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Creating a Minimum Data Set on ageing in sub-Saharan Africa

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Abstract

The World Health Organisation, together with representatives of four sub-Saharan African countries (Ghana, South Africa, Tanzania, Zimbabwe) and other stakeholders, launched a project in 1999 to establish a Minimum Data Set on ageing and older persons in Africa. The project focusses on identifying what data are needed to build knowledge on the situation of older Africans and forging the centralised, in-country collation and dissemination of this information. This paper summarises the current state of the project and touches on issues of data availability and quality, while exploring methods for data collection, integration, collation and dissemination.

Introduction

In 1999, the Ageing and Health Programme[1] of the World Health Organisation (WHO) launched a "Minimum Data Set" (MDS) project in sub-Saharan Africa (SSA). The project may be viewed as an extension of a current trend towards evidence-based decision making world-wide (Murray & Lopez, 1996). A lack of knowledge on the physical, psychological, social and economic well-being of older Africans has placed policy makers and planners at a disadvantage (Cooper, Osotimehin, Kaufman & Forrester, 1998).

Reliable demographic and health statistics data are needed to inform African policy makers, budget planners, and health and social-welfare service providers. The MDS project will focus on meeting these information needs in an environment with scarce economic and human resources. In the context of this project, a Minimum Data Set is a common set of data items, definitions and standards that should be used to collect and report data. These data should be comparable across geographic regions within the continent and over time. The challenge that the MDS project in Africa thus aims to address is to accurately and consistently obtain, store, aggregate, disaggregate and disseminate data on the situation of older persons in sub-Saharan African countries. Other aims are that the project be sustainable, and that the data are updated and maintained.

In meeting this challenge, several issues arise. For example, what are key indicators to inform policy makers about the situation of older Africans? How should these indicators be defined, stored and disseminated? What pertinent data are currently available? How can various sources of data be harmonised[2] and/or integrated? What methods and tools are available to maximise the utility and extraction of information from currently available data, that will minimise a need to obtain additional data?

An ideal database for the MDS would be one that has complete and reliable data on the health, social, economic and mental status of older individuals in the population; integrates various sources of information; and is easy to use, update and disseminate. The reality, in the context of studying ageing and older persons in Africa, is that the data that are available, or which might feasibly be obtained in the near future, are far from ideal. Nonetheless, this hiatus should not impede attempts to collate and disseminate what information is available and to educate stakeholders on how best to use it.

This paper informs readers of the current status and future plans of the MDS project on ageing in Africa, and identifies opportunities for broad stakeholder participation. In the sections below, background and a motivation for the project are given, the project methods are described, the outcome of a project workshop is reported, and future and potential activities of the project are outlined.

Background

Demographic projections bolster a case for greater attention to be given to the situation of older Africans (UNPD, 1998). Fertility and mortality rates are declining, albeit gradually, leading to smaller young populations and larger old populations and, in particular, to an increase in the size of the population aged 80 years and over (see Table 1). The older population (60 years and over) of sub-Saharan Africa is projected to increase from 30.4 million in 2000, to 56.5 million by the year 2025. Over this 25-year period, the older population of Ghana is projected to increase from one to 2.2 million, of South Africa from 3.1 to 4.6 million, of Tanzania from 1.6 to 3.1 million, and of Zimbabwe from 600 000 to 745 000 (USCB, 2000). Table 1 shows percentages of persons in two age groups (60+ years, 80+ years) in the populations of four SSA countries (Ghana, South Africa, Tanzania, Zimbabwe), in 2000 and projected for 2025.

In African countries, ageing-related issues have had a low priority in numerous governmental sectors (cf. Mkai & Ngalinda, 2000; Van den Heever & Booysen, 2000; Madzingira, 2000; Katsriku, 2000). This low priority may be due to a lack of information relevant and specific to the older population and its situation (Apt, 1997). Although efforts to collect data on the status of older Africans have increased in recent years (Charlton, 1998; Mkai & Ngalinda, 2000; Ferreira, Møller, Prinsloo & Gillis, 1992), a paucity of quality

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data remains. The focus of the majority of data collection efforts in SSA countries has been maternal and child health, together with parasitic and infectious diseases, now amplified by the huge burden of AIDS. Efforts to profile the status of older Africans have also been hampered by the data collection instruments utilised. For example, numerous surveys in the region, including the Demographic and Health Surveys, do not generally include older populations, or only include small numbers of older persons in broad age categories.

Table 1

Percentages of persons in two age groups (60+ years, 80+ years) in Africa, and selected sub-regions and countries, 2000 and projected for 2050

Sub-region/Country	Year			
	2000		2050	
	60+ %	80+ %	60+ %	80+ %
Africa	4.5	0.8	11.3	2.3
East Africa	3.9	0.7	9.4	1.8
Tanzania	3.8	0.6	9.7	1.9
Southern Africa	4.7	0.6	12.1	2.2
South Africa	4.6	0.6	12.1	2.2
Zimbabwe	3.9	0.7	14.5	2.8
West Africa	4.4	0.7	10.6	2.1
Ghana	4.6	0.8	12.1	2.7

Source: UN Population Division. 1999. *World population prospects. The 1998 revision.* Washington, DC.

Despite declines in life expectancy as a result of AIDS-related mortality in several SSA countries, population growth is likely to continue, resulting in stable to increasing numbers and percentages of older persons (UNAIDS, 2000; USCB, 1999, 1998). In some countries, the familiar population pyramid is expected to resemble a population chimney as a result of AIDS-related mortality (USCB, 1998). The AIDS epidemics, coupled with internal migration, urbanisation and other demographic "shocks," are changing the situation of the older persons in Africa. For example, studies which have yielded qualitative (Forrester, 1998; Ahenkora, 1999; Mohatle & Agyarko de Graft, 1999) and quantitative (UNAIDS, 2000) data indicate that older family members must increasingly assume custodial responsibilities for adult children and grandchildren affected by AIDS. Older persons who anticipated kin support in old age may find themselves to be primary caretakers once more (Mullan, 1998). These role changes are in addition to the cumulative effects of health and economic inadequacies over a lifetime, which are manifested as disease and disability in old age (Harrison & Howson, 1996; Gorman, 1999; Heslop, 1999).

While the scarcity of data on ageing in SSA is one problem, another problem is the quality of the data. An example of poor quality data are vital registration figures, particularly those pertaining to mortality (cf. Bradshaw, Bourne, Schneider & Sayed, 1995; Timaeus, 1997). However, efforts to improve the quality of vital registration data are under way. For example, the Tanzanian Ministry of Health's Adult Morbidity and Mortality Project (AMMP) has adopted the use of verbal autopsies to determine cause of death, and within surveillance sites, to assess the burden of disease (cf. Chandramohan, Maude, Rodrigues & Hayes, 1998; Kaufmann, Asuzu, Rotimi *et al.*, 1997; Mirza, Macharia, Wafula *et al.*, 1990). In countries where the majority of persons die at home, verbal autopsy approaches, once they are validated for adult deaths, can lead to a cost-effective and sustainable alternative to standard vital registration systems. In other countries, consideration is being given to which studies to conduct which may provide more comprehensive data on ageing.

The most difficult tasks which lie ahead in the different countries for the MDS project will be to determine what data are needed, and how best to collect, analyse and disseminate such data.

The MDS concept

The concept of a Minimum Data Set is not new. Several countries world-wide have recognised a need for comprehensive, standardised information to assess situations of older individuals and thus a need to develop an MDS (Hawes, Morris, Phillips *et al.*, 1997; Rantz, Popejoy, Zwygart-Stauffacher *et al.*, 1999). An MDS can be a minimal, priority or comprehensive collection of items covering all areas in which one might expect to work when assessing the situation and needs of an individual or population, which can be used to trigger research, policy and programmes. A typical motivation for an MDS is to improve the well-being of individuals through increased use of quality information.

The use of minimum data sets is found in varied settings, for example in nursing homes (*www.hcfa.gov/medicare/hsqb/mds20*) and in in-patient surgery units (*www.ecsur.ic.ac.uk/mds.html*), as well as in different countries (Moss, 1995; Borchelt, Vogel & Steinhagen-Thiessen, 1998; Goossen, Epping, Van den Heuvel *et al.*, 1998; Wing, Beevor, Curtis *et al.*, 1998; Kondo, Shido, Kato *et al.*, 1999). Examples of the use of an MDS are for cases of individual patient monitoring, systems and care provider assessments, and national and international comparisons (Ikegami, Morris & Fries, 1997; Ribbe, Ljunggren, Steel *et al.*, 1997).

As a monitoring tool, a serious flaw of an MDS as a database and an outcomes tool may lie in its deliberate effort to provide uniform data, which can reduce the information to the lowest common denominator. Consequently, the validity and robustness of an MDS on ageing and older persons in Africa will need to be tested. To effectively function as an assessment tool and a data repository on ageing in Africa, the MDS will need common data, definitions, triggers and utilisation guidelines, and the capacity to include country-specific data indicators.

Methodology

The MDS project began with a pilot project initiated by WHO to establish informal collaborative agreements with stakeholders in four countries and with international agencies. Initially, the four countries identified as potential participants in the project (Ghana, Nigeria, South Africa, Zimbabwe) were selected because of interest expressed by individuals and institutions in those countries, as well as the comparatively advanced state of gerontological research and data collection efforts in the countries. Nigeria was later replaced with Zimbabwe, primarily because of the unstable political situation in Nigeria during mid 1999. While the pilot project thus only includes anglophone countries in SSA, the project may later be extended to other countries in the region.

Because a primary goal of the MDS project is to establish databases *within* countries, for the project to be successful, it is important that ownership of the databases resides within the countries. The participation of Africans in all aspects of the MDS project activities is intended to involve end users in the processes of the project, so that the activities that are undertaken are relevant to their needs and goals, and they are encouraged to use the results.

During the first year of the MDS project, 1999, WHO secured funding from the United States' National Institute on Aging (NIA) to establish partnerships in the four countries. With the assistance of HelpAge International (HAI), potential stakeholders were identified in each of the countries and contacted about the project. WHO representatives later visited these countries for individual meetings with the potential collaborators, who included decision makers, and representatives of regional organisations, universities, research entities, governmental sectors (particularly health and social welfare ministries, and national statistics offices), donor organisations and local non-governmental organisations (NGOs). The purpose of the meetings was to identify key participants and to invite their participation in the project, as well as to determine what data are available.

Based on what was learned from individuals in the meetings, an exhaustive list of potential indicators to be included in the MDS was constructed. Available literature on older persons in Africa was reviewed, particularly with a view to identifying non-routine published data sources. Part of this process was an examination of which potential MDS indicators were available through either routine or non-routine data sources. The quality of some of the data was assessed and deficiencies in data quality were noted. The use of innovative statistical methods, such as Bayesian statistical inference, multiple imputation of missing data and elicitation of expert opinion (Daponte, Kadane & Wolfson, 1997; Kadane & Wolfson, 1998; Shafer, 1997), was considered, insofar as the use of the methods could be helpful to ensure that "data gaps"[3] did not impede the use of MDS indicators.

Workshop

With additional funding from NIA and WHO, and organisational assistance from HelpAge International, a workshop was held on 20-22 January 2000 in Harare, Zimbabwe. The workshop was attended by:

- *Country participants.* Representatives of governmental agencies, universities and non-governmental organisations in each of the four countries who have an interest in conducting and/or supporting research on older Africans.
- *International agency representatives.* Individuals at organisations who could be resource persons to the MDS project. Entities included the African Census Analysis Project (at the University of Pennsylvania, USA), Macro International, Inc. (based in the USA, it conducts the Demographic and Health Surveys), the United States Bureau of the Census, the United States Agency for International Development (USAID), the Population Council (based in the USA), and HelpAge International (based in London and with an Africa Regional Development Centre in Nairobi, Kenya).
- *Expert consultants.* Several individuals with expertise in the development of methods and techniques for minimum data set development, or with specific research expertise on ageing and older Africans.

A total of 45 persons participated in the workshop. In addition to these persons, representatives of the WHO Regional Office for Africa (AFRO) were present in the workshop. The goals of the workshop were:

(1) To define the terms, goals and objectives of the MDS project.
(2) To critically evaluate the proposed dimensions of the MDS.
(3) To discuss barriers and impediments to the construction of an MDS and conducting research on ageing in Africa, as well as to develop strategies to overcome the barriers/impediments.
(4) To develop a plan for future activities in the four countries to forge the development of the MDS project.
(5) To raise bilateral awareness between international organisations and country participants of resources which could contribute to the MDS project.

At the end of the workshop, participants from each country nominated a focal person(s) or group, to establish a plan of action for the project in their country. WHO has pursued funding opportunities for the continuation of the project and is helping to co-ordinate collaborating activities. In the remainder of this section, we give a definition of an MDS for operationalisation in the project and outline the project goals – as determined in the workshop, and consider indicators for the MDS.

Definition of MDS

A starting point in defining the project was to provide a definition for a Minimum Data Set. The workshop participants agreed upon the following definition:

> *A necessary and sufficient set of potentially available information which is compiled for some defined entity (e.g. country, age group) and permits the conclusive examination of predetermined sets of research, policy and planning issues at desired levels of disaggregation and which can be used for planning, development, monitoring and evaluation of policy.*

MDS project goals

The MDS project goals were set as follows:

(1) To define key indicators with which to construct a Minimum Data Set for understanding determinants of well-being in older Africans.
(2) To determine an optimal way for each participant country to assemble and disseminate the indicators so that stakeholders have access to a comprehensive, reliable and continually updated source of quality data.
(3) To clarify where additional data collection and dissemination efforts should be focussed.
(4) To articulate and develop appropriate and sustainable methods of data collection and analysis of indicators that will assist in the development of policy and interventions to promote the well-being of older Africans.
(5) To determine what actions/resources are needed in SSA to improve the situation of older Africans.

MDS indicators

In breakaway sessions during the workshop, participants were grouped according to interest (policy, data, socio-economic, health) and country to discuss potential elements of an MDS. Each data element in a preconstructed list was reviewed for appropriateness, validity, availability and accessibility. The outcome of this review is a provisional MDS consisting of multiple data elements (indicators) in five broad categories (see Figure 1). Because a goal of the project is to define a *common* set of indicators, these indicators will be finalised through a series of consultations between the country focal groups and WHO until a consensus is reached. It is important to note that an "appropriate" minimum data set can change over time and that the MDS will thus need to be periodically re-evaluated.

Indicators under consideration represent different ways of profiling the situation of older persons, from enumerating events, to describing the prevalence of characteristics in individuals, populations or organisations. Because MDS indicators will be used to assess needs, as well as to monitor and assess the impact of interventions, the indicators should have specific attributes that must be considered during the indicator selection process (Graham & Macfarlane, 1997).

Figure 1

Provisional list of indicators[a] for consideration for inclusion in a Minimum Data Set

Demographic, social and economic situation
Population estimates and projections (current to 2050)
Total mortality rate
Total fertility rate
Migration rates (internal and external)
Life expectancy measures (including disability free, disability adjusted and healthy life expectancies)
Households and housing (physical, social, educational and economic characteristics)

Health, mental and functional status
Self-reported health and emotional status
Physical functional status
Disability rates (physical, functional and sensory)
Top ten most prevalent diseases or conditions for population 50+ years
Top ten causes of mortality for population 50+ years
Tobacco, alcohol and illicit drug abuse rates

Care access and service utilisation
Numbers of government-sponsored or private health-care facilities/professionals
Access to government-sponsored or private health-care facilities/professionals
Access to traditional and/or spiritual caregiver/healer/herbalist
Number of older persons providing daily care to adults and children in households

Old people's homes, family and home care
Numbers of old people's homes, home-care services, and/or community-based services
Access to care and support

Health care and social services financing
Total health expenditure (by sector)
Total expenditure on pensions/social welfare (by sector)

[a] Adjusted for age, sex, level of education and household, where appropriate.

Ideally, an indicator is ethical, useful, scientifically robust, representative and accessible. Unfortunately, few indicators meet all these criteria, but an evaluation of indicators which meet the criteria will, nonetheless, lead to a final list of indicators, and will serve to re-evaluate present indicators, or to add new indicators over time. A brief summary of the criteria (as outlined in WHO, 1997) is given below.

- An *ethical* indicator is one that requires data that are ethically collected, processed and presented in terms of individuals' rights.
- A *useful* indicator is one that can effectively measure progress or performance, either as a direct or proxy measure. Useful data are also aggregatable.
- A *scientifically robust* indicator is valid (it actually measures the issue or factor it is supposed to measure), specific (it only measures that issue or factor), sensitive (it reflects changes in the issue or factor being measured) and reliable (it will give the same value if it is re-assessed on the same population at the same time).
- A *representative* indicator must adequately encompass all the issues or population groups it is expected to cover – in this case, the older population.
- An *understandable* indicator is simple to define and interpret.
- An *accessible* indicator is one for which the data required are readily available, or easily obtainable by validated methods.

Workshop outcomes and plans of action

Following discussion during and subsequent to the workshop, a major emphasis of the MDS project will be on research and data analysis projects, as well as on information dissemination activities that have the potential to influence strategic and resource allocation decisions at regional, sub-regional and country levels. While a timely and reliable MDS may be used to inform national policy development and to guide research efforts on ageing in each country, a lack of financial and human resources may threaten the sustainability of the project.

Each country represented in the workshop identified data-related issues and developed plans of action. While methods not specific to Africa may be useful as a guide, it was agreed that indigenous African solutions should be sought with which to address current and future information needs. Several common elements were identified and are described below.

- *Training.* There is a need to provide training on the use and analysis of data to be contained in the MDS, as well as how to communicate the findings from such analyses.
- *Capacity building.* While routine data sources (e.g. the DHS, population censuses, vital registrations) are easily identifiable, non-routine data sources need to be identified and utilised. In addition, specific elements of the MDS will need to be incorporated into existing routine data-collection mechanisms. The recording of micro-level information also needs to be improved.
- *Financing.* Questions were raised about who would meet the cost of developing and maintaining the MDS, as well as any data-collection efforts initiated as part of the project.
- *Data management.* The issue of how data will be warehoused, accessed and updated was discussed. Ultimately, each country's focal group will need to decide on these issues. Several tools are under development to assist country groups in this regard.[4]

Specific data needs and priorities identified by participants from the four countries as well as plans of action developed by each country group are as follows:

Ghana

The Ghanaian participants identified a need for a consolidated and coherent national policy on ageing. They expressed considerable concern about the quality, reliability and coverage of data in their country. They were also concerned that no data are available for certain MDS indicators. The focal group has subsequently met in Ghana and discussed data and indicators for the MDS, as well as the development and piloting of a country-wide ageing survey, and ways to improve birth and death registrations. The country's national data management system is under review at present and may serve as a platform for data management for the MDS project in Ghana.

South Africa

The South African participants noted that their country has a number of high-quality routine data-collection sources that will provide valuable input to the MDS. Some effort to encourage further representation of issues relating to older persons (such as the disaggregation of "over-60" categories into five-year age groups) is needed. Although there have been several nationally representative studies of the older population, they have been once-off studies and not part of a sustained long-term research effort. Routine repetition of such studies was identified as a potential resource for the

MDS but funding will be problematic. It was noted that the MDS has the potential to co-ordinate an historically disjointed research effort in South Africa. In its comparatively data-rich environment, a major contribution of the MDS project will be not so much to guide data collection as to identify strategies for data sharing and harmonisation, as well as to focus on the development of training (including academic courses) and on the effective use of available data to address gerontology and geriatric issues. In terms of data management for the MDS, it was noted that Statistics South Africa (the national statistics office) uses the Supercross data management system.

Tanzania

A key issue for the Tanzanian group will be to establish functional partnerships between inter-sectoral stakeholders. A core group made up of representatives of government, academia, the media and civil society, working within the context of ongoing projects and with key stakeholders, will be needed to facilitate data collection, management and dissemination. The participants were in agreement on common indicators and were supportive of the project in Tanzania being managed by the Bureau of Statistics, with a two-way communication structure whereby stakeholders both provide data to the bureau as well as retrieve data from it. The Bureau of Statistics currently manages the Tanzanian Socio-Economic Database (TSED) and it was proposed that the database could be used as a platform for the data management functions of the MDS. The Ministry of Health is also reviewing WHO's HealthMapper[4] which could be used as a common data platform.

Zimbabwe

The Zimbabwean participants indicated a wish to influence legislation pertaining to the proposed Care of the Elderly Bill which has been "under consideration" since 1994. Because of a broad range of talents and expertise, the inter-sectoral focal group has the potential to shape programmes and policies for older Zimbabweans and to facilitate the MDS project within the country. An immediate priority identified was a need for training to build capacity for data analysis and data management. Improvement of communication infrastructure was also a priority to aid information dissemination. Several meetings have been held by the group subsequent to the project workshop to deliberate on MDS indicators. The Central Statistical Office and the Ministry of Health and Child Welfare currently use the National Health Information and Surveillance System, but with assistance from WHO Headquarters and the WHO Regional Office for Africa, other potential data management systems are being investigated.

Summing up

The MDS project is an opportunity to foster linkages between conducting research and utilising research results, to improve programmes, policies and strategies to benefit older Africans. The results of the workshop indicate a need for increased resources and stakeholder participation across several sectors, as well as co-ordinated research efforts, and the development of methods and tools for collecting, disseminating and analysing data pertaining to the older population. Ultimately, the MDS project has the potential to equip policy makers with an important cornerstone for any decision maker: accurate and up-to-date essential data. Interested parties are invited to contribute to the effort, be it through the contribution of data and study results, methods of analysis, data management tools, funding sources, or dissemination strategies. Ultimately, we should not lose sight of the underlying goal, which is to ensure that the needs of older people in Africa are better met.

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Notes

1. The Ageing and Health Programme has been integrated in the Department of Health Promotion, NCD Prevention and Surveillance, following organisational restructuring in the Noncommunicable Diseases and Mental Health Cluster at WHO Headquarters.

2. "Data harmonisation" is a relatively new concept. It has been obliquely defined to some extent in Colledge (1999), along with the terms "data co-ordination" and "data integration." We draw on these terms rather heavily and for clarity's sake, define our meanings here. *Data co-ordination:* data are co-ordinated when the collection or compilation of similar sources of data are aligned to have the same definition of units, classifications and data items, or definitions. Any deviations or differences are acknowledged and stated. *Data harmonisation:* data are "harmonised" when similar definitions, classifications and units are used for the data. Harmonisation is stronger than co-ordination, since it implies that the data have been made the same, either through changing the collection methods or the application of statistical methods. *Data integration:* data are integrated when data are mutually consistent and related to the greatest extent possible. Data integration includes both "logical" ("conceptual") integration and "physical" integration, "co-ordination" and "harmonisation". Data integration applies to procedures and systems as well as to concepts and definitions (Colledge, 1999).

3. "Data gap" refers to situations where available data are inadequate for that dimension of the MDS within a particular country. A data gap can mean: (i) a total absence of data, such as no information whatsoever on the mortality rates of a country; (ii) a partial absence of data where, for example, some mortality information is available but not at the desired level of disaggregation; or (iii) a full presence of data where, for example, completely disaggregated levels of mortality are available but are of dubious quality. When "filling in" a data gap, one either collects the data directly, or tries to indirectly estimate the data that might have been observed had one had the funds to collect the data. If data that have not been observed are used, it is important that the methods used when filling in the data gap are adjusted so that the uncertainty about the data is not underestimated. Tendencies towards underestimation can be minimised using Bayesian methods, expert elicitation and multiple imputation.

4. HealthMapper, a geographic data management and dissemination system, is under development and (limited) in-country implementation by WHO. Details are available from Ms Kathy O'Neill (oneillk@who.int). The Population Council has a new data collection and dissemination tool; details are available at http://www.popcouncil.org/hrs/hrs.html. The United States Centers for Disease Control and Prevention (CDC) offers Epi Info 2000 and Epi Map at http://www.cdc.gov/epiinfo/. The WHO Regional Office for the Americas (AMRO/PAHO) has multiple links to some appropriate tools at http://www.paho.org/English/SHA/shasig.htm. The US Bureau of the Census uses and offers CSPro 2.0, a public-domain software package for entering, tabulating and mapping census and survey data at http://www.census.gov/ipc/www/cspro/index.html.

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