# A policy framework to support older persons affected by HIV and AIDS George Petros Institute of Ageing in Africa University of Cape Town

# **Outline**

- Background
- The study, its objectives and methodology
- Study population
- Key findings
- Policy framework

# Background

- South Africa is experiencing the largest HIV and AIDS epidemic in the world
- In 2008 an estimated 5.7 million people were living with HIV and AIDS
- · More than 250,000 people died from AIDS
- Data on infection rates do not include over 50s, even though older men and women continue to engage in sexual relations
- The risk of infection and spread of HIV among older age groups largely goes undetected and untreated

- A consequence of South Africa's high HIV prevalence rate is that the public health system is not coping with the burden of care the epidemic presents
- Older persons are increasingly at risk of infection
- Community structures and individuals, older persons in particular, share the care management of the epidemic

# Aim of the study

To identify challenges and support needs experienced by older caregivers in their contribution to the management of the epidemic at the household level

# **Objectives**

- To determine the nature and burden of care on older caregivers in households affected by HIV/AIDS in three provinces of South Africa;
- To identify factors facilitating and hindering caregiving;
- To construct a policy framework to inform policy makers, planners and NGOs in the design and implementation of appropriate policy and intervention for older caregivers

# Methodology

- A mixed-methods approach was employed, which included quantitative and qualitative research techniques;
- A DoSD database of NGOs involved in HIV/AIDS management was used to randomly select 305 older participants in 3 provinces (EC, KZN, WC)

## In addition:

- Case studies were conducted with ten of the 305 respondents
- Nine key informants from government and NGOs were interviewed

# Sample profile

- The majority of caregivers were female (91.1%) and primary caregivers to both PLWHA and OVC;
- Mean age of the sample was 65.9 years (males 63.4 yrs, females 66.1 yrs)
- 86.2% headed their household
- 66% depended on a social old age grant
- 33% were widowed

# Knowledge of HIV/AIDS (Multiple responses permitted) 97.30% 94.00% 80.30% 67.60% AIDS caused by a HIV contracted wirrus unprotected sex exchange body knowledge health workers

# Caregiving to PLWHA

- · Carers administered medication to the PLWHA
- Prepared meals for the PLWHA daily
- Bathed and dressed the PLWHA's sores
- Hired transport and took the PLWHA to a health centre for treatment
- · Supported the PLWHA emotionally
- Asked for training on how to better care for the PLWHA and OVC
- Lost out on income generating opportunities

# Caregiving to OVC

- Must ensure OVC are fed, clothed, schooling expenses paid
- Must support OVC emotionally
- Have inordinate difficulty in accessing child support grants

# Caregiving situation

- Render care under conditions of extreme deprivation
- Lack formal support; only limited support from NGOs
- Often have limited access to vital services such as potable water and sanitation
- Few caregivers benefit from child support grants for bureaucratic reasons and lack of information

# Consequences of caregiving

- Caregivers develop ailments from stress of caregiving and inadequate access to health care services
- · Existing health conditions are aggravated
- Because of stigma they often render care in isolation and forego a social life

# Selected key informant responses

- This [older caregivers' vulnerability] is a Social Development [ministry] function. Our department's role is to implement the national strategic plan and policy on HIV and AIDS. I cannot say much on this.
- My department knows nothing about the problems faced by older caregivers ... our department has [only] recently become aware of this problem ....there are no strategies nor policies that have been conceptualised to date to address this issue.

# Government responses to HIV/AIDS

- Government does not provide any support for older persons affected by HIV/AIDS
- Government personnel are ageist in relation to HIV infection. Older persons are excluded from counselling, testing and treatment

A policy framework towards supporting older caregivers to inform policy makers, planners and NGOs in appropriate policy development and intervention

### Desired outcome #1

Strengthened capacity of caregivers to care for infected and affected persons and to protect themselves against HIV infection

### Recommendations:

- Review current policy and programme intervention on HIV, to ensure older carers' inclusion and make provision to address their specific needs
- Provide carers with information, counselling support and life skills training to empower them and enhance their caregiving

### **Desired outcome #2**

Improved access for caregivers to essential services (water, sanitation) and health care

### Recommendations:

- Government at district level must ensure older persons have access to HIV prevention and management;
- Government assess older persons' dwelling infrastructure, and improve access to safe water and sanitation to facilitate caregiving:
- Government provide grants to older caregivers to support food cultivation for their household

### **Desired outcome #3**

Involvement of older caregivers/or their NGOs in HIV/AIDS policy development

### Recommendations:

- Government at provincial level review and reformulate policy and programmes to ensure non-discrimination and inclusivity of older carers and their NGOs;
- NGOs identify and help affected households to access social grants;
- Government departments put systems in place to expedite applications for child support grants

### **Desired outcome #4**

Co-ordination of activities to support older caregivers at the district level

### Recommendations:

- NGOs and government at district level build strong working partnerships in which the government assists NGOs to support older caregivers;
- NGOs establish co-ordinating mechanisms at district level to ensure the exchange of information and address caregivers' support needs jointly

# **Desired outcome #5**

Avoidance of ageism, stigma and discrimination

### Recommendations:

- NGOs and religious bodies encourage community leaders to talk openly about HIV/AIDS and its impact on older persons;
- Ageist attitudes of government personnel relating to HIV/AIDS must be changed at provincial and district levels to stamp out discrimination against older caregivers who need help

### **Desired outcome #6**

Engagement and dialogue with traditional healers and religious bodies on the impact of HIV and AIDS on older caregivers

## Recommendations:

- Government and NGOs capacitate traditional healers on the cause and spread of HIV;
- Government at district level involve traditional healers in mainstream public health awareness and management of the epidemic, and discourage futile ministrations to PLWHA
- NGOs and government encourage religious leaders to talk openly about HIV/AIDS, and refute beliefs that the disease is punishment from God

