

# UNPAID HIV/AIDS CARE IN SOUTHERN AFRICA: NATURE, CONTEXTS AND IMPLICATIONS

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- “Home-based care is taking us back to the root of human coexistence. It reminds us that we have the responsibility to care for one another. If we hold hands through this tragedy.... We will be able to retain our humanity and will come out of this epidemic a stronger community” (Joy Phumaphi, Minister of Health, Botswana)

# Introduction

- The Southern African region is home to countries with the highest HIV/AIDS prevalence
- The Impact(s) of HIV/AIDS is upon us ( Barnett & Whiteside (2002). Households and communities, the health & social welfare sectors-key drivers
- Home-based care has become a national policy response to health sector impact in many countries in Southern Africa.
- We have seen a major shift from formal to informal care for PLWHAs in their homes.
- Little is know about the nature, contexts and implications of home and community care the extent of women's contribution to the household & community production of health, particularly HIV/AIDS Care

# Sources of Data

- ❑ Ethnographic study (Participant observation, interviews & desktop review) of 2 high HIV-prevalence, semi-rural communities on the outskirts of Durban, South Africa
- ❑ Qualitative study of volunteers in 4 semi-rural/rural communities in the Durban metropolis.
- ❑ Rapid assessment of 3 HIV/AIDS care programmes in KwaZuluNatal
- ❑ A recent desktop study (extensive review of published and 'grey' literature) and on-going discussions with key-players in Southern Africa.

# What is Home-Based Care?

- Home based care is the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards dignified death (WHO, 2002).

# Nature of Caregiving activities

- Involves a wide range of activities and actors.  
Two main care providers:
- Primary: Main caregivers-usually family
- Secondary caregivers: assistance/respite care
- Volunteer caregivers: increasingly being used in the region. Could be primary or secondary. Fluid but may be the whole range of care work

# Scope of caregiving activities

- Assistance with daily & other activities:
- ADL:feeding, bathing, dressing, transferring, going to toilet
- IADL: housework, shopping, cooking, transportation, and making telephone calls, fetching drugs, monitoring treatment adherence, transport to health facility
- MADL:management of the PLWHAs' affairs such as financial and legal affairs or dealing with doctors or other health or medical personnel.
- Provision of moral & spiritual support to the patient. 92% provided spiritual support (Case, 2005).
- Provision of basic nursing care:skin/mouth care pressure care, support for nutrition

- Care of patients' children while parents are still alive
- Assistance with accessing food parcels, social grants, funeral plans,
- Assistance with funerals and bereavement counseling.
- Counseling of patients and family
- Preparing patients and families to face death. memory boxes
- Care of orphans



# Contexts of HIV/AIDS Care

- High HIV/AIDS Prevalence in SA countries
- The public health system & the shift to home care
- Increase in sick people being cared for at home.  
Over 50% of PLWHAs died at home in SA (Uys, 2003)
- Emergence of HBC organizations & training of volunteers (different level of resources)
- Primary caregivers forego work/reduce work time
- Volunteers teach family members how to provide care or do it themselves:

- Trajectory of HIV/AIDS related illness: fluctuating:
- Time spent more for primary carers :3-24 hours per day.
- Preponderance of women:(Woelk et al 1995; Steinberg et al 2002, Akintola, 2004a, 2005a; Orner, 2005).
- ⑩ Low level of education-10 years (Akintola, 2004a; Orner, 2005, Akintola, 2005)
- ⑩ Typically unemployed, had temporary jobs.
- ⑩ Most lived in abject poverty-5% of caregivers well-off by local standards (Akintola, 2004a)
- ⑩ Poor infrastructure-water, sanitation
- ⑩ No food in many of the affected households

# Context: Gendered:

- FCG= Female heads & single parents & multigenerational HH
- Men may provide ‘gendered’ support or secondary care
- Cultural/social barriers-women/men uncomfortable
- FCG/Volunteers =Some frail/sick elderly & many young ‘vulnerable’ girls served as secondary caregivers
- Stigma-increases burden or caregiver-Stigma is gendered
- Reluctant to report stress due to socio-cultural values:giver stronger than receiver & commitment to volunteering

# Context: Motivations

- Studies have alluded to a no of reasons-gendered (Akintola, 2004b; 2005b Orner, 2005)
- Family members care as a duty which is foisted on them.
- Volunteers: Altruistic/lack of government response-‘I saw people becoming sick, going to the hospital and coming back to die and wanted to help. People were dying like flies’ (Akintola, 2005a)
- Personal reasons- Experience of HIV/AIDS in family.
  - ‘I know how it feels to be sick and dying with AIDS’.
- Hope for a reward training, jobs, marking time, pathway.
  - ‘May be some day government will give us something for our labour because they explained to us that we are volunteering’.

# GENDERED IMPLICATIONS

- Two kinds of implications are discussed:
- Impact on caregivers
- Implications for measurement/costing

# LABOR/BURDEN OF CAREGIVING

- Labor-ongoing cognitive, emotional, and physical work of caregiving (Brown & Stetz, 1999). Physical & mental toil often without recognition or adequate compensation. Also connotes suffering or burden
- Burden refers to the practical difficulties and mental pain experienced by caregivers (Schwartz and Girdon, 2002)

# PHYSICAL HEALTH ISSUES

- Back/body/head ache, fatigue, loss of libido) from lifting patients, HH chores, walking in the sun.
- Reluctant to report stress due to socio-cultural values:giver stronger than receiver & commitment to volunteering
- VCGs=Some were HIV positive or affected (95%)
- Some caregivers were at risk of infection with TB/HIV -Caring without protective devices.
- Personal care activities like bathing & feeding performed by women have greater physical & emotional ramifications than supportive care activities

# PSYCHOLOGICAL & EMOTIONAL ISSUES

- Signs include tearfulness, nightmares, insomnia, worry, anxiety, despair,
- Fears about inevitable death of patient/self, fear of infection with HIV
- Despondency from frequent deaths - & younger girls lack concentration in school.



# SOCIO-ECONOMIC ISSUES

- Stigma, alienation from friends & social activities,
- Volunteers dig into empty pockets to provide support and supplies
- Opportunity cost of caring
- Misunderstanding, straining of relationships between patient & caregiver,
- lack of appreciation & ‘overexpectation’– strains relationship.
- Most are household heads and breadwinners; have to cope with increased cost of living, decreased income from loss of jobs/job opportunities, and transport of dead/funeral costs

# Implications for Children

- Greater physical and psychological burden/financial
- Girl child typically withdrawn from school to care for sick and dying.
- Reduced/no time for extra curricular activities or home work/ Lack of concentration in school
- Physical violence against girl child (Akintola, 2004a).

***Patriarchal structure and power relations in family and society:***

- Gendered influence on caregivers

***Social Representations of:***

- HIV/AIDS

***Social Constructions of:***

- Gender and gendered caring roles

***Caregivers – Who?***

a). Demographic status (Gender, age, literacy level/educational attainment)

b). Relationship with PLWA/Status (spouse, friend, parent, child, volunteer)

c). Socio-economic status (poor, comfortable, rich, employed, unemployed)

d). Knowledge of AIDS caregiving

e) Previous training/experience with caregiving

***Care-giving Activities:***

*Basic nursing care.*

***activities of daily living:*** Feeding, bathing, toileting, transferring, dressing.

***Instrumental activities of daily living:*** house chores, shopping, cooking, dealing with

***Effects of Caregiving***

a). Health (physical strain, emotional & psychological problems)

b). Social (stigma, reduced social connectedness,

c). Economic (financial cost, time, foregone opportunities)

***PLWA***

- Patient stage of Illness
- +ve/-ve effects of informal home care
- +ve/-ve end of life care
- Good death / dying

***Effects on Health Care Systems***

Overstretching health facilities

+ve/-ve end of life care

Frequent readmission to hospital

Effective/ineffective home-based care system.

Good/ poor quality continuation of care

DIAGRAMMATIC REPRESENTATION OF MAJOR CONCEPTUAL THEMES IN THE CAREGIVING PROCESS (Akintola, 2003).

# Voices of disillusioned women

‘I like to ask government to go to those communities and see those sick people out there to see how sick they are. Sometimes we just go into homes and there is nothing like food in the house. People are starving. Even we too as home-based carers have nothing in our homes. It is too difficult for us to go into other people’s houses. We are also hungry. I do not go to work regularly because I cannot go to work on an empty stomach. If you are hungry you do not have patience. The patient is hungry and you are also hungry and there will be no communication between both of you’.

# Conclusions

- Women combine multiple roles as caregivers, heads of households, breadwinners & carry the burden of provision of financial support in affected homes.
- A combination of factors make it difficult for many affected families to provide HBC without undermining wellbeing of family members and volunteers.
- Need to recognize that HBC may be entrenching gender inequalities.

- Home care exacerbates the poverty that already exists in the affected families and communities.
- Limited male involvement in care is a major problem

# Policy Issues

- The need for HBC will increase as positive people become ill.
- Need to recognise & for women's work & a provide for resources to provide logistical + financial support
- Suggest the need for a major role for Social Development institutions and Departments

- Need to explore the possibility of making caregiving attractive by creating a career path. Funders/International development agencies need to assist in this regard.
- Need to involve men in caregiving
- Need to (re)introduce mental health care at the primary care level to provide psychosocial support for volunteers



- Girls must be protected from actively giving care in homes/assist those already denied education. Implications for MDGs. Thus need to assess ability of families to care before discharging patients.
- Home-based care is not a cheap alternative to hospital care, costs are currently borne mainly by caregivers & families

- Community Outreach Centre, St Mary's Hospital, Marian Hill, Durban.
- Sinosizo Home-based care
- Levy Institute
- UNDP- BDP