCT programs, as a more effective and equitable way of meeting the needs of women in the context of HIV. Without such a comprehensive approach, women will continue to be impacted disproportionately by the pandemic, and current strategies for prevention, including PMTCT, and treatment will not be as effective and responsive as they need to be.*

### INTRODUCTION

The AIDS pandemic is challenging societies, and health systems in particular, in myriad ways; many of these challenges involve significant ethical dilemmas. Various ethical issues relating to HIV prevention, testing and treatment have been discussed in published literature, including placebo trials for the

prevention of mother-to-child transmission and, most recently, routine testing.<sup>1</sup> The intersection of

<sup>1</sup> P. de Zuleta. Randomised Placebo-controlled Trials and HIV-infected Pregnant Women in Developing Countries: Ethical Imperialism or Unethical Exploitation? *Bioethics* 2001; 15: 289–311; S. Rennie & F. Behets. 2006. Desperately Seeking Targets: The Ethics of Routine Testing in Low-income Countries. *Bull World Health Org* 2006; 84: 52–57.

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maternal health with HIV and AIDS, however, remains neglected in many respects, including a number of profound ethical questions provoked by current practices in HIV and maternal and reproductive health programs.

Issues related to equity in access to and utilisation of health services are inherently related to the general pursuit of social justice.<sup>2</sup> As historian Allan Brandt predicted 20 years ago, AIDS is the standard by which we may measure not only our medical and scientific skill but also our capacity for justice and compassion.<sup>3</sup> With the feminisation of the AIDS pandemic, it is appropriate, indeed essential, to ask whether efforts to address the pandemic meet the needs of women.

This article argues that the current response to the needs of women in the era of AIDS remains inadequate, and that the prevention of mother-to-child transmission (PMTCT) strategy, which is the principal framework under which women are most able to access HIV services, reinforces and at times exacerbates the larger challenges they face in accessing much-needed sexual and reproductive health services, including maternal care. As such, the PMTCT framework requires a shift to ensure that women's rights and needs, as defined by and enshrined in several global agreements,<sup>4</sup> are more appropriately and adequately met.

The article will first examine ethical questions relating to the implementation of the PMTCT strategy, which is the main entry for HIV-positive women to access HIV treatment and services. The article argues that while comprehensive in scope, the actual implementation of PMTCT strategies has placed overwhelming emphasis on one out of four components – the use of antiretroviral therapy to prevent transmission – such that the rights and

needs of the pregnant woman have in practice become secondary to the overall goal of reducing transmission to the infant. Secondly, the article will argue for a more comprehensive approach that places women's health needs at the centre of AIDS responses, particularly in settings where the pandemic is generalized and there is a push for greatly expanding PMTCT programs, as a more effective and equitable way of meeting the needs of women in the context of HIV.

## WOMEN AND AIDS

Almost half of the 33.2 million people living with HIV are women (15.4 million).<sup>5</sup> In sub-Saharan Africa, where two-thirds (22.5 million) of all those living with the virus reside, the majority (61%) are women.<sup>6</sup> The disproportionate impact of AIDS on women has been widely documented and will not be reviewed again here. What has been less documented and examined, however, despite the emphasis on PMTCT, is the intersection between maternal health and AIDS.

## MATERNAL HEALTH AND AIDS

Approximately 529,000 maternal deaths<sup>7</sup> occur each year, 99% of which occur in developing countries.<sup>8</sup> It is estimated that HIV-positive pregnant women are at 1.5–2 times greater risk of maternal mortality.<sup>9</sup> Indeed, in settings such as southern Africa, where

<sup>2</sup> F. Peter & T. Evans. 2001. Ethical Dimensions of Health Equity. In *Challenging Inequities in Health*. T. Evans et al., eds. New York, NY: Oxford University Press: 25–33.

<sup>3</sup> A. Brandt. 1988. AIDS: From Social History to Social Policy. In *AIDS: The Burdens of History*. E. Fee & D.M. Fox, eds. Berkeley, CA: University of California Press: 147–171.

<sup>4</sup> United Nations. International Conference on Population and Development (ICPD). 1994. *Programme of Action of the International Conference on Population and Development, Cairo 1994*. New York, NY: ICPD; United Nations. Division for the Advancement of Women (DAW). *Fourth World Conference on Women, Beijing 1995. Action for Equality, Development and Peace: Platform for Action*. New York, NY: DAW.

<sup>5</sup> World Health Organization (WHO)/Joint United Nations Programme on HIV/AIDS (UNAIDS). 2007. *AIDS Epidemic Update*. Geneva: WHO/UNAIDS. Available at: [http://data.unaids.org/pub/EPISlides/2007/2007\\_epiupdate\\_en.pdf](http://data.unaids.org/pub/EPISlides/2007/2007_epiupdate_en.pdf) [Accessed 1 Dec 2007].

<sup>6</sup> Ibid.

<sup>7</sup> A maternal death is defined by the World Health Organization as the death of a woman while pregnant or within 42 days of the termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes. See World Health Organization (WHO). 2004. *Maternal Mortality in 2000: Estimates Developed by WHO, UNICEF and UNFPA*. Geneva: WHO. Available at: [http://www.who.int/reproductive-health/publications/maternal\\_mortality\\_2000/challenge.html](http://www.who.int/reproductive-health/publications/maternal_mortality_2000/challenge.html) [Accessed 12 July 2007].

<sup>8</sup> C. Ronsman & W.J. Graham. Maternal Mortality: Who, When, Where and Why. *Lancet* 2006; 368: 1189–1200.

<sup>9</sup> J. McIntyre. Mothers Infected with HIV: Reducing Maternal Death and Disability During Pregnancy. *Br Med Bull* 2003; 67: 127–135.

HIV prevalence is as high as 40%, AIDS has become the leading cause of maternal mortality.<sup>10</sup> Evidence also indicates that HIV-negative women are at greater risk of HIV infection during pregnancy, for physiological, not behavioural, reasons that are not yet understood.<sup>11</sup>

Since the launch of the Safe Motherhood Initiative (SMI)<sup>12</sup> in 1987, several countries have been able to reduce maternal mortality through midwifery care and hospital care at birth, the control of infectious diseases, and the liberalisation of abortion laws.<sup>13</sup> In the majority of countries, however – especially in sub-Saharan Africa, where the risk of maternal death is highest – maternal mortality continues to be an enormous public health problem, with one out of every 16 women likely to die from the complications of pregnancy and childbirth. In this context, the millennium development goal<sup>14</sup> of reducing maternal mortality by 75% between 1990 and 2015 remains a distant dream.

The AIDS pandemic makes the goal of reducing maternal mortality even more elusive unless the maternal health and AIDS fields develop joint strategies for action. Yet, despite repeated calls,<sup>15</sup>

both the maternal health and the HIV communities continue to pay inadequate attention to the associations between maternal mortality and HIV and AIDS, as well as the particular needs of HIV-positive pregnant women. A recent review of more than 2250 published studies on maternal mortality globally from 2000 to 2007 found only 127 articles addressing AIDS as an indirect cause of maternal death.<sup>16</sup> Research was limited to the cultural and political determinants of maternal mortality, highlighting the need to better understand the critical underlying risk factors for maternal mortality and morbidity. With the evidence of the increased risk of maternal mortality among HIV-positive pregnant women, this inattention becomes even more unacceptable.

## EFFORTS TO REDUCE MATERNAL MORTALITY

Prior to the launching of the global SMI, maternal health was in theory addressed within maternal and child health (MCH) programs. Yet, in reality, most of these programs focused more on the health outcomes of the child than the woman.<sup>17</sup> One of the major successes of the SMI was to highlight the woman's right to health in and of itself and not simply to address her health as a means to producing a healthy infant. The sexual and reproductive rights of women, including the right to safe pregnancy and delivery, have been established and widely accepted by the global community.<sup>18</sup> However, fulfilling these rights for the majority of women in the world is an ongoing challenge, with the feminized AIDS pandemic bringing many of these challenges to the fore.

Specifically, in the era of the AIDS pandemic, research, articles and strategies continue disappointingly to focus more on infant/child health than maternal health. For example, a search on Medline

<sup>10</sup> J McIntyre. Maternal Health and HIV. *Reprod Health Matters* 2004; 13: 129–135.

<sup>11</sup> R.H. Gray et al. Increased Risk of Incident HIV During Pregnancy in Rakai, Uganda: A Prospective Study. *Lancet* 2005; 366: 1182–1188.

<sup>12</sup> World Health Organization/United Nations Population Fund/United Nations Children's Fund/World Bank. 1987. Safe Motherhood Initiative. Launched at a joint conference in Nairobi, 1987. For information, see RHO Archives. 2005. *Overview and Lessons Learned*. Online: RHO Archives. Available at: [http://www.rho.org/html/sm\\_overview.htm](http://www.rho.org/html/sm_overview.htm) [Accessed 24 Jan 2008].

<sup>13</sup> A.M. Starrs. Safe Motherhood Initiative: 20 Years and Counting. *Lancet* 2006; 368: 1130–1132. Available at: <http://www.familycareintl.org/UserFiles/File/safe%20motherhood%2020%20yrs%20and%20counting.pdf> [Accessed 24 Jan 2008].

<sup>14</sup> See United Nations (UN). *UN Millennium Development Goals*. Online: UN. Available at: <http://www.un.org/millenniumgoals/#> [Accessed 22 Jan 2008].

<sup>15</sup> W. Graham & J. Hussein. 2003. *Measuring and Estimating Maternal Mortality in the Era of HIV/AIDS*. Workshop on HIV/AIDS and Adult Mortality in Developing Countries. Population Division, Department of Economic and Social Affairs, United Nations Secretariat. New York, NY: United Nations. Available at: [http://www.un.org/esa/population/publications/adultmort/GRAHAM\\_Paper8.pdf](http://www.un.org/esa/population/publications/adultmort/GRAHAM_Paper8.pdf) [Accessed 30 June 2007]; Health & Development Networks (HDN), United Nations Development Fund for Women (UNIFEM) & International AIDS Society's Women's Caucus. 2002. *Women at Barcelona (W@B) Final Summary: W@B post-conference postings and discussion summaries*. Chiang Mai: HDN. Available at: [http://www.hdnet.org/v2/file\\_uploads/users/tina/Women\\_at\\_Barcelona.pdf](http://www.hdnet.org/v2/file_uploads/users/tina/Women_at_Barcelona.pdf) [Accessed 2 July 2007].

<sup>16</sup> D. Gil-Gonzalez, M. Carrasco-Portiño & M.T. Ruiz. Knowledge Gaps in Scientific Literature on Maternal Mortality: A Systematic Review. *Bull World Health Org* 2006; 84: 841–920.

<sup>17</sup> A. Rosenfield & D. Maine. Maternal Mortality – A Neglected Tragedy. Where is the M in MCH? *Lancet* 1985; 2: 83–85.

<sup>18</sup> United Nations. International Conference on Population and Development, *op. cit.* note 4.

revealed that from 1993 to 2003 only 43 papers were published with 'maternal mortality' and 'HIV/AIDS' as keywords, compared to 6200 published papers on child mortality and HIV/AIDS.<sup>19</sup>

In both developing and developed world settings, women's reproductive choices are limited by a range of factors, many relating to gender inequalities. An equally diverse set of determinants influence when, where, how and why many pregnancies occur. These factors are mediated by the availability, quality and accessibility of reproductive health services, including contraception; pregnancy termination; STI detection and treatment; HIV prevention, testing and treatment; and maternity care (antenatal, delivery, and postpartum). Actual practices during the provision of these and other health-related services bring to the forefront the many *ethical dimensions* related to the choices a woman can make and the control she has (or does not have) over her body, her health, and the future of her unborn child.

## MATERNAL HEALTH AND THE PMTCT MODEL: ETHICAL CONSIDERATIONS

The PMTCT strategy, defined by the World Health Organization (WHO) in the late 1990s and endorsed by the United Nations (UN) system, is the framework under which maternal health care is meant to be addressed within AIDS responses. PMTCT consists of four components:

- (1) Prevention of HIV infection among young people and pregnant women.
- (2) Prevention of unintended pregnancies among HIV-positive women.
- (3) Prevention of HIV transmission from HIV-positive women to their infants.
- (4) Provision of treatment, care and support to HIV-infected women and their families.

While comprehensive in theory, in practice PMTCT programs have tended to focus on the third component of the strategy. The intersection between HIV and pregnancy exposes the ethical and legal inequalities inherent in a societal structure that places more value on a woman's reproductive

capacity than her own individual wellbeing. As far back as 2001, questions were raised about the exclusive focus on preventing transmission of HIV to the infant and inadequate attention to the pregnant woman's health.<sup>20</sup> In 2006, WHO revised the PMTCT guidelines to better address the health needs of pregnant women by, among other things, placing greater emphasis on the treatment of the woman.<sup>21</sup> However, given that less than 10% of HIV-positive pregnant women needing PMTCT services currently receive them, it is clear that these revised guidelines are not being implemented.<sup>22</sup>

PMTCT interventions in most developing countries are guided by utilitarian principles that ascribe women the societal roles of vessel and caretaker.<sup>23</sup> For each of the components of the PMTCT strategy, we need to ask, 'Does it work for women?' In other words, does the strategy respect and uphold women's sexual and reproductive rights in and of themselves rather than subsuming their rights under the rights of the infant (to not be infected or orphaned)?

### Component 1: Prevention of HIV infection among young people and pregnant women

The first component of the PMTCT strategy calls for preventing HIV infection among women of reproductive age. Despite repeated calls for countries to scale up prevention services, as of 2006, globally only 9% of sex acts with a nonregular partner were undertaken with the use of a condom. Fewer than 20% of people with sexually transmitted infections, which are known to increase both risk of infection and transmission of HIV, were able to get treatment. In sub-Saharan Africa, only 12% of men

<sup>20</sup> A. Rosenfield & E. Figdor. Keeping the M in MTCT: Women, Mothers and HIV Prevention. *Am J Public Health* 2001; 91: 701-703.

<sup>21</sup> World Health Organisation (WHO). 2006. *Antiretroviral Drugs for Treating Pregnant Women and Preventing HIV Infection in Infants: Towards Universal Access. Recommendations for a Public Health Approach*. Geneva: WHO. Available at: <http://www.who.int/hiv/pub/guidelines/pmtctguidelines3.pdf> [Accessed 4 July 2007].

<sup>22</sup> D. Mbori-Ngacha. Keynote Address. The 2006 HIV/AIDS Implementers Meeting of the President's Emergency Plan for AIDS Relief, Durban, South Africa.

<sup>23</sup> Center for Strategic and International Studies (CSIS). 2006. *Integrating Reproductive Health and HIV Programs: Strategic Opportunities for PEPFAR*. Washington, DC: CSIS Available at: [http://www.csis.org/media/csis/pubs/060712\\_hiv.pdf](http://www.csis.org/media/csis/pubs/060712_hiv.pdf) [Accessed 19 June 2007].

<sup>19</sup> Graham & Hussein, *op. cit.* note 15.

and 10% of women knew their HIV status.<sup>24</sup> These facts point to serious failures in prevention efforts despite proven evidence-based strategies that could dramatically reduce new HIV infections if scaled up.

There are several reasons why prevention efforts are not at the scale and efficacy that they need to be. First, financing from governments and donors is inadequate. Second, there is often misallocation of resources at the country level. Limited human capacity, particularly in the most affected countries, limits the provision of quality services and results in services that are fragmented and/or not integrated with related services. Finally, ongoing stigma and discrimination prevent people from seeking services, particularly those from marginalized groups, who are often at greater risk of infection.<sup>25</sup>

Of ethical concern is the misallocation of resources for ideological rather than scientific reasons, which directly undermines prevention efforts. For example, the United States President's Emergency Plan for AIDS Relief (PEPFAR) earmarks a significant portion of its funds for strategies, such as abstinence-only programs for young people, that have less than solid supporting evidence.<sup>26</sup> PEPFAR also requires organisations working with marginalized groups to further stigmatize these groups by pledging to oppose prostitution as a condition for receiving funds. The impact of PEPFAR funds cannot be understated because they are a significant source of financing for AIDS prevention efforts. While it could be argued that recipient governments are not in a position to dictate terms to the donor, one must also consider the ethical responsibilities of donor governments that attach ideologically driven restrictions to much-needed funds, which results in the infringement on the rights of people to protect their health. Recipients who utilize restricted funds for PMTCT programs can also be challenged to advocate for a change in such policies. Short of that, it is difficult to support the assertion that PMTCT

programs are indeed meeting the needs of women as well as their children.

## Component 2: Prevention of unintended pregnancies among HIV-positive women

Women have inadequate access to contraceptive methods to enable them to decide freely if and when to have children. Currently, more than 120 million couples have an unmet need for contraception globally.<sup>27</sup> The fact that 19 million unsafe abortions occur annually and 68,000 maternal deaths are the result of an unsafe abortion<sup>28</sup> attests to the critical need not only to prevent unwanted pregnancies but also to ensure access to safe abortion services. The lack of comprehensive sexuality education, particularly for young people – which is partly driven by such restrictive approaches as PEPFAR's abstinence-only policy – also contributes to the high rates of unintended pregnancies. Issues related to the prevention and management of unintended pregnancies in the context of HIV infection and the AIDS pandemic pose particular ethical challenges.

Violations of women's right to choice and to control their bodies are an unfortunate part of the history of the family planning movement. While the International Conference on Population and Development in 1994<sup>29</sup> helped shift the focus firmly to a rights-based framework for the provision of family planning and other reproductive health services, the AIDS pandemic has raised new challenges that are increasing the risk of abusive and coercive practices, including forced or coerced abortions and sterilisations.<sup>30</sup>

The reproductive rights of women living with HIV include access to family planning. A cross-sectional study of 1092 HIV-infected men and women attending an AIDS support organisation in

<sup>24</sup> Global HIV Prevention Working Group. 2007. *Bringing HIV Prevention to Scale: An Urgent Global Priority*. Online: Henry J. Kaiser Family Foundation. Available at: <http://www.kff.org/hivaids/upload/pwg062807execsum.pdf> [Accessed 13 July 2007].

<sup>25</sup> Ibid.

<sup>26</sup> Institute of Medicine. 2007. *PEPFAR Implementation: Progress and Promise*. Washington, DC: National Academies Press.

<sup>27</sup> J. Cleland et al. Family Planning: The Unfinished Agenda. *Lancet* 2006; 368: 1810–1827.

<sup>28</sup> D.A. Grimes et al. Unsafe Abortions: The Preventable Pandemic. *Lancet* 2006; 368: 1908–1919.

<sup>29</sup> United Nations International Conference on Population and Development, *op. cit.* note 4.

<sup>30</sup> E. Bell et al. Sexual and Reproductive Health Services and HIV Testing: Perspectives and Experiences of Women and Men Living with HIV and AIDS. *Reprod Health Matters* 2007; 15: 113–135.

Jinja, Uganda, found that 42% of participants were sexually active; 33% practiced pregnancy risk behaviour, defined as having sex without contraceptive or condom use; and 73% did not want more children and were at high risk for unwanted pregnancies. The study concluded that PMTCT and other HIV prevention and care programs should ensure provision of family planning for HIV-infected populations who do not want to become pregnant.<sup>31</sup> The case of Uganda is not an isolated one when it comes to unmet need for contraceptives. This unmet need results in high numbers of unintended pregnancies and high rates of unsafe abortions that contribute to maternal deaths, particularly in countries with highly restrictive abortion laws, but also in countries with permissive abortion laws if abortions are not operationalized in the public health system and therefore remain inaccessible.

There are indeed indications that the need for safe abortion is high among HIV-positive women. Several studies from around the world have shown high rates of abortion among HIV-positive women, both in countries where it is broadly legal and in those with very narrow indications. One study in Europe showed an increase in abortions after HIV diagnosis from 42% to 53%, and another in Côte d'Ivoire showed that one-third of HIV-positive pregnant women had sought an abortion.<sup>32</sup> Women's ability to exercise fully their sexual and reproductive rights, including the right to safe therapeutic abortion, must be upheld. Currently, a very limited number of countries have an explicit provision for therapeutic abortion that includes HIV.<sup>33</sup> In addition to ensuring access to safe abortion services, there is a need for more research on complications of unsafe abortion for HIV-positive women, and the influence of access to antiretroviral treatment on decisions to terminate a pregnancy.<sup>34</sup>

### Component 3: Prevention of HIV transmission from HIV-infected women to their infants

The prevention of HIV transmission from HIV-infected women to their infants through antiretroviral medication is the component of the PMTCT strategy that has been receiving the most attention and resources. The major ethical concern for this component is the continued use of the regimen of single-dose nevirapine (NVP). The ethical questions around the trials resulting in this regimen have been discussed in detail and will not be reviewed here.<sup>35</sup> Current ethical concerns relate to the broad continued use of this regimen in the face of evidence that the resistance resulting from its use in this single-dose form may jeopardize future treatment options for the woman.

Since 2004, there has been evidence that single-dose NVP regimens for PMTCT result in drug resistance in women (and infants) to NVP.<sup>36</sup> These findings were of concern because they raised questions about future treatment options for women given that two out of three of the first-line triple-combination HIV treatments contain NVP.<sup>37</sup> While further studies have since shown that this resistance goes down over time and may not impact future treatment if it is begun six or more months after the initial exposure to NVP,<sup>38</sup> the risk remains of concern.

In the face of this evidence, WHO revised its guidelines in 2005 and made the use of combination antiretroviral treatment the recommended regimen for PMTCT rather than the single dose of NVP during and after delivery.<sup>39</sup> The guidelines note that while it may be necessary to use single-dose NVP as 'an absolute minimum' because of a lack of capacity to provide the recommended combination regimen, 'the specific obstacles to delivering more effective regimens should be identified and concrete action

<sup>31</sup> S. Nakayiwa et al. Desire for Children and Pregnancy Risk Behavior among HIV-Infected Men and Women in Uganda. *AIDS Behav* 2006; 10: 95–104.

<sup>32</sup> T. Delvaux & C. Nostlinger. Reproductive Choice for Women and Men Living with HIV: Contraception, Abortion and Fertility. *Reprod Health Matters* 2007; 15: 46–66.

<sup>33</sup> Ibid.

<sup>34</sup> Ibid.

<sup>35</sup> de Zuleta, *op. cit.* note 1.

<sup>36</sup> J.A. Johnson et al. Emergence of Drug-Resistant HIV-1 after Intrapartum Administration of Single-Dose Nevirapine is Substantially Underestimated. *J Infect Dis* 2005; 192: 16–23.

<sup>37</sup> World Health Organization, *op. cit.* note 21.

<sup>38</sup> M.S. McConnell et al. Use of Single-dose Nevirapine for the Prevention of Mother-to-Child Transmission of HIV-1: Does Development of Resistance Matter? *Am J Obstet Gynecol* 2007; 197: S56–S63.

<sup>39</sup> World Health Organization, *op. cit.* note 21.

taken to overcome them.<sup>40</sup> A review of PMTCT programs in 2006, however, indicated that the majority of women in such programs were given just the single-dose NVP regimen.<sup>41</sup>

While it could be argued for the reasons cited by WHO that single-dose NVP should continue to be provided, its continued widespread use does raise questions about the commitment to provide women with the recommended regimen in a timely manner. With the resources now available to fight AIDS, such as PEPFAR and the Global Fund to Fight AIDS, TB and Malaria, it should not continue to be acceptable for countries to keep invoking the 'limited resources' argument or claim that regimens are too complex to implement in resource-constrained settings as an excuse for not providing the safer regimens for women. Similar arguments were made in the 1990s when advocates were pushing for access to treatment for people living with HIV in settings with limited resources, particularly sub-Saharan Africa. With political will and commitment, access to treatment has improved significantly in resource-limited settings. While recognizing that there are indeed many challenges, there is no reason for there not to be the same improvements in access to treatment for PMTCT. A critical starting point, however, will be the same level of advocacy for the implementation of the more effective recommended regimen.

#### Component 4: Provision of treatment, care and support to HIV-infected women and their families

The final component of the PMTCT strategy has, until very recently, received the least attention, raising the ethical concern about the inadequate attention to the treatment needs of the woman not only during pregnancy but also beyond, despite calls for stronger links between prevention and treatment programs.<sup>42</sup>

<sup>40</sup> Ibid: 9.

<sup>41</sup> T. Smart & L. Sherriff. 2006. PEPFAR: PMTCT Improving but Services only Reaching Small Percentage of Women in Need. *AIDSmap News* 13 July. Available at: <http://www.aidsmap.com/en/news/2D50BFF6-F8B6-465A-85DD-0090FD27E045.asp>. [Accessed 2 July 2007].

<sup>42</sup> Institute of Medicine, *op. cit.* note 26.

While HIV testing during prenatal care is supposed to provide access to HIV treatment beyond PMTCT, maternal and child services within which PMTCT programs tend to be located are generally not equipped to provide HIV treatment. In turn, HIV treatment tends to be provided in stand-alone clinics that the women would have to be referred to.<sup>43</sup> Without strong referral links between the antenatal and treatment facilities, the fourth component of the PMTCT strategy remains very weak.

The MTCT-Plus initiative of Columbia University that began in 2002<sup>44</sup> is the first attempt to fully and effectively implement the whole PMTCT strategy and is an excellent example of what a comprehensive program should look like. This initiative, which was created to counter the limited implementation of the PMTCT strategy noted earlier, places a strong emphasis on the health and rights of women and actively promotes the treatment of the family unit.<sup>45</sup> Once enrolled in MTCT-Plus programs, women and their families receive a wide range of services, including medical care, HIV treatment and medicine to prevent opportunistic infections, patient education and counselling, reproductive health and family planning, nutritional education and support, and services to promote retention of patients in long-term care. The results to date of the initiative are very encouraging: some 12,000 people, half of them women, have been enrolled, and while 69% of women have received single-dose NVP for PMTCT, the number of facilities with the capacity to provide combination therapy is growing.

In addition, while traditional PMTCT programs have been struggling to retain women from testing through treatment for PMTCT, the MTCT-Plus initiative is showing very high retention rates, with less than 600 adults lost to follow-up. This initiative, a model that should be taken to scale, is, however, currently available in only 13 health facilities in

<sup>43</sup> Abrams et al. Prevention of Mother-to-Child Transmission Services as a Gateway to Family-based Human Immunodeficiency Virus Care and Treatment in Resource-limited Settings: Rationale and International Experience. *Am J Obstet Gynecol* 2007; 197: S101-S106.

<sup>44</sup> See International Center for AIDS Care and Treatment Programs (ICAP). Columbia University. 2002. *MTCT-Plus Initiative*. Online: Columbia University. Available at: <http://www.columbia-icap.org/whatwedo/mtctplus/index.html> [Accessed 23 Jan 2008].

<sup>45</sup> Ibid.

eight African countries as well as Thailand.<sup>46</sup> Without such programs, and in light of the recent push towards routine or provider-initiated testing,<sup>47</sup> there are legitimate concerns about the potential for identifying many HIV-positive women during pregnancy as well as the dearth of systems to ensure they get the future treatment care and support they need.

We have discussed some of the ethical issues and challenges with regard to the current implementation of the PMTCT strategy, particularly with regard to how it meets the needs and respects the rights of women. It is important to note again that despite several years into the rollout of the strategy in different countries around the world, only 10% of women who are eligible for PMTCT are receiving the services. This clearly indicates that there are serious challenges and barriers to its implementation. While we believe it is important for the strategy, such as it is outlined by WHO, to be fully and robustly implemented, we also propose that it needs to go beyond what it is so as to better address women's needs for HIV prevention, treatment and care. This is all the more important in light of evidence that PMTCT programs may not be as effective in preventing paediatric infections in real-life contexts, that is, outside of a clinical trial setting.<sup>48</sup>

## GOING BEYOND PMTCT TO TRULY MEETING WOMEN'S NEEDS

In addition to those discussed above, there are a number of other ways that the PMTCT strategy is not meeting women's needs and may even be exacerbating the factors that contribute to the disproportionate impact of AIDS on women.

First is the question of testing. Through PMTCT programs, pregnant women are usually the first in a family to be tested for HIV. HIV-positive women have testified that violence often results from being

found HIV-positive and disclosing one's status. Other consequences can include being forced to leave home or other physical or emotional abuse.<sup>49</sup> In studies on disclosure, 3–15% of women reported negative reactions from partners, including anger, verbal abuse, violence and abandonment. Fearing violence, 16–51% of respondents in studies from Tanzania, South Africa and Kenya did not disclose their status,<sup>50</sup> limiting their access to treatment and care. These findings highlight deeprooted gender inequalities, which, without measures to redress them, will result in HIV-positive women receiving less care and suffering other negative health consequences.

Secondly, while PMTCT programs can result in women being the first in a family to receive treatment, they can also end up jeopardizing this same treatment. Due to the stigma associated with being HIV-positive, many women are coerced into or forced to share their medicines with their spouse or partner, who is unwilling to get tested and get his own treatment. Such sharing of medications can result in drug-resistant strains and ineffective treatment.<sup>51</sup> It is essential therefore to ensure proper support services for women who are tested within PMTCT programs and their families to address these types of challenges. However, there is little evidence of programs outside of the MTCT-Plus initiative that are seeking to do so through the provision of comprehensive medical and psychosocial services for women and their families.

A third concern relates to the equitable access to HIV services. The main point of access to treatment for HIV-positive women, particularly in developing countries, is currently within the context of PMTCT programs. However, because access to these programs is limited to pregnant women, it raises questions around access and availability of HIV treatment for those women living with HIV who do

<sup>46</sup> Bell et al., *op. cit.* note 30.

<sup>47</sup> World Health Organization (WHO)/Joint United Nations Programme on HIV/AIDS (UNAIDS). 2007. *Guidance on Provider-Initiated HIV Testing and Counselling in Health Facilities*. Geneva: WHO/UNAIDS. Available at: [http://whqlibdoc.who.int/publications/2007/9789241595568\\_eng.pdf](http://whqlibdoc.who.int/publications/2007/9789241595568_eng.pdf) [Accessed 3 July 2007].

<sup>48</sup> Abrams et al., *op. cit.* note 43.

<sup>49</sup> *Ibid.*

<sup>50</sup> A. Medley et al. Rates, Barriers and Outcomes of HIV Sero-disclosure among Women in Developing Countries: Implications for Prevention of Mother-to-Child Transmission Programmes. *Bull World Health Org* 2004; 82: 299–307.

<sup>51</sup> R. Macklin. 2004. *Ethics and Equity in Access to HIV treatment – 3 by 5 Initiative*. Background Paper for the Consultation on Equitable Access to Treatment and Care for HIV/AIDS. Geneva: World Health Organization. Available at: <http://www.who.int/ethics/en/background-macklin3.pdf> [Accessed 3 July 2007].

not want or are unable to get pregnant. Indeed, there are reports of women who know that they are HIV-positive seeking to become pregnant in order to receive antiretroviral therapy, which they know is more accessible through PMTCT programs.<sup>52</sup> There have also been anecdotal reports from Tanzania and Burkina Faso of women who are not pregnant and have not been able to access HIV testing in certain health centres because they are told that the HIV test kits are only for pregnant women.<sup>53</sup>

The lack of strong linkages between sexual and reproductive health programs, including family planning and maternal health services, has no doubt contributed to the low uptake of PMTCT services. This low uptake is likely tied to ongoing challenges of improving women's access to and use of sexual and reproductive health care, including maternal health care services within which PMTCT is primarily provided. PMTCT programs will not succeed without addressing the broader context of access to maternal care, and the maternal health field has many lessons to share with PMTCT programs.

Reframing the current response to AIDS to address women's health needs requires the full implementation of two international policy agreements – the Programme of Action of the International Conference on Population and Development<sup>54</sup> and the Platform for Action from the Fourth World Conference on Women.<sup>55</sup> Both agreements comprehensively address the factors that contribute to the disproportionate impact of the AIDS pandemic on women, including their lack of access to comprehensive rights-based sexual and reproductive health care services and their limited ability to access treatment and care if HIV-positive. These important agreements have informed subsequent policy documents, including the UN Declaration of Commitment on HIV/AIDS,<sup>56</sup> as well as the Millennium

Development Goals.<sup>57</sup> Unfortunately, the political will of governments to stand behind and implement these important documents is very weak – in large part because of the resistance to changing powerful societal norms regarding gender roles and status, which the two agreements seek to transform.

## CONCLUSION

In this paper, we have sought to highlight ethical concerns around the PMTCT strategy as it relates to adequately meeting the needs of women for HIV services in order to draw attention to the need for a more comprehensive woman-focused response. The PMTCT strategy is singled out because it is the principal point of entry for women to access HIV services, particularly for treatment. Our concerns include, in particular, the weak emphasis on implementing the first, second and fourth components of the strategy. The continued practice in the majority of programs of using single-dose NVP for PMTCT over the recommended combination therapy is worrisome. The latter is more effective, and is also a better regimen for future treatment options for the woman. We have also underscored concerns relating to the impact of selecting pregnant women for testing without adequate psychosocial and other support systems in place to ensure that they are protected from negative outcomes relating to their status and/or access to treatment, as well as the inequitable access to HIV services for women depending on pregnancy status.

With these concerns in mind, we argue for an AIDS response for women that takes into account the global agreements that have clearly and specifically outlined comprehensive approaches to meeting the needs of women and that are of particular relevance with regards to AIDS. Short of such a comprehensive approach, women will continue to be impacted disproportionately by the pandemic, and current strategies for prevention, including PMTCT, and treatment will not be as effective and responsive to needs as they should be. Certainly, there will continue to be ethical and

<sup>52</sup> Johnson et al., *op. cit.* note 36.

<sup>53</sup> Oral communication with Ellen Brazier, Director of Anglophone Africa Program, Family Care International. 20 September 2007.

<sup>54</sup> United Nations. International Conference on Population and Development, *op. cit.* note 4.

<sup>55</sup> United Nations. Division for the Advancement of Women, *op. cit.* note 4.

<sup>56</sup> United Nations. General Assembly Special Session (UNGASS). 2001. *Declaration of Commitment on HIV/AIDS*. New York, NY: UNGASS. Available at: <http://www.un.org/ga/aids/coverage/Final-DeclarationHIVAIDS.html> [Accessed 25 Jan 2008].

<sup>57</sup> United Nations, *op. cit.* note 14.

other challenges, such as those relating to the guidelines on provider-initiated testing. However, placing those who are currently bearing the brunt of the pandemic in the hardest-hit parts of the world at the centre of the response, and ensuring that their rights are respected and their needs addressed, can only make for a more effective response to the pandemic.

There needs to be a clear message from the global public health community that the systematic refusal to uphold the universally recognized rights of women to healthy sexual and reproductive lives, regardless of HIV status, is not acceptable. Women, including those living with HIV and AIDS, have

been saying this for years, and it is past time that concrete action be taken to redress the situation.<sup>58</sup>

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<sup>58</sup> World YWCA. 2007. *The Nairobi 2007 Call to Action: Declaration and Suggested Strategies for Implementation made at the World YWCA International Women's Summit, July 2007*. Online: World YWCA. Available at: [http://www.worldywca.info/index.php/ywca/world\\_council\\_07/iws\\_women\\_s\\_summit/call\\_to\\_action/call\\_to\\_action](http://www.worldywca.info/index.php/ywca/world_council_07/iws_women_s_summit/call_to_action/call_to_action) [Accessed 13 July 2007].