
Annex: Methodology

The researchers met at the 8th Commonwealth Women's Affairs Ministers Meeting (8WAMM) in Kampala, Uganda and began discussions on the 24/7 involvement of caregivers with people living with HIV and those struggling with the symptoms of AIDS. Building on the discussions and recommendations at 8WAMM – and in the context of the theme for the 53rd Session of the UN Commission on the Status of Women (CSW), which focused on the 'Equal sharing of responsibilities between women and men including care-giving in the context of HIV/AIDS' – the Commonwealth Secretariat decided to work on the issue of women's role in HIV care and support, with a specific focus on their unpaid work.

The environment for the study

The public health sector is a major expenditure item for any government, whether costs are met from redistributing national revenues or from development assistance programmes. In more developed economies, the economic imperative of the last decade has been for health institutions to develop more 'efficiencies' and 'effectiveness'. Operationally these policy approaches have had rather more focus on outputs than outcomes.

One of the chief manifestations of this approach has been to discharge patients earlier from public care facilities. In many countries where HIV and AIDS are of epidemic proportions and hospitals cannot cope, they have just sent all patients 'home'. In making this policy choice, there is a presumption that there is a reserve army of unpaid labour available in the family or community to immediately resume responsibility for the discharged patient. Just who is it that the policy-makers are presuming will do this caring role?

In other growing economies there is increasing pressure on governments for the provision of ever more sophisticated and expensive secondary and tertiary care facilities, at a time when studies in health economics demonstrate that the best investments in health are those associated with prevention, early detection and treatment. The location of many activities that promote or hinder this initial investment in health care is the household. Assuming that providing family health care does not have personal, family and social consequences is unfair, unrealistic and dangerous for health policy.

There are economic costs in respect of the invisibility of unpaid household and community work. We know this from the growing number of national and other time use data sets, from surveys or pilot studies on unpaid work and health care, from decades of narrative captured in a wide range of social science literature and from our own observations and experience. Insufficient or inadequate care at the onset of illness can exacerbate its severity, with costs incurred across sectors. These include the loss of labour from the market sector, the loss or diminution of unpaid productive and reproductive activities when the woman of the house either is ill or has to forego other daily household tasks to carry out caring work, or the loss of education when a child is removed from school to assist in caring roles. The known outcomes of longer-term illness include increasing the possibilities of poverty, poor nutrition or hunger and a range of other vulnerabilities.

It is also important to remember that household work includes the daily maintenance of well-being, which tends to be even more invisible than caring for the sick. Household access to water, hygienic practices and a clean environment are all daily household routines that enable a healthy paid, informal or subsistence labour force to remain productive. This work is of significant economic importance.

Research design

The first study design consisted of three main phases: a literature review, qualitative research with women from households affected by HIV as well as with those involved in caring for family members living with HIV or AIDS, and finally an economic analysis of the cost estimates of the care-giving at the household level, including opportunity costs, a cost benefit analysis and State care costs not incurred.

To a large extent, the literature search supported by the results from the qualitative enquiry changed the direction of the third component from an economic to a rights-based analysis. An extensive search of Scopus yielded a large number of articles directly related to the research topic, and http://www.genderandaids.org/modules.php?name=News&new_topic=10 contained some further directly relevant articles. These are included in the bibliography.

There was a wide variation in local circumstances in the studies of unpaid care in households. Situational analyses were needed to ensure appropriateness to the local setting and to define specific support needs and the nature of the human rights breaches in each circumstance.

The strategic policy questions raised in the literature review were extensive; they were far beyond the scope of a simplistic approach

that might evaluate whether a carer's role was being understood in budgeting processes or assess the implications for addressing women and girls' roles in the HIV care economy in terms of gender-responsive budgeting.

The issues included:

- Access to and ability to utilise information
- Interruption of schooling
- Diminution or loss of income-generating and subsistence activities
- Decrease in food/nutrition especially for children
- Invisibility of women carers; increased invisibility and increased work burden of young carers even when they are not the primary caregiver
- Threat or ceasing of loan repayments, damaging extended family and community relationships
- Increased impact on rural households generally with escalation in impact as a result of global recession and fuel crisis
- Violent households more likely to experience spread of infection
- Whole households subjected to community stigma
- No provision of disinfectant, gloves, soap, bandages, painkillers
- No access to clean water
- Creation of time poverty due to burden of care
- Access to and use of condoms
- No sanitation
- No hygienic living conditions
- No respite for carers
- Destruction of traditional safety nets
- No transport
- Little or no food
- No counselling
- Hopelessly inadequate infrastructure
- No labour-saving technology of the simple grating, threshing, milling, pounding, drying, cooking kind
- No fuel whether wood, dung, gas, kerosene, paraffin, charcoal
- Deteriorating health of caregiver(s)
- Female abandonment by males in the household
- Wives and daughters sent to care for HIV-positive relatives, who live elsewhere, of the males in their household
- Male carers seen as deviant and unmanly
- Orphans

The literature review made it obvious that the research focus in the field would be most usefully situated within a rights-based framework and in particular focused on the dignity of the caregiver in a capability approach analysis. It highlighted different impacts on carers by age, cultural expectations, religion, sexual orientation and gender, most of which are overlaid with stigma.

The second phase of the research involved primary qualitative research with women, men and girls from households affected by HIV as well as with those involved in caring for family members or partners living with HIV or AIDS. This phase consisted of key informant interviews.

Sampling was purposive as the objective of the primary research was to establish the dynamic of the inequality and indignity of women and girls in the HIV care economy where such a dynamic exists, not to establish statistics of the percentage of cases where this occurs in a national sample. Subjects for the interviews and focus groups were chosen directly by the researchers or through a researcher's networks, or brokered by civil society organizations providing support to women and girls in households affected by HIV. The general trend of the primary research was interviews with women involved in the HIV care economy, but this also included information on same sex partners and children involved in care.

The original list of countries was India, Jamaica, Papua New Guinea, South Africa/Namibia, Trinidad and Tobago and Uganda. However, members of the research team attending the World AIDS Conference 2008 were further struck by the invisibility in the vast agenda of unpaid care workers as an issue.¹ With this in mind, and in recognition of the desire of the Secretariat to be able to report early findings to the CSW meeting in New York in March 2009, an extended group of countries and purposive fieldwork criteria were agreed to. An early point made was that not only developing countries of the Commonwealth had exploited the human rights of caregivers: it did not seem that Australia, Canada, New Zealand or the United Kingdom had dealt with the rights of these people either. A further detail was an effort to locate male caregivers. As a first choice, the respondents were to be from the following countries and caring for individuals in the following categories:

- Bangladesh: intravenous drug user in an Islamic household
- Botswana: a nuclear family in receipt of food aid
- Canada: woman prisoner or woman living on the street or child with HIV
- Guyana: woman-headed household/violence

- India: sex worker/semi-rural
- Jamaica: gay man/violence, or stigma and baby mother
- Namibia: a grandmother in the care role
- New Zealand: transgender
- Nigeria: Muslim woman in the compound caring for relatives
- Papua New Guinea: subsistence/rural
- Uganda: a child carer in one of the Christian community care schemes

Ethical assumptions

A list was prepared of persons who might be able to assist with the selection of possible research participants. Ethical guidelines for the researchers were also drafted.

Participant carers would remain anonymous unless they wished to be identified. They would be given a pseudonym in the final report. The carer would be well known to the interviewer, preferably over a number of years, so that her or his story could be checked for internal consistency. The interviewer might also be able to provide prompts if changes in the circumstances of the participant carer had been observed.

The interview would be conducted in the language of choice of the participant, who would have chosen the venue for the interview. The participant should be the principal caregiver living in the same household as the patient, or otherwise the person on whom the patient was completely dependent to meet her or his needs.

The participant/household might be 'rewarded' by the provision of prepared food or another item that saved labour (e.g. water, fuel) for the time the interview took in the carer's day. Arrangements had to be made by the interviewer for any necessary supervision of the patient at this time. If possible, the interview should be recorded for transcription and the transcript checked thoroughly for accuracy with the participant, who might also remember more things – and possibly more rights-based characteristics – after the interview so it would provide an opportunity to add material.

The data received from the fieldwork varied considerably with respect to the management of these particular processes.

A photo was good if possible, but not necessary. No photo needed to be provided if the carer chose anonymity. The patient should not be in attendance at the interview and did not have to know that it was even taking place. The focus of the interview was on the carer

Based on the literature review and reflecting a shift from an economic replacement value focus to the inclusion of a capability and strategic policy intervention approach, a semi-structured interview format was drafted, piloted, reviewed and finalised for distribution.

Interview format

The interviewer was to record as much as possible about the carer before the beginning of the interview:

Name:

Age:

Education:

Distance from hospital or clinic or health centre:

Distance from closest basic shop for supplies:

Number in household:

Access to transport:

Access to drinking water:

Type of fuel used for cooking:

The following questions were to be asked in the interview:

- What is the relationship between you (the carer) and the HIV patient?
- How long have you lived in the same household?
- How long have you been providing care?
- How many of you live here regularly or from time to time? (i.e., who else sometimes lives here?)
- Can you describe a typical day in your life before X became so sick? *This needs to take a lot of time. Go through it carefully. What did you do when you woke up – right through to when did you go to bed?*
- Did you feel you had any choice about becoming the primary caregiver?
- What are the nearest public health services?
- Does anyone come to visit to provide help?
- Does anyone ever come to give you some rest?
- Have you had any advice or training to help you with this work?
- How is your own health?

- Can you describe the hardest physical tasks you have as a carer.
- Are you able to get any free exercise time?
- Can you describe the toughest emotional tasks you have as a carer?
- Have you felt depressed or stressed?
- Can you describe the meals you prepare in a day?
- Are you able to do any work outside the home? E.g. – one at a time – gardening, cooking, petty marketing, paid employment, fetching firewood / water (in case it is applicable)? How has this affected the other adults and children who live in this household?
- What has happened to your finances or savings since you have been a full-time carer?
- Can you go to any community meetings or political meetings?
- Did you ever do any of that – or want to do that?
- Have you ever had a holiday? When was that? What did you do?

Analysis

In the original concept note the third phase of the research was to involve economic analyses, including producing costing estimates of the time expended by women and girls as well as opportunity costs for women and girls for expending labour in the HIV care economy. The costs would be compared to the expenditures, where available, on line items for care, support and treatment in national programming. However, the literature review and the decision taken to work with the capability approach, at the interface of economics and human rights, led to a different analytical framework.

The research team met together in a four-day workshop at the completion of the fieldwork. Each member had read all the fieldwork data. The team wrote the research introduction and one of the ‘capability’ chapters together, so that a pattern was established for the individual pieces of work that would follow.

The research was peer-reviewed by an expert with substantial experience in the field of gender, sexual and reproductive health and population studies, HIV programming and economic analyses of hidden phenomena.

The research report makes visible core dynamics of the role, costs and benefits of mostly women’s and girls’ involvement in the HIV care economy, but with interesting and diverse roles played by men. As the

national response moves to a greater emphasis on community care and home-based care for both people living with HIV and orphans and other children affected by HIV, a cross-cultural gender analysis will greatly strengthen the ability of governments, citizens' groups and international partners to participate in cost effective rights-based care, prevention and treatment programmes in the Commonwealth. The study contributes significantly to economic and human rights policy implications for understanding unpaid 24/7 carers of people living with HIV and AIDS.

Note

1. With the exception of a panel supported by the Stephen Lewis Foundation.