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Review

The impact of HIV/AIDS on the elderly and proposed strategies to curb the effect

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This paper presents policy issues from a study that was conducted by members of the Uganda National Advocacy team on HIV/AIDS Care from July to December 2012. The aim was to explore HIV/AIDS challenges among older persons and strategies that could be used to curb the effect. Respondents were purposively selected older persons from rural and urban areas of Pallisa, Kamwenge, Luwero and Budaka districts. It was a qualitative study. Data was collected using focus group discussions and in-depth interviews with 40 elderly persons at health center IVs. And an interview schedule was administered to 4 key informants who included health personnel working at these health center IVs. Respondents were selected with the help of community leaders and Village Health teams. Others were accessed through snowballing. Elderly persons provided data on HIV/AIDS-related challenges and proposed strategies that could be used to curb the disease. Key respondents provided data on strategies that could be adopted to curb the effects of the epidemic. Data was analyzed using content analysis and descriptive methods. Results showed that older persons were faced with policy issues regarding HIV/AIDS. They included lack of access to ART treatment due to long distances to the health facilities were ART is available, high costs, stigma and isolation by society, negative attitude of the community and nutrition challenges among others.

Key words: Human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), older persons, challenges, policy strategies, Uganda.

INTRODUCTION

This paper aims at conveying the challenges faced by older persons who are infected and affected by Human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) in Uganda and proposes the possible strategies that could be put in place to curb the situation. The policy issues raised were obtained through a qualitative research that was conducted by members of the Uganda National Advocacy team on HIV/AIDS care, support and treatment in conjunction with Uganda Reach the Aged Association (URAA), a national umbrella organization for older persons. The data was collected from July to December, 2012 from four sites (both rural and urban) that included Luwero, Kamwenge, Budaka and Pallisa districts that represented three regions of the country. Individual in-depth interviews and focus group discussions were conducted with ten purposively selected older people at each of the sites after seeking for their consent. The interviews that lasted for almost two hours were carried out at the health center IVs in these districts. Most of the respondents were selected

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with the help of community leaders and village health teams (VHTs) who brought them to the health centers where the researchers were based while others were accessed through use of the snowballing technique.

Following data collection process, data was analysed using content analysis. The analysis involved reading the written scripts, one by one, and in a repeated manner so as to develop a meaning out of them. There was also repeated listening and re-listening to recorded audiotapes, so as to reflect on the data and also, make notes and memos. This was followed by grouping of the data into themes and then sorting the themes according to broad categories. This was done by combining related themes and renaming them as one theme. The developed thematic categories were then re-categorised. Sub-themes were also developed under each of the major themes. In addition, field notes were used to corroborate the themes and to assist in the interpretation of findings. The themes identified included the different challenges that older persons with HIV/AIDS are facing and the strategies that can be used to curb the situation. The findings are reported as policy issues and proposed strategies in the last two sections of the paper.

The interviews produced very good information that needs to be disseminated to the decision makers for action. This paper therefore has been developed purposely to pass on the findings of this study to the right people who can make use of this information in terms of influencing policy and advocacy.

The paper targets the decision makers, officials from Ministry of Gender, Labour and Social Development that directly deal with issues of older persons in the country, Ministry of Health and NGOs that deal with issues of HIV/AIDS such as The AIDS support organisation (TASO), AIDS Care, Mildmay Uganda, Uganda network of AIDS service organisations (UNASO), United Nations Program on HIV/AIDS (UNAIDS), among others. There is need for these organizations to work together and embrace the challenges that are affecting the quality of life of the older persons using the guidance of the proposed policy strategies. However if these challenges are not addressed, the older persons will continue living in deprivation for a greater part of their life time as they age chronologically, which deters them from fending for themselves.

BACKGROUND

Although various interventions have been made by governments to curb its effects, AIDS still remains one of the major challenges of the 21st century. More than 33 million adults and children are still living with AIDS worldwide, of which 22 million can be found in sub-Saharan Africa. During 2009 alone, an estimated 1.3 million adults and children died as a result of AIDS in sub-Saharan Africa (UNAIDS, 2010). And since the beginning of the epidemic, more than 15 million Africans have died from AIDS. This is not a small number that can be ignored. At the present, although access to antiretroviral treatment has started to lessen the toll of AIDS, fewer than half of Africans who need treatment are receiving it (UNAIDS, 2010). In addition, the number of children orphaned by AIDS alone increased drastically from 11.5 million in 2001 to 15 million in 2003; and it is estimated to have reached 24 million in 2010 (UNAIDS, 2010).

However, at one point in time, the HIV prevalence rate in Uganda was seen to dramatically decline. It was estimated at about 18% in the mid and late 1980s, and now the HIV/AIDS prevalence rate currently stands at 6.4% (URAA, 2010). This striking reduction in Uganda was accredited to the open policy on HIV/AIDS and a strong political will to combat the pandemic at that time. However, though the number of people infected with HIV/AIDS in Uganda declined, the impact of AIDS will remain severe for many years to come. Older people have not been spared from the epidemic that has been gripping the continent too (Abrahams and Pia, 2002). Yet in most communities worldwide, older people have not been the major focus of attention largely because of the widely held belief that they do not have much to offer since they have already played their part and have outlived their usefulness in society (Knodel, 2008).

The impact of AIDS, especially in resource constrained settings results in a great deal of physical and psychological suffering (Baden and Wach, 1998). The high levels of morbidity and mortality associated with AIDS is likely to have long-term implications for development. Similar findings have been noted by Knodel (2008) who outlined potential pathways through which HIV/AIDS affects older persons in Thailand and Cambodia. These included emotional distress due to loss of children who are infected by the disease, difficulties in providing material support during illness, increase in care giving activities that requires greater time and effort which eventually impacts even their involvement in income generating activities, adverse community reactions which lead to psychological trauma, stigma and financial stress due to increased expenditure on funeral costs after death. Other impacts included loss of the child's support to the household, high costs of orphan care and loss of future support in old age (Knodel, 2008). This study found comparable challenges impacting older people in most parts of Uganda (Kawuma et al., 2012).

In many countries, the epidemic has killed middle-aged adults and shifted the burden of childrearing onto older people; and this burden is growing as the number of children orphaned by the epidemic continues to increase (Ainsworth and Dayton, 2000; Knodel et al., 2001). Thus,

older people are now playing a key, though arduous role of bringing up children - the world's future capital. Older people also find themselves providing physical, economic, and social support to their sick children; hence having less time to engage in income generating opportunities so as to sustain their livelihoods (Tavengwa-Nhongo, 2004). The epidemic has indirectly changed the role of older people, particularly women who in Africa are less likely to have a regular income. Indeed, Help Age International (2008a, b) highlights the gender division in caregiving activities, with 80 percent of older female caregivers and only 20 percent older male caregivers. This depicts a picture of how to a great extent AIDS has impacted on the older women than the men.

Despite the existence of a great deal of scholarly work on HIV/AIDS in Uganda, there has not been much emphasis on how the epidemic has affected older people in Uganda, which indeed affected planning for them. This is partly because most of the data focuses on the age group 15 to 49 years and it is only recently that additional information on the slightly older age group of 50 to 59 years was included in the data collection tools in the country (Kiiza-Wamala, 2008) but still the analysis of the findings was not done because the current report on HIV/AIDS in the country does not report on older persons (UNAIDS, 2010). Thus, the older age groups have been excluded possibly due to the assumption that AIDS affects only young people. This assumption is however deceptive since there is evidence that the epidemic has affected other members of society, including older people (Knodel 2008). Older people have fallen victims to the disease by being infected and at the same time affected by the disease through caring for the sick children (Best, 2002; Fouad, undated). Many of them have lost economic hope as a result of losing their adult children to HIV/AIDS. Consequently the plague has weakened the traditional social security system based on families and kinship ties. Actually, older people who loss children in their early stages of life are likely to suffer during old age as there will be lack of various forms of support that they need at that time.

Regarding human rights, the HIV/AIDS-related Human Rights include the right to freely receive information, social security, and welfare assistance, but older people are unable to realize these rights because they have been excluded from most of the HIV/AIDS programmes (Knodel, 2009; Help Age International, 2005; Kyomuhendo, 2003). While promotion and protection of such human rights would have reduced older people's vulnerability to HIV infection, trifling efforts have been spent on ensuring that this happens. Consequently, older people have remained trivially empowered to respond to the epidemic (Kyomuhendo, 2003). Most of the ongoing HIV/AIDS awareness campaigns, treatment programmes, and researches in the world over do not target older people (Population Reference Bureau, 2007). Consequently, they end up catching the disease out of ignorance (Mugenyi and Kanyamurwa, 2004). They also take long to know that they are really suffering from the epidemic because of their tendency to largely believe in and use traditional healing methods (Mukasa-Monico et al., 2001).

In 2001, the United Nations Declaration on HIV/AIDS recognized the role played by older people and committed itself to adjusting and adopting economic and social development policies that address the special needs of these people (United Nations, 2001). Unfortunately, very few and moreover ineffective national policies have been put in place (Help Age International, 2005). In Uganda, despite considering HIV/AIDS as a developmental issue in the country's 2025 Vision and Poverty Eradication Action Plan (PEAP) (Asingwire and Kyomuhendo, 2003), older people infected and affected by the epidemic have not been included in most of the development programmes. There are no welfare programmes targeting these people; and no special healthcare programmes for them as there are for children and maternal health (Alun, 2003). There are only a few NGOs like URAA, ROTOM and a few others that are trying to focus on the elderly. Yet, these NGOs are also financially constrained hence they end up targeting only a handful of older people while the majority remain with no rescuer. Likewise, the current government social protection plan (SAGE) that is at pilot stage now is also targeting very few older persons in a few districts (only fourteen) and this is likely to take several years before the actual policy on social protection is developed and implemented hence those who are not receiving the 23000/= UG Shs (the amount of money received by poor people (older people inclusive) through a five year pilot project SAGE (social protection Grant) that is run by Ministry of Gender Labour and Social Development. The amount is 24000 shs but the 1000 is for bank charges so they will receive 23000 shs per months for five years) from this pilot project will remain yearning for some long period of time as they wait for the government plans to move on.

The Uganda's National HIV/AIDS Policy also highlights older people as one of the groups that should be provided with HIV/AIDS voluntary counselling and testing (VCT) services. However, this policy addresses older people on paper because there is nothing much to show on ground (Help Age International, 2006). Most of the VCT services target youths and adults. There are no identified elderly-people-friendly VCT services provided in the country except for one district(Mukono)which out of the initiatives of their leaders, came up as a model district that recognizes older people seeking health care services by providing them with cards which make them receive services as soon as they reach hospital facilities within the district. They are also given a special day in a week to attend to their specific health issues. However, this

model has not yet spread to the other districts yet it is a good practice to learn from.

Uganda's Policy on Antiretroviral Therapy and National Health Policy have not helped matters either. A review of these policies reveals that none of them gives older people living with HIV/AIDS the attention they deserve. While the policy on antiretroviral therapy gives guidelines to the administration of this therapy and it seeks to promote the provision of information regarding ARVs at community and facility levels, it is silent on older people and no reviews have been done to address this gap. Similarly, the various health services highlighted by the National Health Policy, including immunisation, vaccination, medical treatment, antenatal services, and adolescence services, are largely not for older people (Ministry of Health, 2005, 2006). This scenario is dangerous to this group of people. It was cited as one of the major causes of HIV/AIDS deaths among elderly females in Zimbabwe (WHO, 2002; Mutangadura, 2001).

It has also been noted that less priority is given to older people affected and infected by HIV/AIDS in terms of budget allocations both at national and district levels despite there being a policy for older persons (Kawogo, 2008; Government of Tanzania, 2000). Hence they are disadvantaged when it comes to national budgetary priorities. The exclusion of HIV/AIDS infected or affected older people from many of HIV/AIDS welfare programmes not only renders these people more vulnerable to the epidemic but also casts doubt as to whether the programmes have effectively achieved their purposes in the context of the Millennium Development Goal of eradicating HIV. In fact, studies on the impact of HIV/AIDS indicate that nothing much has been done to include older people in HIV prevention and treatment programmes (Hardon, 2005; Bekunda et al., 2004; Alun, 2003; Alun and Tumwekwase, 2001).

The foregoing observations suggest that little is known about the plight of Uganda's older people infected or affected by HIV/AIDS. These issues need to be brought to light so that decision makers can use this information in decision making. Some of the researched issues affecting the older persons are highlighted in the next section:

Policy Issues that came out of the qualitative study

Access to ART

Evidence gathered clearly shows that some older persons especially from the rural areas are still having challenges in accessing ART from health centers. This is as a result of long distances from their home residences to the health centers where they are supposed to get the drugs from and also the high costs involved in transport. On the other hand, witchcraft and religion hinders access to treatment; some of the older persons still believe so much in witchcraft to the extent that even when they are suffering from HIV, they may think they are being bewitched and this leads to delayed diagnosis. In addition, there are community and older persons' misconceptions about HIV acquisition. Some community have a misconception that older persons do not have to have sex and some of the older persons also feel that they are above the HIV acquisition age. These misconceptions make the HIV positive older persons afraid or ignore looking for care, hence leading to late diagnosis.

Stigma and isolation by society towards older persons with HIV

There is both self and community related stigma towards HIV positive older persons.

Neglect: In some families children and grand children neglect older persons and don't take care of them, they would rather want to have the property from the older persons that they don't care about

Negative attitude: To the very old, there is a negative attitude from everybody including the nation, health workers, relatives, community and family members regarding helping older persons. In some situations family members are willing to assist but when the resources are not available, they will not prioritize the older persons.

Nutrition: Older people face nutrition challenges, yet the ART drugs themselves require eating a balanced diet which they cannot afford. Hence those who are on ART face adverse side effects of the drugs as a result of not eating frequently and not having a balanced diet.

Poverty: Majority of older persons are poor. Poverty hinders good nutrition and access to essential needs. They also lack school fees for the children under their care which bars these children from attending school and accessing other social services. The women seem to be more hit by poverty than the men.

Loneliness: They suffer loneliness due to separation or loss of spouse and this affects mostly the ladies because the men normally get the opportunity to remarry.

Drug reaction: Some of the older persons who are using Septrin react to it yet some health centers lack drugs like dapson which could be used as an alternative and they are told to buy yet they cannot afford the costs involved.

Long waiting hours at health facilities: Older persons are still facing challenges of long waiting hours at health facilities which depress them. This is because some health workers don't mind about the older persons during

triage, they are not identified to be served first considering their physical body weakness.

Distance to the health facilities: Is still a challenge to many of the older persons as many of them stay more than five kilometers away from a health facility.

Multiple diseases: Many of the older persons who are infected with HIV have got other diseases that come with old age such as non communicable diseases (NCDs) hypertension, diabetes, arthritis, cancers among others. But when they come for ART treatment the other opportunistic diseases and conditions are not taken into consideration. Hence, a need for a holistic approach in their management.

The pill burden to the older persons: ART drugs cause side effects such as nausea and body pains among others, yet the older persons have other non communicable diseases that come with old age, for which they are taking medication leading to poly pharmacy. No one knows yet the effects of multiple drug interactions due to multiple drug intakes in older people because no study has yet been carried out regarding this challenging topic. This needs to be taken into consideration by pharmaceuticals so that these people could be helped from this burden.

ART prescription and drug adherence challenges: The health workers confessed to be facing challenges in prescribing ART to older persons due to their varying weight and lack of knowledge in geriatrics. There are no geriatricians in Uganda who are specialized in treating older persons. This still leaves a gap in the medical management of older persons in the country. On the other hand, prescription guidelines are not weight related. The current existing guidelines are for pediatric and adults in general, there are no specific guidelines for older persons yet they have different physiological changes including weight loss, increased fat deposition, bone density, reduced lean mass, cardiovascular changes and other changes due to NCDs, hence the need for their specific treatment guidelines.

Adherence: Some older persons fail to turn up on appointment for treatment due to lack of transport and sometimes due to ill health; this affects their adherence to drugs. Some forget to take the drugs on time while others have side effects that hamper them from adhering to drugs and some do not have people who could take care of them.

HIV prevention messages

The current available messages are not age friendly because they predominantly target the youth and are put at health facilities. Access to the messages is not available it is only those who come to the health facilities and are able to read who may access the messages. But even the health facility is not the best place to have prevention messages because when the older people come they are sick and are only thinking about treatment and yet only a few can read and understand these messages. Conversely, health promotion/education programs for prevention are meagerly funded and the budget is only 10% of the total budget. This is not adequate to enable dissemination of messages to the rural community level and yet this is where majority of older persons are located. Messages targeting the older persons should be conveyed in their local languages so that the older persons can understand them well. On the other hand, the older persons are not asking for condoms which could help prevent cross infection during sex activities. Currently majority of the distributors of condoms are young people, this hinders older persons from asking for condoms from the young as it creates stigma. So there is need to involve them in the distribution of condom program. Probably the use of elderly VHTs would help to address this problem.

Disclosure status of HIV positive older persons in the care at the health facilities

Majority of the older persons either have nobody to disclose to or are shy to disclose due to fear of stigma while some are in denial, they have challenges with whom to disclose to and there is no right person. Those who are married do not go for treatment as couples yet they fear telling each other. Some fear the negative reaction that could possibly occur as a result of disclosure. In some scenarios, in an interview with some of the older persons, some older persons were abandoned, a typical example for instance is a lady in Pallisa district who reported being abandoned by her husband for 2 years when she disclosed her status to him and this translated into denial of support from him. Sometimes fear of disclosure affects adherence to medication for some of the older persons who have never disclosed to their spouses or others may fail to start the treatment at all because of fear to be identified as sick.

Proposed policy strategies

Specific guidelines for ART treatment for older persons should be developed to help the health workers in prescribing drugs to older persons at the health facilities. Geriatric training should be included in the existing health training institutions in order to avail geriatric knowledge to health workers. This will enable them to handle and adequately treat older people in health facilities. Many of older persons are sick and unable to access health

facilities due to long distance from the health facilities or costs involved; thus the need for them to be included in home based care services even with ART is critical. Messages on access to ART treatment should be aired on radio in local languages to increase access and the written preventive and treatment messages should also target older persons in order for them to understand the messages. The messages should be delivered in various forms that are old-age friendly. Condom access program should be redesigned to include older persons so as to improve access to condom use by older persons.

Specific health needs of older persons should be included in the existing health promotion programs to involve older persons in the medicine distributors program so that they can distribute drugs and condoms to older persons. This might help in improving access to condoms and drugs. There is need for research to be carried out by the pharmaceutical companies regarding drug interactions which could result from poly pharmacy and also think of reducing the pill burden for the older people who are taking so many drugs several times a day.

Increased sensitization on the relevance of HIV disclosure should be emphasized to encourage older people to disclose so that they can start on the treatment as early as possible.

Nutrition education and services should be incorporated in the ART clinics as many of the older persons who are infected with HIV/AIDS are also facing nutritional challenges.

Since older persons have been highly hit by poverty, there is a dire need for income generating activities for those who are able to do so in order to improve on their quality of life while those that are unable to carry out such activities could be given handouts and social protection. Orphans and vulnerable children programs should take care of children under the care of older persons so that these children can be supported adequately. Legal protection should be given to older persons whose relatives want to grab land and other assets from the older persons. There is also a dire need to revitalize the family social support as this is the main support system to older persons.

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