A STUDY ON ASSESSMENT OF NEEDS, CARE IN THE HOMES AND CLINICAL TRENDS AMONG THE ELDERLY IN KENYA

A RAPID SITUATION ASSESSMENT

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EXECUTIVE SUMMARY

Background

Little is known about the situation of Neuro-Psychological Disorders among the elderly in the Kenya and African countries at larger; although progressive mental deterioration in old age has been recognized and described throughout history. World wide, the populations of people above 60+ years are on the increase. This is despite the rise of deaths due to malnutrition, poverty, human conflicts and infectious diseases including AIDS.

General objective

To determine the needs of the elderly (60+) and their care givers in a rural and urban community, homes for the elderly and medical facilities in Kenya.

Specific Objectives

1. To determine the prevalence of dementia in the elderly using the 10/66 Dementia Research Group Module I format
2. To determine the needs of the care givers of the elderly (60+) in a rural and in community setting in Kenya.
3. To determine the challenges facing the homes for the elderly in Kenya.
4. To extract secondary data on the pattern of admissions to Kenyatta National Hospital of the 60+
5. To extract secondary data on the pattern of patients seen in two Health Centres for patients 60+
6. To review the Government of Kenya Policy on the elderly in Kenya
7. To determine the levels of depression in the elderly seen in the community and urban settings and in the homes for the elderly
8. To determine the level of depression in the elderly in Kenya

Study Design: The study took a cross sectional purposeful design.

Method

The study on elderly was a comparison between: a rural setting and informal urban settlement slum areas using mixed methodologies; in-patient elderly persons and elderly home persons; and

institutionalized elderly person in a general health facility, psychiatric hospital and old people's home.

The quantitative data was obtained using a structured interview schedule; Needs of the caregivers using Module I, all family care givers will be asked same series of pre-established questions in each category that have a limited set of responses. Clinical characteristics: The Community Screening Interview for Dementia (CSI 'D'); Psychological impact for the caregiver are assessed using the 12-item General Health Questionnaire (GHQ-12) as a measure of psychiatric morbidity; and the Zarit Burden Interview (ZBI) as a measure of caregiver strain. Qualitative data was collected using focus group discussion and these information was supplemented using secondary data.

Data Management

Data was analyzed using SPSS version 12.0 and results presented in form of narratives, tables, pie-charts and bar-charts.

Results

The results of the study indicated that the elderly who were of age 60-64 were 47% of the respondents while the elderly who were of age 65 years and above made 53% of the population. At the same time 47.83%, 29.71%, 13.41%, 6.16 and 2.90% of the elderly were widowed, married, single, separated and divorced respectively.

The study further indicated that 50.69%, 27.93%, 16.55% and 4.83 % of the elderly had no education, primary education, secondary education and college education respectively. It was indicated that 37.93%, 24.83% and 20.69% of the elderly were staying alone, with spouse and with other relatives.

The study revealed that majority of the elderly was protestant (87.63%) with the remaining one being of Catholic and Muslim faith. In addition, majority of the elderly were females (74.48%) while the rest were males with 25.52%.

It was also found that 26.90%, 19.66%, 16.55%, 14.48%, 3.45% and 1.38% of the care givers were of 30-39 years, 18-29 years, 40-49 years,> 59 years, 50-59 years and 13-17 years respectively.

The study results showed that majority of the care givers were females (69.96%) while the rest were male (30.04%). Additionally, 43.23%, 37.55%, 9.17%, 6.55%, and 3.49% of the carers were single, married, separated, widowed and divorced respectively. Further, 32.76%, 20% and 13.79% of the carers had secondary level of education, primary level of education and college/university level of education respectively.

The study results showed that majority of the care givers did not consider taking care of the elderly as a financial burden (75%) while 25% of the care givers felt that taking care of the Elderly was adding more financial burden to them.

Majority of care givers believed that taking care of the elderly was no burden to them (65.05%) while 20.76% ,7.96% and 6.23% of the care giver said that taking care of the elderly caused them some moderate ,mild and severe burden respectively.

The results of the study demonstrated that females had a probability of having dementia at 18.83% while males had a probability of 21.93% of having dementia. Rate of diagnosis of dementia among the care givers according to gender was 24.7% for males and 26.02% for females.

The study showed that female care givers had the highest percentage of dementia symptoms than men; with females at 15% and men at 10%.

The study findings demonstrated that most of the female elders had depressive symptoms with 34% of females showing depressive symptoms while comparatively, 18% of males showed depressive symptoms. Most of the patients with dementia diagnosis were females with 27.78% being female elders while 21.62% of male elders had dementia.

Conclusion

Prevalence of depression among the elderly in this study was 6.3%; and was significantly associated with gender. Thus, health care personnel can be educated to look out for depression among elderly who are females since females are more prone to depression than men.

The prevalence of depression among the care givers also calls for policies and practices that identify and support the emotional needs of caregivers.

INTRODUCTION

Little is known about the situation of Neuro-Psychological Disorders among the elderly in Kenya and African countries at large; although progressive mental deterioration in old age has been recognized and described throughout history. Due to lack of evidence about these illnesses in Kenya, provision of care for elderly leaving with these conditions is lacking. Consequently there is scarcity of clinical, epidemiological and phenomenological data on Geriatric medicine. There are limited public physical and human resources for the care of the elderly, a situation that throws back the full responsibly of care for the elderly to families and other care givers. Thus we can infer, given the dearth of health and welfare services for older people that families and other informal caregivers are the mainstay of support (Shaji et al 1996; Li et al 1989; Phanthumchinda *et al.,* 1989). However, we also know little of the psychological and economic impacts upon these caregivers and their local communities.

There is need therefore, to develop a treatment/care strategy to address the frustration and tension among health professionals as well as carers of the elderly when faced with the care of the elderly. How ever, running a special old age psychiatric service would be unaffordable by local communities, not withstanding the fact that institutionalization of the elderly has its own problems. It is important for operational researchers to develop adequate community facilities for the care of the elderly addressing practically the emotional and economic impact of caring for a family with older member in the society. This study was designed to begin pioneering this needed care by doing a rapid situation assessment (RSA) so as to get an idea of what was happening on the ground among people of 60+ years by analyzing secondary and primary data.

Background Information

The United Nations' definition of old age is any person who is 60+ years of age, someone with adverse effect of the passage of time, a desirable process of maturing. As one advanceS in age, there are physical and intellectual declines which are associated with psychological and behavioral alteration in their social and emotional functioning. These physiological changes (wear and tear in old age) influence the development of pathology; to which the elderly are prone (physical and neuro-psychiatric diseases). These disorders are seen less in younger age groups

(Alzheimer's disease International 1999). Aging modifies the reaction to disease, the response to therapy and thus determines prognosis and outcome.

Worldwide, the populations of people above 60+ years are on the increase. This is despite the rise of deaths due to malnutrition, poverty, human conflicts and infectious diseases including AIDS (Alzheimer's disease International, 1999). Statistics at Kenyatta National Hospital show a steady increase in number of older people getting admitted. In 2000, a total number of 4,414 patients aged 60+ were admitted, in 2001 a total number of 5,396 and in 2002 a total number of 5,645 patients of this age were admitted (Kenyatta National Hospital Records Department). According to the Daily Nation newspaper (2007), the number of people 60+ years may triple to two billion by 2050; accounting for nearly a quarter of the expected 9.2 billion global population, a UN report has warned. A third of these people, aged 60+ years globally will be living in developing countries. The growth has come about through fewer babies dying and adults living longer.

Total care of the elderly is a multi disciplinary approach that requires the services of general practitioners, psychologists (clinical/counseling), psychiatrists, nurses, physiotherapists, occupational therapists, social workers, dieticians, speech therapists, chiropodists, hospital administrators and a country's development planners. This also requires all grades of community workers, community agencies for care of the elderly and wide representation from the informal sector, such as family carers, neighbors, friends, church members, school children and any other persons with a desire or interest in participating in support and care of the elderly.

The elderly during the pre-independence era in Kenya

The elderly and grandparents had designated roles in childcare; they provided a useful child minding service; they weaned the infants and lived with them for several years. Children were named after their grandparents and therefore through them, the grandparents' names were carried on to the next generation (3). In many traditional African set-ups, the grandfather remained the head of the family and his generation (son and grandsons) built homes on his piece of land near his homestead. When the parents were unable to look after themselves, it became a responsibility of their sons and grandchildren to give care to them. The aged functioned as leaders at

ceremonies where ritual was important and were able to perform useful tasks such as supervisory roles in labor due to their accumulated experience and skills.

Post-independence era

After colonization, families were moved from their ancestral land to create space for settler plantations. As the traditional solidarity began to shatter, poverty began to set in and the European way of life took root in Kenya and Africa. As it is today, this has made Africa experience major socio-economic changes; the extended family is no longer the norm, and the care that occurred naturally without much conscious planning in communities is now fractured in many parts of urban and rural settings in Kenya. The search for jobs has led to a lot of rural urban migration, promoting social and psychological isolation of the elderly who are always left in the rural setting.

Interventions in Kenya

Old people's homes in Kenya are very few and are run by charitable organizations, for example Nyumba ya wazee in Kasarani which has a capacity of 62 men and women, from poor backgrounds. Other homes are Harrison house and Fair Seat Foundation, which cater mainly for Europeans and former British settlers. According to the daily nation of January 31st 2007, private home care providers (HELMA-Health Management Agency) founded by retired nurses has come up and trains staff in care giving for three months, and recruits the trained staff to private homes which are offering these services for old people who are economically stable to afford these services.

JUSTIFICATION OF THE STUDY

From the above introduction, little is known about the situation of neuro-psychological disorders among the elderly in Kenya. There is strong evidence that the numbers of the elderly is on increase. So far, there is no locally available or published data for Kenya on psychosocial support programmes for the elderly. There are also no policy guidelines that can provide services (treatment and support) from National to grass root levels. On the other hand, Kenya does not have any clear-cut operational framework on the care for the elderly. This can be largely attributed to lack of data on neuro-psychiatric problems of this population in the Kenyan

situation. Thus the study sought to determine the needs of the elderly (60+) and their care givers in a rural and urban community, homes for the elderly and medical facilities in Kenya.

OBJECTIVES

General objective

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7. To determine the levels of depression in the elderly seen in the community and urban settings and in the homes for the elderly.
8. To determine the level of depression in the elderly in Kenya.

STUDY DESIGN

The study took a cross sectional purposeful design.

Target population

The study on elderly was a comparison between: a rural setting and informal urban settlement slum areas using mixed methodologies; in-patient elderly persons and elderly home persons; and

institutionalized elderly person in a general health facility, psychiatric hospital and old people's home.

Instruments

The quantitative data was obtained using a structured interview schedule; Needs of the caregivers using Module I, all family care givers were asked same series of pre-established questions in each category that had a limited set of responses. Clinical characteristics: The Community Screening Interview for Dementia (CSI 'D'); Psychological impact for the caregiver was assessed using the 12 item General Health Questionnaire (GHQ-12) as a measure of psychiatric morbidity; and the Zarit Burden Interview (ZBI) as a measure of caregiver strain. Qualitative data was collected using focus group discussion and this information was supplemented using secondary data. An exposition of the instruments used in the study is given below.

The quantitative data was obtained using a structured interview schedule:

a) **Needs of the caregivers using Module I;** all family care givers were asked same series of pre-established questions in each category that had a limited set of responses. This interview provided little room for variation in responses. The responses were recorded according to a pre-determined coding scheme so as to reduce the researcher's influence on the participant's answers. The researcher maintained a style of interested listening which encouraged the respondents' participation without evaluating the responses. The interviewing skills involved a high order combination of observation, empathetic sensitivity and intellectual ability to judge what the interviewee said. Initial Assessment group that used this instrument was the 10/66 Dementia Research Group and was recorded by Anio Lichtarowicz, a health correspondent for the BBC World Service during the 10/66 Bellagio meeting (http://www.alz.co.uk/intranet/1066/). It was translated and back translated by clinical psychology students of the University of Nairobi who were fluent in both English and Kiswahili, and also their local language or languages to be used in the study (Kiswahili, Kamba, Luo, Kikuyu and Luhya). The instrument has:

    i. Clinical characteristics - The Community Screening Interview for Dementia (CSI 'D') (Hall *et al.,* 1993; Prince, Acosta, Chiu, Scazufca, & Varghese 2003) which combines a test of cognitive function administered to the person with dementia

(COGSCORE), and an informant interview, enquiring after the participant's daily functioning and general health (RELSCORE). Six common behavioural symptoms of dementia; agitation, aggression, repeated vocalizations, wandering, sleep disturbance and incontinence are coded from spontaneous mentions in answers to an open-ended question to the caregiver, 'What do you find difficult about caring for your relative?'. These data were summarized in a single variable as the number of behavioural symptoms of dementia.

ii. Psychological impact for the caregiver are assessed using the 12-item General Health Questionnaire (GHQ-12) (Goldberg *et al.*, 1997) as a measure of psychiatric morbidity, and the Zarit Burden Interview (ZBI) (Whitlatch, Zarit, & von Eye 1991;Zarit, Reever, & Bach-Peterson 1980;Zarit, Todd, & Zarit, 1986) as a measure of caregiver strain. The ZBI has 22 items that assess the caregiver's appraisal of the impact their involvement has had on their lives. It includes questions such as; 'Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?' and 'Do you feel strained when you are around your relative?' It has been very widely used in the USA and Europe, and also in Taiwan (Chou, LaMontagne, & Hepworth 1999) and Japan (Arai *et al.*, 1997;Hirono, Kobayashi & Mori, 1998), but not in developing countries. Its items have strong face validity across a wide range of cultures.

iii. Practical impact is assessed using the Time Spent In Week Before Interview With Dependent (Gilleard et al. 1984) enquiring after all contact time between caregiver and cared for person, whether or not care was being provided. The Caregiver Activity Survey (Davis *et al.*, 1997) assesses the time spent by the caregiver in the last 24 hours in specific care giving activities; communicating, using transport, dressing, eating, looking after one's appearance, and supervising.

iv. Economic impact is assessed using the Client Service Receipt Inventory (Chisholm *et al.*, 2000), a comprehensive assessment of direct and indirect economic costs for mental health services, adapted for use in the developing world. It elicits information on type and cost of accommodation, income (from all sources) for the person with dementia and the principal caregiver, the occupation of the caregiver, the extent to which the caregiver had cut back on or stopped work in order to provide care, unpaid

care provided by family or others in the community, paid care inputs and their costs, and the use (and associated costs) of a variety of health care services.

b) Beck Depression Inventory (BDI)

The original BDI, first published in 1961 was created by Dr. Aaron T. Beck in 1961(Beck *et al.*, 1961), and later revised in 1971 (appendix 2ii). The contents of BDI were obtained by consensus from clinical settings regarding symptoms of depressed patients (Beck *et al.*, 1961). The revised BDI items are consistent with 6 of the nine DSM-III categories for the diagnosis of depression (Groth-Marnat, 1990). These earlier versions consist of 21 questions about how the subject was feeling in the last week. Internal consistency is good, with a Cronbach's alpha co-efficient of around 0.85 (Ambrosini *et al.*, 1991). It is also positively correlated with the Hamilton Depression Scale (Brown *et al.*, 1995) with a Pearson ratio of 0.71. The test was also found to have high one-week test-retest reliability with a Pearson value of 0.93 (Beck, Steer and Brown, 1996).

The BDI is a self-administered self report which takes approximately 10 minutes to complete with demonstrated consistent properties over time and situation over and is also translated in Kiswahili. Internal consistency for the BDI ranges from 0.73 to 0.92 with a mean of 0.86 (Beck, Steer and Garbin, 1988). The BDI demonstrates high internal consistency, with alpha coefficients of 0.86 and 0.81 for psychiatric and non-psychiatric population, respectively (Beck *et al.*, 1988). A meta-analyses of studies on the revised BDI's psychometric properties by Richter and colleagues (1998) report advantages with the revised BDI's high content validity and validity in differentiating between depressed and non-depressed people. Beck, Steer and Garbin (1988) reported that the revised BDI has been found to include 3-7 factors, depending on the method of factor extraction. These include factors that reflect negative attitudes towards self, performance impairment and somatic disturbances, as well as general factor of depression (Brown, Schulberg and Madonia, 1995).

Correlations with clinician ratings of depression using the revised BDI ranged from 0.62 to 0.66 (Foa *et al.*, 1993). Clinical ratings for psychiatric patients are reported as being high to moderate ranging from 0.55 to 0.96 with a mean = 0.72 (Beck *et al.*, 1988, cited in Groth-Marnat, 1990). Groth-Marnat (1990) reported moderate correlations between the revised BDI

and other scales measuring depression such as the Hamilton Psychiatric Rating Scale for depression (.073) and the Zung Self Reported Depression Scale (.76). However, some short comings of BDI on construct validity have been reported by Groth-Marnat (1990), who reported that controversy exists over whether the revised BDI is measuring state or trait variables.

Discriminate analysis had found that the translated version of the revised BDI highly discriminates depressive symptoms in Spanish (Bonicatto, Dew and Soria, 1998), and Persian people (Skek & Hojat *et al.*, 1990). Groth-Marnat (1990) reported that the revised BDI discriminates psychiatric patients from non-psychiatric patients as well as relatively higher scores for patients with major depressive disorder compared to patients with dysthymic disorder. The revised BDI has also been used to discriminate loneliness, stress and self-reported anxiety (Groth-Marnat, 1990).

The BDI suffers from some problems as other self-report inventories, in that; scores can be easily exaggerated or minimized by the client. In addition, for participants with concomitant physical illness, it has been suggested that its reliance on physical symptoms such as fatigue might artificially inflate scores of symptoms of the illness, rather than those of depression (Moore *et al.*, 1998). This places a limitation on its use on medically ill-patients where Hospital Anxiety and Depression Scale (HADS) may be used (Zigmond and Snaith, 1983). However, the HADS is a screening but not a diagnostic instrument and therefore not used in this study which aimed at diagnostic categories.

Although Moore *et al* (1998) alluded to the limitation of the BDI in patients with concomitant physical illnesses; the BDI has been used in people with medical conditions including HIV (Judd *et al.*, 2005; Rabkin, 1996;, Markowitz *et al.*, 1995; Mulder *et al.*, 1994;, Lutgendoff, *et al.*, 1997; Cruess *et al.*, 2003; Blanch *et al.*, 2002 and Zisook *et al.*, 1998). BDI has also been used in people with other physical conditions, such as Parkinson's disease (Stallibrass, 2002) and traumatic brain injuries, (Bedard *et al.*, 2003).

In 1996, the BDI was revised (Beck *et al.*, 1996) to what is referred to as BDI-II and which is what will be used in this study. The 1996 version of BDI was created to fall in line with the

DSM-IV criteria for depression. Like the original BDI, the BDI-II contains 21 questions, each answer being scored on a scale value of 0-3.

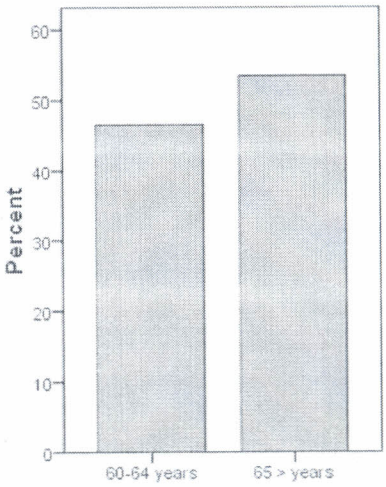
Interpretation of the BDI

Add up the score for each of the 21 questions and obtain the total score. The highest score for each of the twenty one questions is 3; the highest possible total for the whole test is 63. The lowest possible score for the whole test is zero. Only one score was assigned per question.

The interpretation of the scores for BDI depends on the setting, whether in the general population, medical facilities or psychiatric facilities. The interpretations i.e. the cut offs used in this study are those from the general population.

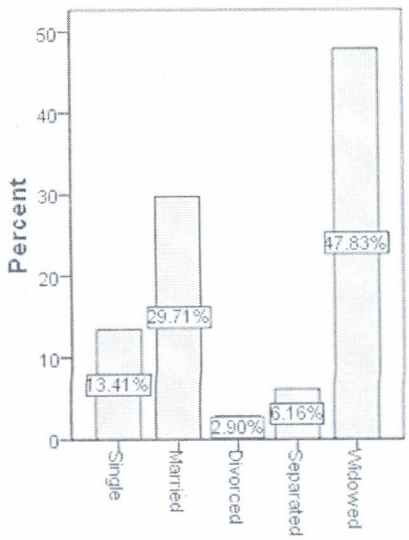
RESULTS

Table 1: Age of the Elderly



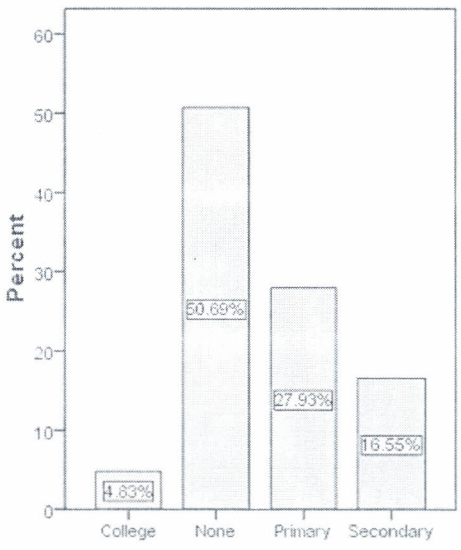
The results of the study indicate that the elderly who were of age 60-64 were 47% of the respondents while the elderly who were of age 65 years and above made 53% of the population.

Table 2: Marital Status of The Elderly



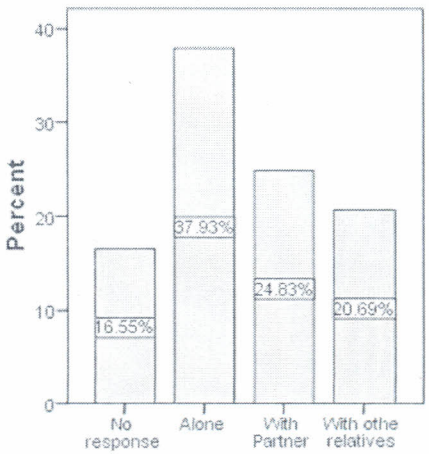
Results showed that 47.83%, 29.71%, 13.41%, 6.16 and 2.90% of the elderly were widowed, married, single, separated and divorced respectively.

Table 3: Level of Education of the Elderly



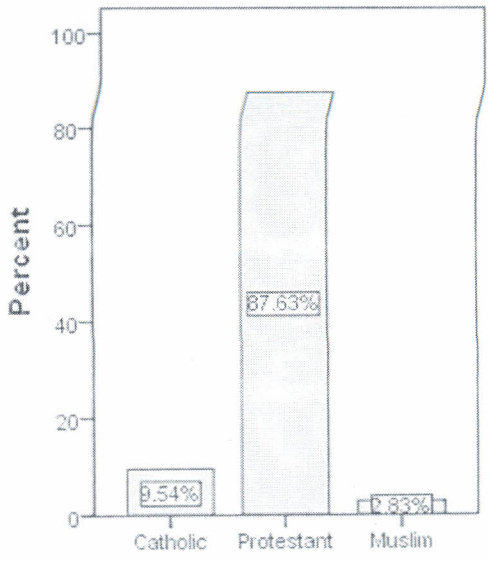
The study findings indicate that 50.69%, 27.93%, 16.55% and 4.83 % of the elderly had no education, primary education, secondary education and college education respectively.

Table 4: Living Arrangement of the Elderly



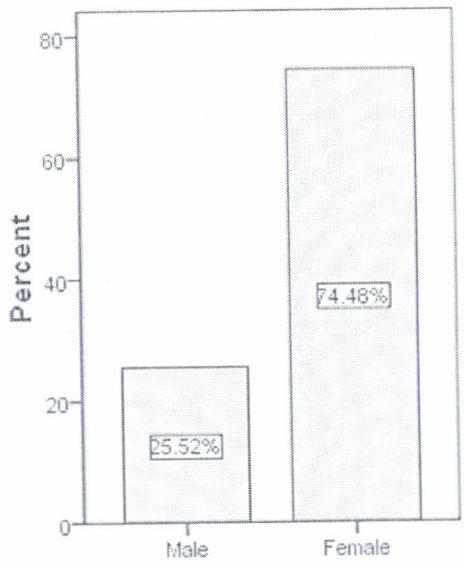
The study findings indicated that [illegible] with spouse and with other relatives.

Table 5: Religion of the Elderly



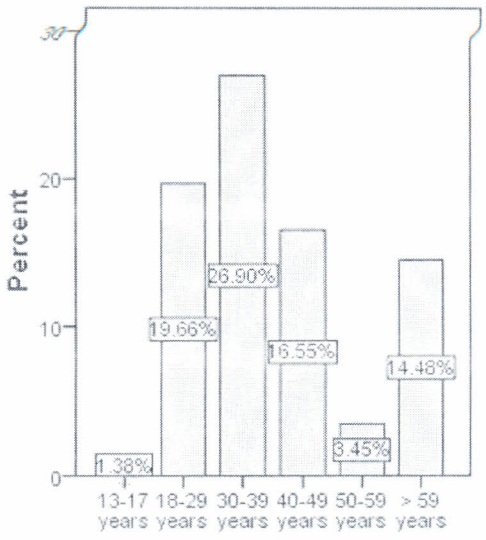
The study findings indicate that majority of the elderly are protestant (87.63%) with the remaining one being of Catholic and Muslim faith.

Table 6: Gender of the Elderly



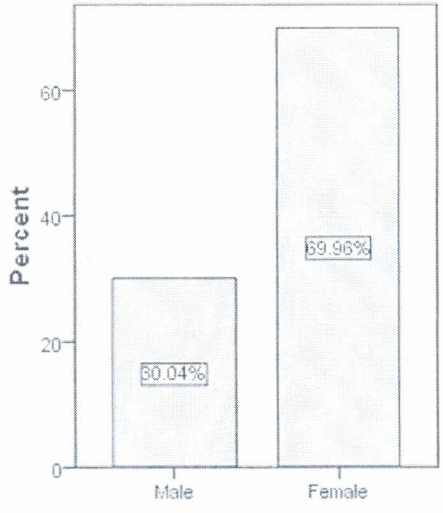
The study finding indicated that Majority of the elderly were females (74.48%) while the rest were males with 25.52% .

Table 7: Age of the care giver



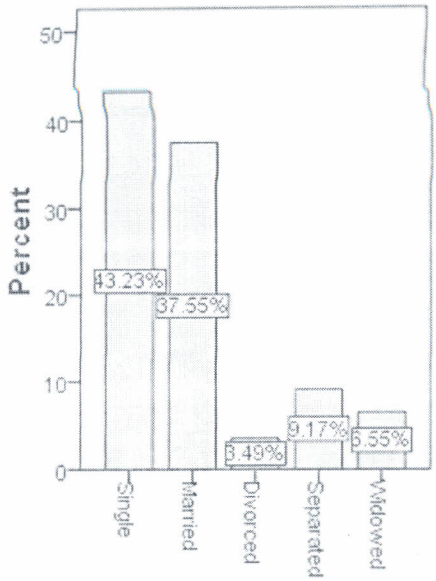
The study finding indicated that 26.90%, 19.66%, 16.55%, 14.48%, 3.45% and 1.38% of the care givers were of 30-39 years, 18-29 years, 40-49 years,> 59 years, 50-59 years and 13-17 years respectively.

Table 8: Gender of the care givers



The study results showed that majority of the care givers were females(69.96%) while the rest were male(30.04%).

Table 9: Marital status of the carers



The findings of the study showed that 43.23%, 37.55%, 9.17%, 6.55%,and 3.49% of the carers were single ,married ,separated ,widowed and divorced respectively.

Table 10: Living arrangements of the elderly

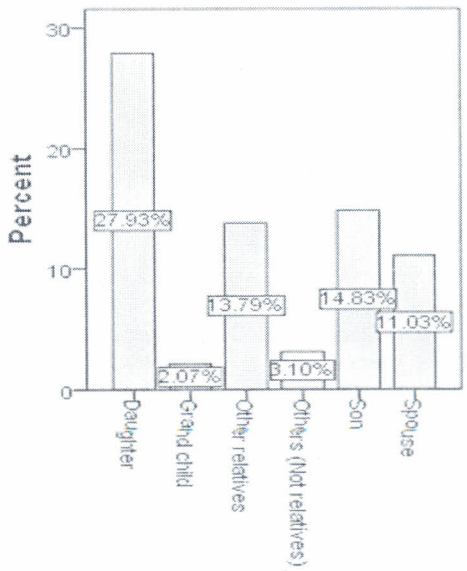
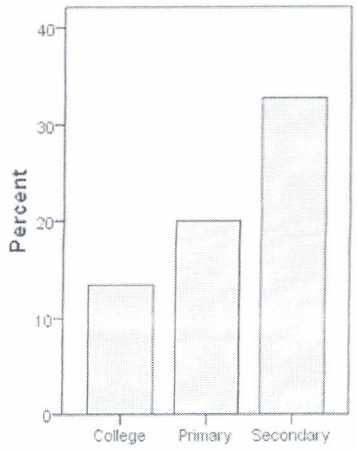
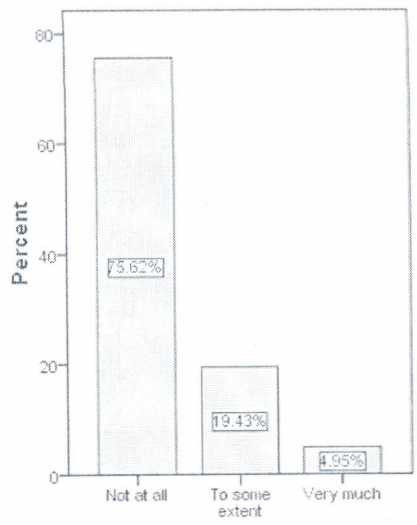


Table 11: Education Level of Care givers



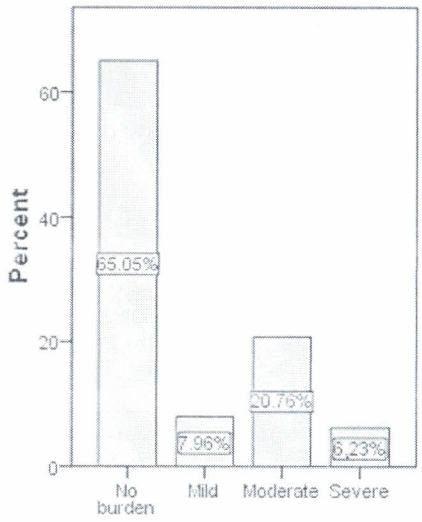
The results of the findings indicate that, 32.76%, 20% and 13.79% of the carers had secondary level of education, primary level of education and college/university level of education respectively.

Figure 12: Financial Capacity of Carers



The study results showed that majority of the care givers did not consider taking care of the elderly as a financial burden (75%) while 25% of the care givers felt that taking care of the Elderly was adding more financial burden to them.

Figure 13:Burden among the Care givers



The study findings showed that majority of care givers believed that taking care of the elderly was no burden to them(65.05%) while 20.76% ,7.96% and 6.23% of the care giver said that taking care of the elderly caused them some moderate ,mild and severe burden respectively.

Table 1: Dementia according to Gender

Gender of Care Givers	No Dementia	Probable Dementia	Diagnosis of Dementia	Total
Male	38(52.05%)	16(21.93%)	19(26.02%)	73
Female	96(56.47%)	32(18.83%)	42(24.70%)	170
Total	134	48	61	243

The results of the study demonstrated that females had a probability of having dementia at 18.83% while males had a probability of 21.93% of having dementia. Rate of diagnosis of dementia among the care givers according to gender was 24.7% for males and 26.02% for females.

Table 2.Depression according to gender

Gender	No Depression	Mild Depression	Moderate Depression	Major Depression	Total
Male	64(88.88%)	5 (6.94%)	2(2.77%)	1(1.41%)	72
Female	141(84.43%)	12(7.19%)	11(6.59%)	3(1.19%)	167
Total	205(85.77%)	17 (7.11%)	13 (5.44%)	4 (1.68%)	239

The results of the study showed that female care givers had the highest percentage of dementia symptoms than men; with females at 15% and men at 10%.

Table 3: Depression among the elderly according to gender

Gender	No Depression	Mild Depression	Moderate Depression	Major Depression	Total
Male	59(81.94%)	4(5.56%)	6(8.33%)	3 (4.17%)	72
Female	140(66.04%)	43(20.28%)	20(9.43%)	9(4.25%)	212
Total	199	47	26	12	284

The study findings demonstrated that most of the female elders had depressive symptoms with 34% of females showing depressive symptoms while comparatively, 18% of males showed depressive symptoms.

Table 4: Dementia among the Elderly according to Gender

Gender	No Dementia	Probable dementia	Dementia diagnosis	Total
Male	43(58.10%)	15(20.28%)	16(21.62%)	74
Female	119(55.09%)	37(17.13%)	60(27.78%)	216
Total	162	52	76	290

The results indicated that most of the patients with dementia diagnosis were females with 27.78% being female elders while 21.62% of male elders had dementia.

DISCUSSION

Socio-demographic Factors of the Elderly

The findings that those more older had a higher rate of widowhood, more so in females is not surprising given the common knowledge that widowhood increases with age and females have a longer life-expectancy than males (WHO 2003). One of the reasons for this difference as it was recorded from observation during the study could be the result of men's severe alcohol abuse behaviour causing the high mortality which can at least from theory be prevented. This explains also why more females than males were recruited into the study, and more females than men living alone. It is also expected that in this age group of 60 years and above half of them had no formal education. These were people born before Kenya became independent when there were few opportunities for education as opposed to the present time when primary education (first 8 years of formal education) is compulsory and therefore no more opportunities for education beyond the primary level. Despite this and perhaps because they lived in urban areas with more opportunities for gainful occupations, the majority of the people had had gainful occupation in their earlier lives. Majority of the elderly were separated, divorced and widowed. This can be explained by the socio-economic status of the elderly which can not only hinder them from affording basic commodities like food, medical services among others.

Socio-demographic Factors of the Care Givers

The fact that 76% of the caregivers were in the prime of their lives and concerned with their own developments and responsibilities to their own families, is illustrative of the still functional social support systems in Kenya - even in an urban situation. The remaining 25% or so in the other extremes of life, either youth themselves needing to be taken care of or people already close to the age bracket of the elderly people or even within that bracket caring for similarly elderly

people is however of concern. Care-work in the Kenyan context is gender based being carried out by women of all ages wherever the need arises. It is therefore not surprising that the majority of the caregivers were female and in particular daughters. The open ended questions on caregiver arrangements in the house revealed the different roles assumed by males and females in this study, where males who had been assigned the roles of caregivers were actually responsible for finances and decision making. This creates the possibility of a hidden group of female caregivers related to males who were labelled caregivers- most likely wives and other female persons. That females as well as males were involved in income generation, points at the double burden that women in these communities have to bear.

It is not surprising that the majority of the caregivers were educated to secondary school level, since this is the norm in Kenya for people living in urban areas, and involved in some kind of gainful occupations. Surprising though is that 14.9% indicated they were farmers. Considering there are no farms in the study site, it can only be assumed that some of the residents of this slum had access to some land (leased or owned) in the neighbouring farming area where they carried out some form of farming activity.

Depression among the Care Givers

The fact that caregivers themselves need emotional support is supported by the finding whereby 8-15% of the caregivers had depression of varying degrees of severity. The prevalence in this cohort operating from and based at the community level is much higher than the average prevalence of depression at community level. The burden of caring for elderly with dementia in a setting with minimal health care support is clearly reflected in the significant association between dementia in the elderly and depression in the caregivers. In a situation where one would expect high levels of frustration and desperation like taking care of the elderly within the context

of low financial support, it is interesting that the level of suicidal thoughts was relatively low. Even then it seemed to have been associated more to, possible social isolation and lack of emotional support for the caregivers as it was higher among divorced and widowed caregivers. This reinforces the suggestion made above that caregivers of the elderly should be accorded emotional support and there is no better forum than by introducing support groups for caregivers within communities.

Dementia among the Care givers

While the majority of caregivers were family members the proportion of non-family caregivers were seen to rise with the severity of dementia, a reflection of the extra burden of care that probably requires the hiring of extra hands to help with the more behaviorally disturbed elderly people on a more full time basis, while the family members pursue income generating activities to generate finances for other activities in addition to providing for their elderly relatives. The male and female caregivers provided different but complementary roles in providing care for the elderly in the community, and the elderly were not perceived as problematic to the caregivers. Dementia on the other hand can be said to have complicated the care-giving process because of related behaviour problems. This further reinforces the need for support groups so that caregivers can learn coping skills from each other. Health professionals may also need education on the skills needed in the management of the elderly in the communities. This should be supported by a policy that recognizes the elderly people as having special needs that require special attention.

Dementia among the Elderly

Forty four percent scored positive for dementia using the instrument employed in this study. It is expected, as found in the study, that dementia increased with age though it is not clear why it should be associated with widowhood. However the most significant aspect of these findings,

regardless of any significant or non-significant association, is the high level of dementia in this population at a time when there is no policy at all for the care of the elderly; leave alone for the care of those with dementia.

Depression among the Elderly

Depression among the women was higher than men with women having 34% while men had 18%. This shows that gender is a factor that affects depression among the elderly, reason for this can be attributed to the socio-cultural context in African culture where the females are expected to play major role than male in family day to day activities even in the old age.

Needs of the Care Givers

The findings of the study showed that majority of the care givers believed that taking care of the elderly was not a burden to them and also it did not add any financial burden to them. The reason for this can be attributed to the socio-cultural belief that the elderly are supposed to be taken care of by other extended family members. This is an indication of the central role that family institution plays in the society and the fact that most care givers are prepared for the task of providing support to the Elderly.

CONCLUSION

Prevalence of depression among the elderly in this study was 6.3%; and was significantly associated with gender. Based on this study's findings, health care personnel can be educated to look out for depression among elderly who are females since females are more prone to depression than men.

The prevalence of depression among the care givers calls for policies and practices that identify and support the emotional needs of caregivers. This can be done through the assessment of family care giver needs that leads to a care plan with support services, caregiver education and support programme, primary care interventions that address the care givers' needs.

The prevalence of dementia calls for the government to develop policies that can be able to provide treatment and support services for the elderly.

RECOMMENDATION

There is need to shift and educate community members, and leaders among other things to support care of the ageing population.

(a) Campaign advocacy targeting all the civil society bodies to increase and step up their assistance to community care programs should be scaled up. National and local campaign advocates, lobbyists, and leaders, both at local and national levels, should be at the forefront in order to achieve an increase in community support for the elderly.

(b) There is need to formulate and enact policies to address the basic needs and rights of elderly persons, the lack of which has contributed to limited prioritization of health for elderly population in health planning, resource allocation, and workforce development, further increasing unmet health needs among the aging population.

(c) There is need to train and equip medical health workers in geriatric medicine so as to meet the needs of the aging population in the communities they serve

(d) There is need to develop care giver education and support programme

REFERENCES

1. Arai, Y., Kudo, K., Hosokawa, T., Washio, M., Miura, H., & Hisamichi, S. 1997, "Reliability and validity of the Japanese version of the Zarit Caregiver Burden interview", *Psychiatry & Clinical Neurosciences*, vol. 51, no. 5, pp. 281-287.

2. Beck, A. T., Steer, R. A., & Brown, G. K. (1996). Manual for the Beck Depression Inventory-II. San Antonio, TX: Psychological Corporation.

3. Beck, A. T., Steer, R..A., Garbin, M.. G., (1988) Psychometric properties of the Beck Depression Inventory: Twenty-five years of evaluation. *Clinical Psychology Review 8 (1),* 77-100.

4. Beck, A.T., Ward, C. H., Mendelson, M., Mock, J., & Erbaugh, J. (1961) An inventory for measuring Ambrosini P.J., Metz C., Bianchi M.D., Rabinovich H., Undie A. (1991). "Concurrent validity and psychometric properties of the Beck Depression Inventory in outpatient adolescents." *J AM Acad Child Adolesc Psychiatry* 30: 51-57.

5. Bedard M., Felteau M., Mazmanian D., Fedyk K., Klein R., Richardson J., Parkinson W., Minthorn-Bigg MD. (2003). Disability Rehabilitation July 8; 25 (13) 722-31.

6. Blanch J., Rousaud A., Hautzinger M. (202). Assessment of the efficacy of a cognitive-Behavioural group psychotherapy programme for HIV-infected patients referred to a Consultation-Liaison Psychiatry Department Psychotherapy Psychosomatic, 71 77-84.

7. Bonicatto, S. Dew, A. M., Soria, J. J., (1998). Analysis of the psychometric properties of the Spanish version of the Beck Depression Inventory in Argentina. Psychiatric Research, *79 (3),* 277-285.

8. Brown, C., Schulberg, H. C., & Madonia, M. J., (1995). Assessing depression in primary care practice with the Beck Depression Inventory and the Hamilton Rating Scale for Depression. *Psychological Assessment 7 (1),* 59-65

9. Chisholm, D., Knapp, M. R. J., Knudsen, H. C., Amaddeo, F., Gaite, L., & Van Wijngaarden, B. 2000, "Client Socio-Demographic and Service Receipt Inventory - European Version: development of an instrument for international research. EPSILON study 5", *British Journal of Psychiatry*, vol. 117, no. suppl.39, p. s28-s33.

10. Chou, K. R., LaMontagne, L. L., & Hepworth, J. T. 1999, "Burden experienced by caregivers of relatives with dementia in Taiwan", *Nursing Research*, vol. 48, no. 4, pp. 206-214.

11. Cruess s., Antoni MH., Hayes et al (2002). Changes in mood and depressive symptoms and related change processes during and cognitive in HIV infected men. Cognitive therapy research 26, 373-392.

12. Davis, K. L., Marin, D. B., Kane, R., Patrick, D., Peskind, E. R., Raskind, M. A., & Puder, K. L. 1997, "The Caregiver Activity Survey (CAS): development and validation of a new measure for caregivers of persons with Alzheimer's disease", *.Int.J Geriatr.Psychiatry*, vol. 12, no. 10, pp. 978-988.

13. Foa, E. B., Riggs, Dancu, C. V. S., & Rothbaum B. O., (1993). Reliability and validity of a brief instrument for assessing Post Traumatic Stress Disorder. Journal of Traumatic Stress. *6 (4),* 459-473.

14. Gilleard, C. J., Belford, H., Gilleard, E., Whittick, J. E., & Gledhill, K. 1984, "Emotional distress amongst the supporters of the elderly mentally infirm", *.Br.J Psychiatry*, vol. 145, pp. 172-177.

15. Groth-Marnat G. (1990). *The handbook of psychological assessment* (2nd ed.), John Wiley & Sons, New York.

16. Hall, K. S., Hendrie, H. H., Brittain, H. M., Norton, J. A., Rodgers, D. D., Prince, C. S., Pillay, N., Blue, A. W., Kaufert, J. N., Nath, A., Shelton, P., Postl, B. D., & Osuntokun, B. O. 1993, "The development of a dementia screeing interview in two distinct languages", *International Journal of Methods in Psychiatric Research*, vol. 3 pp. 1-28.

17. Hirono, N., Kobayashi, H., & Mori, E. 1998, "[Caregiver burden in dementia: evaluation with a Japanese version of the Zarit caregiver burden interview]. [Japanese]", *No to Shinkei - Brain & Nerve*, vol. 50, no. 6, pp. 561-567.

18. Judd, F., Komiti, A., Chua, P., Mijich, A., Hoy, J., Grech, P., Stress, A., Lloyd, J., & Willianms B (2005). Nature of depression in patients with HIV/AIDS. Australia & New Zealand Journal of Psychiatry, 39 (9), 826-832.

19. Kenya National Population and Housing Survey, 1999 (census)
20. Li, G., Shen, Y.-C., Chen, C.-H., Zhao, Y.-W., & et al 1989, "An epidemiological survey of age-related dementia in an urban area of Beijing", *Acta Psychiatrica.Scandinavica.*, vol. Vol 79, no. 6, pp. 557-563.
21. Lutgendoff SK., Antoni MH., Ironson G. et al (1997). Cognitive-Behavioural stress management decreases dysphoric mood and herpes simplex virus-types 2 antibody titiers in symptomatic HIV seropositive gay men. Journal of Consulting Clinical Psychology, 65: 31-43.
22. Markowitz JC., Klerman GL., Clougherry KF et al (1995). Individual Psychotherapy for depressed HIV-Positive patients. American Journal of Psychiatry, 152, 1504-1509.
23. Moore M.J., Moore P.B., Shaw P.J. (1998) "Mood disturbances in motor neurone disease". *Journal of the Neurological Sciences* 160 Suppl 1: S53-S56.
24. Mulder CL., Emmelkamp PM., Antoni MH., Mulder JW., Sandfort TG., de Vries MJ. (1994). Cognitive-Behavioural and experimental group psychotherapy for HIV infected homosexual men: a comparative study. Psychosomatic Medicine, 56, 435-431.
25. Phanthumchinda, K., Jitapunkul, S., Sitthi Amorn, C., Bunnag, S. C., & et al 1991, "Prevalence of dementia in an urban slum population in Thailand: Validity of screening methods", *International.Journal.of.Geriatric.Psychiatry*, vol. Vol 6, no. 9, pp. 639-646.
26. Prince, M., Acosta, D., Chiu, H., Scazufca, M., & Varghese, M. 2003, "Dementia diagnosis in developing countries: a cross-cultural validation study", *The Lancet*, vol. 361, pp. 909-917.
27. Shaji, S., Promodu, K., Abraham, T., Roy, K. J., & Verghese, A. 1996, "An epidemiological study of dementia in a rural community in Kerala, India", *Br.J.Psychiatry*, vol. 168, no. 6, pp. 745-749.
28. Skek, D.T., (1990) Reliability and factorial structure of the Chinese version of the Beck Depression Inventory. *Journal of Clinical Psychology 46 (1),* 34-43.
29. Stallibrass C., Sissons P., Chalmers C., (2002). Clinical Rehabilitation Nov. 16 (7): 695-708.

30. Whitlatch, C. J., Zarit, S. H., & von Eye, A. 1991, "Efficacy of interventions with caregivers: a reanalysis", *Gerontologist*, vol. 31, no. 1, pp. 9-14.

31. Zarit, S. H., Reever, K. E., & Bach-Peterson, J. 1980, "Relatives of the impaired elderly: correlates of feelings of burden", *The Gerontologist*, vol. 20, pp. 649-655.

32. Zarit, S. H., Todd, P. A., & Zarit, J. M. 1986, "Subjective burden of husbands and wives as caregivers: a longitudinal study", .*Gerontologist.*, vol. 26, no. 3, pp. 260-266.

33. Zigmond As, Snaith RP (1983) The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica* 67:361-79.

34. Zisook S., Peterkin J., Goggin KJ., ledge P., Atkinson JH., Grant 1 (1998). Treatment of Major depression in HIV-Seropostive men. HIV Neurobehavioral Research Centre Group. Journal of Clinical Psychiatry 59, 21-30.

APPENDICES

APPENDIX A: CONSENT EXPLANATIONS AND CONSENT FORMS

Appendix A1: Invitation Letter

Dear Sir/Madam,

My name is Prof. David M. Ndetei. I am conducting a study on neuro-psychiatric disorders among the elderly (60+) at Kangemi, Kibwezi, Murang'a and Kenyatta National Hospital. The findings of this study, which will involve people 60+ years of age, their families/carers and health workers, will be useful in establishing; the neuro-psychiatric and common physical disorders that are prevalent among the elderly in the study areas and sites. The role played by carers in the management of these disorders, and the liaison of carers with other medical health workers in these study areas. We will be interviewing the elderly, their carers and medical health workers. We will also interact with elderly and their carers, chief, assistant chief and village elders in focus group discussions.

All the information will be treated in complete confidence and will not be used for any other purpose except for study. We have a set of questions that will provide the guidelines for the interview, and any needed probing. Two research assistants will interview you, one asking the questions and the other recording the answers. We will also use a tape recorder to ensure that we capture all the interviews and all information. Once the information is transcribed the tapes will be destroyed. If however you are not comfortable with the use of a tape recorder, it will not be used, but the interview might take a little longer.

This letter comes as a request that you allow my research assistants to interview you or staffs in your institutions individually or in groups. There will be no individual or institutional rewards for participating in this study. However the results and recommendations will be made available to you after completing the study and results released.

If you agree to voluntarily participate, sign the Consent Form that will be given to you. If you have any queries you think need my personal attention I can be reached on 0722 518365/2716315 or my co- principal investigator Dr. Lincoln Khasakhala on 0722860485/2716315 or through my personal assistant Grace on 0720 957477 who will assist in locating me for your attention.

Yours sincerely,

Prof. David M. Ndetei
Principal Investigator

APPENDIX A2: CONSENT EXPLANATION AND FORM

(Elderly person/Carer (Next of kin or guardian) of elderly person if the elderly cannot consent

I, MR/MS/MRS/Other .....

Whose signature/thumb print is appended hereunder, and being **the elderly person/ next of the kin to ..... (Specify relationship.....)/being the guardian** (cross out what does not apply), and having being explained the nature of the study and the right to withdrawal anytime without loss of any benefits, do voluntarily agree that **I/my** relative (cross out what does not apply) can participate in this study. The nature and purposes of the study has been fully explained to me. I understand that all the information that I give will be treated with the strict confidence and that it will only be used for the purposes of the said study. I also understand that I am free to withdraw or withdraw my relatives from the study, at any time, and that such an action will not result in any withdrawal of treatment or privileges due to me as a patient/patient's caregiver of location of Kangemi/Kibwezi/Murang'a/Kenyatta National Hospital. I further understand that I am not going to gain materially from participation in this study and that my relative's name will not appear in any publication resulting from this study. I have also been made to understand that there will be no invasive procedures. I have been made to understand that the results of the study may benefit me and/or relative in terms of improved liaison services medical health workers.

Respondent's name.....

Respondent's signature ..... Date. ...../.../2007.

Witness (who took the consent) Signature..... Date. ...../.../2007

APPENDIX A3: ASSENT BY THE PATIENT

We have been given permission by your next of the kin (.....) or guardian that we include you in a study we are conducting a study on neuro-psychiatric disorders among the elderly. Although we have that consent we would like also to have your own permission to include you in the study. If you agree we will ask you a series of questions. We will not give you any injections or take your blood for the purposes of this study. We will keep all the information confidential. You can also withdrawal your permission anytime but this will not affect in anyway the treatment you get. While you may not benefit directly except referral to Medical facilities, the results will benefit other people in similar circumstances once we understand the neuro-psychiatric problems among the elderly in Kenya and can work together with medical person for the better welfare of the patients. If you agree to participate sign/thumb stamp below

Respondent's name.....

Respondent's thumb print ..... Date. ...../.../2007.

Witness (who took the consent) Signature..... Date. ...../.../2007.

APPENDIX A4: CONSENT EXPLANATION AND FORM
(Medical care givers)

I, DR/MR/MS/MRS/Other

.....

Whose signature/thumb print is appended hereunder, voluntarily agree to participate in this study. The nature and purposes of the study has been fully explained to me. I understand that all the information that I give will be treated with strict confidence and that it will only be used for the purposes of the said study. I also understand that I am free to withdraw from the study, at any time, and that such an action will not result in any withdrawal of treatment or privileges due to patient/patient's caregiver among the elderly when they visit me for treatment. I further understand that I am not going to gain materially from participation in this study and that my name will not appear in any publication resulting from this study. I have also been made to understand that I stand to suffer no harm because of my participation in this study. Finally, I have been made to understand that the results of the study may benefit me in terms of improved liaison services between the carers and other medical health workers.

Respondent's name.....

Respondent's signature ..... Date. ...../.../2007.

Witness

Signature ..... Date. ...../.../2007.

Appendix B: Research Instruments

B1 Socio-demographic data

Section B1 (i): Socio-demographic characteristics of elderly person

1 Date of birth: Age _____ (years)
2 Gender: Male/Female
3 Tribe: ----------
4 Religion: _____
5 First Language: English/Kiswahili/ Other ____
6 Marital Status: Single/ Married/ divorced/ separated/ widowed
7 Living situation: (a) Alone/ with partner.
(b) With other relatives (name relative and relationship 1--------/relationship----------
2----------/relationship ----------3----------/relationship----------4--------
------/relationship ----------5----------/relationship----------6----------
/relationship ----------7----------/relationship----------
8----------/relationship ----------9----------/relationship----------
(c)With others (Name and relationship)
1----------/relationship ----------2----------/relationship----------3--------
------/relationship ----------4----------/relationship----------

8 Living environment: Flat/ house/ sheltered/ residential/ nursing/ other
9 Previous occupation---------- Partner's (previous occupation) ----------
10 Education _____ (years) Highest level of education attained----------
11 Current status: In-patient/ day patient/ Community patient/ (psychiatric/geriatric/other
12 Main diagnoses (DSM-IV/ICD-10): _____
Main neurological problem(s)_____
13 Current Medication: _____
14 Disease prevention (e.g.) blood pressure/smoking/sleep_____ 15
Pattern/exercise _____
15 Random blood sugar_____
16 Does the person have a carer? Yes / No
17 Is the person a carer? Yes / No
18 Has he/she been ever been admitted after attaining the age of 60? Yes / No
19 If yes, for what medical problem(s)
_____
_____

20 How many times has she/he been admitted_____?

21 If admitted more than once, what were conditions at the admission?

(i) Admission 1_____ (ii) Admission 2
_____

(iii) Admission 3 _____ (iv) Admission 4
_____

(v) Admission 5 _____

Section B1 (ii): Socio-demographic characteristics of primary carer

Date of birth: Age _____ (years)
Gender: Male/Female
Tribe: ----------
Religion: _____
First Language: English/Kiswahili/ Other ____
Marital Status: Single/ Married/ divorced/ separated/ widowed
Living situation: ---------- (in relationship with the elderly person).

(b) With other relatives (name relative and relationship 1--------/relationship----------
2----------/relationship ----------3----------/relationship----------
4----------/relationship ----------5----------/relationship----------
6----------/relationship ----------7----------/relationship----------
8----------/relationship ----------9----------/relationship----------

(c)With others (Name and relationship)
1----------/relationship ----------2----------/relationship----------
3----------/relationship ----------4----------/relationship----------

Relationship with the elderly person _____

Occupation---------- Partner's if married (occupation) ----------
Education _____ (years) Highest level of education attained----------

B2: Focus Group Discussion

B2 (i): Focus Group Discussion -Family care giver

General

1. Do you have elderly persons in this community/institution? If so what are the common psychiatric and physical problems in this area?

2. How are these persons with psychiatric and physical problems perceived by the family members? What about by the community/health care staff members?

3. Are there activities in this community that the elderly persons are unable to participate in at community level due to their condition?

4. Are there supportive mechanisms for the various types of psychiatric and physical problems to enable elderly persons in community and other social programmes in the community?

Health Care

1. Are elderly persons with psychiatric and physical problems able to access health care services wherever they need them?
2. Are there specialized providers who assist elderly persons with psychiatric and physical problems at these facilities?
3. Do elderly persons with psychiatric and physical problems receive preferential treatment at these facilities?

Domestic & Sexual violence

1. Do elderly persons with psychiatric and physical problems experience domestic or sexual violence from family members? And what about from the community?

2. Are there services for the victims of violence in this area or community?

3. Do elderly persons with psychiatric and physical problems receive legal advice whenever they are physically or sexually abused?

Drug Abuse

1. Are there elderly persons involved in drug and other substances abuse in this community?

2. Are Homes for the elderly in this community/Province?
   Are there rehabilitation centres for those already using drugs and other substances?

3. Do you think the use of drugs and other substances may cause friction in families of elderly persons?

B2 (ii: Focus Group Discussion -elderly

General

1. What are the common psychiatric and physical problems among the elderly problems in this area?

2. How are the elderly with psychiatric and physical problems perceived by their family members? What about by the community/health care staff members?

3. Are there activities in this community that the elderly persons are unable to participate in at community level due to their condition?

4. Are there supportive mechanisms for the various types of psychiatric and physical problems to enable elderly persons in community and other social programmes in the community?

Health Care

1. Are elderly persons with psychiatric and physical problems able to access health care services wherever they need them?
2. Are there specialized providers who assist elderly persons with neuropsychiatric and physical problems at these facilities?
3. Do elderly persons with neuropsychiatric and physical problems receive preferential treatment at these facilities?

Domestic & Sexual violence

1. Do elderly persons with psychiatric and physical problems experience domestic or sexual violence from family members? And what about from the community?

2. Are there services for the victims of violence in this area or community?

3. Do elderly persons with psychiatric and physical problems receive legal advice whenever they are physically or sexually abused?

Drug Abuse

1. Are there elderly persons involved in drug and other substances abuse in this community?

2. Are there homes for the elderly persons in this community in the province? What about those already using drugs and other substances?

3. Do you think the use of drugs and other substances may cause friction in families of elderly persons?

B2 (iii): Focus Group Discussion-Medical care givers

General

1. Do you have elderly persons who are seen or admitted in this institution? If so what are the common neuropsychiatric and physical problems in this seen?

2. How are these elderly persons with neuropsychiatric and physical problems perceived by the medical workers? What about by their relatives?

3. Are there activities in the community that the elderly persons are unable to participate in at community level due to their condition?

4. Are there supportive mechanisms for the various types of neuropsychiatric and physical problems to enable elderly persons in community and other social programmes?

Health Care

4. Are elderly persons with psychiatric and physical problems able to access health care services wherever they need them from this institution?
5. Are there specialized providers who assist elderly persons with neuropsychiatric and physical problems at this institution?
6. Do elderly persons with psychiatric and physical problems receive preferential treatment at this facility?

Domestic & Sexual violence

4. Do elderly persons with psychiatric and physical problems experience domestic or sexual violence from family members? And what about from the community?

5. Are there services for the victims of violence in this institution?

6. Do elderly persons with psychiatric and physical problems receive legal advice whenever they are physically or sexually abused?

Drug Abuse

4. Are there elderly persons involved in drug and other substances of abuse that are seen in this facility?

5. Are Homes for the elderly in this community/Province?
   Are there rehabilitation centres for those already using drugs and other substances?

6. Do you think the use of drugs and other substances may cause friction in families of elderly persons?

APPENDIX C:

APPENDIX C1: NEEDS OF THE CAREGIVERS USING MODULE I

MODULE 1 – INITIAL ASSESSMENT

Notes for health workers

What is the purpose of this module?

a) to establish whether or not the older person is likely to be suffering from dementia
b) to find out what are the main difficulties experienced by the caregiver
c) to see which of the modules of the intervention might benefit the caregiver

How will I cover this module?

This module could be covered in the first session.

Who should attend this session?

You should gather this information from the principal caregiver, which is the person who is most involved with providing care for the person with dementia, and who is best informed about the daily life of that person. Remember that while the principal caregiver is usually one of the family members living with the person with dementia, it may turn out to be a family member, or a neighbour or friend who is living elsewhere.

What is the content of this module?

There are FOUR sections to this module:

1) SCREENING FOR DEMENTIA
Three simple questions to see whether it is likely at all that the person suffers from dementia. If the answer to all three questions is 'no' then if there is a problem, it is unlikely to be dementia
2) IDENTIFYING DEMENTIA
Some more questions about the abilities and daily life of the older person. At the end of this section you simply add up the score from all of the questions (including the first three) and from this you will have a reasonably clear idea of whether or not the older person suffers from dementia. You can also use the caregivers answers to these questions to summarise the main problems that they are having to face.
3) AWARENESS OF DEMENTIA
Some questions about the caregiver's awareness and understanding of what is happening to the older person
4) CAREGIVING ARRANGEMENTS IN THE HOME
Some questions to discover
a) who are the family members?

b) who lives at home with the person with dementia?
c) in what ways do they help out the principal caregiver?
d) what behavioural problems are the family caregivers having to cope with?
e) how burdened do they feel by caring for the person with dementia?

1) SCREENING FOR DEMENTIA

First ask these three questions and score 0 (no) or 1 (yes)

1. Have you seen a change in her daily activities in the past several years? {ACTIV} _

No	0
Yes	1

If yes, ask the carer to describe what they have noticed and note it down here:

2. Has there been a general decline in her mental functioning? Please describe {MENTAL} _

No	0
Yes	1

If yes, ask the carer to describe what they have noticed and note it down here:

3. We all have slight difficulties in remembering things as we get older, but has this been a *particular* problem for her? {MEMORY} _

No	0
Yes	1

If you have marked 'Yes' for any of these questions please administer the rest of the informant section of Community Screening Instrument for Dementia (CSI-D).
This will establish the presence of dementia, and will also act as a guide to the activities of daily living that are a particular problem for the person with dementia

2) IDENTIFYING DEMENTIA

Continue with the following questions, scoring 0 (No), ½ (sometimes), 1 (yes or often)

4. Does she forget where she has put things? {PUT} _

No	0
Sometimes	½
Often	1

5. Does she forget where things are usually kept? {KEPT} _

No	0
Sometimes	½
Often	1

6. Does she forget the names of friends? {FRDNAME} _

No	0
Sometimes	½
Often	1

7. Or members of the family? {FAMNAME} _

No	0
Sometimes	½
Often	1

8. Does she forget what she wanted to say in the middle of the conversation? {CONVERS} _

No	0
Sometimes	½
Often	1

9. When speaking does she have difficulty saying the right words? {WORDFIND} _

No	0
Sometimes	½
Often	1

10. Does she use the wrong words? {WORDWRG} _

No	0
Sometimes	½

Often 1

11. Does she tend to talk about what happened long ago rather than the present? {PAST} _

No 0
Sometimes ½
Often 1

12. Does she forget when she last saw you? {LASTSEE} _

No 0
Sometimes ½
Often 1

13. Does she forget what happened the day before? {LASTDAY} _

No 0
Sometimes ½
Often 1

14. Does she forget where she is? {ORIENT} _

No 0
Sometimes ½
Often 1

15. Does she get lost in the community? {LOSTOUT} _

No 0
Sometimes ½
Often 1

17. Does she get lost in her own home, e.g finding the toilet? {LOSTIN} _

No 0
Sometimes ½
Often 1

18. Does she have difficulty performing household {CHORES} _

chores that she used to do,
e.g preparing food or boiling a pot of tea?

No	0
Sometimes	½
Often	1

NB – Score 0 if you feel that the difficulty is caused by a physical health problem (for example weakness or frailty causing problems in lifting cooking pans)

19. Has there been a loss of a special skill or hobby she could manage before? {HOBBY} _

No	0
Yes	1

20. Has there been a change in her ability to handle money? {MONEY} _

No difficulty	0
Some difficulty	1
Can not handle money	2

21. Does she have difficulty in adjusting to change in her daily routine? {CHANGE} _

No	0
Sometimes	½
Often	1

22. Have you noticed a change in her ability to think and reason? {REASON} _

No	0
Yes	1

23. Does she have difficulty feeding herself? {FEED} _

Eats cleanly with proper utensils	0
Eats messily with a spoon only	1
Simple solids such as biscuits	2
Has to be fed	3

3) If the score is 8 or more then the person almost definitely does have dementia

List here the problems with thinking and memory, and the problems with daily activities that you have identified

Problems with thinking and memory
Problems with daily activities

Now discuss your findings with the caregiver. You will find the questions on the next page useful.

3. AWARENESS OF DEMENTIA

We have been talking about problems with thinking and memory, and also about problems with everyday activities.

You have told me that she has recently developed problems with ..... (read out the problems you have listed on the previous page)

What or who do you think is the cause of these problems?

(write the answer below – give as full as possible account of the answer that you are given)

Do you have any idea as to what is going to happen to her in the future?
For instance are you hopeful that you will find a cure?
Do you think that things will in general, get better, get worse, or stay the same?
(write the answer below – give as full as possible account of the answer that you are given)

What do your family members think is the problem?

Are they sympathetic/ understanding/ supportive, or not?

(write the answer below – give as full as possible account of the answer that you are given)

What do neighbours and others in your community think is the problem?

Are they sympathetic/ understanding/ supportive, or not?

(write the answer below – give as full as possible account of the answer that you are given)

Ask the following question if there is a local word used to describe a dementia like syndrome – for example 'Chinnan' in Kerala

Have you heard of 'Chinnan'

Do you think that she may be suffering from 'Chinnan' Yes / No

Have you considered that an illness of some kind affecting the brain Yes / No
may have caused her problems?

Have you heard of an illness called dementia, or Alzheimer's Disease? Yes / No

If yes....

What do you understand by this?
(write the answer below – give as full as possible account of the answer that you are given)

At this point, explain to the carer that you feel, from the answers that she/ he has given you, that it is probable that she suffers from dementia.

Give some brief information, using the materials that you have been given

- Although dementia mainly affects older people it is not the same as ageing, it is an illness
- Dementia is an illness, like any other, but affecting the brain
- The older person with dementia cannot help their behaviour
- There is no cure
- One can expect further deterioration over time
- However, there is much that can be done to help
- Support from the family is crucial

Other family members will need to have the problem explained to them

4. CAREGIVING ARRANGEMENTS IN THE HOUSE

Who lives in this house?

Write down their names and ages, their occupation, and their relationship to the person with dementia (e.g son, granddaughter etc)

Name	Relationship	Age	Occupation

Which of these persons is involved in providing care? What do they do?

Which other family members, or family friends have close links with the family?

Name	Relationship	Age	Occupation

Which of these persons is involved in providing care? What do they do?

For how long can they be left on their own? _ _ hours

Do they have any of the following problems

Problems with hygiene (washing, keeping clean) Yes/ No
If yes, describe below ....

Problems with dressing Yes/ No
If yes, describe below ....

Problems with using the toilet and/ or incontinence Yes/ No
If yes, describe below ....

Problems with repeated questioning or calling out Yes/ No
If yes, describe below ....

Problems with clinging to the caregiver Yes/ No
If yes, describe below ....

Problems with aggression Yes/ No
If yes, describe below ....

Problems with wandering Yes/ No
If yes, describe below ....

Problems with loss of interest or activity Yes/ No
If yes, describe below ....

How burdened do you feel caring for your relative?
No Burden
Mild
Moderate
Severe

Financial Issues:
Do you have enough money to meet all the expenses incurred towards patient care?
Very much
To some extent
Not at all

Have you or anyone else had to give up work, or cut back on work to care for the person with dementia?

What are the extra costs which you have to meet?

Medicines _____

Medical consultations _____

Paid daytime or nighttime care _____

Laundry _____

Lost income _____

Other costs _____

TOTAL _____

How much family income do you have to meet these costs? _____

Are you aware of the help available locally for older people?

Notes for centres – You will need to construct some appropriate questions depending upon the nature of the local services (if any)

APPENDIX C2: BECK'S DEPRESSION INVENTORY

Form Week: _____ Institution Code: _____

Below are groups of statements. Please read each group of statements carefully. Then pick out the one statement in each group, which best describes the way you have been feeling the **PAST WEEK, INCLUDING TODAY!** Circle the number beside the statement you picked. If several statements in the group seem to apply equally well, circle each one. **Be sure to read all the statements in each group before making your choice.**

Ya fuatayo ni mafungu ya sentensi. Tafadhali soma kila fungu kwa makini. Chagua kutoka katika kila fungu sentensi ambayo yaelezea vyema ulivyokuwa ukihisi JUMA LILILOPITA NA UNAVYOHISI LEO! Ashiria sentensi moja au zaidi ya moja uliyochagua katika kila fungu kwa kuweka alama ya mviringo juu ya nambari ya sentensi hiyo. Hakikisha umesoma sentensi zote katika kila fungu kabla ya kuchagua sentensi iliyo sambamba na unavyo hisi.

	ENGLISH	*SWAHILI*
1	0 I do not feel sad. 1 I feel sad. 2 I am sad all the time and I can't get out of it. 3 I am so sad or unhappy that I can't stand it.	0 *Sina huzuni.* *1 Nina huzuni.* 2 *Nina huzuni wakati wote na siwezi kujiondoa katika hali hii ya huzuni.* 3 *Nina huzuni sana mpaka siwezi kustahimili/kuvumilia.*
2	0 I am not particularly discouraged about the future. 1 I feel discouraged about the future. 2 I feel I have nothing to look forward to. 3 I feel that the future is hopeless and that things cannot improve.	*0 Sijavunjika moyo hasa na siku za usoni.* 1 *Nahisi nimevunjika moyo na siku za usoni.* *2 Nahisi sina ninalo tarajia siku za usoni.* 3 *Nahisi nimekata tamaa ya siku za usoni, na naona mambo hayawezi kuwa bora zaidi.*
3	0 I do not feel like a failure. 1 I feel that I have failed more than the average (normal) person. 2 As I look back on my life, all I can see is a lot of failures. 3 I feel am a complete failure as a person.	0 *Sijihisi kama nimeanguka maishani.* 1 *Nahisi nimeanguka maishani zaidi ya mtu wa kawaida.* 2 *Nikiangalia maisha yangu yaliyopita naona nimeanguka sana.* 3 *Nahisi nimeanguka kabisa maishani.*
4	0 I get as much satisfaction as I used to from things I normally do. 1 I don't enjoy things the way I used to. 2 I don't get real satisfaction out of anything anymore. 3 I am dissatisfied or bored with everything.	0 *Naridhika na mambo kama ilivyo kawaida yangu.* 1 *1Si furahii mambo kama nilivyokuwa nikifurahia.* 2 *Sitosheki tena kikamilifu na jambo lolote.* 3 *Sitosheki wala sichangamshwi na chochote tena.*

5	0 0 I don't feel particularly guilty. 1 I feel guilty sometimes. 2 I feel quite guilty most of the time. 3 I feel guilty all the time.	0 *0 Sihisi hasa kama nina hatia fulani.* 1 *Nahisi nina hatia wakati mwingine.* 2 *Nahisi nina hatia wakati mwingi.* 3 *Nahisi nina hatia wakati wote.*
6	0 I don't feel I am being punished. 1 I feel I may be punished. 2 I expect to be punished. 3 I feel I am being punished.	*0 Sihisi kama nina adhibiwa.* *1 Nahisi kama naweza kuadhibiwa.* 2 *Natarajia kuadhibiwa.* 3 *Nahisi nina adhibiwa.*
7	0 I don't feel disappointed in myself. *1 I am disappointed in myself.* 2 I am disgusted with myself. 3 I hate myself.	0 *Sihisi kama nimeikasirikia nafsi yangu.* 1 *Nimeikasirikia nafsi yangu.* 2 *Najidharau.* 3 *Najichukia.*
8	0 I don't feel I am any worse than anybody else. 1 I am critical of myself for my weaknesses or mistakes. 2 I blame myself all the time for my faults. 3 I blame myself for everything bad that happens.	0 *Sihisi kama mimi ni mbaya zaidi ya mtu yeyote yule.* 1 *Najisuta (kujitoa makosa) sana katika makosa yangu ama udhaifu wangu.* *2 Najilaumu wakati wote kwa makosa yangu.* 3 *Najilaumu kwa ovu lolote linalo tendeka.*
9	0 I don't have any thoughts of killing myself. 1 I have thoughts of killing myself, but I would not carry them out. 2 I would like to kill myself. 3 I would kill myself if I had the chance.	0 *Sina wazo lolote la kujiuwa.* 1 *Nina wazo la kujiua, lakini sitalitimiza wazo hilo.* 2 *Ningetaka kujiuwa.* 3 *Nitajiuwa nikipata nafasi.*
10	0 I don't cry any more than usual. 1 I cry more now than I used to. 2 I cry all the time now. 3 I used to be able to cry, but now I can't cry even though I want to.	0 *Silii siku hizi zaidi ya vile ilivyo kawaida yangu.* 1 *Nalia siku hizi zaidi ya ilivyokuwa kawaida yangu.* 2 *Nalia wakati wote siku hizi.* 3 *Nilikuwa nikiweza kulia, lakini sasa hata nikitaka kulia siwezi.*
11	0 I am no more irritated now than usual. 1 I get annoyed or irritated more easily than I used to. 2 I feel irritated all the time now. 3 I don't get irritated at all by the things that used to irritate me.	*0 Sikasirishwi kwa urahisi siku hizi zaidi ya ilivyo kawaida yangu.* *1 N akasirishwa kwa urahisi zaidi ya ilivyokuwa kawaida yangu.* 2 *Nahisi nimekasirishwa wakati wote siku hizi.* 3 *Sikasirishwi kamwe na mambo ambayo yalikuwa yakinikasirisha.*
12	0 have not lost interest in other people. 1 I am less interested in other people than I used to be. 2 I have lost most of my interest in other people. 3 I have lost all of my interest in other people.	0 *Sijapoteza hamu ya kujihusisha au kujumuika na watu.* 1 *Hamu yangu ya kujihusisha na watu imepungua zaidi ya ilivyokuwa.* 2 *Nimepoteza sana hamu yangu ya kujihusisha na watu.*

		3 *Nimepoteza hamu yangu yote ya kujihusisha na watu.*
3	0 I make decisions just as well as I ever could. 1 I put off making decisions more than I used to. 2 I have greater difficulty in making decisions than before. 3 I can't make decisions at all anymore.	*0 Ninafanya uamuzi kuhusu jambo lolote kama kawaida.* *1 Ninahairisha kufanya uamuzi zaidi ya vile nilivyokuwa nikifanya.* 2 *Nina uzito mkubwa wa kufanya uamuzi kuliko hapo awali.* 3 *Siwezi tena kufanya uamuzi wa jambo lolote lile.*
4	0 I don't feel I look any worse than I used to. 1 I am worried that I am looking unattractive. 2 I feel that there are permanent changes in my appearance that make me look unattractive. 3 I believe that I look ugly.	0 *Sihisi kuwa naonekana vibaya zaidi ya vile nilivyokuwa.* 1 *Nina wasi wasi kuwa naonekana sivutii.* 2 *Ninahisi kuwa kuna mabadiliko yasio ondoka kwenye umbo langu yanayofanya nisivutie.* 3 *Nina amini ya kuwa nina sura mbaya.*
5	0 I can work just as well as before. 1 1 It takes an extra effort to get started at doing something. 2 I have to push myself very hard to do anything. 3 I can't do any work at all.	0 *Naweza kufanya kazi kama vile ilivyokuwa hapo awali.* 1 *Nilazima nifanye bidii, ndipo nianze kufanya jambo lolote* 2 *Inabidi nijilazimishe sana ili niweze kufanya jambo lolote* 3 *Siwezi kabisa kufanya kazi yoyote.*
6	0 I can sleep as well as usual. 1 I don't sleep as well as I used to. 2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep. 3 I wake up more than 2 hours earlier than I used to and cannot get back to sleep.	0 *Ninalala kama kawaida yangu.* 1 *Silali vyema kama nilivyo kuwa nikilala hapo awali.* 2 *Naamka mapema kwa saa limoja au masaa mawili, ambayo sio kawaida yangu, halafu ni vigumu kupata usingizi tena.* 3 *Naamka mapema zaidi ya masaa mawili, ambayo sio kawaida yangu, halafu siwezi kupata usingizi tena.*
7	0 I don't get more tired than usual. 1 I get tired more easily than I used to. 2 I get tired from doing almost anything. 3 I am too tired to do anything.	0 *Sichoki zaidi ya nilivyokuwa nikichoka hapo awali.* 1 *Nachoka kwa urahisi zaidi ya kawaida yangu.* 2 *Nachoshwa (Nachokeshwa), karibu na kila jambo ninalofanya* 3 *Ninachoka sana hata siwezi kufanya lolote.*
8	0 My appetite is no worse than usual. 1 My appetite is not as good as it used to be. 2 My appetite is much worse now. 3 I have no appetite at all anymore.	0 *Hamu yangu ya chakula sio mbaya zaidi ya vile ilivyokuwa hapo awali.* 1 *Hamu yangu ya chakula sio nzuri kama vile ilivyokuwa hapo awali.* 2 *Hamu yangu ya chakula ni mbaya*

		zaidi siku hizi. 3 *Sina tena hamu ya chakula hata kidogo.*
19	0 I haven't lost any noticeable weight, lately. 1 I have lost more than 2 kilograms. 2 I have lost more than 5 kilograms. 3 I have lost more than 7 kilograms . I am purposely trying to lose weight by eating less Yes _____ No _____	0 *Sijapunguza uzito wa mwili wakuonekana hivi karibuni.* 1 *Nimepunguza uzito wa mwili zaidi ya kilo mbili.* 2 *Nimepunguza uzito wa mwili zaidi ya kilo tano.* 3 *Nimepunguza uzito wa mwili zaidi ya kilo saba.* **Ninakula chakula kiasi kidogo kwa kusudio la, kujaribu kupunguza uzito wa mwili** *Ndivyo* _____ *Sivyo* _____
20	0 I am no more worried about my health than usual. 1 I am worried about physical problems such as aches and pains; or upset stomach; or constipation. 2 I am very worried about physical problems and it is hard to think about much else. 3 I am so worried about my physical problems that I cannot think about anything else.	0 *Sina wasiwasi usio wa kawaida kuhusu hali yangu ya afya.* 1 *Nina wasiwasi kuhusu shida za mwili kama vile maumivu hapa na pale; au shida ya tumbo, au kufunga choo.* 2 *Nina wasiwasi sana kuhusu matatizo ya mwili mpaka inakuwa nivigumu kuwaza jambo lengine lolote.* 3 *Nina wasiwasi sana kuhusu matatizo yangu ya mwili mpaka siwezi kuwaza jambo lingine lolote.*
21	0 I have not noticed any recent change in my interest in sex. 1 I am less interested in sex than I used to be. 2 I am much less interested in sex now. 3 I have lost interest in sex completely.	0 *Sijaona mabadiliko yoyote hivi karibuni kuhusu hamu yangu ya kufanya mapenzi.* 1 *Hamu yangu ya kufanya mapenzi imepungua zaidi ya vile ilivyokuwa.* 2 *Hamu yangu ya kufanya mapenzi imepungua sana siku hizi.* 3 *Nimepoteza kabisa hamu yangu ya kufanya mapenzi.*