Chapter 21
Caring for the Elderly with Dementia in Africa

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Abstract Most of Africa's population is young. However, the fastest growing portion of Africa's population is that of those aged 60 years and above. Africa's older people suffer two common neuropsychiatric disorders namely Dementia and Depression in addition to numerous physical ailments. In the past, Africa's elderly were treated with much reverence and respect; and Africa's extended family system ensured their welfare whereby strong family bonds held together generations of the old, the matured, the youths and the children for the benefit of all. Today Africa is undergoing rapid demographic and socio-economic changes due to money economies, globalization, the migration of the young in search of jobs (brain drain, rural to urban migration etc.), and the HIV/AIDS epidemic. Growing old, in Africa today, translates into poverty, penury and anguish. There is no official social security system and pension schemes for the few are erratic. This, therefore, leaves the burden of care of the elderly, especially those with dementia, to the family/relatives with the actual caretakers being mostly women, often daughters or younger wives. These are the ones who carry the burden of care for the majority of the old and demented in Africa, a situation which has become increasingly unsustainable. The practice of putting the elderly away in nursing homes or homes for the aged is alien and repugnant to most African cultures and ways of life. There is thus a need to revisit the traditional African family support system and modify it to suite the modern changed lifestyles and realities of today's Africans and yet be in tune with the age-old African family system of caring for their old. The practical solution, for every African family with ageing frail parents, or grandparents, is to have a "granny apartment" and continue to care for their elderly including those with dementia and other infirmities. This way the African elderly will continue to live with their families in dignity till death and avoid the misery that, otherwise, awaits them in old age.

Keywords Old age • Dementia • Misery • Family • Burden of care • Granny apartment • Africa

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Aging in Sub-Saharan Africa

The elderly, also called Senior Citizens, have been variously defined in different countries, cultures and communities. Most western countries with long life expectancies consider a cut off of 65 years of age which denotes the retirement age in these countries as also being considered the age to be considered elderly. In developing countries, such as Uganda, most of the population is young and life expectancy is low. In Uganda, for example over 50 % of the population is below 15 years of age and life expectancy is, on the average, 51 years [1]. Thus, in developing countries the cut off age to be considered elderly is 60 years. Indeed, the WHO defines being elderly as either 60 or 65 years for a developing or developed country respectively. In this paper the elderly will be defined as 60 years and above.

Worldwide the population of the elderly is increasing at alarming rates [2]. This includes developing countries such as are found in Sub Saharan Africa including Uganda [3, 4]. For long, the emphasis on the demographic and health characteristics in sub-Saharan Africa has been on the high rates of fertility and on mortality from infectious diseases such as Malaria, Tuberculosis and HIV/AIDS and less on non-communicable diseases (NCDs) [3, 4], but this changing as the population of those over 60 years in increasing. The elderly suffer a proportionately higher burden of the NCDs be them physical or mental as well as a host of psychosocial problems. This, combined with the frailty of the elderly, their poor economic status, social isolation and deteriorating physical and mental health necessitates a need to care for them. This is a universal problem of increasing research interest. However, in Africa, there is very little in terms of research activities and data regarding old age especially in Sub Saharan African countries including Uganda. Yet whereas the ageing process in the developed world happened over a long period of time, that in Sub Saharan Africa, Uganda inclusive, is happening in a matter of a few decades [3, 4]. The attendant diseases of old age are therefore hardly addressed in Sub Saharan Africa. This includes the age-related brain degenerations, such as Dementia [3, 4].

Caring for the Elderly in Africa

Worldwide, people are living longer than ever before, a trend which has been taking place over many decades in developed countries but a relatively new phenomenon in developing countries but who have the largest numbers of people in the world. It is estimated that nearly 63 % of the population aged 60 and over are living in developing countries, and it is further projected that by 2050 nearly 1.5 billion older people will reside in developing countries [2]. These figures include Africa. This puts a huge demand on all systems of care and social services on the communities and governments of developing countries to care for their elderly folk [5]. In Uganda, the projected population of older persons today (2014) is estimated to be

Table 21.1 Population of persons ≥ 60 years in selected African countries, 2000–2025[a]

Country	Year 2000 population ≥60 years in thousands	Year 2025 population ≥60 years in thousands	% increase over 5 years in people ≥60 years	% increase of general population
Algeria	1,838	4,852	260	**140**
Kenya	1,260	2,166	170	**120**
Nigeria	5,599	10,944	200	**170**
CAR	180	261	150	**130**
South Africa	3,006	4,875	160	**80**

[a]Source: US Bureau of the Census International Database

1,540,000, indicating an overall growth rate of 40 % of people 60 years and above in a period of 10 years [1]. Today, the elderly constitute over 3.2 % of Uganda's population [6]. Such demographic shifts call for new research and legislative provisions to address this concern. Table 21.1 illustrates the demographic changes seen in some selected African countries regarding people aged 60 years and above [7].

In Africa, older people typically constitute the poorest groups of society. For example in Uganda according to the 'Uganda Reach The Aged Association', over 64 % of the older persons survived on less than one Dollar ($1) a day [19]. They did not have access to regular income and the majority did not benefit from social security provisions. The vast majority lived in rural areas where over 85 % of the active ones were engaged peasant subsistent farming. Many depended on one meal a day; others survived on one meal in two or more days, a situation that affected their health negatively [4, 8]. Various studies have found the elderly to often have many untreated health problems such as hypertension, stroke, diabetes, heart diseases, eye problems (trachoma and blindness), which diseases often lead to complications and permanent incapacitation [10]. Some of the most common mental health issues and concerns were depression, dementia, various psychoses, delirium and substance abuse (www.Agingcare.com). In Uganda, studies conducted at Mulago National Referral Hospital in Kampala reported similar findings with a reported 48 % prevalence of psychiatric morbidity among the elderly patients admitted on the non-psychiatric wards [12]. Depression and dementia were the most common mental health problems with a prevalence of 13 % and 8 % respectively [12].

Psychiatric services are poorly distributed in Africa, concentrating in urban areas and leaving many rural communities with no services [1]. Such services for the elderly are even more scarce. The vulnerability of the elderly in Uganda has increased especially over the last 30 years with elderly women bearing the brunt of it [1]. It is compounded by triad of "a culture which denies inheritance rights to women, the burden of HIV/AIDS orphans under their care and the absence of government run Social Security provision". Thus to be elderly and mentally ill in Africa, e.g. with dementia, is to live a life of misery, suffering and penury [1].

Traditionally, Africa had had established social networks that protected the elderly. These systems ensured strong bonds within the extended African family system consisting of multiple generations of the old, the grownups, the youths and the children [3]. These relationships provided for the needs of the old. The elderly were regarded with the utmost of respect as they were seen as the repository of knowledge and wisdom. However socio-demographic changes in Sub Saharan Africa have caused the elderly to be neglected resulting in much misery and penury with no economic security, no health care and no social supports [1]. The main causes of this problem has been the changed economic system (to a cash economy), massive rural-to-urban migration, the brain drain, relentless wars, political instability, the HIV/AIDS epidemic and the failure of Sub Saharan African governments to put in place and implement programs that address the needs, concerns and care of older persons [1]. This has thus left the burden of care for the elderly to relatives. With the African extended family system rapidly disintegrating, the demented elderly in Africa have suffered the most with these changed circumstances as they have become a burden to everyone. The HIV/AIDS epidemic has added more insult to injury by leaving the elderly to look after the many AIDS orphans whose parents have died [1]. There is also now a new sub-epidemic of the elderly HIV-positive individuals with significant HIV-associated neuro-cognitive disorders (HAND) which complicates the clinical picture and care of dementia in the African elderly [15]. Thus in summary, today the elderly in Africa are no longer playing the important role in society they used to. They are not acknowledged and the prevailing negative attitude towards them causes them much suffering, poor health, depressive disorders and somatic illnesses. The elderly are often segregated and marginalized leading to loneliness, loss of self-esteem and economic deprivation [3, 5–9, 11]. They are often abuse, exploited or their property stolen. Older women have even been abused sexually and physically, the latter following allegations of witchcraft practice and sorcery. A number of older persons have lost their lives, property or have been maimed in such circumstances [11].

Dementia in Africa

Dementia is defined as progressive global cognitive impairment, principally presenting as increasing forgetfulness and the problems which ensue hence from. The problem of dementia in Africa is increasing, especially with the increasing population of older people, the relentless HIV/AIDS epidemic which is now in its fourth decade and the increasing numbers of man-made accidents [1]. There are thus various causes of dementia in Sub-Saharan Africa. These include trauma, infections (especially HIV/AIDS), substance abuse (alcohol), CNS neoplasm, cardiovascular disease but most importantly for the old, the age-related brain degenerations. It is this last factor, the care for those suffering from the dementias of old age in Sub Saharan Africa, that this chapter will focus its concentration.

Gerontological Studies in Africa: The Case of Uganda

Studies addressing the elderly in Sub Saharan Africa are few and scattered, especially those addressing care burden. Najjumba-Mulindwa (2003) found that the elderly sick in Uganda lacked social support and care, always had feelings of negativity, frustration and powerlessness, were poor and often went hungry [11]. In a study of the elderly hospitalized on general hospital wards, Nakasujja et al. (2007 found a prevalence of depression at 13 % and dementia at 8 % [12]. The factors associated with the elderly's psychological distress were poverty, lack of social support and female gender [12].

Musisi et al. [16] in a Ugandan study of the elderly accessing psychiatric care at Mulago National Referral Hospital found the most common disorders to be Dementia at 46 % and Depression at 30 %. These were followed by alcoholism, bipolar disorder, anxiety disorder and psychotic disorder, with each being at about 6 % on average. Of these elderly psychiatric patients, the Male:Female ratio was 2:3, again showing that there were more elderly women than men. Their age range was 60–96 years (Mean = 74.1) with about half of them (49.1 %) being married. Of the married, the majority were men (77 %). Of the rest who were not married, the majority were widowed (40 %) with the biggest majority of this group being women (85 %). These figures suggested that among the elderly in Uganda, men remained married or remarried after losing their spouses but the elderly women remained unattached hence calling for care from others, mainly family. Only 6 % of the elderly were either divorced or separated and only 2 % were never married and these were Catholic nuns who lived in institutional care at their denominational mission stations. Thus in terms of care of these elderly, the majority of whom suffered either dementia or depression, the burden of care fell to the family with only 2 % being in institutional care. The question then was "Who, among the family members, actually looked after the elderly?" Table 21.2 shows the sources of care and support for the elderly psychiatric patients in Musisi's study [16].

As Table 21.2 shows, in that study, Musisi et al. (2008) found that the majority of the elderly, (58.9 %), were being looked after by their children especially daughters (32.3 %) who looked mostly after their ageing widowed mothers in about half

Table 21.2 Sources of care for elderly psychiatric patients

	Males (N = 22)	Females (N = 31)	Total (N = 53)
Source of support[a]	n (%)	n (%)	n (%)
Daughter	2 (9)	15 (48)	17 (32.3)
Son	6 (27)	8 (25.6)	14 (26.6)
Spouse	8 (36)	3 (9.6)	11 (20.9)
Self	4 (18)	4 (12.8)	8 (15.2)
Grandchildren	2 (9)	1 (3.2)	3 (5.7)
Others	1 (4.5)	1 (3.2)	2 (3.8)

[a]Some of the elderly had more than one source of support/care

(48 %) of the cases [16]. The sons looked after their ageing parents in 26.6 % of the cases and they did this in almost equal numbers (25.6 % mothers and 27 % fathers). Spouses looked after the elderly in 20.9 % of the times but this was mainly (younger) wives looking after their (elderly) husbands (36 %), meaning that men tended to remarry in old age but the widowed or separated/divorced elderly women remained unattached. About 15 % of these elderly looked after themselves with no one else to help and 6 % were found to be in extreme states of neglect with dementia, malnutrition and in very poor states of clothing, self-care and household environment. For these, only the neighbors paid cursory calls to them once in a while to give them food, water or do some house chores like laundry. The following case report illustrates this point.

Case Report I: Elderly Man with Dementia in Poor State of Care

GM was a 92 year old widowed elderly gentleman who lived alone in a rural area in his tin-roofed house with no piped water and no electricity (Fig. 21.1). He was a Retired Civil Servant. He had married two wives and had had 12 children. His first wife died of natural causes as a young elderly. He then lived with his second wife after retirement from the government job but she also died later on leaving him as a widowed elderly. He decided to live alone trusting his pension income and he would till the land for food. He had lost four of his children to HIV/AIDS and he helped look after some of the orphaned grandchildren. Three of his living children lived abroad in Europe and only rarely visited him when on vacations and only for a short time.

Fig. 21.1 Elderly and widowed GM with dementia in rural Uganda

The rest of his children were also grown up and lived in the city and only occasionally visited him in the countryside. His grand children had also grown up and had moved to the city looking for jobs. Most were unemployed and offered no help to GM.

GM did well for about 10 years after retirement at age 60. Then, he was still strong and healthy. Later on, his health began failing, beginning with his vision and he became functionally blind. He developed hypertension and often went into heart failure. He could no longer go to the city for his pension payments because it was too far and it became too expensive. His physical health waned and he could not till the land as strongly as before. His food production fell and he often went hungry. His memory then began failing and later developed frank dementia. He lost weight, developed malnutrition and anemia. He became quite frail and had no one to help him. Only the neighbors would pay courtesy calls to his house to give him food, water and do some of his laundry. Some delinquent youths on the village began stealing his farm foods and even items from his house. Some of his far stretched land was usurped by encroachers. There was no one to help. He fell into extreme poverty and neglect till some two grandchildren organized themselves on a rotating basis to visit him biweekly. Even then, this was not enough. GM needed continuous help on a daily basis.

HIV/AIDS, Dementia, and the Elderly

The Availability of Highly Active Anti-retroviral Therapy (HAART) has improved the lives of many people living with HIV/AIDS, thus enabling them to live longer lives. Moreover with the HIV/AIDS epidemic now in its fourth decade in Africa, many individuals infected with HIV in middle age are now of old age. These elderly living with HIV/AIDS are more likely to be vulnerable to the multiple social, psychological and physical problems associated with HV/AIDS including HIV-associated neuro-cognitive disorders or HAND with HIV-Associated Dementia (HAD) being the most problematic [18]. In a study of HIV immune-suppressed individuals at risk of cognitive impairment in Kampala, Uganda, Sacktor et al. (2009) reported that, in untreated HIV-infected individuals with advanced immune-suppression, HIV-associated dementia (HAD) was more common among patients infected with the subtype Clade D virus than among those infected with subtype Clade A virus [15]. These findings provided the first ever evidence demonstrating that HIV subtypes may have a pathogenetic factor in their capacity to cause cognitive impairment. With subtype Clade D being more common in Africa, this finding added further evidence of the risk of dementia neuro-pathogenesis among HIV-positive individuals in Africa, especially those who had had the infection for longer periods or in the more severely immune-suppressed as is likely to be the case in the elderly HIV-positives.

As regards to the care of the HIV Associated Dementia patients, Musisi et al. (2009) investigated the socio-demographics, clinical profiles and social supports of

Table 21.3 Socio-demographic characteristics of elderly HIV- positive patients in care, Kampala

Characteristic	Number (N=118)	Percentage (%)
Sex		
Female	48	40.7
Male	70	59.3
Age (years)		
60–69	103	87
70–79	9	8
≥80	6	5
Marital status		
Married	44	37.3
Widowed	39	33.1
Separated/Divorced	10	8.5
Never Married	25	21.2
Occupation		
Employed/pension	23	19.5
Peasant Farmer	14	11.9
Self employment	22	18.6
Unemployed	59	48.9

HIV-positive elderly individuals in Uganda as seen at a specialized HIV care Centre in Kampala, Uganda using retrospective chart abstractions. Table 21.3 summarizes their demographic characteristics [17].

Among these elderly HIV-positives, the Male:Female ratio was 3:2 with 87 % being young elderly aged 60–69 years, 8 % were aged 70–79 years and 5 % 80 years and above. Over 37 % were married, 33 % widowed and 30 % unattached. About half of them (48.9 %) were unemployed and had no income with almost 30 % engaging subsistence self employment or peasant farming and only 20 with employment or pensions. Thus almost 80 % of the elderly HIV positives had no reliable source of income. Table 21.4 summaries their source of support.

Over a third (33.3 %) of these elderly HIV-positives said they were self-reliant and needed no support. However some 46 % felt they needed support but didn't get any. These latter lived in very poor conditions and were in most cases unattached as regards to their marital status (i.e. widowed, never married, divorced/separated). Family/relatives provided care/support in only about 20 % of cases and non-relative friends in 3.5 % of cases. Only 15 % of these elderly HIV-positives felt they had good enough support. None of the respondents were in institutional care.

In summary most of the elderly HIV-positives, who in most cases had HIV-associated neuro-cognitive disorders (HAND) including HIV-associated dementia (HAD) did not have care. They, in most cases, had to rely on themselves. Often they missed their appointments for follow up HIV care. A few lucky ones had a family member, usually their child, who looked after them. There was much secrecy regarding their illness of HIV/AIDS. The following case report illustrates these points.

Table 21.4 Sources of support and care of HIV-positive elderly with psychiatric illness

Support[a]	Number (N = 118)	Percentage (%)
Provided by		
Self-reliant	36	33.3
Family	19	17.7
Friends (non-relatives)	4	3.5
No support	49	46
Perceived quality of support		
Good	16	15
Fair	28	25
Poor	15	14
No support	49	46

[a]Some respondents had more than one source of support/care

Case Report II: Elderly Woman with HIV-Dementia Being Looked After by Her Children

WG was a 74 year old widowed HIV-positive lady. Her husband had died 15 years earlier from a long illness which the family, when in public, claimed to be cancer but which no one talked about. The family had lived in a war area and WG had been raped by soldiers, but this was kept as a family secret. Many years later, GW contracted Pulmonary Tuberculosis (PTB) which was successfully treated. Because of the doctor's suspicion, an HIV test was done and found to be positive. This was 10 years ago. WG was reluctant to tell her children of this diagnosis. It is when she lost a lot of weight as well as her hearing that she confided in her oldest daughter who worked in a hospital. She was then started on Anti-retroviral drugs (ARVs) which she took religiously. For over 5 years, WG developed progressive forgetfulness and would even lose her way home. She forgot where she had placed items including money, forgot her children's names and had been unable to take care of her Activities of Daily Living, ADLs. She also developed a seizure disorder. Her children were all grown up and busy with their families and jobs. WG had no one to look after her and she often missed her doctor's appointments and would forget to take her medications. On a psychiatric consultation, a diagnosis of HIV-Associated Neuro-cognitive Disorder (HAND) was made, more specifically HIV –Associated Dementia (HAD). The E.N.T consultant felt she had also developed central (nerve) hearing loss from the HIV involvement of the eighth cranial nerve given the virus's neurotropic propensity. Her seizure disorder was also part of her HAND.

Discussions regarding her care were held with her son and two daughters. Her son decided to convert two rooms of his "Servants Quarters" into a self contained "In-Law Apartment". He then moved his mother to permanently stay with his family who would look after all her needs including feeding, ADLs and taking her to hospital to attend for her HIV/AIDs care. GW is doing well, being looked after by her son and his family.

Conclusion

Africa is changing and changing very fast. Africa's population is young. However, the fastest growing portion of Africa's population is that of those aged 60 years and above. Studies in Africa's older people have shown them to suffer two common neuropsychiatric disorders namely Dementia and Depression [11–14, 16]. In the past, Africa's elderly were treated with much reverence and respect and considered the repository of wisdom; and Africa's extended family system ensured their welfare. Africans had established social networks that protected the aged, enhanced family support in situations of difficulty and provided strong bonds within the extended family system whereby generations of the old, the matured, the youths and the children all benefited [3, 4, 8, 11]. With the rapid demographic and socio-economic changes taking place in Africa today, the changed relations in a cash economy, globalization and the migration of Africa's young in search of jobs abroad (brain drain) or in cities (rural to urban migration), and the HIV/AIDS epidemic have all made it difficult for families to continue looking after their elderly as was the case before. Growing old, and especially very old, in Africa today translates into poverty, penury and anguish. Pension schemes are poorly administered and often not sufficiently indexed to inflation or cost of living. Indeed one soon learns not to trust in a pension. Moreover a number of government systems are run by corrupt officials who often make it difficult to receive one's pension money until a bribe is paid. There is no official social security. With the exception of religious missionary stations (usually Catholic missions), there is virtually no institutionalized care for the aged in most of Sub-Saharan Africa such as nursing homes or homes for the aged. This, therefore, lives the burden of care of the elderly, especially those with dementia, to the family/relatives. As well illustrated by the Ugandan studies, the actual caretakers in the families are usually women, often daughters or younger wives. These are the ones who carry the burden of care for the majority of the old and demented in Africa.

With the old African extended family system increasingly disappearing and in the absence of official social security, today's aged in Africa face a dilemma of existence. The question then of what should be done becomes imperative. The practical idea of putting the elderly away in nursing homes or homes for the aged is alien and repugnant to most African cultures, thinking and ways of life. Yet current governments in Africa do not have adequate pension programs, social security or health insurance to cater for the aged. There is thus a need to revisit the traditional African family support system and modify it to suite the modern changed lifestyles and realities of today's Africans and yet be in tune with the age old African family system of caring for their old. This new approach should be driven by the African belief that the aged are an important part of the family and community who play a very functional and valuable role in society. This is the traditional belief of Africans which should be cherished and enhanced to care for the aged and especially those with dementia in Africa. In this vein, I conclude by recommending that for every African household with ageing parents/grandparents, building "granny apartments" will help not only in the care of the elderly with dementia and other infirmities but also ensure family continuity. This is in addition to lobbying governments to estab-

lish community based support programs formulated by government policies for the specific social and health needs for the elderly. This way the elderly will continue to live with their families in dignity till death and avoid the misery that awaits them in old age where there are no such initiatives.

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