

**FAMILY HOME-BASED CARE ON THE WELLBEING OF ELDERLY
WITH SENILE DEMENTIA IN ONDO STATE**

BY

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I certify that this research work was carried out by MR AYENI ADEBUSOLA RAPHAEL of the department of Nursing Science, Faculty of Basic Medical Sciences, Obafemi Awolowo University, Ile-Ife under my supervision.

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Supervisor

.....
Date

DEDICATION

This study is dedicated to God Almighty for His protection upon my family and to my wife for her endurance in pursuing higher degree and to Oluwatimilehin and Mary-Queen Ayeni for their understanding.

Also to all Family caregivers and their elderly living with dementia in Nigeria.

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ABSTRACT

This study identified the home-based care needs and level of care given to elderly with senile dementia; developed and administered a self-care nursing intervention package; as well as determined its impact on wellbeing of the care recipient. This was with a view of exploring the effect of the family home-based care on the wellbeing of the elderly with senile dementia.

The research was conducted in Owo Local Government in Ondo-State using a quasi-experimental design. Fifty six (56) care recipients (elderly person living with dementia) and their respective family caregivers (n=56) selected by purposive sampling formed the sample. Twenty eight (28) were assigned to experimental and control groups in dyad. Four (4) instruments were used; Modified Caregivers Assessment Questionnaire, Blessed Dementia Scale (Activities of daily living), Mini-Mental State Examination and Self-Care Assistance Nursing Intervention Observational Checklist/Scale. The Self-Care Assistance Nursing Intervention (educational) package was administered to experimental group in two-sessions after the collection of baseline data. Post intervention were conducted at eight weeks (1st post- test), and sixteen weeks (2nd post-test). Data collected were analyzed with the aid of Statistical Package of Social Sciences (SPSS). Statistical techniques employed includes percentages, mean scores and student t-test.

Results showed that the home-based care needs of the elderly with dementia centres around Activities of Daily Living (ADLs) 87.8%, Instrumental Activities of Daily Living (IADLs) 57.3% and Psychosocial needs (95%). At pre-intervention, analysis revealed that the level of care given to the elderly with dementia were only fair (53.6%) and good (46.4%) for the experimental group; and fair (50%) and good (50%) for the control group. However, at first post-intervention, the level of care given recorded by the experimental group had appreciated

(fair-7.1%, good-78.6% and excellent-14.3% with mean of 70.9 ± 9.3) while the control group recorded fair (39.3%), good (46.4%) and excellent (14.3%) with a mean of 64.5 ± 14.0 respectively. The results of second post-intervention for the experimental group revealed a drastic improvement in the level of caregiving (good 21.4% and excellent 78.6% with mean of 85.2 ± 8.4). No significant improvement was observed in the level of caregiving by the control group (fair-57.1%, good 42.9% and mean score of 58 ± 10.1). Further analysis showed that there was no significant difference between the self-care assistance provided by experimental and control groups ($t = -0.20$, $P = 0.802$) at pre-intervention. At first post-intervention, there was significant difference between the self-care assistance provided by experimental and control groups of family caregivers in the home-based caregiving for the maintenance of care recipients' wellbeing with ($t = 2.54$, $P = 0.01$). Similarly, at 2nd post-intervention there was very significant difference between the self care assistance provided by experimental and control groups of family caregivers in the home-based caregiving for the maintenance of care recipients' wellbeing with ($t = 12.85$, $P < 0.001$).

The study therefore concludes that the Self-Care Assistance Nursing Intervention package improves the home-based caregiving and also enhances the wellbeing of care recipients.

CHAPTER ONE

INTRODUCTION

1.1 Background to the Study

Dementia in its many forms is a leading cause of functional limitation among older adults worldwide and will continue to ascend in global health importance as populations continue to age and effective cures remain elusive (Mathers & Loncar, 2006). Besides, its consequences on the affected individual, it also has a major impact on everyday living of families, placing an emotional burden on the whole family unit (Pinquart & Sörensen, 2003). It is a common condition among the elderly, affecting an estimated 6.4% of all persons aged 65 years and older, based on a major study of prevalence of dementia undertaken in eight European countries (Lobo, Launer, Fratiglioni, Andersen, Di Carlo & Breteler, 2000; Berr, Wancata & Ritchie, 2005). In Nigeria community-based studies, the prevalence put at 2.29% to 2.79 % with Alzheimer's disease (AD) accounting for 1.41 %-1.86%, being the most common type (Yusuf, Baiyewu, Sheikh and Shehu, 2010). Although, dementia was initially thought to be rare in developing countries including Nigeria (Osuntokun & Ogunniyi, 1994; Ogunniyi & Akinyemi, 2010), however, there has been recent estimation in 2007 which suggested that about 33 million people worldwide are suffering from this hard to treat ailment, of which 60-70% are presently residing in developing countries including Africa (The Lancet Neurology Editorial, 2008). Surveys of communities in Central Africa revealed prevalence rates of dementia similar to those observed in higher-income countries with approximately 10% of those over age 65 affected (Guerchet, M'belesso, Mouanga, Bandzouzi, Tabo, et al, 2010).

Though the burden of dementia is currently low in sub-Saharan Africa, population ageing, lifestyle changes, increasing vascular factors, poverty, malnutrition, wars and the HIV pandemic

may cause future increments (Kalaria, Maestre, Arizaga, Friedland, Galasko, Hall et al., 2008). This can be supported by demographic report that the number of demented individual will increase spectacularly with the rapid increase in Nigeria population and the percentage number of 65years elderly and above (Olarenwaju, Saheed & Sunkanmi, 2011). The Nigeria total population from the last population census was about 140 million; out of this about 76 million constitute the dependent population which made up of both the children below age 18 and the elderly above age 60 (NBS, 2007). This figure shows that about 54% of Nigeria's total population is dependent population and the proportion of the elderly population out of this is about 25% and this is expected to increase over the year going by the population transition demographic theory (Olarenwaju et al, 2011). It can be foreseen that, despite mortality due to communicable diseases, poverty and human conflicts, incidence of dementia is destined to increase in the developing world because of increase in the number of ageing population (Kalaria, et.al, 2008). According to the Alzheimer's disease International (ADI) Delphi consensus study 2005, by 2040, 71% of all people with dementia will be living in developing countries.

There are various types of dementia (Alzheimer's and Vascular being the common one), but there are several underlying principles of treatment that can be applied to all patients. Non-medication interventions are the cornerstone in the treatment of dementia ("Kaplan & Sadock's, 2009), this was supported by evidence that psychosocial intervention yield positive result by focusing on care recipients and caregivers on how to cope and adapt to dementia (Vernooij-Dassen, Leatherman & Rikkert, 2011) It was also reported that, it is preferable to delay institutionalization as long as this is feasible and within the caregiver's capacity to do so, since patients with dementias diseases enjoy a longer life expectancy when not institutionalized (South Africa Family practice, 2012). Hence, supportive home-based care prolong the life of person

with dementia and the family caregivers. Dementia is not merely a problem of memory. It reduces the ability to learn, reason, retain or recall past experience and there is also loss of patterns of thoughts, feelings and activities (Van Gelder, Tijhuis, Kalmijn, Giampaoli, Nissinen, & Kromhout, 2004). Additionally, mental and behavioral problems often affect people who have dementia (Burn, Jacoby & Levy, 1990), which may influence their well-being and family caregivers (Alzheimer's disease international, 2008). The need for organizing an intervention care assistance that will help people living with dementias and their family caregivers is very important (Pinquart & Sorensen, 2006).

Caring for someone with Alzheimer's disease, dementias, and other brain-impairing disorders can be more stressful than caring for someone with a physical impairment (Wills and Soliman, 2001; Moise, Schwarzing, & Um, 2004), because caring for someone with cognitive disorder can be all day job due to the unpredictability of the care recipient's behaviour (Family Caregiver Alliance, 2008). In the later stages of dementia, carer burden may increase. Georges, Jansen, Jackson, Meyrieux, Sadowska, & Selmes (2008) survey found that half of those caring for someone with severe dementia spent in excess of ten hours per day in caring tasks. McLaughlin & Jones (2011) found that carers of people with Down's syndrome and dementia become increasingly isolated as the severity of the dementia increased and existing services became unable to cope. In addition to the above, chronic care is a broader concept, which refers to a partnership between patients and families, health care teams, and community supporters (WHO, 2002),

Home-based care is proven to deliver better outcomes for patients, yield lower costs and reduce admissions to hospital. Older people with dementia have the same priorities, preferring to remain in their own homes for as long as possible rather than move to residential care homes or other types of assisted housing (Goldsmith, 1996). Some studies have reported positive effects of

home care services including reductions in functional decline (Beswisk, Reesk, Dieppe, Ayis, Gooberman-Hill, et al, 2008). Research has shown that certain core social and emotional needs tend to be neglected for people with dementia when they are in long term care setting. Newbrunner, Chamberlain, Borthwick, Baxter & Glendinning(2013) found that family caregiver in UK reported that hospitalization resulted in dehydration, sores and a lack of nutrition because the impact of the dementia had not been taken into account by staff. The new approach is to plan for each person with dementia individually, to have the best possible outcome by meeting their needs (Department of Health and Family Services, 2009.) This is because as dementia worsens individuals may neglect themselves and may become disinhibited and may become incontinent (Gelder *et al*, 2005). Incontinence, hearing impairment, and mobility impairment are consistently associated with dementia in developing countries (Prince, Acosta, Ferri, Guerra, Huang et al, 2011).

Most of the dependent elderly population dwells at their own or at a family home, hence the theme for year 2012 World Alzheimer's Day was "Dementia: Living together".Not only is the home environment a place where they can retain a sense of independence and well-being, it is also more cost-effective if a person is living at home for a longer period of time due to the high costs of institutionalized care (Tinker, 1997).

In Nigeria, the thrust of health care is towards preventive care, especially for children and pregnant women, rather than the care of the aged. The multigenerational living system in Africa helps in the care of elderly (Yusuf et al, 2011), but socialization, acculturation, education, urbanization, high level of poverty and unemployment ravaging the nation at large, have led to degeneration of family ties. "This scenario has spatially torn families apart, made life uneasy for