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Editorial

Social Determinants of Maintaining Nutrition in Older Adults with Advanced Dementia

J. Woo

Department of Medicine & Therapeutics, Faculty of Medicine, The Chinese University of Hong Kong, Hong Kong SAR, China

Corresponding Author: Jean Woo, Department of Medicine & Therapeutics, Faculty of Medicine, The Chinese University of Hong Kong, Hong Kong SAR, China, jeanwoowong@cuhk.edu.hk

Abstract

Dysphagia is recognised as part of the frailty syndrome, especially for those at the end of life. There is a tension in management between the need to optimize nutrition status as part of the management of oral frailty, and respecting the wishes of patients and/or family members in the form of advance care planning and advance directives regarding to artificial nutrition and hydration. Management will likely be influenced by many social determinants, rather than solely be based on evidence from clinical research..

Key words: Frailty, dementia, advance care planning.

Introduction

There are clear cut and well accepted guidelines regarding the use of artificial feeding for patients who cannot swallow, for example after major trauma, acute stroke, or chronic neuromuscular degenerative diseases: initially nasogastric tube (NGT), then consideration of percutaneous endoscopic gastrostomy. Controversy arises in cases of vegetative state where advance directives may prohibit artificial feeding. The situation with older adults with dementia may be less clear cut. Problems with chewing, swallowing and other oral pathologies affecting oral food intake are becoming recognised as part of the frailty syndrome, using the term oral frailty (1, 2). Much research has been devoted to detailed assessment, followed by various therapies to improve muscle function involved in swallowing. It is a common problem in both hospital and community settings (3, 4). At the same time optimizing nutritional status is a cornerstone in care of older adults, among whom malnutrition is an important issue and predisposes to various adverse health outcomes, as well as being a key measure in the maintenance of physical and cognitive function as part of healthy aging (5, 6). Dementia is a cause of death, although many lay people are not aware of this, because of its long trajectory towards death in terms of years. With the promotion and legislation of advanced directives, under the broader context of advanced care planning, the inclusion of dementia in such discourses becomes increasingly important. Meaningful discussions would need to be held before an advanced stage is reached, so that the wishes of the patient may be respected.

In this issue, Yuen et al (7) describes a quality improvement initiative undertaken in non-acute hospitals caring for older adults with advanced dementia in Hong Kong, where NGT feeding prevalence is higher compared with the US, but not Taiwan. Over a number of years, the clinical team has engaged in various end of life care programs, especially the promotion of advanced directives and advance care plans for those in non-acute settings. It is known that in the last years of life, hospital admissions are more frequent, and a common cause of death is pneumonia. A significant percentage would likely be a result of aspiration (whether of food, saliva, or regurgitated stomach contents), which may not be prevented by NGT insertion, since they represent part of the oral frailty spectrum. Most NGT are inserted during episodic care in the acute setting, where there is a pressure on beds and shortage of personal care staff. Hospitals usually allow carers from families for personal care such as feeding. Such patients are transferred to non-acute hospitals where patients may have recovered from the acute episode, to enable NGT to be discontinued. The study reported that careful hand feeding is possible and did not result in increased incidence of aspiration pneumonia nor hospital readmissions compared to a historical control group. Although the study showed that worthwhile quality improvement initiatives can be achieved, its value lies in highlighting various social determinants underlying the high prevalence of NGT insertion for such patients.

Culturally, Chinese people tend to avoid discussions about possibility of death and therefore advance directives. Many do not understand that dementia is a cause of death. Food is a very important part of care: one must not die of hunger. Such views are prevalent across all social gradient of society, including doctors. This may account for the current institutional practice of referring everyone to speech therapists to assess dysphagia. Invariably the risk of aspiration will be pointed out with a recommendation of NGT insertion. One may view this as a by-product of the management culture of establishing guidelines for all, as a medico-legal defence mechanism. Highly educated family members have sued hospitals for aspiration pneumonia. This occurred in a bedridden patient with dementia on NGT, who had a bout of diarrhea during an episode of feeding. Aspiration occurred during a change of incontinence pads.

Staff shortage is another reason for use of NGTs: it is an expedient way to maintain nutrition compared with

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careful hand feeding. This is particularly relevant in long term residential care settings. The Covid-19 pandemic puts a spotlight on this issue when no visitors were allowed. It is pertinent to ask whether such policies, or general lack of long term care policies that are evidence based, contributed to the very infectious omicron fuelled fatality rate at the beginning of 2022, a world record, where the majority were residents of long term care institutions (8). Poor nutritional status was shown to increase Covid-19 hospital mortality (9).

In the context of advanced care planning and advance directives, those with dementia represent a challenging group. On the one hand early discussion may not be welcomed. If left too late, family members may not feel able to make surrogate decisions, the default option being to avoid dying with an 'empty stomach'.

The initiative reported by Yuen et al did not include nutritional assessments, economic implications in terms of staff numbers required, nor proximity to death. It is likely that the population studied may not represent all those at proximity to death, since follow up data was available for 12 months. An automatically generated index based on frequency of hospital admissions and number of chronic diseases used by the Hospital Authority may give some indication of the proximity of death (average life expectancy 6 months), so that serious illness conversations may be initiated at an appropriate time, to include discussions regarding nutrition. While some family members value handfeeding for their family members with severe dementia, as a way of communication and expression of love, not all may afford to do so, this being another example of health inequality. In the last analysis this study is important in providing evidence to health and social care professionals, as well as policy makers, in debating long term care policies for older adults, bridging the gap between research, clinical care, and policies.

Conflicts of Interest: None declared.

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