Review Article

Strategies for home nutritional support in dementia care and its relevance in low-middle-income countries

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Abstract

Older people suffering from dementia are prone to develop malnutrition. Ensuring adequate nutrition among such patients has always been a challenge for the carers due to the pathological and chronic nature of the disease. In this article, the author tries to analyze the use of five different strategies in providing adequate nutrition for such patients in their own homes by the carers using a narrative literature review method. The strategies include nutrition screening and assessment, training and education program for the caregiver, mealtime environment and routine modification, provision of nutritional supplements, and role of artificial nutrition and hydration (ANH). An attempt was made to critically engage the readers while exploring the feasibility and challenges involved in implementing such strategies in resource-poor settings like low-middle-income countries. The article concludes that the first four strategies should be used in tandem to prevent the risk of malnutrition. It does not recommend ANH and concludes that it does not bring in any added benefit and may worsen the quality of life.

Keywords: Dementia, home care, nutrition

Burden of the Disease

Dementia is a syndrome caused by a variety of pathological changes in the brain which when becomes severe causes decline in day-to-day activities.[1] The majority of cases are Alzheimer's disease (50%–75%) and vascular dementia (20%—30%) followed by less common conditions such as frontotemporal dementia and mixed dementia.[1,2] Age is the single most important risk factor followed by gender with higher incidence rate seen among women than men.[3–5] Other risk factors include genetic factors, ethnicity such as South Asian, cardio vascular risk factors such as diabetes, lifestyle factors such as smoking, and head injury.[6]

Many low-middle-income countries (LMICs) are relatively young; however, old age population is expected to rise in large LMICs such as India.[7] In comparison to many western countries, it is still the family that provide primary care to elderly population in these region. In India, presently there is 1 older person for every 10 working-age population and this is expected to become 1 in 3 by 2100.[7,8] With the rise in elderly population, there will be a proportionate rise in the number of people living with dementia as the prevalence of the disease in that age group is between 5% and 7%.[7] According to Prince *et al.* (2013), there will be a proportionate increase of those affected with dementia by 225% between 2010 and 2050, and the majority of these dementia cases would be residing in LMICs.[9] In 2010, 57.7% of the dementia cases were in LMIC and is expected to become 63.4% by 2030 and 70.5% by 2050. Since most of the care in LMICs are being provided by family members, in this review I am focusing on nutrition care in person's own home mostly provided by informal carers.

Association between Dementia and Nutrition

One of the important aspects of dementia care is maintenance of adequate nutrition. Two of the clinical conditions commonly seen

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among dementia patients are weight loss and malnutrition.[10-12] The pathological explanations for weight loss are multifactorial and not properly understood. Some of the changes include brain atrophy, appearance of new molecules like Apolipoprotein E, proinflammatory agents like cytokines in brain tissue and blood, etc.[13-16] These changes will lead to the development of functional disabilities like olfactory and taste dysfunction, attention deficit causing reduced food intake, poor muscle co-ordination leading to loss of eating skills, etc., As the disease progresses, people will have difficulty to comprehend sensory inputs because of which they fail to understand the meaning of food items and behavioral problems causing disturbed eating habits.[17] Difficulty in swallowing seen in later stages prompts them to refuse food, which will ultimately lead to anorexia and weight loss. Poor nutrition will invariably lead to micronutrients and essential fatty acids deficiencies which trigger the production of factors like free radicals that initiate tissue damage, thereby worsening the dementia.[17] Various studies have found that malnutrition can increase the risk for infections and multiple hospitalizations, further deteriorating the financial burden of the disease. It has also been noticed that a moderate weight loss by 3% in 3 months can significantly increase mortality among older population.[18-20] These deleterious effects of malnutrition should not be ignored while caring for people with dementia.

Considering the fact that the disease is more prevalent among older women, mostly the informal caregiver will be an older male spouse. This can complicate the feeding process further as the caregiver himself may be dealing with multiple co-morbidities and physical disability, requiring care. Bilotta *et al.* (2010) have shown that stress among informal caregiver could cause more than 3% weight loss within 3 months in people with Alzheimer's disease.[21] A caregiver who is overburdened would not invest much to improve the feeding nature of the patient.[22] Therefore, in an informal setting, not just the patient but also the caregiver needs to be taken into consideration while planning strategies for adequate nutrition. To make the situation worse, the financial burden of the disease itself will indirectly cause the carer to focus less on nutritional needs, especially in LMIC countries. Thus, the association between dementia and weight loss is quite complicated making it a complex vicious cycle as summarized in Figure 1.

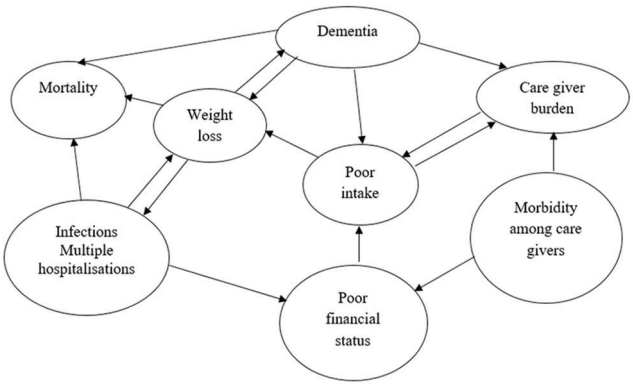

Figure 1: Vicious cycle of dementia and nutrition. Source: Author's own

Strategies to Ensure Adequate Nutrition

Ensuring adequate nutrition at home in a chronic, debilitating, and care-dependent condition like dementia is always a challenge. A multipronged approach, addressing the patient and the carer, needs to be carried out to bring in a desirable effect. Awareness, information, and implementation are the three main principles on which the home care nutritional care plans have been built.[20] In the following section, I will explore five strategies that can be implemented to ensure adequate nutrition.

Nutritional Screening and Assessment

Early identification and treatment play a vital role in providing better nutrition for dementia patients.[23] Even when the disease gets diagnosed, assessment of nutritional status and the emphasis on the need for adequate nutrition often get ignored. This is mainly because of the overwhelming nature of the disease and poor awareness regarding malnutrition and its deleterious effects on such patients. At the time of disease diagnosis, a thorough clinical nutritional assessment is needed to look for signs of nutritional deficiencies. Anthropometric assessment of height, weight, and body mass index (BMI) will help in identifying the normal and malnourished subjects requiring special attention. The traditional way of assessing dietary intake using 24 hour food recall is very time consuming and may not represent a typical pattern followed by the patient.[24] Numerous screening tools like mini nutritional assessment (MNA) and malnutrition universal screening tool that can be easily applied in a community setting are available to identify malnourished adults or those who are at the risk of malnutrition. MNA, one of the commonly used applied tool, has high sensitivity and specificity and can be easily implemented by the carer with minimal training.[25] In addition, there are tools available to identify the aversive feeding behavior (AFB) or learned refusal patterns like poor mouth opening to food, throwing tantrums during feeding like spitting out food, etc. Once assessment is complete, the clinician or the dietician should design a complete diet including adequate amounts of carbohydrates, protein, micronutrients like vitamin and minerals, and essential fatty acids. In addition, care should be given to prepare a diet plan including locally available, easily prepared food items so that caregiver compliance could be ensured.

Training and Education Programs for the Caregiver

Caregiver is the most important link in ensuring proper nutrition for the dementia patients who are dependent on them and training them is an important aspect of dementia care. Because of the high prevalence of the disease among women, it is usually the male spouse who will be assuming the role of caregiver. For many, this may be totally a new role that they may be getting accustomed to and usually will be fraught with apprehension and doubt regarding their choice of meal being correct or not. It is always important to hear out their apprehensions as it has been shown that caregiver strain can adversely affect the nutritional status of the dementia patient.[26] The Alzheimer's Disease International, London, has brought out certain instructions for the caregiver, which is summarized below [Table 1].[27]

Table 1: Feeding instructions for caregiver. Source[27]

Appetite stimulation	Regular snacks and small meals Food according to patient's preference Stronger flavors Keep food soft and warm Maintain a relaxed atmosphere Try and eat with the patient, interacting with them, irrespective of the response Encourage participation in meal preparation during the early stage of the disease
Not eating food	Do not consider it as not wanting food and stopped eating as completed eating Encourage gently Consider "finger food" like fruit slices
Loss of feeding skills or AFB	Needs to be fed by the caregiver Understand that AFB is not intentional Do not rush while feeding Provide independence where ever possible Watch out for nonverbal communication through eye contact or body language Do not try to feed while anxious or irritated Feed while conscious and alert, preferably in a sitting up position to avoid aspiration

A multicentric controlled trial was carried out including Alzheimer's patients residing at home and their carers from three main European countries to assess the impact of carer education on nutritional wellbeing of the patients. The intervention was carer education on consequences of poor nutrition, coping with stress, use of MNA to assess malnutrition, dietary recommendations, tips to increase protein and energy intake, AFB, and practical dietetics. The control group had routine clinical evaluation. The total study period was 1 year and the patients' weight, nutritional state, cognitive function, and behavioral disorders were assessed at baseline and reassessed at 6 and 12 months. Although the study did not find any statistically significant increase in weight in the intervention group, it has been noticed that the nutritional status measured using MNA remained same in the intervention arm, whereas it decreased significantly in the control arm.[28] Another cluster-randomized trial conducted in Spain also showed similar results with no significant weight gain, but significant improvement in nutritional status among the intervention group.[29] Although there is a dearth of evidence to support weight gain by the patients through caregiver training, this intervention should be promoted primarily because it was clearly found helpful in preventing worsening of the nutritional status. In addition, such sessions would give the carers an arena to bring up their apprehensions and difficulties.

Mealtime Environment and Routine Modification

Various government services like National Health Service (NHS), National Institute on Ageing, etc., and nonprofit organizations like Alzheimer's Disease International (ADI) have brought out practical guides to improve mealtime experiences.[30] The main points in these strategies have been summarized below.

1. Use mealtime as a time for interaction with a happy warm tone in the voice; naming food and drinks may trigger memory
2. Make the person sit in a comfortable position
3. Do not rush; let the patient takes adequate time to complete the meal
4. Maintain the routines, keep a calm and familiar atmosphere and be sensitive to person's frustrations. Some may respond well to soothing background music
5. If gets easily distracted, consider snack packs
6. Consider changing meal times to the time of the day when the person is more settled
7. Consider finger food idea which can be easily picked by the patient
8. Small amounts at frequent intervals
9. Ensure hydration by frequent fluid intake
10. Good quality lighting of the dining area.

Studies are available describing the positive effects of family-style mealtimes on the quality of life and nutritional well-being on the nursing home residents though these residents are not particularly suffering from dementia.[31,32] Also little evidence is available regarding the positive effects of aforementioned mealtime strategies implemented at homes of dementia patients which leave room for future research.

Nutritional Supplements

Provision of carbohydrates and protein nutritional supplementations are another strategy that can be considered in patients with dementia. Such supplements are commercially available, ready to make, and usually can be given in liquid forms to the patients in desirable quantities at regular intervals. To understand its impact on weight and BMI, ADI has conducted a meta-analysis using eight controlled trials done on dementia patients which had intervention as macronutrient supplements. The results provided clear evidence supporting macronutrient supplementation causing increase in weight and BMI [Figures 2 and 3].

But meta-analysis did not talk about databases searched, search strategies, and reason for selecting the articles they have finally included in the analysis. This casts doubt on the validity of the results of the meta-analysis, calling for further research in this area. But this does not rule out the role of macronutrient supplements; a Cochrane review looking into the effect of protein and energy supplementation among elderly population at risk of malnutrition showed weight gain with supplementation.[33]

Is there any role for micronutrient supplementation in dementia? In 2011, the European Society for Clinical Nutrition and Metabolism (ESPEN) has put up an expert group to create nutritional guidelines for various disease conditions considering grade of evidence and strength of recommendations.[34] The guideline they have put forth for dementia does not recommend supplementation of micronutrients like vitamins, minerals like selenium, copper, etc., as they were found to have nil effect on cognition.[23]

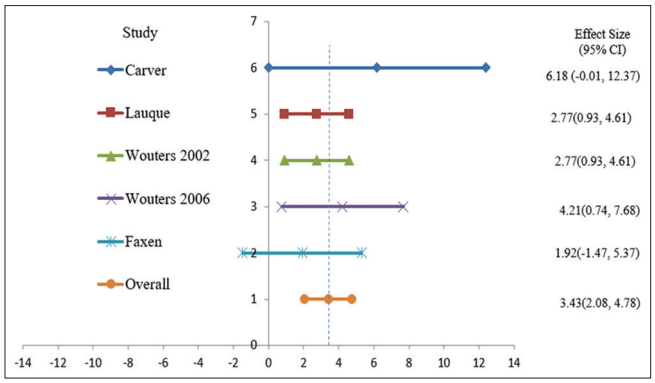

Figure 2: Forest-plot showing the effect of oral nutritional supplementation on % change in body weight. Source[27]

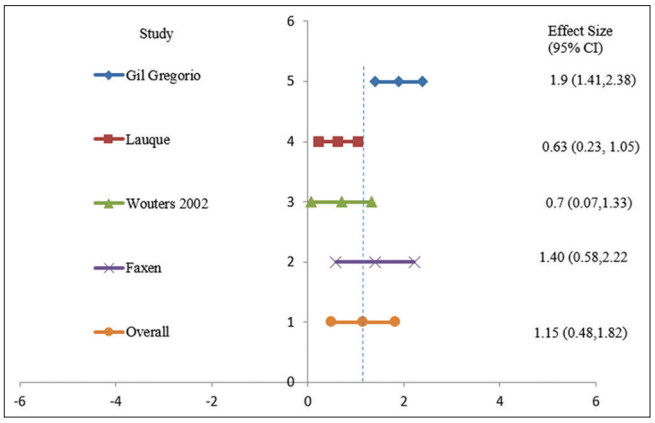

Figure 3: Forest-plot showing the effect of oral nutritional supplementation on BMI. Source[27]

Role of Artificial Nutrition and Hydration (ANH)

Artificial nutrition includes enteral nutrition, parenteral nutrition, and parenteral fluids. During the terminal stage of the disease when feeding becomes extremely difficult, the natural tendency of the carer is to resort toward artificial nutrition. Many of the carers are informed only about the benefits of tube feeding without mentioning about the hazards like infection, aspiration, etc., prompting them to opt for it.[35] Some of the relatives may even want to give percutaneous endoscopic gastrostomy for their loved ones to restore feeding.[36] Most often such patients will be restraint to prevent them from pulling the tube out, which is quite undignified and derogatory. Also, such restraints can precipitate aggressive behavior prompting them to injure themselves.[37] The ESPEN guidelines strongly recommend against this practice as the sensation of hunger is poor among dying and if we force feed, only very little gets absorbed. The rest may get regurgitated leading to cause other medical conditions like aspiration pneumonia, thereby worsening their quality of life. Although the evidential support for this guideline is poor, with the absence of controlled trials and systematic reviews, it endorses the role of palliative care in reducing the discomfort in such patients.[23]

Challenges in Implementing these Strategies in LMICs

Although the aforementioned strategies are clinically sound and viable, implementing them in resource-poor settings like LMICs is a challenge. Some of the main limitations include the low health literacy and stigma, limited access to health care, and economic barriers. In many countries, dementia is not often recognized as an organic disease condition of the brain but is accepted as a normal part of aging. Their altered behavior often get misunderstood as wilful activities done with an intention to cause more trouble for caregivers. This misinterpretation may expose care recipient to abuse, distress, and stigma.[38] Access to health care is still a challenge in many LMICs. People, especially in rural areas, have to travel far for medical support. Many a times dementia is identified as a disease with nil effective cure which prevents many carers from investing much in such patients. It is also an additional economic burden on the family, incurred directly from the disease and its complications and indirectly from the loss of carer income.[39]

If we analyze the aforementioned strategies in the background of these challenges, we realize that the practical application of these clinically sound strategies may not be easy. Most of the nutritional screening tools are evolved in a developed country setting and may not be very relevant and user-friendly in LMICs. Training of the carer and routine modifications are widely accepted strategies with proven beneficial effects on the nutritional status. This can be implemented in LMICs with slight modification of the methods incorporating the sociocultural and economic background of each region. Oral nutritional supplementation using commercially available products may not be feasible in a resource-poor setting; locally available, easy to make, and culturally and religiously acceptable substitutes need to be identified to bring in the desired effects.[40,41] I would not consider ANH in a resource-poor setting because it is expensive without having any proven benefits.

In a country like India, primary health center doctors often play the interface between people living with dementia and health care system. They are aptly positioned in the continuum of care playing a vital role in early diagnosis, timely referral, and providing carer guidance and support to adapt with long-term care needs. In addition, they will be having a proper understanding about care recipients' social, cultural, and financial background. Therefore, making primary care doctors aware of aforementioned strategies will help in successful penetration of these methods into the community. It will also help them to customize these strategies according to the demands of the society they serve.

Conclusion

The objective of the article was to compare various strategies to ensure adequate nutrition for older people with dementia in their own home. Evidence was presented exploring the role of five strategies: nutritional screening and assessment, training and education programs for the care-giver, mealtime environment

and routine modification, nutritional supplements, and ANH. Most of the evidence put forward here were looking into scientific and clinical efficacy of these strategies. It has also briefly analyzed critically, the feasibility of implementing these strategies in LMICs. In resource-poor setting like LMICs, the article concludes that screening, caregiver education, mealtime and routine modification, and nutritional supplements should be used in tandem to ensure adequate nutrition at home for people with dementia. It does not recommend ANH for nutrition as it involves procedure like gastrostomy which is expensive. There is also a clear lack of evidence in terms of controlled trials and systematic reviews supporting its benefits.

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Conflicts of interest

There are no conflicts of interest.

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