Thinking ahead – the rising tide of AIDS orphans

Wim Delva, An Vercoutere, Isabelle Dehaene, Sara Willems, Marleen Temmerman, Lieven Annemans

For many years the worldwide community has been committed to the fight against HIV/AIDS. Many battles have been fought already. The implementation of prevention of mother-to-child transmission of HIV and increased accessibility of antiretroviral (ARV) treatment in developing countries are the latest milestones in the world’s response to AIDS. In addition to piloting and monitoring prevention and treatment programmes, a significant part of research nowadays focuses on the demographic, geopolitical and economic impact of AIDS, both at present and in the future. Furthermore, mathematical modelling experts have provided insights on how prevention and treatment (or the lack of it) may influence future trends of the HIV epidemic. Perhaps the latest trend in public health research on HIV is an increased focus on assessment of home- and community-based care programmes for people and/or families affected by HIV/AIDS.1

These insights into the effectiveness and efficiency of HIV prevention, treatment and support tend to focus on today’s adult population. Now that HIV/AIDS is claiming more lives daily, the population of AIDS orphans is growing at a staggering rate. By 2001, 14 million children had lost one or both parents to AIDS and many millions more have been affected since then. By 2010, more than 1 in 5 children will be orphaned in Botswana, Lesotho, Swaziland and Zimbabwe. This will occur unless there is a massive increase in the availability of ARV therapy.2 It is estimated that in South Africa the tide of AIDS orphans will peak at about 3.1 million maternal orphans under the age of 18 in 2015.3 HIV prevention programmes are not able to bring about short-term reductions in the number of AIDS orphans owing to the time lag between behavioural changes (and therefore a change in HIV incidence) on the one hand and parental mortality due to HIV/AIDS on the other. Access to ARV treatment for all HIV-positive people does have this potential impact on the number of AIDS orphans in the short term (for South Africa an estimated 50% reduction by 2015), and although many countries increased their political and financial commitments in 2004, roll-out of the World Health Organization (WHO)'s 3-by-5 programme is far behind schedule, with an estimated 700 000 people on ARV therapy or about 12% of the approximately 5.8 million people currently needing treatment in developing and transitional countries.4

In the face of this huge and fast-approaching challenge, policy makers, researchers and communities are starting to realise that adequate action needs to be taken promptly in order to safeguard orphans’ rights to proper nutrition, shelter, education, health care and physical and social security. Recently, research alliances, community-based organisations and government initiatives have been mushrooming all over sub-Saharan Africa in an attempt to alleviate the plight of AIDS orphans. As a result, new data on nutritional status, poverty, school enrolment and psychosocial wellbeing among AIDS orphans are accumulating rapidly. However, a number of issues have not yet received due attention from policy makers and researchers.

Intuitively, it could be assumed that growing up without parental care and love and being unable to attend school because of caring for sick parents and/or lowered family income, will leave many children and adolescents trapped in a social and pedagogical vacuum. For these reasons, the next generation of children will not only be more vulnerable to HIV/AIDS, but they will also be more at risk of suffering from unemployment, gender discrimination, exploitation and other forms of structural inequities.5 We know this is to be expected but we do not know how bad it is going to be, let alone how many lives and dollars these consequences are going to cost. As we cannot afford to just wait and see, mathematical modelling of the AIDS orphan tide under different scenarios of ART roll-out is imperative to estimate the amount of support required and the resources needed.

Furthermore, little is known about priority setting in care and support for the next generation. However, a report for the World Bank has made some suggestions in this regard, viz. that priorities for improving child welfare are subsidisation of...
vocational training programmes and of households fostering orphans so as to cover the cost of food, supplies and school enrolment. While vocational training programmes could increase productivity among bereaved adolescents and help young women to quit commercial sex work, subsidies to extended families should keep orphans out of orphanages, thus maintaining a family structure for children, at a lower cost than an orphanage. However, it is difficult to estimate the cost-effectiveness of different care and support programmes as their long-term effects and avoided costs are vague. In addition, costs of administration, co-ordination and monitoring by local and national governments need to be explored, and increased efforts should be made to develop models for efficient money transfer from donor organisations directly to the care-giving entities.

Worldwide, communities of political leaders, researchers and grass roots caregivers need to meet and discuss a multipronged response to the next wave of devastation caused by HIV/AIDS. Not only should the specific hazards and needs of AIDS orphans be put on the international agenda, but deadlines should also be in place to ensure that both policy makers and field workers are ready in time. Special attention should be paid to equity issues so as to prevent a research bias favouring interventions by professional caregivers in urban, formal settings above more informal and/or rural coping strategies.

On the level of development and public health research, multidisciplinary alliances by mathematical modelling experts, health care providers, sociologists, health economists, anthropologists, educationalists and public health experts need to be formed. In fact, the whole of society needs to be involved and to think actively about what needs to be done, and by whom. In this challenge, health care providers play a key role. From the point of view of health care provider-patient communication, primary HIV prevention should discuss the consequences of HIV infection for the patient’s children. From a caregiver’s point of view, both parents and children should be guided through the different stages of HIV infection so as to allow the family to be emotionally and functionally prepared for life without one or both parents. In addition, primary health care practitioners should be sensitive to providing follow-up support for the family left behind, and they should be aware of and alert to the increased vulnerability characteristic of AIDS orphans. Only through concerted social effort will the millions of children likely to be orphaned in the near future regain the chance to develop into healthy, happy adults. Make no mistake, their health, social wellbeing, psychological development and positive contribution to society are at stake.