BRIDGING THE GAP

Extending palliative care services to older people in two East African countries
Report compiled by

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GLOSSARY OF ACRONYMS

APCA  African Palliative Care Association
CBO  Community-Based Organisations
FBO  Faith-Based Organisation
FGD  Focus Group Discussion
HAU  Hospice Africa Uganda
HIV / AIDS  Human Immunodeficiency Virus / Acquired Immune Deficiency Syndrome
HtA  Help the Aged
IDI  In-Depth Interview
IGAs  Income-Generating Activities
KARIKA  Kenya Aged Require Information, Knowledge and Advancement
KEHPCA  Kenya Hospice and Palliative Care Association
NGO  Non-Governmental Organisation
OVC  Orphans and Vulnerable Children
PCAU  Palliative Care Association of Uganda
PEPFAR  President's Emergency Plan for AIDS Relief
ROTOM  Reach One Touch One Ministries
TAFU  The Aged Family Uganda
UN  United Nations
URAA  Uganda Reach the Aged Association
USG  United States Government

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**EXECUTIVE SUMMARY**

**Background**
In sub-Saharan Africa, with an overwhelming communicable and non-communicable disease burden, the palliative care needs of aged people have never been more urgent. However, services that target this group often lack the necessary skills to provide effective palliative care.

**Aims**
This qualitative study aimed to: (i) describe the current life experiences of, and care services for, aged people and identify their unmet palliative care needs; (ii) provide recommendations for the integration of palliative care into existing services for the aged, and; (iii) highlight the key components of a provisional palliative care research agenda for older people in Africa.

**Methods**
Using in-depth interviews and focus group discussions, data was collected in Kenya and Uganda from: managerial and front-line staff of, and patient- and carer-clients receiving support from, rural- and urban-based organisations for the aged; managerial and front-line staff of, and patient- and carer-clients receiving support from, palliative care service providers covering approximately the same catchment areas as the aged organisations; and national coordinators from the two national palliative care associations.

**Main findings**

**Socio-demographic characteristics of patients**
Four focus group discussions and 30 in-depth interviews were conducted in Kenya (n=41); 5 FGs and 25 in-depth interviews in Uganda (n=48), resulting in a total of 89 study participants.

**The policy and medico-educational context**
- In an era of donor-funded, disease-specific vertical programming across Africa, palliative care services that explicitly address the needs and welfare of the aged irrespective of their diagnostic categories are non-existent in the study countries.
- Palliative care policy development remains relatively embryonic in many African countries, where it remains a relatively new discipline, especially in relation to the elderly.
- These problems are compounded by the absence of effective medical education that addresses the specific aspects of ageing and the aged.

**Typical daily life for the aged and their carers**

**A Life of the aged and their needs**
- Whilst many aged try to lead active lives, the lives of many are characterised by inactivity, dependency and social isolation.
- Central to the problems that can compound a sense of social isolation is poverty, a financial destitution that impacts negatively upon people’s ability to access the health services they need.
- These financial problems are exacerbated for those aged who look after orphans and vulnerable children.
- Even where siblings exist as potential care givers to the aged, offering support can be problematic.
- Vulnerability to the actions of family members and family circle members can sometimes be compounded by competition over land rights.
- For some aged, functional impairment is marked by unmanaged pain.

**B Life of a carer**
- Given the primarily home-based nature of the services they receive, carers are central to the lives of aged patients, and are primarily linked by family ties or by community linkages.
- Some carers find coping with their caring responsibilities difficult, even with support.
- These challenges are exacerbated when the service providers attempting to address the needs of the aged fail.
- The needs of patients’ carers are not necessarily always addressed.
- For some carers, neglect of their needs as carers, isolating them from the care process, can be made worse by an undervaluing of their role.
- Additional pressure can arise from the aged patients themselves.

**Care services received by the aged**
The aged receive a range of care services dependent upon the service they are attached to.

**Limitations of existing care services**
- Current limitations are multiple and characteristic of many home-based care services on the continent: insufficient staff numerically; inadequate finances; and inadequate health skills.
- In terms of the aged’s health needs, staff training (and the purchase of the necessary medical equipment) is critical.
- Palliative care should be embedded into existing services for the aged.
Other palliative care service training gaps include bereavement counselling, a wider community sensitisation to the value of the aged and the maximisation of the quality of their lives, and the easing of painful symptoms. There is recognition that palliative care service providers are not necessarily easily placed to address these gaps, as many are already struggling to meet existing service demand. Additionally, existing palliative care services are not sufficiently trained to address the specific needs of the aged.

Addressing service limitations and integrating services
Respondents suggested integrating palliative care services for those for the aged at two different levels: (a) training (especially on pain management) from established palliative care organisations, and; (b) joint advocacy as part of a more long-term strategic partnership between the two types of organisations.

Recommendations
Integration
A Training
- This could range from one-off training sessions that provide staff members of aged care organisations with basic palliative care knowledge and skills, or more substantially as part of an ongoing training programme that could have an embedded mentoring component to it.
- Central to this training would be the need to be sensitive to, and address, the concept of patients’ total pain.

B Community partnership model
- Pursuing a more significant community-based model of care provision based around a strategic partnership between both organisations would necessitate, in the first instance, a meaningful dialogue to clarify what the precise nature of that model could and should be, given the financial constraints facing the care organisations, the attitude of local communities, and the sensitivity and cultural expectations of local populations.

Part of this model could entail:
- the development of effective and transparent referral pathways that negate the need for hospital referrals;
- the harmonisation of the two services so that any areas of duplication are minimised and service delivery cost effectiveness is maximised;
- the development of effective access routes for pain assessment and management based around a tiered care approach, possibly entailing immediate family members in the first instance to provide rudimentary care and to highlight changes in patient need, referring to more specialist attention where the need arises;
- effective joint advocacy to advance the aged care policy agenda (e.g. for the development of geriatric training modules and ultimately pre- and in-service training courses, that begin to address the training deficits of young medical practitioners);
- the joint development of service development funding proposals;
- substantial and recurrent mutual staff training programmes, and;
- community sensitisation to the needs and inherent value of the local aged.

Given the financial and human resources constraints facing both organisation types, there will be cost implications arising from such integration work that cannot be borne by existing budgets and will require external funding.

Research agenda
- A feasibility study to determine the extent to which community financial support of a palliative care / aged service similar to the Kerala sustainability model is possible in an African setting.
- A quantitative survey of aged patients’ life experiences and services received to enumerate the extent of the problems encountered.
- A study of the pathways to palliative care followed by aged patients to determine their nature and any delays in presenting problems.
- A study of the knowledge, attitudes and practice of palliative care health professionals in respect to the aged.
- The development and evaluation of training programmes to encourage the participation of the aged in the research process.
- A geographical comparison (both within and between countries) of the principal barriers faced by the aged in accessing palliative care services.
- A comparative study of community attitudes to death and the dying process, and the aged people’s perceptions of end-of-life care (both traditional and palliative care).
- Lastly, the funding of dedicated aged research positions to advance this research agenda that combines international training experience with in situ practical research work.
1.0 BACKGROUND

1.1 The global picture
As a consequence of increased life expectancy, it is estimated that the number of older people (defined as those people aged 60 years and above), will more than triple globally by 2050, increasing from 606 million in 2000 to a projected 1.9 billion (United Nations, 2003). Moreover, there will also be an increase in the proportion of people constituting the oldest old (i.e., those 80 years or older); whereas they currently comprise 11 per cent of the 60+ age group, this is anticipated to grow to 19 per cent by 2050 (United Nations, 2003).

Additionally, the number of those people aged 100 years or older is projected to increase 15-fold over a comparable time scale, from approximately 145,000 in 1999 to 2.2 million by 2050 (United Nations, 2003).

Whereas 6 out of every 10 older people currently originate in resource-constrained regions of the world, by 2050 this will increase to 80 per cent (United Nations, 2003). In these regions, the proportion of the population aged 60 years or over is estimated to rise from 8 per cent in 2000 to nearly 20 per cent in 2050 (United Nations, 2003). The majority of these older persons are women (UNDESA, 2006). In resource-constrained countries, there are 85 men for every 100 women over 60; for the over 80s, there are only 73 men for every 100 women (UNDESA, 2006).

Ageing is a process associated with various health-related complications. More specifically, these features of population ageing will increasingly bring important challenges to health care policy makers as the pattern of diseases (i.e., in terms of morbidity and mortality) evident within society change. More specifically, the epidemiological transition will result in an increased importance attached to diseases and fatalities attributable to non-communicable diseases vis-à-vis infectious diseases (Phillips, 1994).

1.2 The aged in sub-Saharan Africa
Recent United Nations (UN) and civil society initiatives – especially the 2002 Second UN World Assembly on Ageing and the ensuing Madrid International Plan of Action on Ageing (Anon, 2002) – have stressed that population ageing is a present-day and integral development challenge for Africa that must be addressed, the latter calling for ageing to be included in national social and economic development policies. These global declarations were recently echoed regionally by the African Union’s adoption of the Africa Health Strategy, 2007-2015 (African Union, 2007) which refers to the alarming rate of growth of chronic diseases linked to non-communicable demographic changes (including hypertension, stroke, diabetes, and chronic respiratory disease), recognises the role of older people as carers of orphans and vulnerable children (OVC), and calls for the disaggregation of collected data by age and gender to enable more focused action.

Notwithstanding the minimal policy and programmatic advances on such initiatives (Aboderin & Ferreira, 2008), in sub-Saharan Africa adaptation of the UN’s definition of ‘older people’ is problematic, often rendered inappropriate to the setting (Anon, 2007a). Indeed, resource-abundant country definitions are often being replaced by more complex, if ultimately arbitrary, multi-dimensional socio-cultural definitions:

In rural situations, where birth registration is poor or even unknown, physical features are commonly used to estimate a person’s age. The colour of a person’s hair, failing eyesight and diseases such as arthritis are some features used to define an older person. More complex definitions embrace a host of social and cultural issues and may include, for example, the person’s seniority status within his / her community and the number of grandchildren which he / she has. (HelpAge International, 2002: 3).

Moreover, the UN definition is commonly associated with legal entitlement to age-specific pension benefits. Considering that the majority of older persons in sub-Saharan Africa live in rural locations and work outside the formal employment sector, with no expectation of receiving formal retirement benefits, this chronological age-based definition has minimal relevance. Moreover, this fact is compounded in those societies where life expectancy is incomparable with those high levels evident in resource-abundant countries.

Irrespective of this important definitional distinction and the problems that it gives rise to (e.g., cross-national data non-comparability), there is a growing body of work on the plight of those who are considered aged in the region. In particular, not only do elderly Africans exhibit those debilitating

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1 This primarily results from sharp declines in mortality rates, particularly through the prevention and / or treatment of diseases associated with premature death. More specifically, the advent of specific treatment for a range of infectious diseases (e.g., tuberculosis, respiratory infections and gastroenteritis in childhood), in addition to immunization against many others (e.g., diphtheria, poliomyelitis and measles), has contributed to the survival of millions of children to adulthood throughout the developing world.

2 Defined as a region comprised of those countries located south of the Sahara desert.

3 This multi-dimensional definition of the aged commonly entails a combination of chronological, functional (e.g., change in capabilities – invalid status, senility and change in physical characteristics) and societal definitions (e.g., change in social role – change in work patterns, adult status of children and the menopause) (Anon, 2007a).
diseases found among the elderly in resource-abundant countries, but the absence of national welfare programmes (e.g. pensions, benefits) and the trend toward urbanization and serious economic stress among the younger adult population, is slowly eroding (if not definitively eliminating) the extended family network (Habte-Gabr et al., 1987). Moreover, older people are normally the primary carers for OVC infected and affected by HIV / AIDS (Anon, 2004) – in Botswana, Namibia, Malawi, South Africa, Tanzania and Zimbabwe, for example, up to 60 per cent of orphaned children live in grandparent-headed households (Monasch and Boerma, 2004) – for whom they often perform an important health communication role (Aubel, 2006; Aubel, Touré and Diagne, 2004). As the rate of ageing in resource-constrained countries is greater than that in resource-abundant countries, the former will have less time to initiate appropriate societal adaptations to address the multiple consequences of population ageing (United Nations, nd).

The problems faced by the aged are compounded nationally in many African countries by, for example: limited available expertise in geriatric medicine, which is not taught in many medical and nursing schools; the absence of integrated national policies for the care of the aged; the lack of national councils to coordinate existing and new programmes for the aged; the absence of effective clinical components within many existing care programmes for the aged; and the cross-cutting features of health care systems' functioning (i.e. their limited financial and human resource capacities, their core agendas and priorities, and their specific HIV/ AIDS programmatic foci, that has 'crowded out' care for age-related non-communicable diseases) (Aboderin, 2007). Despite these significant challenges, there is a relative dearth of high-quality relevant, accessible and useable research and credible data sets that can provide an understanding of the social, cultural, economic and familial contexts within which these challenges occur (Apt, 2005; Gachuhi & Kiemo, 2005; Ferreira & Kowal, 2006; Kowal et al, 2002; Nhodongo, 2005), an essential prerequisite to inform attempts to address these challenges (Aboderin, 2005). Indeed, most of the significant health-related research conducted in the continent (e.g. the Demographic and Health Surveys) focus on people in the reproductive age bracket of 15-49. As Asagba (2005: 40) noted regarding the case of Nigeria, the absence of a rigorous research base to inform policy development for the aged is critical:

_Lawmakers are not sufficiently sensitized to the scope, nature or seriousness of older people’s problems, nor to the broad economic and social development implications of leaving these problems unaddressed in the context of rapid population ageing. The key cause of Nigeria’s failure to act on ageing is thus the dire lack of comprehensive, high-quality evidence of the magnitude, nature and implications of the population ageing challenge, that would serve to sensitize policy-makers._

In an era where increasing life expectancy rather than improving the quality of life is a stated UN millennium goal for sustainable development, one area of gerontological care provision that has been both neglected and under-researched across the continent is that of palliative care for the aged.

### 1.3 Palliative care defined

Since its origins in the care of patients in the United Kingdom with advanced malignant disease in the 1960s, palliative care has evolved rapidly in resource-abundant countries from the margins of oncological practice to the centre of mainstream care for those with progressive, life-limiting illnesses (Clark, 2007).

The World Health Organization (WHO) describes palliative care as:

_An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2002)._ Based upon Dame Cicely Saunders’ articulation of the relationship between physical and mental suffering as ‘total pain’ (i.e. physical symptoms, mental distress, social problems and emotional difficulties) (Clark, 1999), palliative care essentially has two critical components: pain and symptom control (including the administration of oral morphine for severe opiate-sensitive pain) and supportive care (which attends to the psychological, social, spiritual and cultural needs of both the patient and their family). As such, it uses non-pharmacologic as well as pharmacologic interventions, attributing equal importance to both to address the holistic needs of the presenting individual. Importantly, non-pharmacologic management is not a substitute for care in settings where drugs are unavailable (Mpanga-Sebuyira et al., 2006). Consequently, an organisation only providing one of these two components of palliative care is not providing palliative care in its entirety: pain control without effective
psychosocial care is anaesthesiology; psychosocial care without adequate pain control is simply supportive care. Moreover, the needs of people requiring palliative care vary over time, as pressing issues for patients and families surface and disappear (see Figure 1), so that the proportion of total care given as disease-modifying / curative treatment (e.g. treatment for opportunistic infections or antiretroviral therapy) and the proportion given as palliative treatment (e.g. pain and symptom control) also varies. Additionally, palliative care has traditionally been viewed as a ‘last resort’ intervention in the care continuum, to be delivered once a person was considered to be dying, signalled by the ending of the need for curative treatment. As Figure 2 shows, however, this traditional view has been replaced by one that sees palliation introduced in the earlier stages of the disease progression in conjunction with disease-modifying treatment as part of an integrated continuum of care (Selwyn & Rivard, 2003).

The need for palliative care services changes in type and intensity based on an unpredictable disease progression (hence the distorted line in Figure 1 depicting alternating periods of physical and emotional stability), the availability of treatment (e.g. chemotherapy), and the needs of the patient and their family. Addressing these multiple and varying needs comprehensively requires the input of many people, ranging from family members to health professionals, and from community members – including traditional healers – to non-governmental organisations or community-based organisations, to ensure a continuum of service provision through all stages of illness: diagnosis to progression through end of life and bereavement. As the illness progresses the types of services needed also changes:

*It is this provision of comprehensive care across a continuum from home care and community support to institutional services (primary, secondary and tertiary), social services, and back that will ensure the needs of patients and their families are met.*

*These services should create a ‘continuum of care’ that is adapted to fit in as much as possible with the lives of the people needing care. This means that services should be delivered at times and places that are convenient for patients and their carers and in a manner that is culturally and socially sensitive (Mpanga-Sebuyira, 2006).*

### 1.3.1 Pain and symptom control

Whilst not palliative care per se, pain and symptom control is the defining feature that distinguishes palliative care from generic supportive care. Guidelines issued by the WHO outline a stepped approach to controlling pain, ranging from non-opioids with or without adjuvants, to strong opioids with or without non-opioids and adjuvants.

According to the WHO pain ladder (see Figure 3), opioids must be available to manage pain in patients whose pain has not been adequately controlled by the use of non-opioids, weak opioids and the addition of adjuvants. In addition, it is required that all analgesics are delivered:

- by the ladder (i.e. according to the WHO pain ladder);
- by the clock (i.e. titrated for consumption at regular intervals to avoid the unnecessary and distressing experience of breakthrough pain);
- by the mouth (i.e. oral morphine dispensed for ease of administration, particularly in the African home care setting).

![Figure 3: The WHO Pain Ladder](source:www.who.int/cancer/palliative/painladder/en)
1.4 Palliative care in Sub-Saharan Africa

To achieve adequate palliative care, the WHO recently recommended an enhanced four-component public health model for delivering palliative care services (see Figure 4) (Stjernsward et al., 2007).

Figure 4: Enhanced WHO Public Health Model

The components of this model are:

**Government policy** – the national government health and regulatory authorities should establish and support a policy that makes palliative care a high priority in the health care system.

**Education / training** – the public, policymakers, and regulators should be informed of the benefits of palliative care, and health care professionals should be trained to assess and manage pain using the three-step ladder.

**Drug availability** – the essential drugs for palliative care, including opioids such as morphine, should be made available.

**Implementation** – among opinion leaders, with suitably trained manpower, incorporation into strategic and business plans, and the establishment of palliative care standards, guidelines and measures.

Current provision of palliative care in Africa is, however, patchy, often provided from centres of excellence rather than integrated into the mainstream health care system. Indeed, for the overwhelming majority of Africans who currently endure progressive, life-limiting illnesses, access to culturally appropriate, holistic palliative care (that includes effective pain management) is at best limited, and at worst non-existent (Harding and Higginson, 2004). Sub-Saharan Africa has twice as many deaths per 1,000 head of population annually compared to that of North America, yet only 1.5% of global palliative care resources compared to 55% in the latter (Anon, 2007b). Moreover, a recent survey of hospice and
palliative care services on the continent found not only that 44.7\% (21/47) of African countries had no identified hospice or palliative care activity, but that only 8.5\% (n=4) could be classified as having services approaching some measure of integration with mainstream service providers (Clark et al., 2007).

However, the growth of awareness of the need to expand palliative care in Sub-Saharan Africa, and the increasing availability of funding to realise that need, have resulted in major developments in patient care in recent years, with increasing numbers of care providers demanding the acquisition of palliative care skills.

1.5 Palliative care and the aged

Significant linkages exist between palliative care and geriatrics: e.g. frailty syndrome, elderly cancer, neurodegenerative disorders, end-stage organ failure, elderly with chronic pain; and the bereaved elderly. As Lo and Woo (2006: 35-36) noted:

Both palliative care and geriatrics focus on patient-centred holistic care, emphasising quality of life, adding life to days when days can no longer be added to life. Both specialties take a patient-centred rather than an organ-based approach, carefully considering the benefits and burdens of intervention and treatment in advanced disease and age... Both geriatricians and palliative-care physicians attend to families’ needs, e.g. ameliorating bereavement and stress associated with caregiving for the demented and the terminally ill ... Older people are [also] more likely to face bereavement, for which counselling and support should be available.

Indeed, using Dame Saunders’ concept, the potential components of ‘total pain’ experienced by the aged are shown in Table 1.

Moreover, there is a growing recognition of the need to establish closer links between palliative care and the aged globally. Indeed, the theme for the 2007 World Hospice and Palliative Care Day was Across the Ages: From children to older people, emphasising that people of all ages need access to hospice and palliative care, either as patients, as family members, or as informal carers of people facing progressive, life-limiting illness.

1.5.1 Palliative care and the aged in Africa

Whilst there are positive developments occurring in palliative care in Africa, they are primarily associated with addressing the impact of the HIV / AIDS pandemic and with the non-aged. The specific requirements of the African aged (e.g. potentially enduring age-related conditions, compounded by HIV / AIDS, poverty, social isolation, bereavement and loss arising from their children’s premature death, and the burden of caring for their grandchildren and / or OVC) are largely neglected:

Like children of HIV, the elderly are becoming more vulnerable. Unfortunately the elderly are a less attractive group to charities. They may receive assistance as a by-product. But few groups are targeting their needs. (Lau & Muula 2004: 409)

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<tr>
<th>PHYSICAL PAIN</th>
<th>PSYCHOLOGICAL PAIN</th>
<th>SOCIAL PAIN</th>
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<td>Pain from cancer</td>
<td>Worry</td>
<td>Poor living conditions</td>
<td>Indignity</td>
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<td>Pain from metastases</td>
<td>Anxiety</td>
<td>Financial hardship</td>
<td>Meaning of suffering</td>
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<td>Pain from treatment</td>
<td>Fear</td>
<td>Inadequate communication</td>
<td>Meaning of life</td>
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<td>Pain from joints</td>
<td>Negativity</td>
<td>Inadequate information</td>
<td>Purpose of life</td>
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<td>Pain from trauma</td>
<td>Low self-esteem</td>
<td>Loneliness</td>
<td>Value of life</td>
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<td>Pain from wound</td>
<td>Despair</td>
<td>Isolation</td>
<td>Sanctity of life</td>
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<tr>
<td>Pain from sores</td>
<td>Depression</td>
<td>Neglect</td>
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<td>Pain from immobility</td>
<td>Demonisation</td>
<td>Abuse</td>
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<td>Pain from poor oral/dental hygiene</td>
<td>Derealisation</td>
<td>Burden on family/carers</td>
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Source: Lo and Woo (2006: 38)
In a region where finite national budgets face multiple pressing demands, the African aged remain a low priority. Moreover, even where palliative care services exist and provide care for the aged, engaging this ‘special population’ can prove problematic, especially with respect to HIV / AIDS:

Older people may not seek care because they fear the stigma of HIV / AIDS as well as because they may be dealing with other health problems. A large number of older people are caring for their children’s children, as their own children have died through war, HIV, or famine. Thus a grandmother may be caring for many orphaned grandchildren without support from her own children. For her, finding time and money to obtain her own palliative care is a challenge on top of meeting her grandchildren’s essential survival needs. The elderly who have seen their children dying from HIV / AIDS may also fear the disease and believe that ‘nothing more can be done for them’. This, along with a belief in ‘traditional medicine’, means that they may put off accessing palliative care. (Downing, 2006: 326)

Existing organisations for the aged generally lack the specialised skills and experience necessary to deliver palliative care effectively to their clients. Moreover, many of these organisations are financially insecure, small-scale and populated by volunteers. This study explores the potential for, and means by which, palliative care services can be integrated into existing services for the aged.

2.0 THE STUDY
This exploratory study was undertaken in two African countries (i.e. Kenya and Uganda) through a primary partnership between the Ugandan-based African Palliative Care Association (APCA), and the UK-based Help the Aged (the funding agency). APCA developed secondary partnerships with the national palliative care associations in the two countries (i.e. the Kenyan Hospice and Palliative Care Association [KEHPCA] and the Palliative Care Association of Uganda [PCAU]), as well as Nairobi Hospice, to assist with the study’s implementation.

2.1 Study aims
The aims of this study are two-fold: long- and short-term. The long-term goal is to advocate for, and support, the integration of palliative care into existing care services for the aged across the continent. The short-term goal is to assess the palliative care needs of aged people in two African countries (i.e. Kenya and Uganda) to inform longer-term programme development (i.e. integration of palliative care services into existing services for the aged).

2.2 Study objectives
There are three study objectives:

- To describe the current life experiences of, and existing care services for, aged people and identify their unmet palliative care needs in both countries.
- To provide evidence-based recommendations for the future effective integration of palliative care into existing services for the aged in Africa.
- To highlight the key components of a provisional palliative care research agenda for older people in Africa.

3.0 METHODS

3.1 Study design
Given its exploratory nature, the study utilised qualitative research methods (i.e. in-depth interviews [IDIs] and focus group discussions [FGDs]) (Silverman, 1999).

3.2 Study population
Data was collected from the following groups: managerial and front-line staff of, and patient- and carer-clients receiving support from, organisations for the aged (based in a rural and urban setting); managerial and front-line staff of, and patient- and carer-clients receiving support from, palliative care service providers covering approximately the same catchment areas as the aged organisations; and national coordinators from the two national palliative care associations.

3.3 Recruitment
Respondents for the IDIs and FGDs were recruited using a purposive sampling frame. Whilst certain staff members were easily identified (e.g. service managers⁴), potential respondents receiving support and care as a client, or support as a carer of a client, were identified by the relevant organisational staff.

The inclusion criteria for staff were:

- Adults (i.e. aged 18 years or older)
- Able to provide informed consent
- Fluently speak a language in common with research staff (i.e. English, Luganda⁵ or Kiswahili).

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⁴ Defined as the person who is the lead authority in an organisation who is responsible for the operational aspects of palliative care service delivery (e.g. Director of Clinical Services).
⁵ Luganda is the most commonly used of the 19 Bantu languages spoken in central and southern Uganda (see http://en.wikipedia.org/wiki/Languages_of_Uganda, accessed 01/07/07).
Where possible, the purposive sampling frame was employed to ensure a diverse staff sample with respect to:

- Age
- Gender
- Professional background
- Care training and experience with the aged

The inclusion criteria for clients and carers were:

- Aged clients and carers (as defined by the relevant organisation)
- Able to provide informed consent
- Sufficient physical and cognitive capacity to participate in a qualitative interview
- Receiving care / support for a minimum of 6 weeks
- Fluently speak a language in common with research staff (i.e. English, Luganda or Kiswahili).

Where possible, the purposive sampling frame was employed to ensure a diverse client and carer sample with respect to:

- Gender
- Location (i.e. rural and urban)
- Family size / child responsibility
- Diagnosis

3.4 Informed consent

Each potential participant (client and staff member) was provided with the relevant information sheet by the researchers to enable them to decide whether to participate. This sheet was read aloud by the researcher in the interviewee’s preferred language; those who indicated their agreement to participate were provided with a consent form to be signed or marked before the interview commenced.

3.5 Data collection

In addition to collecting basic socio-demographic data to profile the respondents, a number of interview schedules were used in this study. Dependent upon the respondent involved, the interview schedules are based around the following key areas:

- Typical daily life for the aged and their carers
- Care services received by the aged
- Limitations of existing care services
- Addressing service limitations and integrating services.

3.6 Data processing and analysis

Digitally recorded data collected from the IDIs and the FGDs were first copied onto a memory stick for back-up purposes. Each digital recording file was accorded a unique identification number that correlates with the paper records of the interview process held separately by APCA researchers. The original copies of the recordings were transcribed verbatim (and translated into English when they had been conducted in Luganda or Kiswahili) to ensure an accurate recording of the views and experiences expressed by the study participants. For interviews conducted in local languages, translations were agreed by two researchers conversant with the language. To ensure the anonymity and confidentiality of the respondents, the transcribed data was subject to restricted access. All digital files were stored on password-protected computers in a secure location; all hard copy data is stored in a locked filing cabinet. All data (both electronic and hard) is to be retained with restricted access at APCA for at least 7 years after the conclusion of the study, after which they will be verifiably destroyed.

The transcribed and translated interviews were entered into NVivo7®, a software package that facilitates the effective coding and recalling of text (Bazeley, 2007). Each interview was analysed using content analysis to appreciate the nature of the collected data before emergent themes were identified using the ‘template analysis’ approach. This approach, described by King (1998), is comprised of four phases:

- An initial ‘template’ is generated from the original interview schedule.
- This template is used as a reference for reading and interpreting the transcribed interviews.
- Additional themes are added and themes modified on the basis of the transcribed interviews.
- The final template is produced by a second rater who verifies the themes and makes any necessary additions or modifications.

3.7 Data triangulation

To ensure the common themes evident from the interviews had validity, different groups of stakeholders were categorised and interviewed separately as respondents (Guion, 2002). Moreover, the interpretation of the data was further validated by consulting a small sample of interviewed respondents.
3.8 Ethical approval
Ethical approval was secured within each country from the Nairobi Hospice Standards and Ethics Committee, and the Uganda National Council for Science and Technology by the study’s Principal Investigator.

3.9 Distress protocol
The distress protocol for data collection was as follows: any respondent who appeared to become distressed during data collection was offered the opportunity to cease the interview and to either abandon or restart the interview when they were comfortable. The interviewer would pass on any information or request to the relevant staff member at the concerned organisation at the interviewee’s request. All information was treated as confidential except in the situation of the interviewee’s safety being at risk, in which case the information would be acted upon. All participants were recruited in accordance with the ethically approved recruitment protocol.

4.0 RESULTS

4.1 Socio-demographic characteristics of patients
As Table 2 shows, 4 FGDs and 30 IDIs were conducted in Kenya (n=41); 5 FGDs and 25 IDIs in Uganda (n=48), resulting in a total of 89 study participants.

Table 2: Study Sample by Country, Nature of Interview, and Sex

<table>
<thead>
<tr>
<th></th>
<th>Kenya</th>
<th>Uganda</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>FG</td>
<td>ID</td>
</tr>
<tr>
<td>Rural carers</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>Urban carers</td>
<td>1 (2)*</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Rural patients</td>
<td>1 (5)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Urban patients</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Rural Front-line staff</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Urban Front-line staff</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Rural service Managers</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Urban service Managers</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>National Coordinators</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Senior Managers</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>2 (7)</td>
<td>2 (4)</td>
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</tbody>
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* Figures in brackets refer to the number of FG participants.
** These are volunteer carers rather than related family / immediate community members.
*** Mixed group, predominantly female.

Following an outline of the policy and medico-educational context for palliative care for the aged, the ensuing sections report on the following themes:
- Typical daily life for the aged and their carers
- Care services received by the aged
- Limitations of existing care services
- Addressing service limitations and integrating services

4.2 The policy and medico-educational context
In an era of donor-funded, disease-specific vertical programming across Africa (De Maeseneer et al, 2008), palliative care services that explicitly address the needs and welfare of the aged irrespective of their diagnostic categories – especially HIV/AIDS and cancer – are non-existent in the study countries. For example, despite Hospice Africa Uganda reporting that those aged 60 and above account for 20 per cent of all patients they see, they are not referred to the service for age-related illnesses.

We don’t take them just because they are elderly or we don’t take strokes ... we just take people with HIV or AIDS ...

To ensure their anonymity, statements from different respondents are denoted by, for example, the referent ‘RES UPC61’, where ‘RES’ refers to the respondent, ‘U’ for Uganda, ‘PC’ for palliative care and 61s for the respondent’s identification number. Other alternatives include ‘K’ for Kenya and ‘AG’ for aged organisations and ‘MOD’ for the researcher who moderated the data collection.
Moreover, whilst Uganda has incorporated the right to palliative care into its national health policy, and included morphine as an essential drug in the primary care treatment of cancer pain (Clark et al., 2007; Harding et al., 2003; Merriman, 2002; Stjernsward, 2002), palliative care policy development remains largely embryonic in many African countries, where it remains a relatively new discipline (Collins et al., 2007), especially in relation to the elderly.

As far as I know there is no geriatric medicine in the medical schools at all at the moment ... the training of doctors here is very much towards curing ... they are not that much interested in somebody who is not going to be cured; and somebody who is not going to jump out of bed and run out of the ward within two days ... because geriatric medicine has not yet been taught in our schools, people are not aware of the physiology of ageing (RES UPC61).

At the moment I know only one person who has geriatric training and that is Dr Anne Merriman, the founder of Hospice Africa Uganda. The rest I am not very sure (RES UPC60).

No there are no policies for palliative care, it’s sort of a new concept ... we are trying to push policies for it ... like recently I was in (a) workshop ... and I did a presentation on palliative care, and it was obvious that most people in the workshop ... had not given palliative care a consideration (for) the elderly people and it was like a new concept to them that the elderly people need palliative care ... I don’t think that there is specifically any project that has really targeted the elderly people in palliative care (RES KPC32).

I don’t think there is a policy for the elderly. All I know is that palliative care here in Uganda is for all as long as they have HIV/AIDS and cancer because when the palliative care concept came in here, actually the focus was pain and symptom control for HIV, initially for cancer then later on HIV also came in because health professionals didn’t have the knowledge of how to control their pain, the HIV/AIDS pain (RES UPC60).

Indeed, policies that are specifically for the aged irrespective of any palliative care component are still at the advocacy stage:

Yeah, apparently the policy is in, ok we have a draft policy as we talk now, which will be put in place very soon but we don’t know soon as to when because the government has been talking about this draft policy for over even six years now ... So, we may talk about the policy there is a draft policy but there is no policy for older persons ... There are very few organisations advocating for older persons, so you find that the voice is not a very big voice to ... talk about issues concerning older persons (RES UAG64).

Many of those who go to a health worker ... the health worker treats them as if they were 21 and they die of the drugs. They do, some of them actually die of the drugs. Take an example of hypertension. Your blood pressure rises as you get older and indeed it’s because as you get older your arteries are becoming hard ... So that needs a higher pulse pressure. The pulse pressure is between the diastolic and systolic pressure, so if my blood pressure is 120/80 when I am 21, I’d expect it to maybe be 180 over 80 when I’m 80 ... And if you bring that down very rapidly, you get a stroke! And what would the doctors say? ‘Oh they had hypertension, they got a stroke,’ when it was the drugs that did it (RES UPC61).

The older persons are not comfortable with the youth; young medical personnel do not have the patience to deal with older persons so that is why I recommend that government should start up courses in gerontology so that some people are specifically trained to deal with older people. Such staff will have the patience to deal with the problems of older persons. This is why older persons are always complaining that when they go to hospitals they find these young boys and girls ... they harass etc., so ... giving them this training (will) help them handle such patients better (RES UAG59).
4.3 Typical daily life for the aged and their carers

4.3.1 Life of the aged and their needs

Whilst many aged try (sometimes forced by necessity) to lead active lives, the lives of many are characterised by inactivity, dependency and social isolation.

I don't have peace (in the) day. It is now thirty years since I got sick and my hands turned lame. I cannot do anything for myself, not even washing; they wash for me. MOD: That means when you wake up ...
I just sit. I don't have anything I can do (RES UAG58).

They (the aged) are in need of fellowship because most of them are lonely (RES KAG33).

I need company; I am being cared for by a stranger and my daughter comes home very late, so I am very lonely (RES UPC51).

I find desperacy (sic) among the old people. They are lonely, they are desperate, their life has no meaning and they are very negative. So it's a psychosocial need. Everything you talk about it's like, 'For me, it is finished. I don't have a child; I stay in here by myself'. You can break it down to loneliness, to desperacy (sic) as a psychosocial need (RES UAG63).

Well, I have so many needs, sometimes I am lonely since most of my children are away and my husband is away; you really need someone to talk to (RES UAG57).

Most of the older persons, their children died as a result of HIV and a result of constant wars in Uganda. Now, when their children die, they remain isolated. Nobody can take care of them ... Therefore we say they are isolated. Sometimes even they don’t have somebody to converse with. They are socially affected. You can even just send a staff (member) to that older person only to converse (with) that older person. Yes, we call it (a) befriending service; befriending an older person (RES UAG64).

Central to the problems that can compound this sense of social isolation is poverty, a financial destitution that impacts negatively upon people's ability to access the health services they need:

The need that is here is that of money ... The greatest problem we have here is money, no other problem (RES KAG21).

Their needs are mostly financial, that is rent, which is a big issue. Another one is food and since most of them are like abandoned and they don’t have anyone else, we will say social support and also health needs (RES KAG11).

Rent is the main need. I have two children but they don't have a job, they depend on casual jobs which are unreliable. My husband died and did not leave us a home. And I had four elderly sons who died one year ago. I now stay with one who cannot assist neither can I assist him ... I just pray to God to give me food ... (RES KAG20).

My problem is that my legs are swollen and very painful, I was advised to go to Mukono (health centre) in the maternity ward and get free treatment, but even I do not have the two thousand shillings to take me there (RES UAG58).

They (the aged) have economic problems. Most household being headed by older persons are in bad condition; you find a home earning less than a dollar a day. So the issue of poverty is very important and something must be done to improve the situation and wellbeing of these people ... The second issue is the health problem which is closely linked to the income they are earning. When we talk of sickness and poor health in older persons in Uganda sometimes they must travel long distances to get to the nearest health centre. Some of them can no longer walk long distances, have no stretchers or facilities that can ease life for older persons. One time I found men carrying an older person on a chair that was tied on to a bicycle and they had to walk over 20 kilometres to get to the nearest health centre where this old man could get care (RES UAG59).

Housing: in terms of the houses but also in terms of the sleeping conditions – in terms of where they sleep. Lack of beddings, lack of mattresses, lack of beds; we have provided for all those ones who are under our care now but they had nothing ... Hygiene, latrines zi [Swahili slang
for none); you will be surprised that 28% of the older people we help in Mukono had no proper latrines. A few others had latrines which you could not use... They have no income security so they don't have spending money that if I want to do this I can buy it myself; if I want some food, if I want this in my house I can get it. You will be surprised I know all these seniors we help live on less than 20,000/- a month.7 We have tried to quantify it. A few may be between 20 and 30,000/- but more than 50% spend less than 20,000/- a month on themselves ... so they lack income security (RES UAG63).

These financial problems are exacerbated for those aged who look after OVC:

The needs of these children are so many. One, these children do not have parents, so something like (school) fees is a problem, they need fees. These children live with their grandparents, these grandmothers, a good number of them, don't have permanent accommodation. These children need accommodation, these children need care, they need extra care, because they live with the old most of the time. They need care, love, security, the needs of the children are so many that we can't list all of them (RES KAG13).

Many of their children have passed away because of the illness leaving them grand children with no care, for example, school fees and other needs ... those old people you see have grand children and some of their sons who have poor siblings some are handicapped, others are sick ... (RES UAG2).

Even where siblings exist as potential care givers to the aged, offering support can be problematic:

(Some) elderly have their sons here in Nairobi while they were ... upcountry, so they have (to) rely on their children to support them. And at times it becomes a problem because their children cannot send them home because there will be no one to take proper care of them. You find that in our society it is difficult to hire a house help, and when they are here in Nairobi it becomes difficult for them to stay in the house, because the old people need their space. So that issue of being unsettled socially and even economically which makes them to be affected even psychologically and even spiritually ... so the whole sickness and age is disorganising and unsettling to the person and the family (RES KPC34)

For others, the problems of support can be more serious:

Some aged people, like they have their sons or daughters from abroad. Some of them they send money but through sending money, reaching these people around them, the money is diverted. They don’t talk to the aged ones that so and so sent some money to help ... you in such and such. They just neglect the elderly person. Then these people start suffering ... others have got houses which they (are) renting. When money comes and these people whom they had entrusted with collecting the money from the tenants, they may end up misusing it (RES UAG42).

Vulnerability to the actions of family members and family circle members can sometimes be compounded by competition over land rights:

Some of them (the aged) suffer a problem of land. Land wrangles; you find that many of them they have stayed in these areas for quite a long time. Now it so happens that a tycoon comes around, he wants land and somehow they are being thrown out of this land or the best they can even do, they just give them a small piece of that land. Now even when the senior can go and you know use his hands to find something to eat; the land is limited, he cannot find space to dig from. So that is also a big problem (RES UAG45).

For some aged, functional impairment is another characteristic of their daily life:

I cannot do anything ... serious, I am paralysed, especially in the legs ... The other part of my body is okay, it’s just my legs that are affected, I can do things that require a stationary body ... my legs limit me; I cannot walk (RES UPC47).

Because of my health I am restricted from walking a moderate distance, bending or lifting light objects and visiting my friends. Because of my age and health condition, I have difficulties in bathing myself and (in my) ability to use (the) latrine and dressing. I have to depend on (the) support of others (RES UAG54).

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7 This equates to approximately £6.
For some this impairment is marked by pain of a varying intensity:

I have no big challenges apart from my illness. I feel pain like you would feel pain when you are ill but it's like a pricking pain at night (RES UPC49).

The main problem I have is with this illness. I don't have peace at night. I cannot cover myself with a blanket, yet I have been treated for over ten years but there is no difference. I experience new pain every day (RES UAG58).

I have severe pain in the throat and I find hard to feed. I also feel bad being unable to move I cannot see anything outside this room ... (RES UPC51).

There is nothing I do, because I cannot walk or even crawl. I stay here from morning to day break, I just get my rosary and pray ... My biggest challenge is pain; I have a burning pain in the legs, its eating me up (RES UAG56).

Because of the severe pain she experiences, she cries a lot and attracts attention from neighbours and this makes me feel uncomfortable. At times I get scared that neighbours think that I torture her (RES UPC37).

Some carers find coping with their caring responsibilities difficult, even with support:

The patient is stressed and me as a daughter-in-law and being my first experience with such a disease, I am somehow scared but the hospice did for us some counselling as a family and we are kind of coping with the problem but it is tough for us because we do not know what to do with the patient especially when she starts crying and speaking many things ... (RES KPC5).

Like carrying her to and from bed, cleaning dirt when she has soiled her bed. At times she develops a mental problem. For example, she might wake up and tell me that she wants to make a trip to visit her children or even talk unconnected things. This worries me lots (RES UPC37).

It's so stressing doing all this work and then getting to work on time. This is why (I) am breaking down, stress ... May be the patient he should be counselled. He is a difficult person to deal with, you know all about denial and stigma (RES UPC36).

I ... need support to care for my young child because I don't have money to care for both my grandparents and my child. Yet the father of my child rejected giving me any support unless I go back to him and I cannot leave my grandparents for him. So the problem is with this child and she is in the age of going to school (RES UAG2).

4.3.2 Life of a carer

Given the primarily home-based nature of the services they receive, carers are central to the lives of aged patients, and are primarily linked by family ties or by community linkages.8

My day is quite long as I have to wake up at 6:00am to prepare her breakfast and give her drugs. Then at around 10:00am I have to give her again medicines and breakfast. At around 2:00pm I prepare her lunch. And that is how I spend my day caring for my patient (RES UPC38).

I start my day very early in the morning at around 5.00am. I go and dig then come back, I prepare children for school like brushing their shoes, prepare them something to eat. I then prepare for the old lady as well, then wake her up because she usually wakes up late. I take the animals for grazing then go back to the garden, collect firewood and many other activities that I do which make me weak as someone looking after the old person ... because of her weakness I let her do some little work she can and leaves the rest to me. I don't want to make her tired ... Thereafter I go to do my other activities and animals as well. I also look after my mother (RES UAG2).

The following quotations are derived primarily from this type of carer. One Ugandan aged organisation 'employs' non-family member volunteer carers, who are either reimbursed for the travel and food expenses they incur in the course of their work, or paid a nominal amount by the family themselves to perform their caring tasks, thereby enabling family members to perform other roles. Such volunteers quoted below are UAG41, UAG42 and UAG46.
These challenges are exacerbated when the service providers attempting to address the needs of the aged fail:

They all need food, and the problem (is) we don’t have enough food to feed them, and so we have to give little little so that each can go feeling at least they have been fed, and it cannot be done so regularly, so we have to do it only on Saturdays, that is only when we give food ... (Also) if anyone of them falls sick, you know these old people fall sick very often because of their age, so in case one of them falls sick we have to (dig) deep our hands into the pockets for the hospital funds and such ... sometimes the bills are so big that even us we cannot manage and so we encounter very big problems (RES KAG8).

Despite these pressures, the needs of patients’ carers are not necessarily always addressed:

What I would like to add on is to request those people periodically to evaluate and get to know our needs and to respond to those needs accordingly. I also request that (X) should as well get us a day and sit with us carers (to) discuss the problems concerning these old people we are taking care off. Most of the time those people don’t tell what their problems are exactly, yet it’s us who stay with them so we know all that is happening.

MOD: Have you ever been called to discuss concerning the old people or you discuss them together with them on Wednesday as a group?
A. No! ... they don’t allow us. This is the first time (RES UAG2).

For some carers, neglect of their needs as carers, isolating them from the care process, can be made worse by an undervaluing of their role, or neglecting their own food needs:

Sometimes out there we meet ... we find people; people there minimize us, eh? They take us sometimes to be house girls like that ... They under look you ... Some people ... anger quickly, like that. Any slight mistake, someone is angry with you ... You find something has, you have failed to do it as she wanted you to do it, so you find someone is angry with you. Eh, people there, the relatives of the patients we look after, they want also to ... eh ... to be the bosses over you, like that ... They don’t want you to go outside there. They want you to stay on the patient. If that patient cannot make her move or we make them move anyway but sometimes when she has moved she is there, you want also to be outside. But they...others cannot give you that freedom (RES UAG41).

Like mistreating and mistaking. Relatives mistreat us. You go there they take you as a houseboy. Through looking for a patient, the following day they’ll just tell you that, ‘You know what, there is a dustbin there but you know, we don’t have any person who is a man ... any kid around so you just take for us this thing there’. Another day they just tell you that, ‘You know what, you go and shop for us things like...’; so, you came for a certain programme, they change you ... they divert you to other programmes (RES UAG42).

MOD: You visit someone on average for an hour to two hours a day. So what you are talking about is when you go there they won’t give you any snack or drink or are you talking about when you’ve been with them for the whole day?
RES: Exactly, for the whole day or the night. Most of them they take it for granted. They can say, ‘Ah since ... I think he will be paid,’ and yet you can go there as a volunteer minus the payment. It’s one of the challenges we face (RES UAG46).

This can also translate into indifference for support as someone is ‘paid’ to assist, inactivity which questions the notion of support from the extended family:

Another challenge, some of the relatives are saying that we are paid. Now when we go there ... when you ask for help like positioning the patient ... you can call somebody (and) ... they refuse...somebody can say that, ‘You are paid, you have to work,’ like that... Someone can tell you that, ‘You are paid; you should not rest’ ... so we face those things ... such challenges, like that...eh...saying that because we are paid, eh, we should not rest we should not sleep, oversleep. You should keep on looking throughout the night, which is very, very hard. A human being must rest; it is human (RES UAG41).

Another challenge, when we are working on a patient especially in a hospital or at home ... if that patient, their condition ... changes, some of the relatives are saying that, ‘You are...’; or pressure, if that patient got a ... high pressure, some (relatives) are saying that you have not given medication to that patient. They abuse, they have a tendency of abusing us: ‘What have you done to our patient, or our mum? Now she’s going to die, you will see; you have not given him/her medication’; which is not good. They are saying like that (RES UAG41).

9 For the sake of confidentiality and anonymity, ‘X’ is used as a substitute for any named individuals or organisations.
Additional pressure can arise from the aged patients themselves:

*There are some places where we go and we find harsh patients … who harass us, who pressurize us, eh? Like those ones whom we were telling you that they don’t want to see you seated. They don’t want you to see you resting even if all the work is finished but they don’t want you to ... see you seated down because you have come to work ... You don’t have to sit, eh? ... But it is not because we are not working, just someone wants to pressurise you ... wants to treat you in a bad way (RES UAG4).*

### 4.4 Care services received by the aged

This section profiles the various organisations participating in this study (see Table 3), outlining where relevant the main services provided to the elderly receiving generic aged care and palliative care.

#### Table 3: Participating Study Organisations

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<th></th>
<th>AGED</th>
<th>PALLIATIVE CARE</th>
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<tbody>
<tr>
<td></td>
<td>RURAL</td>
<td>URBAN</td>
</tr>
<tr>
<td><strong>KENYA</strong></td>
<td>KARIKA Ageing and HIV/AIDS Programme</td>
<td>Nairobi Hospice</td>
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<tr>
<td></td>
<td>Lavington United Church</td>
<td>Kenya Hospice</td>
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<tr>
<td></td>
<td></td>
<td>KARIKA Ageing and Palliative Care Association</td>
</tr>
<tr>
<td><strong>UGANDA</strong></td>
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<td>The Aged Family Uganda</td>
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<td>Hospice Africa Uganda</td>
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<td></td>
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<td>Palliative Care Association of Uganda</td>
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<td>Uganda Reach the Aged Association</td>
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#### 4.4.1 Kenya

#### 4.4.1.1 KARIKA Ageing and HIV/AIDS Programme

An acronym for Kenya Aged Require Information, Knowledge and Advancement, KARIKA was founded in 2003, pursuing a vision of a community empowered through self-help reliance and self-sustainability to contribute towards a self-reliant nation. Based in Riruta, Nairobi province, KARIKA neighbours one of the largest slums in Nairobi. The organisation seeks to:

- Assist older people to assess public facilities, especially health care services;
- Impart home-based care skills to youth to enable them to assist older people in their homes;
- Undertake projects aimed at improving the livelihoods of the aged in and around Kenya, and;
- Develop links with non-governmental organisations (NGOs) in Kenya and internationally interested in assisting older people.

Towards these ends, KARIKA provides (via nine staff members) a number of programmes (i.e. aging and HIV/AIDS; basic health care; non-formal education; social justice and governance; and life skills for income-generating activities [IGAs]), with finances based around the donations of well wishers and various IGAs (e.g. sewing and knitting, weaving, soap making, cookery and bead work). These programmes are directed towards 50 grandmothers (aged between 55-89 years), 56 orphans and 24 vulnerable children; and, via a private home owned by Thogotho Home for the Aged, a number of grandfathers.

Recruits to the KARIKA programme are primarily identified within the local community:

*In the beginning we were supplying food for them so they used to come for food. When they came for the food is when we first saw them, then we began with them, and these ones who have come they bring their friends, their neighbours so we come close to them in that way. MOD: How do you recruit new ones? Is it the older people who go talk to the other people so that they can give you information? How do you get new members, older people? The new members, most of the time as we walk in the villages. We do home visits, so as we visit the homes we see the elderly people (RES KAG12).*

#### 4.4.1.2 Lavington United Church

Based in the Westlands constituency of Nairobi Province, and sponsored by Methodist, Anglican and Presbyterian churches, in partnership with Helpage International, Lavington United Church is a faith-based community organisation committed to helping the poor, aged and disadvantaged realise a better life, both spiritually, socially and economically. Through its social services department, the church works in the slum areas (i.e. including Gatina, Kamitha, Kangemi and Kawangware) adjacent to the Lavington suburb, seeking to equip aged members of the community with the knowledge and skills to enable
them to become self-reliant (especially in terms of the basic necessities of life: food, shelter and clothing). Via its Adopt-a-Granny project (which is run by social workers and volunteers), services for the aged include:

- Rental support of 300/- per month
- Food support
- Medical support
- Sharing the Christian message and discussion of social issues, with the intention of improving the aged people's status, nurturing self-worth, and assisting them to attain their full potential.

As one respondent noted:

One of the projects in Lavington United Church ... most of these old people come from Kawangware, which is like a 30 minute walk to the slum, and currently we have about 60 aged who are supported by this project. Now the church came up with this programme because there was need in the community, because most of these grannies had been left alone and the church sponsors some of the children. As we did home visits we realised that some of the children sponsored here stay with the grannies; it is like they are the caregivers and that is when the church established this programme to cater for these needs (RES KAG33).

Finances for the organisation are derived from partnerships with other charitable organisations, the monthly Holy Communion offertory at Lavington United Church, and donations from other churches, church members, friends of the church and other well-wishers.

4.4.1.3 Nairobi Hospice

Founded in 1987 by Ruth Woolridge and Jane Moore, initially around care provision for cancer patients, Nairobi Hospice is one of eight organisations in the country providing palliative care.10 is situated in the Kenyan capital in the grounds of Kenyatta National Hospital, serves a 20km radius catchment area, and has services provided by 18 staff members. As one respondent commented:

Nairobi Hospice has two main missions: one is to help those patients suffering from life-limiting illness. Right now we focus on counselling those patients with HIV and AIDS ... We also include training for people in palliative care, for people in the medical field and those ones who are not also in the medical field ... The people that we take care of are everyone across the board, from the youngest to the very old. We have even taken care of patients of 100 years old and a one year-old patient, so our services are for everyone regardless of the age and regardless of their social or religious affiliation and so on (RES KPC34).

Referrals to the service are predominantly through Nairobi hospital, but also from the district hospitals:

There is a test that the Nairobi Hospice was to do, so when we came we were referred to Kenyatta National Hospital for the test, so we took our patient to the medical college within Nairobi University. We brought the results to Nairobi Hospice then we started the normal visits (RES KPC5).

Financially supported in the United Kingdom by the Nairobi Hospice Charitable Trust and in Holland by the Nairobi Hospice Foundation – Holland, the Hospice is dedicated towards alleviating the suffering of patients with life-limiting illnesses through services, training and advocacy and pursuing their motto: ‘Putting life in their days, and not just days into their life.’

4.4.1.4 Kenya Hospice and Palliative Care Association

The Kenya Hospice and Palliative Care Association (KEHPCA), formally registered in 2005, is currently based in the premises of Nairobi Hospice, Kenya, and seeks to achieve, amongst others, the following objectives:

To harmonise palliative care and to promote standards for hospice and palliative care nationally by bringing together, in a common forum, all organisations involved in such activities throughout Kenya:

- To promote training, capacity building, and research in palliative care;
- To advocate for recognition of palliative care as a key component of health care services and as one of the essential elements of primary health care;
- To facilitate the development of a curriculum for adoption in medical training at universities and medical training centres in Kenya;
- To create awareness about the needs of, and care for, the terminally ill;
- To play a role in the equitable establishment of hospices and / or palliative care teams throughout Kenya.

10 Others include: Meru, Kisumu, Nyeri, Eldoret and Coast (Mombasa) – all established hospices – and palliative care teams in two mission hospitals: Chogoria Hospital and Maua Methodist Hospital, both in Meru district (Wright & Clark, 2006).
4.4.2 Uganda

**4.4.2.1 Reach One Touch One Ministries**

Established in 2003, Reach One Touch One Ministries (ROTOM) is a Christian non-profit organisation, operational within the Mukono (Mukono County) and Kabale districts (Rukiga County) of Uganda, whose mission is to enable the elderly and their dependents to acquire a bearable form of existence spiritually, socially, mentally, economically and physically, and to equip them with life skills which can help them live dignified lives.

From 2003 when we started with only one older woman, it’s now helping 358 older people plus 100 orphans under their care ... we have (without me) 10 staff. Out of those 10 staff, two are administrative staff, the Finance and Administrative Manager plus an Administrative Assistant, the rest are field staff. We call them Senior Care Workers. They care for the older people and our approach is out reach ... Up to now we do not have a home; we do not have residential institutional support. So what we do, we go to communities, we work with local councils and churches to identify the neediest older persons and we enrol them into our programme, which we call Senior Sponsorship Programme. When we enrol them into our programme they get the benefits which we offer, which is: a weekly visit; a weekly fellowship with each other to support each other (psychosocial supporting kind of group or peer counselling); a monthly supply of groceries; free, complete medical care – if somebody falls sick, whether it is for one day or forever, we commit to help cover the expenses of medical treatment, which is doctor’s professional fees, plus the cost of drugs. For some, we also cover the cost of care, like for feeding, those who have nobody completely but it is limited. It is actually discretionary, it’s kind of case-to-case basis. It’s not within our policy but we give this much for transport or for food. But sometimes we find that older people have no family and we have pay for the treatment (RES UAG63).

The health scheme is in part facilitated by a card-based identification system:

Each of us was given a card. When you get sick you take that card with you and show it in Mukono Health Centre. They give you treatment then ROTOM pays the bill (RES UAG58).

ROTOM also started providing an income-generating project:

What we have done is provide small animals like piglets, chickens and goats so that they can sell and maybe buy, say, something for the children. And its only seven months old that we are trying that out, we want to see if it works so that we can mainstream it in all the areas where we have old people. Because the challenge is that old people are also not very good at managing income generating projects. They are weak, especially the ones we help. We target the very weak and they are really not able to work hard. So we are trying to see if the grandchildren can work with the grandmother to look after the chicken and it is a challenge because the child has to go to school and the grandmother is weak. We are starting with only those 100 orphans and their grandmothers so if it works, we mainstream it as a source of income security. (RES UAG63).

Recruitment to the ROTOM service is not disease-specific and primarily undertaken by involving the local community:

So the criterion is they must be poor and we have an index for the poor ... It covers areas like housing, health condition, number of orphans under your care, source of income, do you have any investments do you have like land, do you have a house from which you can get income, do you have any savings somewhere? ... We do not have (disease) criteria because we do not review diagnosis at the time of entry. We use a lay man’s opinion of your health status. I mean … if you look sick and you have been sick for a while either you have been not able to go and work in the garden, sometimes we discover your sickness after but we have not said that who has this sickness, has a higher priority. No, we do not (RES UAG63).

Normally the age starts around 64 onwards. Anybody that falls under that age bracket is counted as a senior but still we consider a few other things as we do the selection, like ... the state the senior is in, financially, could be well off. There are some seniors that are well off. Those ones don’t qualify but the ones that ... we call them, ‘the needy of the needy’ ... the ones that are really in the need. Could be financially – has no one to provide, probably he is isolated, he is neglected; those are the ones that we go for ... Normally we work hand-in-hand with the local leaders and church leaders in particular areas ... we give them the criteria written; they read through and find these people that can match the criteria. They go out from their...
villages, they identify them and depending on the criteria of course, they go around... (We then) go on the ground to interview these people to find out more (RES UAG45).

The organisation has three main funding sources, all of which are externally generated: first, Senior Sponsorship, where an individual sponsors a senior for a certain amount of money every month; second, project funding (one example of this is the Stephen Lewis Foundation-sponsored Grandmothers Support Project, with the aim of providing psychosocial, medical, economic and spiritual support to poor grandmothers in Bukinda sub-county, Kabale district, enabling them through improved physical and emotional health to raise the grandchildren in their care); and third, general donations, especially from whites; somebody hears about our work and just says I'll give you an amount of money. Do with it whatever you want (RES UAG63).

In recent years they have acquired two acres of land to build a Senior Citizens’ Centre that will house and care for abandoned, very sick and terminally ill aged.

4.4.2.2 The Aged Family Uganda

Established in 2000, and operational in the districts of Kampala, Wakiso, Luwero and Mukono, The Aged Family Uganda (TAFU) seeks to ‘have an independent older person with dignity. Therefore our work is empowering the older people for independence and dignity; empowerment for independence and dignity’ (RES UAG64).

As one of the founders of TAFU recalled:

Ah well, it’s like professionally we are teachers and we wanted to come up with a voluntary service to the community... We looked at the marginalised groups. The aged or older persons were the group of people who were not catered for by many of these organisations. That’s why we came up and said that voluntarily we can do that so we started slowly up to today but the idea is basically that... Personally I grew up with my grandmother who is really aged and I remember seeing the way she used to struggle for our wellbeing when we were very young. I still also have that and I thought that maybe there are some organisations... which can come up and people of good will to help the older persons, then they can also be put in line like any other marginalised groups of people to be considered to fight for their rights (RES U64).

The services primarily offered by TAFU are care-based:

Care involves... visiting an older person, social contact, talking with the older person, advising on meals, cleaning the environment where the older person stays, fetching water, collecting firewood, advising on the administering of medicine, provided the doctor has prescribed the medicine. Sometimes we go as far as involving transport; transporting the older person to either hospital or a nearby clinic... When the project coordinator goes to an area, we identify what we call parish coordinators. Now the parish coordinators they have got three tasks. The first task is to identify the neediest older person who needs our services; another task is to assist TAFU to recruit volunteers11 and to monitor the work of the volunteers then advising TAFU. After getting the volunteers, now the volunteers can do the work, the real work of caring for an older person. Most of our volunteers have got at least three old people they are caring for; visiting the older person twice a week; at least twice a week for one hour (RES UAG64).

In some instances, TAFU also assists with transport to the relevant health centre:

Sometimes you may find that they (the aged) can provide food but they can't provide transport to the hospital maybe for the checkups. Then TAFU comes in with a van, it comes, it picks the patient, takes the patient to the hospital with the care takers, they administer, it brings the patient back then they wait to see when he is supposed to be taken (RES UAG42).

Referral to TAFU services is primarily achieved in three different ways, two of which are informal in nature:

What happens in most cases, when the relatives contact TAFU, TAFU goes there to look at the home, to look at the patient, the conditions of the patient and what he needs. Then after seeing the patient, the home area how it looks, the facilities to use, that's when they contact you as a volunteer then they tell you we have got such a patient, he is in this area, the home is like this, these are the facilities used within a home and we are to go there, that's where we want you to go. Then they will take you to introduce you to the family. They are the ones to introduce you to the family. Then there are some others who say that, 'There is an elderly person down there who has no body to attend to but I think I saw that the Aged Family... deals with

11 These volunteers are reimbursed for any food and transport costs incurred in the course of their work in the community.
the elderly. You go and tell them that there is somebody here'. So that one will come ... Then at times you find that as you move around, you say, 'Jajja muli mutya'[granny, how are you doing?] like that so ... as you interact, they will get to know you and say, 'Eh, come again'. So that's how, actually the three approaches are used (RES UAG42).

Financially, TAFU faces the challenges of many similar African organisations seeking to address the unmet needs of the aged in society:

That is the biggest tasking work we find. Soliciting finance is very difficult more specially for the organisations which advocate for older people. We always get comments like, 'that is not a target area' from them. 'It's not a good area'. 'Old people are going to die'. Therefore we try as much as possible to get finance but in most cases we fail (RES UAG64).

4.4.2.3 Hospice Africa Uganda
Established in 1993, Hospice Africa Uganda (HAU) pursued a vision of establishing:

A hospice that would be adapted to the culture and to the economic circumstances in Africa ... (that) would be modelled in one country then through this model help Africa to get off the ground ... The objectives were to provide a service, first of all, with very good standards to serve patients in a different catchment area; secondly to start training both health professionals and non-health professionals, so that this form of care would be available throughout Uganda; and thirdly to assist other hospices throughout Africa in their work by being a model and by training for them (RES UPC61).

The work of HAU, one of eight organisations in the country providing palliative care, includes:

(Providing) services to patients who are needy and this service should be accessible to all people in the villages. And we normally see patients at Hospice, others are seen in hospitals and others seen in their home. As you know, cancer; by the time they come here, their diseases are really terminal. They present in their later stages so most of them are being referred to Hospice for palliative care ... at the moment we have about 337 patients on the programme and we move in a catchment area of 20km away from here (RES UPC62).

Whilst some referrals are conducted directly from the community, many are via referral hospitals, especially the Mulago Hospital:

I got to know about HAU through a doctor friend of mine who has a clinic around this village. I approached him and referred my patient to Mulago Hospital. It is from Mulago that she was referred to HAU for further management. And it is this doctor friend who brought the HAU doctors to start offering the care to my patient from home (RES UPC35).

It was in Mulago Hospital where she had been admitted for long and it is the health care workers who referred her referred to HAU Makindye (a district of Kampala) for more specialised palliative care (RES UPC38).

4.4.2.4 Palliative Care Association of Uganda
Established in 1999 to help support and promote the development of palliative care and palliative care professionals in Uganda, the Palliative Care Association of Uganda (PCAU) is comprised of organisations and professionals from throughout Uganda with an interest in palliative care. The objectives of the association fall under three main areas: capacity building, advocacy and networking.

With a current membership of over 345 individuals and organisations (comprised of multiple stakeholders involved with HIV/AIDS and cancer and traditional medicine), PCAU currently operates in eight districts of Uganda: Hoima; Iganga; Jinja; Kamuli; Kampala; Lira; Mbarara; and Mukon; six additional districts are currently being assessed for operational coverage: Arua; Gulu; Kasese; Kibale; Kitgum; and Soroti.

As one respondent commented:

(The) Palliative Care Association of Uganda is mandated with the task of spreading palliative care throughout the whole of Uganda. (It tries) to scale up palliative care in the districts by supporting health professionals who have been trained by Hospice Africa Uganda, Mildmay (International) and bringing them together so that they can work together and support patients with life-limiting illnesses in their own districts ... (It) support(s) palliative care ... promote(s) palliative care throughout Uganda ... (It does) capacity

12 Others include: Mobile Hospice Mbarara and Little Hospice Hoima (incorporated under HAU), Kitovu Mobile Home Care, The Mildmay Centre, Joy Hospice, The Palliative Care Unit at Lira Regional Referral Hospital, and the Association François-Xavier Bagnoud (Wright & Clark, 2006).
building, that is by training, mentoring to enhance palliative care knowledge and skills in the health professionals ... (It does) advocacy at all levels and setting standards is also (its) role and then to strengthen networking and collaboration is also another role ... (RES UPC60).

4.4.2.5 Uganda Reach the Aged Association
Formed in 1991, and an affiliated member of HelpAge International, the Kampala-based Uganda Reach the Aged Association (URAA) that is operational in 58 districts of the country and works with approximately 83 groups, coordinates the activities of age care organisations based in Uganda. Additionally, it advocates for the mainstreaming of issues affecting older people into the wider development agenda to engender a lasting improvement in their lives, to ensure that the quality of their lives are improved, and that the dignity of older persons in Uganda is preserved (Uganda Reach the Aged Association, 2006). More specifically, the URAA works in the following areas:
- Policy development
- Advocacy
- Information and research
- Strengthening organisations for older people
- Improving the socio-economic position of older people.

The URAA is primarily funded via HelpAge International, with additional funding derived from project-specific grant proposals.

4.5 Limitations of existing care services
Current limitations for services directed towards the needs of the aged are multiple and characteristic of many home-based care services on the continent: insufficient staff numerically; inadequate finances; and inadequate health skills.

"We have some problems we really encounter, like the issue of money. You know money is a problem in an organisation like this and we have very many grandmothers, some of them don't have even (have a place) to stay so sometimes, like our children, they just disappear, and we don't know where they are ... Ok we feed them by selling some of these things handicrafts etc. If we don't sell they will not have anything, they have not eaten, so they will go away so we can't produce (RES KAG13).

Finances are always a problem because most patients are from the slum areas and require financial boost (RES KPC15).

This can result in an overburdening of scarce human resources:

"On our part we have inadequate staff because there are 60 grannies and I am alone, so it becomes challenging to attend to all of them effectively ... Some (of their relatives) ... have abandoned them leaving their care to the church. The role of this programme was not to cater for their needs completely but to give a hand to the aged and their families to enrich their lives but everything has been left to us. The old people over depend on this organisation and do not try to seek help from their family members (RES K11).

In terms of health needs, staff identified training (and the purchase of the necessary medical equipment) as critical:

"In terms of the health services we offer, when they have serious problems it becomes a challenge. The elderly need a lot of money to spend on health because they have so many diseases but the services are not provided ... Some of them have very complicated diseases but we don't have funds to take them to good hospitals. We are not able to address those major diseases (RES KAG33).

"I want to know how to ... measure high blood pressure and diabetes, then the malaria. I want them to teach me. I think I can make it ... Anyway we need training ... in fact we need training. We really want it (RES U41).

"As (X) is lacking the funds, when we reach there in the field, we lack the medical tools like the gloves, or measuring for temperature.
MOD: The thermometer?
Yeah the thermometers and those for measuring pressure, they are not enough. As we keep on rotating those machines are not enough. They are few and for us we are many (RES U46).

Also, there is a specific need for palliative care to be embedded into existing services for the aged:

"I don't know if my definition really of palliative care is the best one I have but I may say all the aged people need palliative care. According to my definition, I am saying palliative care is providing care to somebody so that he may have the social impact of feeling that there is somebody who cares for him but not necessarily that when
you provide the care, you will cure the disease ... Therefore, most of the old people need palliative care so that they can be cared for and when it comes to time of death, they can die, not miserably but they can die with dignity and independence ... (Additionally) most of the older people, they get disease and they come up with what we call natural cure. They heal naturally without any medication. Sometimes they heal, sometimes they don’t heal. Therefore if palliative care can come up with medication at least to the older people, much as they have reached their old age, they can be cared for, they get medication, then they die when they know that at least somebody has been caring. And I am quite sure that if they get medication, you can be improving on their longevity and they can live longer ... if we can get doctors specialists in cancer and dementia. Even geriatric doctors but then we don’t have even a geriatrics doctor (RES UAG64).

Another service is the government or any organisation should provide us with ... there is need for, to train, we lack a geriatrics doctor. There is no doctor who can really know ... a doctor for the aged. We lack a doctor who can maybe look after an aged that so and so is suffering from such and such a disease (RES UAG46).

I know some of those organisations that are caring for the elderly ... they will go out, take care of these patients, the elderly, physical care like the basic nursing care, turning the patient, feeding the patient, you know, keeping the patient company, those kinds of things. And then I’m sure when it comes to pain and symptom control they would then look for somebody who has knowledge in that area to help (RES U60).

Other palliative care service training gaps include, for example, bereavement counselling and a wider community sensitisation to the value of the aged and maximising the quality of their lives, and easing painful symptoms:

Then another one is will writing. Writing the will, eh, since most of the aged we are working with didn’t go to school, they are green about writing wills and so on and so forth. So there is need for that service also (RES UAG46).

Since (palliative) care involves giving care to the sick people who are not expecting to survive, their life expectancy has reached the climax, and then we need to sensitize the families not to abandon those people. Because you reach there and people they can say ‘No’ since this person is not going to live, its better we leave him or we leave her to die alone. We need to sensitize to reduce the aged people who are dying miserably (RES UAG46).

Of course, the health care is basic. We cannot manage pain and other symptoms. Probably partnering with an organisation that can support this would be a great strength ... We cannot afford employing medical personnel and for this reason we cannot offer serious medical care yet many older persons cannot travel long distance to get to the nearest health facility. Worse still, drug stock-outs or unavailability compromise the essence of the long travel, so providing care within the homes can help greatly and since we already have home care teams a partnership would be great (RES UAG59).

The (X) provides only basic care. We don’t go to the medical part of it. We only provide medical basic care ... They should train more people to handle the aged; geriatrics doctors (RES UAG64).

I don’t know if this is termed as palliative care but there are old people who do not have HIV/AIDS, who will not have cancer but who will be in a condition that requires continuous pain relief, that requires almost 24/7 assistance to be able to live in terms of going to the latrine, in terms of feeding, in terms of washing and all the time ‘eh amagumba ganuma’ (eh, my bones are hurting) (RES UAG63).

There is also the recognition that palliative care service providers are not necessarily easily placed to address this palliative care gap, as many are already struggling to meet existing service demand for both inpatient and home-based care services.

I should say this, at management level we have had this outcry from the population around. Most people wished we had an in-patient facility because as much as we are offering home-based care, at times these patients are very sick and would need an in-patient management. Most of the time we have been referring them to the main hospital. Most people feel we are handicapped by the fact that we cannot have some of them admitted here. We cannot be able to do that because of human resources. We need to have more staff on board, maintain them, keep them, and even take care of the patients. That has been a hindrance to making better quality of our services to our patients because most of them would want to be admitted and nursed here (RES KPC19).
Ok, well right now I wouldn’t say that here is something that is hindering me from like looking after patients but maybe on the side of patients…well, most of them are what…they are poor. As I said, most of them don’t have carers and somehow it is not easy like for a hospice staff to be at home like every day, you get it? Like to be there like 24 hours in a home … yeah, so maybe we don’t have that service yet (RES UPC43).

Additionally, existing palliative care services are not sufficiently trained to address the specific needs of the aged:

The other issue is differentiation between the three groups in the medical team for training youth and the elderly. They have different needs but the approach which (we are able to) offer … does not tally with the three groups. There are special needs for the children, special needs for the elderly, and special needs for the middle aged (RES KPC18).

4.6 Addressing service limitations and integrating services

Respondents suggested integrating palliative care services for those for the aged at two different levels; level one primarily entailed relevant training (especially on pain management) from established palliative care organisations, and joint advocacy directed towards advancing the aged agenda; level two is a more challenging and qualitatively substantial form of integration that, though not explicitly and coherently defined by a majority of respondents, is clearly manifested as a potential model of service delivery: that is, a more long-term strategic partnership between the two types of organisations that not only includes training to eradicate existing skill gaps but additionally is community-based, entails the localised identification of need, and differentiated treatment options according to patient need, and situates follow-up care within the community.

4.6.1 Training

Training to address existing skills limitations is recognised by respondents as necessary, in palliative care specifically (especially in pain management, which is one of the defining differences between generic care for the aged and specialist palliative care) but also in basic medical skills generally:

The … gap I see is lack of education because maybe I am just volunteering out of passion and I don’t have the qualification. If only I went to school and I was really impacted with community development and taking care for the aged in a high class manner I could offer my services in a professional manner. If there was a situation where they are falling sick, or dealing with somebody who is aged and are not feeling well, I don’t have knowledge on the illness. If only we had knowledge we would help (RES KAG6).

I don’t think they (aged organisations) have the skills to offer proper geriatric care to these patients. And you will find that most of them are using volunteers or people whom they have trained but they are not … they don’t have a nursing or a medical background but because these people are interested in caring for these patients, they may just go in and start caring for these patients without the nursing or the medical background. So I would think that is a challenge especially if they find that somebody has a symptom that needs to be managed medically (RES UPC60).

One of the needs is having trained personnel in terms of either social gerontology or geriatrics. People at whatever level who are able to deal with older people’s needs, medical needs and psychosocial needs; they need to be trained and I cannot, I am not able to train my staff or even find trained staff (RES U63).

We know that when people start aging the next thing is death. We do not have capacity to handle people nearing death. In Uganda people think about dying (from) another perspective. Some think older persons should be left to die like dogs. Palliative care would really benefit older persons in this perspective, especially those dying of HIV. Anyway, I personally believe that death is death and it’s painful, so it is important that if people must die then they should die with dignity, without pain. I think we need to partner seriously with palliative care providers to help people have dignified and pain-free deaths. Older persons out there are found dead in homes and for three days nobody passes by, when one finally passes by they found dead and the corpse has been there for three days. So if we can partner with palliative care providers we can improve on the way older persons are dying in Uganda (RES UAG59).

We need more training, deeper training, at least if possible … we need to go deeper as far as pain management is concerned and that one will be through deeper training (RES UAG42).

Yeah, like the physical part of it, pain control, where I know in the (X organisation) they just have auxiliaries working on these patients. So when they reached on the
side of pain control, they want us to intervene ... I think for them they only have this step one – the aspirins, the panadols, and even they can’t do with morphine because it is supposed to be kept in a hospital (RES UPC62).

In the morning they have somebody who works as a nurse within (the aged organisation) but may need even to be trained and get these skills and get to know the palliative care and at least if you, as you have mentioned, that you have those organisations which deal with elderly, we need them to come and get at least this package (of training) even if they are not professional we have some allied professionals. We need to train them and we see how they really inspire their skills and ... if there is a medical can really come and do the health professional and disseminate that palliative care to elderly patients in their homes (RES UPC62).

If it can be found that within the elderly there are some who need palliative care, we can enter into the programme for the aged and help in providing the services for them, maybe through training the care givers or just connect them to the nearest providers of the palliative care. So we can help them introduce palliative care into the programs which already exist (RES KPC32).

A potential challenge will be the extent to which the two organisations are not seen as in competition with each other. This can in part be minimised if the partners work together on a reciprocal basis, such as generating co-funding for training opportunities, and also using the skills of personnel from aged organisations to inform those of palliative care staff used to addressing disease-specific conditions rather than the specific needs of this age group:

There is always a challenge when you are trying to introduce something new to an organisation ... We also need to convince them that we are not competing with them. We should also assist in sourcing for funds for training and sensitising their workers and show them that (they are) in need for palliative care for the elderly. We may ask them to attend the training in Nairobi hospice may be twice a year to identify the training they need whether it is a health or non health-professional training. We also need to provide the drugs for palliative care to the centres to make them available for them to use. Resources will also be one of our major challenge since if you have to provide services you will need materials, personnel and these requires a lot of funds to be availed.

MOD: Do you have the suggestions on the ways in which the challenges can be overcome?

I think we should work with the organisations that are dealing with the elderly people, and this will be an entry point into the lives of the elderly, for example, Health AIDS Kenya, Health AIDS International and Help the Aged. We should also work with the palliative care providers to see the special needs that are not provided in their care and also provide funds for the provision of these palliative care as well as addressing other issues apart from these cancer and AIDS that the elderly have that might need palliative care (RES KPC32).

There was also a need for advocacy work:

We also need legal support to push the policy for older persons in Uganda. It's lacking up to date! ... right now we are operating in a vacuum in terms of policy. So that is a serious hindering factor operating without a policy is like operating in vacuum; we have nothing to back us up and operating without government support is not easy in Uganda. There is no way we can fall back to government because the constitution does not recognise us. This is a very big challenge: we cannot ask for government support (RES UAG59).

I may say that the biggest percentage of our work on the old people has not been covered. (X organisation) cannot even cover 1% of the needs of the older people ... There is a biggest gap for first of all advocacy that people may understand that the old people have got a lot of problems (RES UAG64).

4.6.2 Community involvement

A potentially more challenging integration between the two types of care organisations could be premised upon the involvement of the community. In this respect there is an ongoing debate within palliative care circles regarding the extent to which the community involvement model that has been advanced in Kerala district, in south-west India – which has been described as an ‘example of high-quality, flexible and low-cost palliative care delivery in the developing world and illustrating sound principles of cooperation between government and NGOs’ (Seamark et al., 2000) – can be replicated in other resource-poor settings. The Kerala model, which entails a network (called the Neighbourhood Network in Palliative Care) of community-based, volunteer-led autonomous initiatives (that replaced the previous hierarchical doctor-led service) linked to the palliative care centre based in Calicut, Kerala, uses volunteers in multiple capacities, with the frontline staff with clear role delineation to address non-medical work (to avoid potential disputes with qualified
health professionals), such as history-taking, explanation of medical regimens, provision of emotional support, educational initiatives and administration work (e.g. planning and organising the service, raising funds, administering the day-to-day activities of the programme, attending to and organising support for patients’ social and financial needs, and organising rehabilitation programmes), with the first three undertaken on a domiciliary basis, thereby enabling these services to gain insight into the patients’ socio-economic circumstances (Rajagopal & Suresh Kumar, 1997). As its principal advocates stated:

_The pain and symptom control clinics with satellite units seen in Kerala seem a very appropriate model for reaching the maximum number of patients at minimum cost (Rajagopal & Suresh Kumar, 1997)._  

However, doubts have been raised regarding the feasibility of replicating the Kerala model in other resource-poor settings (Ekbal, 2000), given the area has a number of idiosyncratic features (e.g. Kerala has the highest literacy rate and health indices in India, along with 66% of the total 100 palliative care services in the country, covering a population of more than 12 million people (Kumar, 2007), while many volunteers are highly socially and politically motivated, often with much better administrative and organisational skills than the average health care professional). Indeed, its proponents do not advance Kerala as a ‘one-size-fits-all’ solution to the considerable variation in social ecology that exists in resource-poor countries (Kumar, 2007). Moreover, the service delivery model advocated by Kerala is underpinned by a sustainability model that is premised upon a funding base that is 90 per cent locally generated, primarily through small donations (e.g. one rupee per day or even less) collected from households, shops, or individuals), on the understanding that the community is willing to support these initiatives because the principal beneficiary is the community itself.

Responses from some study interviewees suggested that replicating this model might not be unproblematic in the two countries:

_The other problem is bigger, which is more of an awareness and voice problem. People take older persons ... first of all they think older persons are OK. Your family takes care of you, which is not necessarily true these days because there are more poor young people who come to care for them. For the communities and the authorities and other organisations to know that they (the aged) are not OK and therefore take responsibility. It's like an awareness problem, it's a network problem and we need to be a bigger voice, many of us saying the same thing so that people can respond to it. So that even families can say, 'No we cannot leave our people to just go' (RES UAG63)._  

Actually among the many challenges, one of them (is) ... in fact the communities themselves, they look at these elderly as people who are now useless. For them they think that spending much time looking after the elderly is just a wastage (sic) of time. Even the elderly themselves they say that, ‘Ah, after all I'm going to die, why should I struggle to do a, b, c, d?’ At times we try to educate them that, ‘Now you do this, you’ll live for more years’. ‘After all, I’m going to die. Why should I continue suffering?’ So, at times they look ... people in that stage they look at themselves as useless in addition to what the community look at them (RES UAG42).

However, one suggestion to address such views was to start a sensitisation process in local schools and churches:

_There is (the need for) awareness ... it will take time to convince others to donate money. That's why I have started awareness in churches and schools. The plan I have is to start work on the jajjas (grandmothers) clubs in schools so that there is a club which talks about old people and if possible raises support for old people in their schools (RES UAG63)._  

_I would love to say that these programmes should come down to schools, right from primary. And, for example, you say that we have to train these children that we have sick people either in hospitals or even at home so they come up knowing and we get some ... maybe a day in a week whereby you get a group of children to visit some patients in the hospitals and they see how people ... which experience ... which conditions, in fact hard conditions these patients undergo. Because you find somebody who has never seen even a patient, from primary one, that child has never seen a patient who is admitted in a hospital ... Throughout primary level then secondary, those are the people that are giving us headache ... So I think this programme should come down to schools and we get them, these children come to know. In fact if from primary if we come to know that there is a need of caring for patients and you grow up like that, I think our communities will be OK (RES UAG42)._
And telling the community... that it is... that is how we go through. Every person today is young then there is a time when they will become old. Know that being an old person is not a what... is not a crime (RES UAG42).

Now I have discovered, you know, during my stay in ROTOM that seniors are very valuable kind of people. They can do much more, they just need a hand; someone to show them what to do... If somebody out there could stand and help them to know that they are people of substance, people that can still offer something to the changing of the society or to the government, it would be very good (RES UAG45).

Additionally, any community model that was centred around volunteers from the local community poses an additional potential challenge:

Even another gap is this word ‘volunteers’. In many communities people really don’t know the meaning of volunteering; that’s also another gap. If you tell people, ‘at least you can volunteer to help so and so’. No... Most of the people in Uganda have not understood the meaning of the word volunteering... According to the community, they think that type of work is done by whites but in Uganda they are not in favour of that word. Volunteering, they are not in favour of that word. If you use the word volunteer, you have to talk and talk and talk. Therefore they expect that a volunteer should be somebody who should be paid for the services he does by the government; that a volunteer at the end of the day should be paid (RES U64).

Given the limitations of over-reliance on volunteers, it was suggested that there could be training within the community, using a combination of dedicated community-based care givers and family members.

MOD: So these are different people who will need to be trained within the community?
Yes, I think we can have community care givers and families so that say the caregivers can support the family members. I think the key is the family as long as people have family. But the funny thing is that some of these people do not have family they are attached to and family... it really beats me. I don’t see why I would want or wish my father or mother to die. I would rather want to do everything I can but people don’t. You come at home and this lady has been in whatever, pupu (faeces) for hours and when you tell them they say, ‘anti oyo naye! Ah! Buli kaseera tubela tulongosa tulongosa!’ [Eh, that one also! Ah! Every time we are cleaning, cleaning!] they get tired. And you know even that person can slacken but for a staff it’s your responsibility because you are trained. There you can hold somebody accountable. But you cannot hold somebody accountable just for being a volunteer... Even primary level, if we train them on how to clean an older person or how to administer a certain drug, they will provide the service (RES UAG63).
Training people on how to do that so they can do that kind of care based in the communities like they may be affiliates or associates of (X organisation) based in the communities where we work that are trained in that. And when that training is provided, we provide them with things to use, and provide them with the facilitation in terms of finance. So that’s how I can incorporate palliative care, continuous care for them and then the drugs for those who need drugs. They are basically pain killers because I don’t have the majority. Pain killers which are not even the extreme ones not like the cancer kind of pain; the ordinary bedridden person … The other way of integrating palliative care into care for older people is just maybe to have some regular training financed but accessible to all those who are working with old people … The other one would be an ambulance service … Having an ambulance service accessible to these people when they are in critical condition to be run to a facility where they can get more professional care (RES U63).

Given the nature of the care provided, the resource limitations of existing palliative care providers, patient transport costs and their cultural preferences for care locations, localising care as much as possible was perceived as ideal, with partnerships centred primarily around the community:

Our service is really home-based. We want to see them at home because many patients, when a research was done by people, they found that many patients, they wanted to die at home when the family members are there. So at least we want them to be in a home because even if we send them in a hospital, the expertise can’t do anything much, they’ll just put on IV bottles just to prolong the process … when the palliative care specialist is here, he will just go and see the patient … then the frequency of reviews will depend on the condition of the patient, but mainly home-based (RES UPC62).

If we can be given basic care from the homes and we are saved the burden of going to hospitals unnecessarily, it’s a burden for an old person and nobody seems to have interest in us, which is so bad (RES UAG57).

However, it was recognised that there might be a need for institutionalised care provision for a minority of desperately needy patients, but this is the exception to the community-orientated rule:

The other issue is what I have not been able to deal with, like I said, I cannot build a house for everybody or even provide somebody to care for them. That problem beats our assumption that older people always stay in their own homes and therefore there is no need for institutionalisation. Maybe not now but I think there will be a need because if I did not bring this old man here, I don’t know where he would be. I have had to bring old people from their house to live in another old person’s house. And I complicate even problems for those older people because now their relatives say, ‘Why do you bring this one here?’ So a place, maybe not as a rule but a place where some people can go for hospice care or for care when they are very weak, when they cannot care for themselves (RES UAG63).

These partnership networks must work better together, including other non-palliative care ones that address the needs of the aged:

(Organisations) should talk about other organisations offering the same services such that the information is circulated out very fast even to other people who are not aware … such that whoever goes in a certain area he also talks about other organisations that almost offer the same services … Like (X organisation) … those guys … they came with a different programme. So such organisation confuses people. For them they look for the sick people in the hospital so some people get mistaken with the two – the aged and the bedside because these ones look for the old, needy but those ones for the bedside look for the sick people. If you are a kid or an elderly, so some people get confused with the two (RES UAG42).

What is being tentatively suggested by the respondents is a modification of a model of care provision that is currently employed in palliative care in Tanzania; i.e. the Selian model (Hartwig et al, 2008). Not only is this model community-based in nature, it is centred on the provision of relevant training (i.e. a 21-day HBC course on the provision of physical, emotional and spiritual support to people dying of HIV/AIDS, cancer and other diseases) to community volunteer caregivers recruited from a network of churches, and tiered interventions (including ultimately referral to the organisation’s medical team) according to the severity of the presenting problems.
5.0 DISCUSSION
This study aimed to:

- Describe the current life experiences of, and existing care services for, aged people and identify their unmet palliative care needs in both countries.
- Provide evidence-based recommendations for the future effective integration of palliative care into existing services for the aged in Africa.
- Highlight the key components of a provisional palliative care research agenda for older people in Africa.

It is clear from the study respondents that the lives of many aged people in Kenya and Uganda are characterised by social isolation, despair, and poverty. Whilst these life situations are evidently commonly experienced by the aged who receive aged care services, and those who receive palliative care services, it is the issue of adequate pain assessment and management, including appropriate analgesic drugs (in conjunction with other palliative care and generic health care services, such as bereavement counselling) that is especially deficient in care services for the aged, the component that in part defines the essence of palliative care.

Currently, integration between these two services is minimal. More specifically, given the donor-driven funding and disease-specific remit of palliative care organisations, organisations for the aged typically only refer patients, ordinarily via established referral hospitals, diagnosed with HIV/AIDS or cancer, when the diseases have progressed.

Importantly, the primary means for addressing this deficient synergy between aged and palliative care organisations was centred around palliative care training, or a more significant and potentially problematic (but not necessarily implausible) more strategic working partnership that ultimately has its fulcrum based in the community. Importantly, however, the model provisionally outlined by respondents is that of an implementation model only and does not consider the financial sustainability issues that are at the epicentre of the Kerala model. However, given the extent and severity of the poverty that characterises the lives of many African study respondents, and the limited coverage of current aged care services, it is unlikely that local communities can make any effective contribution to the recurrent costs of such services in a way that is anything more than nominal, rather than sufficient to attain a funding critical mass that eradicates the need for external additional funding, such as non-governmental organisations (Callaway et al., 2007).

Additionally, the faith-based Selian model that the proposed integration model echoes is importantly reliant upon ‘evangelicals’ rather than ordinary volunteers, people whose motivations for engaging in such work is typically spiritually-driven altruism (Powell & Mwangi-Powell, 2008).

5.1 Limitations
In addition to the usual limitations of qualitative research (e.g. the failure to enumerate the issues addressed renders generalizing its findings problematic at best), this study was based upon self-reported data – which possibly resulted in socially desirable responses – from a non-randomly sampled population. However, this study explicitly aimed to identify and explore some of the primary palliative care issues in the lives of aged people rather than quantify their prevalence, and attempted to ensure the validity of the resulting data by consulting with a small number of interviewed respondents and triangulating the data collection process by using different groups of stakeholders.

6.0 RECOMMENDATIONS
Before highlighting the key components of a provisional palliative care research agenda for older people in Africa, this section proposes a number of additional recommendations based upon the proposed two levels of potential integration. These currently non-prioritised recommendations are broad-brush at this stage and will be refined into specific proposals subsequently.

6.1 Integration
6.1.1 Training
This option could be implemented to varying degrees of rigour, from one-off training sessions that provide staff members of aged care organisations with basic palliative care knowledge and skills, or more substantially as part of an ongoing training programme that could have an embedded mentoring component to it, within a learning environment that is mutually pedagogic in nature, so that staff from aged organisations exchange their experiences of working with and tending to the needs of the aged with palliative care staff. Central to this training would be the need to be sensitive to, and address, the concept of patients’ total pain, which could be advanced in part through country- or regionally-focussed advocacy and campaigning work with various potential palliative care partner organisations.
6.1.2 Community partnership model
Pursuing a more significant community-based model of care provision based around a strategic partnership between both organisations would necessitate, in the first instance, a meaningful dialogue to clarify what the precise nature of that model could and should be, given the financial constraints facing the care organisations, the attitude of local communities, and the sensitivity and cultural expectations of local populations.

Part of this model could entail the development of effective and transparent referral pathways that negate the need for hospital referrals, the harmonisation of the two services so that any areas of duplication are minimised and service delivery cost effectiveness is maximised, the development of effective access routes for pain assessment and management based around a tiered care approach (starting in the community on a home-based care basis – possibly entailing immediate family members in the first instance, where they exist, to provide rudimentary care [e.g. change dressings, dispense drugs, maintain pain charts, and provide massage and physiotherapy] and to highlight changes in patient need as they arise – and referred for more specialist attention where the need arises), effective joint advocacy to advance the aged care policy agenda (e.g. for the development of geriatric training modules and ultimately pre- and in-service training courses, that begin to address the training deficits of the young medical practitioners the aged report feeling uncomfortable with), the joint development of service development funding proposals, substantial and recurrent mutual staff training programmes, and community sensitisation to the needs and inherent value of the local aged.

Inevitably, given the financial and human resources constraints facing both organisation types, there will be cost implications arising from such integration work that cannot be borne by existing budgets and will require external funding.

6.2 Research agenda
Whilst establishing a palliative care research agenda in Africa is not without its challenges (Harding et al., 2008), the growing interest in establishing an evidence base to underpin palliative care service provision in Africa is a component part of a wider impetus to advance a global palliative care research agenda (Powell et al., 2008). Central to this is the Declaration of Venice, a product of the European Association for Palliative Care and the International Association for Palliative Care to develop a global palliative care research initiative, with a special focus on non-industrialised countries (Anon., 2006).

Pivotal to any short-term research agenda for palliative care and the aged could be an evaluation of any resulting service integration models, be it simply the incorporation of training into the work of aged organisations or the more substantial community-based integration model. Such an evaluation could entail a quasi-experimental study design, using patient-level outcome indicators (e.g. the APCA African Palliative Outcome Scale [Powell et al., 2007]) as the ultimate measure of service improvement, in combination with a cost-effectiveness analysis to determine comparable programme costings.

In no prioritised order, additional research could include:
- A feasibility study to determine the extent to which community financial support of a palliative care / aged service similar to the Kerala sustainability model is possible in an African setting.
- A quantitative survey of aged patients’ life experiences and services received (using the present study’s primary themed areas of investigation) to enumerate the extent of the problems encountered.
- A study of the pathways to palliative care followed by aged patients to determine their nature and any delays in presenting problems.
- A quantitative study of the knowledge, attitudes and practice of palliative care health professionals in respect to the aged.
- The development and evaluation of training programmes to encourage the participation of the aged in the research process. Not only would such work attribute value to the aged, it will also empower their role in the research process, and potentially increase the validity of the resulting data collected.
- A geographical comparison (both within – i.e. rural and urban – and between countries) of the principal barriers faced by the aged in accessing palliative care services;
- A comparative study of community attitudes to death and the dying process, and the aged people’s perceptions of end-of-life care (both traditional and palliative care);
- Lastly, the funding of dedicated palliative care and the aged research positions to advance this research agenda that combines international training experience with in situ practical research work.
7.0 REFERENCES


7.0 REFERENCES CONTINUED


