

NUTRITIONAL WELL-BEING OF PERSONS WITH DEMENTIA- SOME GOOD PRACTICES IN DEMENTIA FAMILY CARE IN KERALA

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Abstract

Purpose: We conducted this study to explore the practical knowledge base identified and developed by families for caring persons with dementia which will have wider application in families, institutional settings, developing training modules and practice guidelines in the field of quality dementia care. Design and Methods: It is a qualitative study using case study design. The universe of this study is the whole families in Kottayam district of Kerala having persons with Dementia, who are cared in families itself. We employed purposive sampling and have selected six families with good care practices as samples for detailed case study. These families were selected by consulting doctors and social workers working in association with ARDSI, Kottayam Chapter. Primary data for the study was collected from the family members (primary care givers) of the dementia patients and interview schedule was used as the tool of data collection. Data analysis and interpretation has done using the techniques and methods of qualitative researches like acoustic recording and transcription. Results: Even though the family care givers are not trained for providing care; they have developed their own strategies and techniques to provide maximum comfort to the patient through nutritional well-being by adequate food and fluid consumption. Implications: All the good practices identified are already proved effective by the families through years of practice, so it have wider application in different settings and in developing training modules and practice guidelines for quality dementia care.

Key words: Dementia, Quality Care, Person with Dementia (PwD), Family Care, Good practices.

INTRODUCTION

Dementia is primarily (but not solely) an affliction of the elderly, and the prevalence increases dramatically with age to include almost a third of the population over 85 (Mahandra, 1984). The term “dementia” was probably coined in the first century A.D., but for the next millennium or so was generally quite ill-defined and often used (along with delirium) to refer to insanity in general (Lipowski, 1981; Mahandra, 1984). It is also likely that no real distinction was made between dementia and the changes in cognitive function associated with normal aging (Mahandra, 1984).

It is well recognized that the number of older adults who suffer from dementia has been increasing and will continue to do so over the coming years. In fact, nothing short of a three-fold rise in the number of people with Alzheimer’s disease is expected to occur between 2000 and 2050 (Zimmerman *et al.* 2005). Alzheimer’s disease and related dementias (ARD) are progressive, degenerative illnesses affecting mental abilities, emotions, behaviour, and physical functioning (Patterson *et al.*, 1999). They can create an overwhelming burden for family caregivers, negatively affecting their physical and mental health (Burton, Zdaniuk, Schultz, Jackson, & Hirsch, 2003; Peacock & Forbes, 2003; Schulz & Martire, 2004). The numbers of persons with dementia double every 5 years of age and so India will have one of the largest numbers of elders with this problem. It is estimated that over 3.7 million people are affected by dementia in our country. This is expected to double by 2030. It is estimated that the cost of taking care of a person with dementia is about 43,000 annually; much of which is met by the families. The financial burden will only increase in the coming years. The challenge posed by dementia as a health and social issue is of a scale we can no longer ignore. Despite the magnitude, there is gross ignorance, neglect and scarce services for people with dementia and their families (The Dementia India Report, 2010).

Early in this century, the term “organic psycho syndrome” was used by Bleuler to refer to a set of behavioural manifestations of chronic diffuse cortical damage. The behavioural manifestations involved decrements in memory, judgment, perceptual discrimination and attention, emotional liability, and defective impulse control (Lipowski, 1981). This was essentially the classification adopted by the American Psychiatric Association (APA) in the early editions of its *Diagnostic and Statistical Manual of Mental Disorders* (DSM-I and DSM-II; APA, 1952, 1968). Specifically, the DSM-II defined “organic brain syndrome” as a “basic mental condition characteristically resulting from diffuse impairment of brain tissue function from whatever cause,”

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and manifested behaviourally as an impairment in orientation, memory, intellectual functions, judgment, and affect (Lipowski, 1981). In this classification, brain dysfunction resulted in a single behavioural syndrome, regardless of the etiology and site of neuropathology (Lipowski, 1981).

The diagnostic criteria for dementia also require that a specific organic factor (or factors) can be either demonstrated or presumed (through the exclusion of all “functional” mental disorders) to be etiologically related to the disturbance. Dementing disorders that share a common symptom presentation but differ in etiology are distinguished in the DSM-IV. For example, the DSM-IV includes, among others, disorders such as Dementia of the Alzheimer Type, Vascular Dementia, Dementia Due to HIV Disease, Dementia Due to Head Trauma, Dementia Due to Parkinson’s Disease, and Dementia Due to Huntington’s Disease.

Adequate Food and Fluid Consumption

Declining capacity to eat and drink independently, and subsequent malnutrition and dehydration, have long been recognized as serious problems for institutionalized elderly, particularly for those with impaired mobility and cognition (Van Ort & Phillips, 1995). Malnutrition, or undernourishment resulting from insufficient food intake, is reported in up to 85% of nursing home residents (Simmons & Reuben, 2000), and dehydration has been documented in as many as 60% of residents (Fries et al., 1997; Holben, Hassell, Williams, & Helle, 1999). Consequences of malnutrition include weight loss, infection, impaired wound healing, immune deficiency, development of pressure sores, and even mortality (Volicer, Warden, & Morris, 1999). Dehydration can result in constipation, urinary tract infections, renal disease, pneumonia, hypotension, and delirium (Spangler & Chidester, 1998; Volicer et al.).

Insufficient consumption or inappropriate food and fluid choices can contribute directly to a decline in a resident’s health and well-being. Adequate assistance, preventive screening and intervention for nutritional problems will help to assure the overall health of residents suffering from dementia and will prevent unnecessary complications. Dementia may lead to reduced food and fluid intake, due in part to decreased recognition of hunger and thirst, declining perceptions of smell and taste, dysphagia (swallowing difficulty), inability to recognize dining utensils, loss of physical control, such as the ability to feed oneself, apraxia (impairment of ability to move) and depression.

Residents with dementia may lose the ability to communicate hunger and thirst. Residents may refuse to eat because of physiological or behavioral conditions, or they may do so because they are at the end of life. Addressing dementia-associated problems and helping to ensure adequate intake of food and fluid requires a concerted staff effort. As found by others (Kayser-Jones, Schell, Porter, Barbaccia, & Shaw, 1999; Keller, 1993), the study conducted in USA in 2005, shows that prevalence of low food intake (54%) and low fluid intake (51%) is high among residents of long term care, specifically among those with cognitive impairment. While these figures are lower in RC/ AL facilities than in nursing homes, they still average approximately 50% overall. There are, however, noticeable differences between this observed prevalence and facility staff-reported prevalence of eating difficulties (13.7%) and drinking difficulties (6.9%).

There are three care goals in this area according to Alzheimer’s Association, USA. They are: 1) To have good screening and preventive systems for nutritional care to avoid problems such as weight loss, malnutrition, pressure ulcers, infection and poor wound healing. 2) To assure proper nutrition and hydration so that residents maintain their nutritional health and avoid unnecessary health complications, given resident preferences and life circumstances. 3) To promote mealtimes as pleasant and enjoyable activities. (Jane & Peter, 2006).

DESIGN AND METHODS

Study Overview

The major objective of this study was to identify good techniques and strategies developed by each family for caring persons with dementia according to different conditions of the family such as age of person with dementia, behavioural patterns, nature of the disease, other age related physical problems, environmental factors, economic conditions, educational and vocational status of other members, number of family members etc. One of the specific objective of this study was to explore the good practices in the care practice area - nutritional well-being through adequate food and fluid consumption.

Each family has a unique system of caring persons with dementia. So case study method is employed for this study. The objectives of this study demand an in-depth study of each family and very minute things, data which generally appears irrelevant and ignored are the most important, and this is the knowledge which is explored in this study. This is a qualitative study, regarding the good care giving techniques and strategies developed by families themselves which no longer be scientifically studied and recorded properly. The universe

of this study is the whole families in Kottayam district having persons with Dementia, who are cared in families itself. The researcher employed purposive sampling. He has identified six families with good care practices as samples for detailed case study by consulting doctors and social workers working in association with ARDSI, Kottayam Chapter. Primary data for the study was collected from the family members (primary care givers) of the dementia patients and interview schedule was used as the tool of data collection. Data analysis and interpretation has done using the techniques and methods of qualitative researches like acoustic recording and transcription. The full interview was recorded using the audio recorder. Based on the transcription, case history of each patient was formulated and interpretations were made from it.

RESULTS

Major findings of the study can be summarised as follows: The place where the patient is having food can play an important role in nutritional well being. In most of the families, the patient is serving food in the public dining area with other members. In one family, patient is serving food in the veranda (sit out) of the house. The family noticed the place most comfortable to the patient. We cannot blindly recommend the family to take a particular place for the patient to have food. What we need is to promote mealtime as pleasant and enjoyable activity. So it is the interest of the patient is important and the family should identify the most comfortable place for the patient.

The person with whom the patient is having food is relevant in the context of adequate food intake. In most of the families the person with dementia is having food with the other members of the family. The presence of close relatives provides a comfort zone for the patient who sometimes can be disturbed due to cognitive impairments. It was noticed in a family that the verbal encouragement provided by the husband while the wife (the person with Dementia) is having food has a good impact. The presence of grand children while having food is an encouragement for a person with dementia to have food. Families follow no separate time schedule and menu for the patient, every item is served to them. Fluid intake is a serious concern and a family developed a strategy to ensure adequate fluid intake. Rice, being an item served two or three times in a day is never served as rough and dry, it is served as 'kanji' (a mix of rice and rice soup).

Importance of special menu and time schedule for the person with dementia is a serious concern in two dimensions. First, the nutritional content of the item served and second, the likes of the person. In case of patients who never ask for food, every item is served in mouth using hands or spoon at regular time. When food reaches near the mouth, the patient will open the mouth and will receive the food. The quantity of food consumed by the patient at a time may be less. So a special time schedule is need, and it is identified by a family and introduced a schedule. The patient is served coffee and a snack (Rusk) at 5.30 am and breakfast at 8.30 am, lunch at 1'o clock and tea at 2.30pm, snacks at 5pm and dinner at 8.30pm.

DISCUSSION

Even though the family care givers are not trained for providing care; they have developed their own strategies and techniques to provide maximum comfort to the patient. The findings of this study have a peculiarity that, all the good practices identified are already proved effective by the families through years of practice. A trial and error mechanism is already applied by the families in each practice. So the good and something found to be very relevant in specific situations and have universal application is specially noted in this study. They have wider application in different settings and in developing training modules and practice guidelines for quality dementia care.

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