

DISABILITY AND CARE-GIVING IN OLD AGE IN A NIGERIAN COMMUNITY

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SUMMARY

Aim: To describe the pattern of disability and care for older community residents in a selected Nigerian location.

Method: Older persons living at home in Okporo Community were first identified through the traditional ruler and his assistant. The socio demographic profiles and any present diseases of these older subjects were obtained through a face- to face interview and they were subsequently assessed with the modified World Health Organization Disability Assessment Schedule Short version (WHO DAS-S). The primary care givers of the older subjects were interviewed to obtain their actual care giving role. A summarized Zarit Burden Interview and the twelve item General Health Questionnaire (GHQ-12) were used to measure the emotional impact on the caregivers.

Results: A total of 102 older subjects were recruited, with about 47% having some form of disability. Many comorbid physical diseases were reported. Most of the older subjects' children had left the community and females were the main care providers. Help with self-care was the greatest problem reported by the carers and care giving was regarded as very heavy burden associated with high emotional distress.

Conclusion: Disability is high in community elderly subjects. Care giving is proving a great challenge in the face of children deserting their parents, and increasing harsh economy. There is need for a systematic, realistic plan to implement qualitative care policy for older Nigerians.

Key words: Older subjects, disability, care-giving.

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INTRODUCTION

Reports from different parts of the world indicate that virtually every nation is graying.. According to a recent World Health Organisation (WHO) report, today, there are more than 600 Million persons aged 65 years and over throughout the world and this population is expected to double by 2025 and hit the billion target by 2050¹. The same source estimates that majority of the increase in the number of old people around the world will occur in the developing countries. Prince has shown that there are 4 different patterns of the trend in ageing around the world²

There is a projection that in general, people will live longer than ever before. Living longer brings along with it increased health risks- both physical and psychological. These risks may lead to disabilities and other associated features.

The WHO makes a distinction between impairments, disabilities and handicaps³. Impairments are concerned with loss or abnormality of psychological or anatomical structure/function. In principle,

impairments represent disturbance at the level of the organ. Disabilities, on the other hand, reflects the consequences of impairment in terms of any restriction or lack of ability to perform an activity, in the manner or within the range considered for a human being. This reflects disturbance at the level of the person. On another hand, handicaps are disadvantages for a given individual, resulting from an impairment or a disability, that limit or prevent the fulfillment of a role, that is normal (depending on age, sex, social and cultural factors) for that individual; this reflects disturbance between the individual's performance and the expectation of the individual or of the group of which he/she is a member³.

The WHO Disabilities Assessment Schedule (WHO DAS II) emphasizes that disability is not the same as psychiatric symptoms or specific psychological impairments associated with mental disorder⁴. It often depends on various extraneous and personality - related factors, some of which antedate, and some follow, the development of psychiatric disorders.

Disability can be manifested only in a social context (which will be defined by the norm of age, gender, culture etc.) The restriction or lack of ability to perform an expected activity may be in the area of self care (like washing, dressing, eating etc); social interaction / contact, participation in house hold activities; marital role; parental role; sexual role; occupational role; interests and information; behaviour in emergency situation and general behaviour⁴. Persons with disability may require care. Care and care giving have been variously defined. The American Psychiatric Association defined caregiver as any person involved in the treatment or rehabilitation of a patient; includes the psychiatrist, and other members of the traditional treatment team as well as community workers and other non-professional⁵. Depending on the context, others have defined a care giver as an adult individual who reports that he or she is now providing or has provided within the last 12 months, assistance with at least 2 or more instrumental activities of daily living or at least one activity of daily living to some one over the age of 50 years⁶. Yet others see care givers as those 18 years or older either providing informal care to a relative, friend, aged 50 or older, or those who have provided informal care to such a person at some point the prior 12 months⁷. Evidently care giving differs from one situation to another and is a complex phenomenon, such that no one definition can consistently apply across the board. In practical terms, some have divided care-giving and care givers as "formal" and "informal," informal care-givers referring to those carers who are not paid to do so, example social services department, private agencies etc.

The Alzheimer's Society of the United Kingdom (U.K) defined carers as people who look after relatives, friends or neighbours who require /need regular help or support because of disability, illness or the effect of old age⁸. The Society opines that caring can cover a wide range of activities, and carer may help with personal care, assist with practical tasks or generally keep an eye on the person. Not everyone who provides this type of care recognize themselves as a carer; they may think of themselves as simply having additional family responsibilities or take for granted that they should provide regular help for a neighbour, friend or relative in need

World over, it is generally agreed that family members are the main carers ---spouses, daughters etc. In Africa, without social security provision in most countries, the family is definitely in the forefront in providing care for the elderly. Indeed family care of the elderly has been regarded as the key to the long-term care system⁹.

Providing care for disabled or dependent older persons can be both burdensome and stressful. Though presenting a lot of challenges and difficulties, care giving can also bring reward to the care-giver. Lawton and colleagues developed the care giving satisfaction scale which indicates what satisfaction care givers derive¹⁰. It is generally agreed that providing care takes skill, patience, and time.

However, emphasis of most researchers has been the impact (physical and emotional) of care on caregivers. Care giving in old age is known to be associated with numerous negative health consequences, increasing both morbidity and mortality¹¹. The emotional and physical health effects on the caregiver sometimes depend on the actual status of the (disabled) old person being cared for. For example, some workers have reported that caring for some one with dementia is many times over more likely to be associated with negative outcome compared to caring for old persons with other health status or disability¹².

Our experience at the Nnamdi Azikiwe University Teaching Hospital has been limited only to care of persons with dementia. Ineichen¹³ opines that there is an increasing trend of growing pressure on caregiver and a greater likelihood that for many elderly people, there will simply be no relatives around to care.

Caring is a difficult task which can produce "burn out". There can be conflicts between the duty of caregivers and their own family needs, feeling of duty/ responsibility to their parents. Care-giving involves practical assistance in the home (example: meals, laundry, cleaning up of faeces/ urine for the incontinent, bathing, dressing, sitting, etc).

Studies of disability and care giving in the elderly are few in developing countries. Following the African Union (AU) and Madrid plan of Action on Ageing 2002, some African Countries (including Nigeria) have formulated national policies on ageing and health.

Such policies can only be meaningfully implemented if there are basic available data on the health and well being of the elderly in such countries. We therefore decided to study disability and care giving in a Nigerian Community.

MATERIALS AND METHODS:

The Setting: The study was done at Okporo, a Community in Orlu Local Government Area of Imo State (Eastern Nigeria). The community was selected purely on simple probability sampling. There are 9 hamlets in Okporo (Umueke, Umudara-Ezike,

Umudim, Ududu- Umuechem, Abara, Umuebele, Ubaha, Akwa-akuma and Umuocham). Okporo is a rural community with some hamlets having rural electrification. There are no pipe-borne water, tarred roads or other such facilities. The major occupation of the people, who are mainly of Igbo extraction, is farming. It was not possible to obtain the exact population of the community but the traditional ruler estimated that it could be up to 20,000. The study period covered January to February 2005.

Instruments: The study used a survey method with questionnaire containing three sections. The first section contains sociodemographic information about the older person, including self-reported physical or mental illness. The second section on the other hand contains information about the care-giver to the older person including a summarized form of the Zarit burden interview. The third section is a short version of the WHO Disability Assessment Schedule (WHO DAS-S) (14). The WHO DAS-S is designed for the recording of the clinician's assessment of disabilities by mental and physical disorders.

An open-ended question was used to determine the greatest problem faced by the caregiver in providing care for the (disabled) older person. The GHQ-12 (15) was scored for each caregiver to assess the emotional outcome of providing care.

The WHO DAS-S is not a questionnaire but is meant to be rated after obtaining information from relevant sources (like family members, medical records, observation of the client etc). We therefore used the WHO DAS II to convert the WHO DAS-S into a questionnaire so that it could be administered by non-clinicians. Each of the sections of the WHO DAS-S was cast into a question using exactly the same question of the relevant section in the WHO DAS-II. The WHO DAS-II is a semi-structured interview schedule designed for the comprehensive evaluation of the social functioning of patients with health problems-including physical diseases, mental disorders and alcohol/substances.. The WHO DAS II is increasingly being used to assess disability and quality of life in physical diseases (16). The WHO DAS-S covers personal care, occupation, family/household, functioning in a broad social context and any specific ability. It is rated on a six-point scale, from zero (no disability) to five (gross disability). Disability could be measured independently on the area covered, and total disability could be summed by addition of all the sections.

The Zarit Burden Interview (17) is a 22 item questionnaire, which enquires into the level of burden felt by a care giver.

Each of the first 21 items is rated on a five-point scale from zero (never) to four (nearly always). We collapsed the 22 items into a summary of the total burden of care.

Procedure: First, an experienced psychiatric research assistant was trained in the instruments (using the local language / vernacular ie. Igbo). The study was then fully explained to the traditional ruler of Okporo Community (The Ezeugo) who gave consent that the survey be done in his domain. A village elder (i.e. one of the red Cap Chiefs) in consultation with the monarch provided a list of all persons in Okporo Community who were aged 60 years and above. This was possible because Okporo is a small community and the village elder knew virtually everybody who are just younger, peers or older than himself. To make it a little easier, Igbo communities have "age grade" which is like a social club of contemporaries such that one could know nearly everybody in his or her community who are about the same age. This is obtainable throughout South-Eastern Nigeria (the Igbos).

With the list, the research assistant approached the potential respondent. (There are no street addresses; households are located by descriptions). After obtaining a verbal consent, the older person was administered sections one and three of the study instrument. The age of any older person who did not know when he or she was born, was estimated by use of national and local historical events- including the age of the firstborn child, the period of reign of different Okporo Monarchs. The principal care giver of the older person was then administered section two of the instrument. Where there was more than one person who provide assistance to the older person with any activity of daily living (care), the primary or principal care-giver was identified as the one who provides much of the care, and physically lives with the older person. If at the initial call a potential listed respondent was not met at home, three more return visits were made at different times of the day; after the third return visit and it was still not possible to meet the subject a record of "not at home" was made.

RESULTS

A total of 117 older persons were listed but only 102 (73 males and 29 females) were studied, representing about 87.2% response rate. Table one shows the sociodemographic characteristics of the 102 older persons. All the subjects professed the Christian religion.

Each subject had a range of children from 1 to 12; all together, the 102 subjects had a total of 502 children.

Table 1: Socio-demographic characteristics of the sample

Characteristics	N	(%)
Sex		
Male	73	(71.6)
Female	29	(28.4)
Marital Status		
Married (Male 62, Female 8)	70	(71.6)
Widowed (Male 19, Female 12)	31	(30.4)
Single (Male, 1)	1	(1.0)
Working status		
Still actively working (Male 11, Female 13)	24	(23.5)
No longer working	78	(76.5)
Membership of 'social group'		
Yes	102	(100)
No	0	(0)
Living Arrangement / Situation		
Living alone (4 Male, 5 Female)	9	(8.8)
Living with relations	93	(91.2)
Level of Education		
Nil	97	(95.1)
At least 2 years primary	3	(2.9)
At least 2 years secondary	2	(2.0)
Tertiary	0	(0)
Age		
Male (Range) =	60 - 100 years	
Female (Range) =	60- 96 years	
Mean Male age =	71.3 ±5.3 years	
Mean Female age =	75.1 ±6.7 years.	

Table 2: Distribution of the major reported illness by sex.

Illness	N	(%)
Male:		
Arthritis	14	(13.3)
Impaired vision	8	(7.6)
Hypertension	6	(5.7)
Forgetfulness	6	(5.7)
Diabetes mellitus	5	(4.8)
Malaria	5	(4.8)
Difficulty with hearing	3	(2.9)
Frank Mental disorder	3	(2.9)
Cancer	3	(2.9)
Liver disease	2	(1.9)
Tuberculosis		(1.9)
Female:		
Arthritis	15	(14.3)
Impaired Vision	10	(9.5)
Hypertension	6	(5.7)
Stroke	5	(4.8)
Diabetes Mellitey	4	(3.8)
Malaria	4	(3.8)
Forgetfulness	4	(3.9)
Frank Mental disorder	1	(0.9)
Total number of illness reported =	105	

In most households a range of zero to 7 children were no longer living at home. Of the 502 children, only 84 (16.7%) were living at home. About 97% of the older persons not living alone were living mainly with their daughters, and the rest were living with their sons or daughters-in-law. Nine subjects (8.8%) were living alone. Forty-four of the subjects (43.1%) did not report any illness whereas the rest (58.9%) reported some illness, ranging from one to 5 different ailments in one individual.

Table 2 shows the distribution of the major reported illnesses.

The 102 subjects reported a total of 105 illnesses, giving an average of at least 1.03 illness per study subject.. Those who reported some illness had suffered their ailments between 6 months and 10 years. Majority of those who reported illness (73%) were currently taking herbal preparations. A total number of 48 subjects (47%) reported some form of Disability on the WHO DAS-S. In all, 146 disabilities were reported, ranging from one to 3 disabilities in one subject.

Table 3 shows the distribution of the subjects according to gender and disability (score).

Six subjects reported having outstanding specific abilities (despite the fact that there may be some disability). These 4 males and 2 females were described as outstanding in making raffia mats / craft and teaching African traditional music/ dance. All the older subjects belonged to some form of social group (age grade, village union, religious order etc.) Although 54 subjects (52.9%) did not report any significant disability, the majority of them still needed some material support or some form of assistance in certain daily activities.

Ninety persons (84 females and 6 Males) were providing some care for their older subjects; 86 regarded themselves as indispensable to the older persons. Fifty-nine of the care providers were spouses (58 wives, and one husband); 7 daughters-in-law, 5 grand- daughters, 5 daughters, 4 house helps, 3 grandsons, one son and one great grandson. The primary care providers received assistance from some other family members.

The age range of the female care providers was 17 - 59 years (mean 47.6 years) and of the males 17 - 80 years (mean 28 years); over , care providers were aged 17- 80 years, with a mean of 46.3 years. Fifteen persons had provided care for between 6 months and 2 years, the rest for over 10 years. The greatest problems reported by the care providers were: help with self care(55%) (ie. assisting with older person's movement, bathing, feeding, cleaning up, disposal of urine/feaces) and material provision (30%) (ie.

procuring food, herbal/other medications, time/money spent in arranging for treatment. Other care providers reported continuously bringing the older person's memory back as their greatest problems. About 12% of the care providers reported "distress" and sleepless nights as their greatest difficulty in care giving. On the summarized Zarit Burden Interview all the care givers (97.5%), except one (2.5%) expressed that providing care for their older relatives was a very heavy burden to them. Providing care interfered with the work of the care givers (47 petty traders, 19 students, 15 farmers and 3 teachers)- resulting in missing work and cutting down on their work. Two care providers had no other jobs apart from their care providing role (full time care- giving).

Whether living alone is a result of the older person not having children or the children having migrated out of the community, this has serious public health consequences and psychosocial importance to older ones. For one, there is no form of social security or benefits to older persons in Nigeria

At present there are no well organized old people' homes or institutions for the elderly in Nigeria; a few available homes (about 3 in the whole country) are run by charitable organizations often championed by the Catholic Church and these can only take care of an insignificant number of the destitute elderly. Living alone as an older person in Nigeria is a terrible nightmare. Very recently, the Federal Government of the Federal Republic of Nigeria articulated a policy for ageing and health in the country but its implementation is an uphill task.

Table 3: Distribution of the subjects according to gender and disability score.

Disability Parawok	0		1		2		3		4		5	
	M	F	M	F	M	F	M	F	M	F	M	F
1. Personal Care	7	8	1	0	1	0	2	1	4	3	-	-
2. Work	13	14	3	1	1	0	2	1	6	6	-	-
3. Family	14	12	2	2	4	2	2	3	5	1	1	0
4. Broad social Context	5	4	3	5	2	1	2	0	2	0	-	-
Total	39	38	9	8	8	3	8	5	17	10	1	
Grand Total	77		17		11		13		27		1	

DISCUSSION

About 9% of the subjects were living alone. In pervious works, Uwakwe reported that 3% - 7% of older Nigerians lived alone^{18,19} This is a new trend compared to the original Nigerian traditional family setting where no older person lived alone. This is a definite indication that times have changed and the elderly are gradually being left on their own. Although Nigerians had used multiplicity of children as a social security, of the 502 children belonging to the 102 older persons, only about 17% were still living at home. Due to change in values and harsh economic conditions, many young ones have fled the villages for greener pasture either in major cities within the country or overseas. Sometimes the migrated children totally lose touch with their parents.

This new policy does not seem at the moment to have any impact on the life of elderly Nigerians. The preservation of the tradition of age grades, town unions, religious orders provides a social network system for older ones; all the 102 older subjects belonged to one social group or other. To an extent, this cushions some of the adverse consequences of living alone, including loneliness. These social groups have regular meetings and can provide not only companionship but other useful assistance to the elderly. This culture should be encouraged and maintained. Children dissenting their parents and increasing harsh economy create a huge crater in community elder care. There is need for a systematic realistic plan to implement qualitative care policy for

Diseases (arthritis, hypertension, stroke, diabetes mellitus and impaired vision) were the commonest reported illnesses. The diagnoses were provided to the older persons or their relations by health care professionals. As these subjects were not physically examined, nor their medical records reviewed, we speculate that this may be under reporting. Most Nigerians may either not be told or know what diseases they are suffering from; however, chronic physical conditions are more likely to be known as they attract multiple consultations and are long-lasting. Only 3 of the subjects were reported to have frank mental disorders. It is possible that these were subjects with obvious disruptive or behavioural problems arising from mental disorders. It is almost certain that the rate of mental disorders was much higher. Subjects with internalizing, mental disorders (like depression or anxiety) are not likely to regard or report such as mental disorders. In a previous community study of mental disorders in the elderly involving the use of diagnostic interviews, Uwakwe reported a rate of 23%¹⁸. Eight of the subjects had forgetfulness as their major problem. These were likely cases of possible (early) dementia or other cognitive impairments. This seems to be confirmed by the care givers' complaint that their greatest problem was to remind the older subjects all the time. Benign forgetfulness is not likely to pose such a problem. Co-morbidity of diseases was common which is in line with the general trend of disease patterns in the elderly. Chronic diseases, mental disorders (especially dementia and other cognitive disorders) and co-morbidity are not uncommon in elderly individuals.

Nearly one out of every 2 subjects had some form of disability-ranging from very mild to very severe. Disability could be associated with the presence of physical and mental disorders in old age. Various forms of disability have been described in the elderly²⁰. Some have argued that the prevalence of disability is contingent on the definition used²¹.

Both the WHO DAS-11 and WHO DAS-S clearly defined disability. Doubtless, disability was common among our subjects. Yadav reported that over 50% of 1209 elderly (community) Singaporeans had some form of disability²². Our result is in close agreement with this. Although the settings and age groups differed, upwards of 26%-92% disability prevalence is reported in the literature^{22,23}. On the other hand, Cutter has argued that changes in socio-economic

status, disease exposure, use of medical supportive aids, improved medical technology, have contributed to decline of disability in the elderly by 1% or more per year in the past several decades²⁴. These factors can hardly be said to apply forcefully in developing countries like Nigeria where impoverishment seems rather to be on the increase. Though disability may have early onset, Nigerians are not likely to make use of modern health care facilities- either because these are not accessible or affordable. Most of our subjects for example were taking native herbs for their ailments. Diagnosis of physical or mental disorders may be made by orthodox health care providers for older Nigerians, but the pathway to care often involves a cycle starting with spiritual healing, through native and orthodox care back to folk medications. In all, it would seem that chronic diseases (either mental or physical) account for greater functional disability and resource utilization in the elderly²⁵. This makes disability a topic of public health importance. The relevance in poor developing countries with increasing number of the elderly cannot be over emphasized. Health care planning for the elderly should also address the issue of disability. Although we recognize that there were more males than females in the sample, most of the care givers were females and family members. This is in line with most other studies²⁵. The family remains the bedrock as the source of care for older persons in Nigeria. Though many young people are migrating out of rural communities to urban areas or overseas, the extended family system still exists despite gradual erosion. The point has been made about the total non-existence of social security or disability benefit for older Nigerians. This is the more reason why the traditional extended family care should be strengthened. Without alternative to replace this cultural heritage, its disappearance will simply lead to total abandonment of older persons.

Community care is now advocated for most people with mental disorders, this ought to be considered in the context of the family arrangement. Policy makers in developing countries should develop supportive strategies to enable families continue to care for their older relatives. This may be done through community arrangements as in family support system grants and provision of primary health care centers with attractive subsidy for both older persons and their care givers. Institutional care for older persons in Nigeria sounds "unnatural" and may be regarded as taboo by most folks. However, when and if there is absolute need, some form of modified institutions patterned after African way of life can be

Arranged for older Nigerians who must need them. Interestingly, as in the developed world, old persons are also becoming care providers for other older persons. These 'old' co-resident carers will require special care and treatment so that they can sustain their care giving role. Some families hire house helps (in our sample there were four house helps ,all females serving as care providers). This is a new trend in Nigeria following changes in times. Where all children are away and decide to hire house helps to care for their older relatives, such house helps will require some kind of "supervision" . If this is not done, it could lead to elder abuse. Such abuse will be more likely where care for self-help is needed by the older persons. The care givers expressed this aspect of care as the greatest difficulty they faced. This is understandable, considering what it entails to clean up an older person who is incontinent (either bladder alone, bowel alone or both bladder and bowel). It requires enormous commitment and selfless-interest to dispose the urine and feaces of another person on regular basis. House helps are not trained care givers, and thus will require sufficient incentive and motivation to enable them provide quality care. In a poor country like Nigeria with raging inflation, high unemployment rate, material provision for older persons is a huge task. A good number of the care givers in our study gave the need for material provision as the greatest problem they faced. Most works report high rates of emotional disorders in those providing care for disabled older persons ²⁵. Nearly all the care givers in our sample reported that care giving was a great burden. Considered altogether, interference with the care givers' private life and work, material implication of care, and the actual duty of care itself, it can be appreciated why this has been described as a heavy burden. It requires no emphasis that the family can no longer be left to go it alone. Old age associated disability requires enormous amount of care. Time has come for governments, non-governmental organizations, communities, other agencies to come together and pool their resources to provide qualitative and adequate care for the disabled senior citizens of our land. Policies without implementation are as good as none. What is needed is translation of plans into actions. This way, the care of disabled elderly as a joint responsibility can be made a little easier for all concerned.

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