6. HIV and Gender-based Violence: The Rights of Unpaid Women and Girl Carers

CEDAW General Recommendation 19 (1992) states that 'gender-based violence, which impairs or nullifies the enjoyment by women of human rights and fundamental freedoms under general international law or under human rights conventions, is discrimination within the meaning of article 1 of the Convention'.

CEDAW General Recommendations on health say that States should ensure the removal of all barriers to women's access to health education and information in the area of sexual and reproductive health and allocate resources for programmes directed at adolescents for the prevention and treatment of sexually transmitted diseases, including HIV and AIDS. The General Recommendation on HIV/AIDS directs States parties to increase their efforts to disseminate information to increase public awareness of the risk of HIV infection and AIDS, especially in women and children.

The Committee on the Rights of the Child, in its General Comment No. 3 (2003), while setting out that the right to health (article 24) is central to combating HIV among children, notes that HIV affects a child's civil, political, economic, social and cultural rights. It further notes that the right to life, survival and development (article 6) and the right to have his/her views respected (article 12) should be the guiding themes in the consideration of HIV and AIDS at all levels of prevention, treatment, care and support.

Situating rights

As noted earlier, the 1949 Universal Declaration of Human Rights (UDHR) sets out in Article 1 that 'All human beings are born free and equal in dignity and rights'. It emphasises the 'inherent dignity' and 'equal and inalienable rights' of all members of the human family as the foundation of freedom, justice and peace in the world. Therefore it has been asserted (Pulea 2010) that dignity provides the rationale for the requirement of respect of persons (Lebech 2004) and it has also been described as 'the shaping principle...' (Andorno 2009) that reinforces the intrinsic worth of human beings.

Following on from the above, women's rights are seen as an indivisible part of human rights, and the UN Conference on Human Rights in Vienna in 1993 recognised that women's rights in the personal sphere are as important as their rights in the public sphere. The CEDAW Committee issued Recommendation No. 19 in recognition of the pervasive and persistent violence against women in different forms and how this impairs or nullifies the enjoyment by women of human rights and fundamental freedoms. Violence against unpaid women carers is a violation of their rights to dignity, personal security and the enjoyment of all freedoms.

The Convention on the Rights of the Child (CRC) sets out the framework of rights that enable a child to live in dignity and enjoy her or his rights in various spheres of life (family, community, school, etc.). General Comment No. 3 asserts that the HIV epidemic 'impacts on the daily life of younger children, and increases the victimisation and marginalisation of children, especially those living in particularly difficult circumstances'. In the case of child carers – or indeed those children requiring care from older siblings – any form of violence against them and/or violation of their rights to health, education, food and adequate and safe housing is in breach of the CRC. Although child labour is a violation of a child's right to dignity and impinges on a her or his enjoyment of all other rights, the realities of impoverished and vulnerable households has meant that children continue to engage in unpaid household chores and often drop out of the school system to become full-time carers in households affected by HIV.

As rights holders, unpaid women and child HIV carers in households are entitled to social justice that ensures their access to resources, protects their person from any form of violence and accords them dignity in their daily lives.

Experiencing violence: examining the voices of women and young carers

In Bangladesh, when Hamida's husband becomes angry, '... then he becomes cruel to me. It is really painful for me.' As an HIV-positive injecting drug user, he is unable to continue work as a rickshaw puller and has resorted to picking up waste for recycling and selling to finance his drug addiction. She has had to step in with paid employment (care-giving and counselling with an NGO) and also provide the unpaid work required for the maintenance of the household. Living with violence at the hands of her husband is not only physically

draining but also emotionally unbearable as she grapples with working out a future for her children.

Her children seem to offer some hope. However, her young 11-yearold son has had to stop education and begin waged employment.

'Nobody helps me in my daily household work ... I could not able to continue my son's education but my daughter is going to school by staying with my sister. My son is working too for helping the family. If don't work then where we get the food? ... I am being upset by thinking what will happen to my children in my absence. Who will take care of them and who will provide them with food?'

The children's situation – relocation and being with extended family for access to education in the case of the daughter (an example of a positive outcome of government policies on girls' education) and waged work for the son – reflects the difficult choices for vulnerable families as they try to balance development gains and benefits with financial demands and decisions. While the girl's access to education is an obvious gain, it needs to be understood in a context where she may not go on to pursue education beyond the primary level given cultural and economic constraints.

As domestic violence is often shrouded in a culture of silence, women not only rarely speak up but are also unable to defend themselves. Women's subordination and socialisation and the gender dynamics within a community often prevent or deter them from approaching the police or traditional authority. Even when legislation on domestic violence exists, enforcement is problematic. Given Hamida's HIV status and her many physical and emotional burdens, her socioeconomic rights are breached and her right to dignity is compromised.

In Uganda, Jessy also faces uncertainty and violence as she struggles with being the primary caregiver for her sero-positive mother and her younger siblings. Her father died in 2005, and her mother's health took a turn for the worse in 2007 after she tested positive. They live in a cramped settlement with Jessy constantly worrying about the future and struggling to provide full-time care without adult help or supervision. Her circumstances are not conducive to her personal safety as she attempts to also make some money to feed her family.

"... [during free time] I am not resting but thinking of what is going to happen to my young ones when mother passes away. My mother's sickness is on and off, but the hardest time I have ever gone through was when she collapsed in the night and I was alone with her in the house, nobody to help me carry her to the bed. I wanted to call my uncle who was 5 km away from us but I did not have any airtime on mother's phone. I was forced to scream to draw

the attention of the neighbours but unfortunate for me only one lady came out but she did not have a mobile phone. She remained in that condition until 5 am when I jumped on a Boda Boda [local bikes used to transport people] to go and call my uncle.'

"... I used to wash clothes for some people to enable me to get some little income but I stopped after escaping rape from a man who deceived me to pick the clothes from the house and wanted to force me into sex."

The intergenerational burden of HIV has placed a grandmother in Namibia in a vulnerable position as she struggles to cope with caring for her grandchildren, whose lives have been blighted by AIDS. Emily says:

'Five of us live in this house – the oldest child, a 16-year-old boy is somewhere on the street. His name is S. I don't even know if he went to school today. The girl, W, is only here for one year. Then there are the twins H and C. I take care of all the children. I have had the 16-year-old boy since he was 4 months old. His mother, my daughter, died. The twins belong to my neighbour, a woman who passed away. The girl, W, is staying here to study. She is my granddaughter. Her mother is not one of those infected. I have been looking after the children for over 10 years ... The 16-year-old has an attitude about him and it stresses me out ... He has not yet attacked me, but his attitude tells me that it is only a matter of time. I feel so emotional about it but only God can help.'

Hamida, Jessy and Emily are made vulnerable by their situations as carers in households severely affected by HIV, which leaves them open to the threat of violence. In Hamida's case, violence at the hands of her husband reflects the structural causes of gender-based violence, which are founded on patriarchal norms and perpetuated by cultural constructs of gender roles. The intersection of violence against women and girls and HIV has been highlighted by women activists, and HIV-positive women's experience of violence in its various forms was identified at the 2010 Vienna AIDS Conference. These range from non-consensual testing and disclosure of results to stigmatisation, isolation, disinheritance and ostracism by family and community, forced sterilisations and forced abortions. Because it is shrouded in a culture of silence and has taken a long time to be named, labelled and recognised as a violation of women's and girls' human rights, domestic violence often remains unchecked. Too often women have paid for this with their lives.

The challenge of addressing women's and girls' needs and interests as sero-positive persons and/or carers within the broader context of structural inequalities of sexual violence, economic dependency and unequal access to ART often poses problems when designing policy

and programme solutions. An integrated approach to the elimination of violence against women and girls in the context of HIV would have to consider legislative measures, legal interventions, affirmative actions, training of the police and judiciary, improved reporting, data collection and monitoring, public education, programmes targeted at abusive men, support services, health measures and protective mechanisms, and the intervention of community and religious leaders. Such an approach would be women-centred and consider abused women's and girls' particular needs and interests within the framework of their daily realities and social relations.