

Development and validation of a methodology to examine the impact of AIDS on older Africans

Introduction

Although sub-Saharan Africa (SSA) has just 10% of the world's population, around 84% of the estimated adult and child deaths by the end of 1999 had occurred there; seven out of every ten new HIV infections were in this region¹. This contributes to the continued devastation of individual and family life. Recent studies in Eastern and Southern Africa indicate that women and children are AIDS' greatest victims.² Zimbabwe has been one of the countries hardest hit by the pandemic in SSA.

Through necessity or voluntary contribution, older Africans - particularly older women, - are key human resources for combating AIDS and alleviating its sequelae. Older women have a fundamental role to play, as they are one of the main providers of care for AIDS patients and orphans. Older Africans are taking on new roles in providing care and financial support for their HIV/AIDS infected children, undertaking child rearing roles within their extended families, as well as continuing their more traditional roles as advisors to their adult children and grandchildren. They are largely absorbing the huge additional burdens placed on families and societies by the AIDS pandemic.

Contrary to the knowledge about the impact of AIDS on children in SSA,³ little is known about the impact of AIDS on older peoples, their health needs, their role in care and the response of health systems to their current situation. However, even without much hard data, we know that immediate and substantial support is required to avoid further devastation to this and the next generation of Africans.

The project will start with a pilot study for which Zimbabwe has been chosen because of its high HIV prevalence, existing strong NGO support, as well as active collaborating partners, the fact that the WHO African Regional Office (AFRO) is based in Harare, and the interest manifested by the AFRO.

Objectives⁴

- I. To develop, test and validate a research methodology based on complementary approaches (qualitative and quantitative) towards intervention-oriented surveys to assess the impact of AIDS on older Africans.
- II. To identify barriers that prevent the provision of support to older people in the context of HIV/AIDS.
- III. To create a body of evidence on the needs of older people dealing with the HIV/AIDS pandemic.
- IV To develop policy and programme interventions with government, NGOs and academia for supporting older persons as caregivers and as surrogate parents for orphaned children.
- V. To initiate capacity-enhancing programmes with health and social welfare services, especially primary health care providers and home-based caregivers, and to respond to the impact of the pandemic on older caregivers.
- VI. To explore the feasibility of establishing a multi-centric study based on the research methodology developed for this pilot project in other sub Saharan Africa countries.

¹ UNAIDS/WHO fact sheet, 1999.

² Ntozi JPM. Effect of AIDS on children: the problem of orphans in Uganda. *Health Transition Review*. 1997; 7(suppl): 23-40.

³ UNICEF, Community Based Orphan Assistance in Zimbabwe, 1998. (Similar studies have been conducted in a number of SSA countries, e.g., Malawi, Botswana, Uganda)

⁴ It is hoped that following the validation of the methodology through this pilot study, a multi-centre study will be initiated in several sub-Saharan countries. Such studies would generate the much needed data on which to base the effective interventions designed to support older people faced with the consequences of the HIV/AIDS pandemic in Africa.

Methodology

The project methodology is based on the following steps:

- Develop a research methodology of qualitative and quantitative methods
- Apply, test and validate the methodology
- Critically appraise the data generated; disseminate and discuss the relevance of the findings for policy and programme implications in Zimbabwe
- Test the methodology in other SSA countries.

Research programme: The planned project will include a participatory approach using research methods that result in both qualitative (*focused group discussions, key informant interviews, institutional assessments, household interviews*) and quantitative (*develop a questionnaire, test and validate the questionnaire, analyse results*) methods. Sample frame will be determined by using in country experts, based on census enumeration areas and country HIV/AIDS prevalence data.

Broad stakeholder participation: It will involve consultation with local stakeholders and service providers to help identify what the key areas of investigation should be. At the same time, this will improve local capacity by drawing on local expertise for consultation, data generation, and analysis of results.

Advocacy: The results from the research programme will provide the evidence needed to advocate for sustainable interventions that improve the capacity of health systems. This will be especially pertinent for primary health care systems in responding to the health needs of affected older people.

Programme implementation: The research team, in collaboration with key local stakeholders will **identify feasible interventions and best practices**, local stakeholders and WHO will then have the data needed to approach funders or decision makers to implement the identified interventions and other recommended strategies.

Feasibility of project and research methodology

The participatory research methodology that will be employed “*enables local people to share, enhance and analyse their situation, to plan and to act*”. It supports decentralised planning and more democratic decision-making, as well as placing value on social diversity, sustainability, enhance community participation and empowerment. Similar methodology has been employed by the World Bank to assess country poverty situations in about 50 countries. Mr. Robert Agyarko, the primary investigator on this project, has previously participated in one project⁵ and directed another project⁶ applying this methodology. He has subsequently tested the applicability of mixed-method research and analysis for this type of project using the results from these previously conducted projects. An immediate benefit of this methodology is the possibility of immediate identification and implementation of intervention. In addition, it leads to advocacy as it unfolds.

⁵ with the World Bank's Participatory Poverty Assessments (PPAs) in Ghana (1994-1996);

⁶ with HelpAge International to assess the contributions of older people to development and their utilisation of services in Ghana and South Africa (1998-1999).

Table 1. Research Focus and areas of concentration.

RESEARCH ISSUES	Methods used to obtain qualitative data about research issues	Quantitative data derived from research issues
Barriers to access and utilisation of services such as health care and credit. Perceptions of services, including views (or awareness) of recent changes.	Institutional diagramming Semi-structured interviews Time lines of services-e.g. health	Number of facilities in the area (gov't sponsored, church or community sponsored, traditional). Number and type of staff/facility Transport available to facilities.
Social (familial and community) and Institutional barriers to effective care by older people e.g. Inheritance, neglect, violence, abuse (<i>systemic and verbal</i>), witchcraft accusations and violation of older peoples' rights Vulnerability related to AIDS stigma. Differences in perceptions by gender.	Problem and solution identification and ranking Time lines, trend analysis and historical profiles Institutional Analysis (formal and informal)	
Responsibilities, obligations within households (support to AIDS patients and orphaned children; provision of food; payment of school fees, etc.) by gender	Semi-structured interviews 'decision making matrix' Ranking and scoring of household resource allocation and distribution.	Average household size and composition by age, sex (region/location specific). Number of children living in household with older person as household head. Number of households with at least one HIV+ person or AIDS patient and one person 60+ years. Number of older household members with daily caregiving responsibilities. Number of surviving children/grandchildren by age and sex. Total yearly household income. Age-specific labour force participation. Sources and amounts of income per household member per year (or month?).
Nature of care and burden of care of AIDS patients and orphans	Daily and seasonal activity charts, activity and problem ranking	Age and gender specific educational and literacy levels. Number of older household members with disability/health condition.
Role and support of civil society organisations and community institutions in care provision	Institutional mapping Semi-structured interviews	Number of support agencies/services in region/location. Number of community based services (day care centres, respite care, old people's homes)
Perceptions and indicators of wealth, well-being, poverty. Seasonal stress: food security, health, income, expenditure, activity (selected occupational groups)	Wealth/well-being grouping, for criteria and indicators. Semi-structured mapping Seasonal calendar – By occupational/residential group- activity income, expenditure, health	Self-rated health (very good, good, fair, bad, very bad) Self-perceived well-being (use validated SF-36 in Africa?) Number of households below poverty level Yearly and seasonal household expenditure (breakdown)
Coping or fallback strategies in times of crisis	Livelihood analysis Semi-structured interviews Ranking exercises	Numbers with alternative sources of income (livelihood strategies).

Month	Activity	Product/Output
Aug/ Oct	Finalising work plan, research agenda and contacting NGOs, AFRO, government sectors and other relevant stakeholders in project country.	Identified participating ministries, academic institutions and NGO's
Nov.	<p>Planning meeting with academic institutions NGOs, AFRO, government health sectors and other relevant stakeholders on project objectives.</p> <p>Country visit to redefine and finalise research agenda and plans of action for data generation.</p> <p>Develop survey instrument.</p>	<ul style="list-style-type: none"> • Research themes agreed upon with experts from each country • Local researcher co-ordinator selected • Field sites chosen • Participating institutions and researchers selected
Jan-Mar	Conduct participatory rapid assessments in Zimbabwe.	<ul style="list-style-type: none"> • Fieldwork conducted by research team • Data collected
April -May	<p>Analysis of research findings (collating site findings and synthesising data into draft country report)</p> <p>Finalising of draft country report by local research co-ordinator and research team)</p>	<ul style="list-style-type: none"> • Data collated • Draft site and country reports ready • Final draft report produced
May-June	<p>Dissemination Workshop that would bring together stakeholders from countries in the SSA region.</p> <p>Finalising of Draft Country report into a final WHO document for policy and programme advocacy.</p>	Identified best practices, programme advocacy and feasible interventions.