

QUALITY OF LIFE OF PATIENTS WITH EARLY ONSET DEMENTIA IN NIGERIA

Abstract

Dementia is a major cause of disability and mortality among the elderly, it becomes early onset of dementia, when it occurs before the age of 60years. It is the loss of cognitive abilities, particularly the loss of memory; it is one of the most dreaded conditions of old age. Around 5% of the population aged 65 and above is affected by dementia, and its prevalence rises with the rate nearly doubling every 5 years. The paper examines the effects of EOD on QL of patients. The study used the key informant interview research tool to achieve its aim and objectives, thereby collecting data to answer its research questions. Purposive sampling was used, while ethnographic summary and content analysis were used to analyse the data. The results showed that the quality of life of patients with EOD is generally poor, in that the illness brings about the crippling of finance, loss of memory and independence, loss of position in the society. The study recommends detecting factors that can prevent or postpone the disease, and educating the public on OED. Such interventions would have a major positive public health impact and reduce some of the common fears and anxieties of becoming older.

Key words: Dementia, old age, early onset, quality of life, Nigeria

INTRODUCTION

Dementia is not a specific disease as it refers to a group of symptoms caused by brain disorders. It is a general term used to describe the deterioration of mental activities. Memory loss is a common symptom of dementia, but it is not the only symptom. Other symptoms include losing the ability to solve problems, control one's emotions and successfully communicate verbally.

Some patients respond to cognitive training, such as memory exercises. For patients, whose dementia, include behaviour problems, treatment with behaviour modification may result in some improvement. EOD can be difficult to diagnose, even when signs of early dementia are present. It has a profound effect on the quality of life of patients, as its symptoms are serious, the sense of loss for the people, with EOD are enormous which are the following:

- Memory problems, especially short term memory loss
- Poor judgment and language problems, which includes the pronouncement of words
- Erratic changes in moods, behaviour and personality.
- Disorientation in time, place and the person
- Difficulties in recognition, understanding and comprehension
- Agitation and Hallucination

The diagnosis given as early stage of dementia is a long process, as patient need to be monitored consistently, and tested overtime in order to confirm EOD (Pratt, 2009), as the condition can be confused with other mental health issues, such as depression, psychosis or brain tumour.

The complications that come with early onset dementia, has an impact on the quality of life (QOL) of patients. There is an interruption of family life, as patients may still be raising children; there is the loss of employment, and also the crippling of finances. There are losses in independence and initiative, leading to inability to take care of oneself and also non-participation in social activities, leading to social exclusion and loneliness.

Burden of Early Onset Dementia (EOD) combined with possible loss of employment can cripple a family's financial situation. However, while the diagnostic process of early onset dementia is taking place, dementia symptoms can wreak havoc on personal relationships and work obligations. EOD places a significant burden on the individual, family and the immediate community. The implication of EOD on the QOL of patients is that the patient's behaviour and

abilities get diminished and distorted. Therefore, What is early-onset dementia (EOD)? How can early-onset dementia (EOD) have an effect on the physical, socio-economic, emotional well being of the patient? What causes early-onset dementia, can it bring about possible loss of employment, which brings forth financial handicaps? Does social status have anything to do with management of dementia? These and other questions shall be probed into in the course of this study.

METHODS AND MATERIALS

The study population concerns the population of Federal Neuro-psychiatric hospital Nigeria, which includes the inpatients, outpatients, the doctors and social workers of the hospital. The study population includes patients who are of the ages of 45-60 and above. The sampling technique used is non-probabilistic, which is any sampling procedure, with no pre-assigned probability of including a particular unit into the sample. Purposive sampling is used in this study; sample size for this research work is 25. The research instrument is key informant interview method (KII) to be used with the doctors and social workers of the patients in the hospital; it is a conversation between the interviewer and the respondent, with the purpose of eliciting certain information, this is possible through the following:

- Cognition or understanding by the respondent of what is required.
- The respondent has knowledge of the required information.
- Motivation on the part of the respondent to answer the questions accurately.

Ethnographic summary is to be utilised, Quotes would be identified, using exact words that are descriptive, representative of the respondents' views, and illustrate a particularly interesting perspective of one participant or respondent.

DISCUSSION OF FINDINGS

The subtopics identified highlight the key issues and common topics discussed during the interviews. Speaking with these individuals and hearing their stories enabled the capture of an insightful and detailed glimpse into their everyday lives. Through these interviews, it became clear that individuals with early onset of dementia have many challenges—physical, emotional, and even financial—and that the impact of this condition on quality of life should not be overlooked.

Embarrassment and self-consciousness were recurring themes throughout the interviews. Respondents felt anxiety when in public places and around large groups of people or strangers. They did not want their behavior to be noticed, and several respondents said that they could often “feel” people staring at them. The embarrassment experienced by the respondents can reach levels that cause social phobia. Respondents discussed avoiding social situations altogether to reduce distress caused by embarrassment. There appears to be a sense of isolation caused by feeling “different” that can lead to actual isolation, and this may have a significant impact on self-esteem and overall happiness.

In this study, respondents discussed their daily challenges with these, and other, simple tasks. Being able to perform ordinary activities requires extra thought, time, and effort by the respondents. This can not only be frustrating, but can also affect desires and choices. As one interviewee pointed out, she eats foods that are easiest to eat rather than foods she would like to eat. This everyday annoyance can wear on the individuals and greatly affect their behavior.

All of the participants had tricks they employed to manage their condition. In order to maintain their abilities, they had to adapt and develop new strategies to perform tasks such as eating and writing. These strategies were helpful for everyday activities as well as in their hobbies and careers. All of the respondents spent time sharing their inventive means of working around their condition. Although tasks were still burdensome, they were able to alleviate some frustration by creating these original tricks. The respondents were able to adapt, and others with Early Onset of Dementia (EOD) would benefit from learning about some of these strategies. Support from both family and friends were also a topic of discussion in all of the interviews. Some respondents spoke of early onset of dementia often with their family members because, as individuals associated with them, they could personally understand the burden of the condition. Others would joke about early onset dementia together with their family as a coping mechanism. However, some rarely discussed the condition with family because it was simply an “accepted” part of the family and not a constant cause of concern. Half of the experiences described with friends were supportive. Half of the respondents stated that friends were helpful when their behaviours were especially challenging and that they did not feel the need to hide their behaviour around them. The respondents’ comments about their experiences with Early Onset of Dementia (EOD) illustrate the utility of support systems for individuals affected with this condition. In any situation where an individual faces a difficult, having a support system in place or a social

worker can be of great benefit. Medical providers should make it a practice to ask about the support systems in their patients' lives. Family and friends can be supportive and necessary for coping. If an individual does not have family or friends to talk to about their difficulties with EOD, a referral to a support group or a social worker would be recommended as a place or person to openly talk, share strategies, and heal.

Also related to social setting, several respondents remarked that they were frustrated with the public's ignorance about EOD and the misconceptions that result. Strangers would often falsely label the subjects as drunk or mad. These assumptions were distressing, and trying to correct these assumptions and educate people about EOD on a daily basis became tiresome for the respondents. Several respondents noted that many people understand or have at least heard of Parkinson's disease, but early onset dementia, a much more common condition causing memory loss, is not well-known. Some respondents discussed the need for increased public awareness. The respondents hoped that greater public knowledge about Early Onset of Dementia (EOD) would make their condition less unusual, and the hurtful comments and assumptions made out of ignorance would be reduced. Healthcare providers should discuss comfortable and concise ways of explaining EOD to strangers. Providers may also give patients educational materials about EOD, which they can hand out to others. Developing a strategy for what to say when false assumptions or questions arise may be helpful in reducing embarrassment and anxiety.

The final key theme identified throughout the interviews was a positive outlook present in all respondents. While a previous study by Louis et al. (2007) has shown a higher rate of depression in individuals with EOD, several respondents felt that there were many worse conditions than early onset of dementia, and said that they felt lucky that this is all they have. They compared early onset of dementia (EOD) to other conditions including Parkinson's disease, and Multiple Sclerosis. Many were hopeful that research would soon identify the cause of EOD and effective treatments would soon follow. Several respondents also expressed that they had accepted EOD and learned to make the best of it. In conclusion, not nearly enough is known about the unique characteristics of early onset of the disease or the problems faced by those who have them. There also remains an inadequate amount of data available on the actual number of early onset individuals and their conditions. This study recommends a number of steps be taken in order to meet the needs of the early onset dementia patients.