

# UNPAID CARE WORK AND VOLUNTEERISM

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## Shifting health care to the home and communities

The HIV and AIDS epidemic has meant that an increasing number of chronically ill people need ongoing assistance with care and support. In Africa, there has been a gradual shift in the model of care of people living with HIV and AIDS from hospital care to home-based care. Programmes providing home based care services are now a key component of the response to HIV and AIDS.

Home based care is conceived as a means of alleviating the strain on overburdened and under-resourced hospitals whilst providing better and more holistic care to chronically ill and HIV and AIDS patients<sup>1</sup>. However the effectiveness of these programmes in many countries remains questionable. Among many governments and communities today these home based care programmes are based on the unrecognised, under-valued and frequently unpaid work of women and girls.

Unpaid care is mainly located within the realm of volunteer work. This results in unpaid care being seen as work that does not require payment and is not regulating in by laws or policies relating to other forms of work. A major thrust in the MAKING CARE WORK COUNT campaign will be to locate unpaid care work within the scope of formal paid employment and to lobby for policy and legislation for unpaid care work.

## Volunteering

Volunteering represents a subset of unpaid work. Beneria (1999) defines volunteer work as unpaid work performed for recipients who are not members of the immediate family and for which there is no direct payment<sup>2</sup>. Volunteer work includes both work done for formal non-profit organisations as well as help and care provided in an informal manner for other individuals. These volunteers are usually members of the community who are otherwise unemployed, and who receive training to care for people in their homes.

Some volunteers are referred to as 'community volunteers' as they are volunteering, and are not in paid employment, however, others are working through organisations or the government. Some are formally recognised and perhaps supported, compensated or remunerated by an organisation or the state, while many others are simply caring for family and neighbours with no organisational support, compensation or remuneration.<sup>3</sup>

UNAIDS refers to informal volunteers' as friends and neighbours who care for sick people they know out of a sense of love or duty. 'Formal volunteers' are recognized as those who have been recruited, and supervised by an organisation.

## The burden of care

Care giving activities may include the following:

- Provision of physical and emotional support to patients.
- Work such as carrying, lifting and bathing of patients who are in the terminal stages of their illness,
- Cleaning those with frequent bouts of diarrhoea among other debilitations.

Family members and volunteers often take on household chores and assist with the care of the children of the sick people. For volunteer caregivers, their work involves transferring knowledge by training family members on how to care for the sick, visiting several homes a day, working long hours and walking in heat of day to assist. Many volunteer caregivers become the primary caregivers of the sick person.

## Challenges

- Lack of skill and information on how to care for the ill.
- Lack of financial support.
- Lack of effective support structures as hospitals are unable to give families the necessary support as they take care of their family members at home.
- Compassion fatigue or burn out.
- Poverty, as they are required to stretch their already limited resources in an endeavour to help terminally ill relatives.
- Stigma and discrimination causing physical and emotional stress.
- Physical stress of having to walk several kilometres daily to clients.
- Lack of protective clothing, such as gloves.

## Recommendations

- There is need to redefine volunteer-based programmes and relocate the work within the realm of formal labour.
- Primary health care models should be reviewed; notably the role of the trained community health workers in relation to family and volunteer caregivers. Clarity is also needed on training and payment for home based caregivers.
- Policy makers and donors need to consider the specific needs of caregivers when drawing up policy and funding priorities. Caregivers need assistance with material and emotional support and may have medical needs of their own, including access to treatment. In view of the psychological and emotional stress of care giving there is need for the introduction or revival of mental health programmes at primary care level. Initiatives to provide economic and emotional support to caregivers are needed.
- Finally and most importantly, governments and health departments need to acknowledge that home based care is not a cheap option. More often, the costs are hidden and defrayed onto the caregivers and communities who are least able to carry the burden.
- Governments need to develop and implement policy and legislation on unpaid care work.

1. 'Reducing the burden of HIV AIDS Care on Women and girls', VSO Policy Brief, 20062.

2. Extracted from 'Conceptual guide to the unpaid work' module, Prepared by Abetha Mahalingam, Nancy Zukewich, and Krista Scott-Dixon, 1999.

3. UNAIDS (2001). "AIDS epidemic update". Geneva: Joint United Nations Programme on HIV/AIDS.

If you would like more information on the campaign contact the GEMSA secretariat on +27116226597 or email [admin@gemsa.org.za](mailto:admin@gemsa.org.za) or go to [www.gemsa.org.za](http://www.gemsa.org.za).

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