Caring for individuals with dementia: The Nigerian experience

*A. Ogunniyi, K. S. Hall, **O. Baiyewu, **O. Gureje,
F. W. Unverzagt, S. Gao and H. C. Hendrie
*Departments of Medicine and **Psychiatry, College of Medicine,
University of Ibadan, Ibadan, Nigeria and
Indianapolis Study of Health and Aging, Indiana University,
Indianapolis, Indiana, USA.
E-mail: ogunniyi@skannet.com.ng

Summary

Recent epidemiological data, mainly from cross-cultural studies, have revealed that the burden of dementia and Alzheimer's disease (AD) the most common type, is significantly lower in developing than in the industrialized countries. Caring for individuals with dementia is a major consideration because most developing countries do not have the resources to provide comprehensive care in institutions. Home care that is practiced is ideal given the cultural scenario especially with the extended family support. Public policies on the care of the elderly however need to be well articulated and implemented. Hypertension was the most frequent medical co-morbidity of the demented subjects and about a third of subjects with AD were hypertensive, which may support vascular hypothesis in AD pathogenesis. The important behavioural disturbances experienced by caregivers and the associated stress levels were highlighted. The model used on the Indianapolis-Ibadan Dementia Study which involves periodic home visits, and empowerment of caregivers through regular meetings is envisaged to make caring for these individuals easier and adaptable in other African communities.

Keywords: ***Dementia, Caregiving, Co-morbidity, Developing countries.***

Résumé

Des données épidemoilogiques recentes surtout à travers des études inter-culturelles avaient montré que le fardeau de la maladie de la démence et du Alzhermer (MA) le type le plus fréquent est sensiblement en baisse dans les pays en voie de développement que dans les pays industrialisés. La prise en charge des individus atteints de la démence est une chose principale parceque la plupart des pays en voie de développement n'ont pas des resource pour contruire des institutions de la santé moderne. Des soins dans des maisons sont ideaux étant donné le scénario culturel en particulier avec le soutiens de la famille au sens large. On a besoin de mieux préciser et mettre en application la politique des relations publiques sur des soins des personnes âgées. Hypertension était la comorbidité médicale la plus fréquente des patients tombés en démence et environ un tier des sujets atteints de Ma hypertensif ce qui pourrait supporter l'hypothèse vasculaire dans la pathogenèse MD. On avait soulingné les troubles de comportement très importants connus par des médecins et des niveaux de la tension liée.

L'utilisation du modèle d'étude de la Démence d'Indianpolis-Ibadan qui avait impliqué des visites périodiques à la maison, et authorisation donnée aux médecines a travers des réunions régulière est envisagée pour faciliter et permettre des soins assidus pour ces individus et adaptable dans d'autres communautés africaines.

Introduction

Longevity is the norm rather than the exception worldwide in contemporary times and African countries are not excluded from this graying revolution. Increased life expectancy is associated with the need for care provision. One group of elderly individuals, those suffering from dementia, is particularly in need of such care because of their impaired performance of the activities of daily living (feeding, dressing and grooming). Special care provision for them is thus essential for the preservation of the essence of life and to avoid preventable domestic accidents and other dangers. In western countries, a lot of information is available on the pattern of care available, but this is not so in developing countries where information on dementia is rather sparse. Community-based, cross-cultural studies have revealed that the burden of dementia is significantly less than in the developed countries.[1-3] The incidence rates of dementia and Alzheimer's disease in Yoruba Africans were 2-3 times less than in African Americans.[1] The total annual cost of caring for individuals with dementia is enormous, and in one study was as high as $83 billion[4], which is far more than most developing countries faced with economic strife can afford. It therefore becomes important that appropriate caring methods be designed for demented subjects in developing countries. This communication compares the existing care patterns in western and developing countries as well as highlighting a model adopted on the Indianapolis-Ibadan Dementia Research Project (I-IDRP), which other developing countries can adopt to empower caregivers.

Comparison of care patterns in developing and developed countries

In western countries, between 30 and 50% of older persons live alone when their spouses die.[5,6] The I-IDRP data showed that more than 40% of African Americans lived alone[7], which implies that living alone is not the prerogative of any particular ethnic group. Subjects with mild to moderate dementia are cared for at home by spouses and children. However, when dementia becomes advanced with marked dependence or with disturbing behavioural and psychological manifestations, institutionalization becomes inevitable. Up to two-thirds of demented subjects are cared for in nursing homes.[6] Health care facilities, pensions and insurance schemes adequately provide for this type of care provision. Such facilities are however poorly developed in many developing countries.

In developing countries, on the other hand, family

*Correspondence

cohesion is very strong with notable extended family ties, and home management is the favoured pattern. The average family size is 6 persons and living arrangement is multi-generational[5]. In the Idikan community where the I-IDRP study took place, only about 15% of elderly subjects lived alone[7]. Many factors favour home care. They include: avoidance of stigmatization resulting in concealment within families. Family members are more likely to keep those afflicted at home to avoid family embarrassment resulting from hallucinations and delusions.[8,9] Others in the community may adduce this to possession by witchcraft, and such individuals may unfortunately be killed prematurely by stoning. There is thus a great tolerance of deviant behaviours within families. In a study in Nnewi, Uwakwe reported that all the 10 religious ministers surveyed believed that dementia was caused by evil spirits, and only 10-20% of the responders opined that drugs could be useful in treatment or supported orthodox therapy[10]. It was therefore not surprising that a lot of money is expended on seeking alternative care including sacrifices and visits to religious homes[11]. That form of therapy is however not recommended as it was not found to be associated with demonstrable clinical and economic benefits. Secondly, data from the I-IDRP study showed that about two-thirds of the demented subjects had mild disease[12], which can still be adequately managed at home. Even in developed countries, home care is recommended at this stage. Thirdly, many families cannot afford the prohibitive cost of hospital care, and many older persons live below poverty line with meager income with only about 6% earning any pensions[13]. Therefore, afflicted relations are managed at home with the resources available. The lack of public policies on adequate care of the older persons and lack of health insurance or social security scheme have not helped matters. This dismal financial capability makes home care a favoured choice. Fourthly, institutionalized care is frowned upon because of the stigma of destitution attached to the use of nursing homes[14]. Generally, it is believed that it is better for the older persons with family to die at home than to be abandoned in such homes. It is therefore not surprising that nursing homes are very few, and are only patronized by those without strong family ties or those with disabilities. Some wealthy families, mainly in urban communities, employ the services of domestic helpers to assist in caring for their older members at home.

The I-IDRP - Care arrangements for demented individuals

I-IDRP is a longitudinal, cross-cultural, trans-national study that compared the epidemiology of dementia and Alzheimer's disease (AD) in African Americans and Yoruba. Details of the study methodology and results have been published elsewhere[1,2]. A total of 98 demented individuals were diagnosed between 1992 (when the study started) and 1998 (the end of the second incidence wave). Alzheimer's disease (AD) was diagnosed in 80 subjects (81.6%), and only 34 of them were alive by the year 2000. In a separate study, we had reported that dementia caused a 3-fold increase in the risk of dying (odds ratio = 2.83)[15]. All the demented individuals are cared for at home, and relations provided supportive care. Seventy five percent of the care givers are women, and consisted mainly of the sisters and daughters. All the caregivers saw the subjects daily and 92.5% lived with the subjects. The average age of the caregivers was 42 years and about 60% of them had been to school (average of 7.4 years of schooling) [16]. The care pattern consisted of twice monthly home visits of the demented individuals by research staff [17]. Their health problems were recorded and medications supplied. Whenever more specialist care was required, as judged by the nurse practitioners, physicians were requested to do home consultation. If necessary, hospital admission followed moreso if the cases appeared terminal. The cost of caring for these subjects was borne by funds from the project. Relations living with the subjects were also encouraged to notify the research staff (either during field survey or to visit the research office) should any subject fall ill in the intervening period. In addition, monthly meetings are held with the caregivers. At such meetings, caregivers are allowed to discuss freely the problems encountered as well as troublesome behavioural/ psychological symptoms, and to proffer solutions. They are taught coping skills and tactics for dealing with difficult situations. Such meetings have facilitated social networking of caregivers and served to create a diversion from the problems at home. This reduced stress experienced by the carers, and the meetings have contributed in no small measure to build trust in the study and to facilitate getting the sick ones to hospital in time. It is well documented that the caregivers are vulnerable to the stress of looking after demented individuals and their health could also be in

Table 1 Factors favouring home care for demented individuals

Cultural beliefs - respect, pay-back opportunity, spiritual causation
Avoidance of family stigmatization
Limited belief in orthodox care
Support from and tolerance of extended family members living in same household
Limited facilities for institutionalization

Table 2 Medical co-morbidity of demented subjects

Total Number*		90
Male : Female		20:70
Dementia subtypes:		
Alzheimer's disease		74(82.2%)
Probable	66	
Possible	8	
Vascular dementia		10(11.1%)
Others		6(6.7%)
Co-morbidities:		
Absent		32
Present		54 (44AD; 10VD; 4others)
Hypertension		36(26AD; 7VD; 3 others)
Osteoarthritis		9 (all AD)
Others**	13	

** 8 excluded due to incomplete data*

*** Neurological diseases (6); Respiratory disorders (2); Dermatologic diseases (2); Gastrointestinal disorders (2); Unspecified (1).*

jeopardy [18]. They experience adverse psychological, physical, social and financial consequences including depression and loss of earnings. In our study, the caregivers also enjoy medical care when they attend the meetings with free supply of medications. These measures have largely improved the compliance of our caregivers and contributed to the excellent community perception of the I-IDRP. Brodaty and others[18], using meta-analysis, have shown that counseling of carers, education; support group programme, stress management; training and treatment can reduce caregivers' psychological morbidity and help people with dementia stay at home longer. These essentially are the strategies devised for the Idikan subjects.

Other care concerns

i) Medical co-morbidity

The diagnosis of dementia does not preclude the existence of other medical conditions which may contribute to morbidity or accelerate death. The I-IDS methodology incorporates detailed clinical assessment of all the demented subjects followed by relevant laboratory investigations and neuroimaging (Brain CT scan) before consensus diagnoses and subtyping are made. The pattern of medical morbidity in elderly individuals in Idikan community had been published earlier[19], and the same methodology was used for this analysis. Ninety subjects, comprising 20 males and 70 females, were included in the analysis with 58 of them (64.4%) having medical co-morbidity. The most frequent medical problem was hypertension (BP > 140/90 mm. Hg.), which was documented in 36 subjects (40.0%). Of the 10 subjects with vascular dementia, 7 (70%) were hypertensive as against 35% of the AD cases. The frequency of hypertension was 38% in the 65-74 years age group, 33% in the 75-84 age group, and 50% in those older than 85 years. Osteoarthritis diagnosed in 9 cases (10%) was the second most frequent, and all the cases were females, and they were diagnosed as suffering from AD. There were 6 subjects with neurological diseases, and two each with chest diseases, gastrointestinal disorder and skin diseases. One demented subject had unspecified illness.

ii) Behavioural and psychological disturbances.

Behavioural and psychological symptoms (BPS) occur in the moderate to severe stages of dementia but could also be early manifestations in patients with Lewy body dementia, a case of which had been documented in a Nigerian [20]. BPS could be very distressing and contribute to early institutionalization in western countries. Result from the I-IDRP showed that the frequencies of these BPS were lower in the Yoruba demented subjects compared with African Americans and Jamaicans [9]. A major concern for the Yoruba caregivers was about the demented family member being involved in embarrassing situations. Using the Neuropsychiatric Inventory (NPI), Baiyewu and others have identified the frequent BPS to be eating change (42.5%), depression (32.5%), irritability (27.5%), apathy (25%), agitation/anxiety (20%) and night-time behaviour (17.5%) [16]. However, higher frequency was not synonymous with caregiver distress. The most troublesome stressors were: night-time behaviour, disinhibition, anxiety, agitation/aggression and irritability in that order of frequency. Whereas, hallucinations, euphoria/elation and appetite change were low stressors [16]. This implied a great degree of tolerance of deviant behaviour by family members probably to preserve family integrity. Although medications can ameliorate some of the distressing BPS, many families cannot afford their cost. Drug use is therefore limited, just as there is a dearth of adequately qualified manpower in psychogeriatrics in developing countries.

Discussion

Increasing life expectancy in much of Africa implies that many more dementia cases are going to emerge with time and add to the strain on resources available for health care provision. Caring for individuals with dementia is universally a formidable problem that is both demanding and causes a lot of distress. Public policies on the care of the elderly are poorly developed in Nigeria as in many African countries in the sub-Saharan region. Due to the huge financial demand for adequate care provision, home care will still be the method of choice for most developing countries, as long as the extended family system still holds strong. It is however being gradually eroded with recent rural-urban migration and pursuit of paid employment [14]. Dwindling family sizes especially in the urban centres with emphasis on more nuclear set-up contribute to the dismantling of the extended family system. Domestic helpers are also likely to be harder to come by because many families are sending their children to school which is the objective of the universal basic education scheme to brighten their future. In recent times, the pursuit of gainful employment overseas termed "brain drain" has also added to the pressure on families to seek other ways for caring for their older persons with dementia. The consequences of all these will be a need for governments to have clear-cut policies on the care of older persons with or without dementia. One suggestion will be the establishment of day-care centres at community levels to augment whatever can be provided at home and thus contribute to the reduction of stress on care givers. Teaching the caregivers coping skills as had been devised on the I-IDRP is also a step in the right direction.

Apart from the social aspect of caring for subjects with dementia, it is essential to manage medical co-morbidities. In the I-IDS programme, hypertension has featured as a major contributor to morbidity. Thus, appropriate measures need to be taken to control blood pressures to reduce its devastating damage to various organs in the body of demented individuals. The high frequency of hypertension in this cohort is age-related as has been shown in the national survey on communicable diseases [21]. The diagnosis of hypertension in about a third of the AD cases would support the notion that vascular factors may be important in AD pathogenesis [22].

In conclusion, this review has shown that the home care method adopted for caring for demented individuals in developing countries is ideal in the present economic circumstances. It is based on cultural beliefs and thrives on extended family support. The possibility that the support currently enjoyed may disappear with economic pursuits and

rural-urban migration places the responsibility on governments to articulate and implement special policies on the care of older persons so as to ease burden on caregivers. The pattern of care provided for subjects on the I-IDS involving periodic visits and empowerment of caregivers through regular meetings can serve as a useful model for other African communities.

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