

HOW SHOULD PATIENTS WITH DEMENTIA AND FOOD REFUSAL BE MANAGED?

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ABSTRACT

Anorexia of ageing is contributed by physiological changes, comorbidities, medications, and social factors. Food refusal in older adults with dementia is one of the behavioural and psychological symptoms of dementia. Modifying diet texture, fluid consistency, feeding techniques, and environmental factors can assist in overcoming food refusal. This case illustrates the challenges encountered in patients with dementia demonstrating food refusal behaviour, measures that can be taken to optimise their nutrition, and how these challenges may impact their long-term care.

Keywords: dementia; food refusal; long-term care; patient-centric

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INTRODUCTION

Patient's Revelation

"Doctor, why is my mother refusing to eat even her favourite food? Will she starve to death?" Madam C's daughter asked, as the patient refused all meals over three days.

CASE HISTORY

Madam C is a 74-year-old Chinese female with Alzheimer's disease (AD) and behavioural and psychological symptoms of dementia (BPSD) with a background of diabetes mellitus, hypertension, hyperlipidaemia, and frequent falls. She was homebound and required assistance for her basic and instrumental activities-of-daily-living. She lives with her husband, who is her primary caregiver. She has three daughters who occasionally visit her.

Madam C has had short-term memory loss since 2016. Her baseline Mini-Mental State Examination (MMSE) score was 24/30 in September 2018. Blood investigations were unremarkable, but brain imaging revealed a possible left interhemispheric meningioma, which was believed not to be the cause of memory decline after review by neurosurgeons. Follow-up appointments revealed new cognitive deficits,

agnosia, and executive dysfunction, with MMSE score gradually deteriorating to 16/30 in April 2019. Madam C was diagnosed with Alzheimer's Disease in May 2019 and started on donepezil 5 mg ON. In July 2020, Madam C became easily agitated and she was started on fluoxetine 10 mg OM. However, despite a trial of various anti-depressants and anti-psychotics, there was increasing physical aggression and verbal abuse towards family members.

Eventually, Madam C was admitted to an acute hospital in January 2022 for worsening BPSD as family members were unable to cope with her behaviour at home. Her family eventually decided to place her in a dementia nursing home (NH) and she was transferred to a community hospital while awaiting placement.

ISSUES AND PROGRESS IN THE COMMUNITY HOSPITAL

When Madam C was admitted, her agitation worsened. Hence she was reviewed by the visiting Geriatrician consultant, who stopped memantine (which may cause paradoxical agitation) and fluvoxamine (did not appear to have effect), while increasing the quetiapine dose for agitation.

Madam C also had fluctuating appetite, demonstrating food refusal behaviour. She lost 10 kg in less than three months, from 50.6 kg (30 Jan 2022) to 40.2 kg (3 Apr 2022). As a result, she had recurrent episodes of hypernatremia, hypokalaemia, and acute kidney injury secondary to dehydration from poor oral intake. This was managed with intravenous (IV) hydration and electrolytes correction, but she would pull out the IV cannula whenever she improved clinically.

GAINING INSIGHT

In managing Madam C, the following questions arose:

1. How do we manage Madam C's food refusal and optimise her nutrition?
2. How can we pace with Madam C's family to understand her condition (dementia) and cope with the complications (food refusal)?

MANAGEMENT

Non-Pharmacological Intervention

A. Multidisciplinary Team (MDT) to Support Feeding Strategies

Madam C was managed by a team consisting of doctors, nurses, therapists, a dietitian, and a social worker. Nurses

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were briefed by family members on her preferences and values. Specifically, Madam C's daughters reported that she was very thrifty and disliked wasting food, hence she would comply better with feeding when she was told that her meals and oral nutritional supplements were very expensive. Madam C's appetite also improved when her husband brought her favourite home-cooked foods. Gentle coaxing by nurses and family members were also practised to encourage Madam C to eat.

B. Nutrition Intervention

Initially, Madam C was on a regular texture diet of choice but mostly refused food and only drank liquids. Oral nutrition supplements (ONS) such as Pulmocare, assorted flavours of Fortisip compact protein, Glucerna vanilla liquid, and Ensure strawberry were prescribed by the dietitian. Existing medical conditions, caloric concentration, palatability, patient's taste preference, and tolerance were taken into consideration to decide on the most suitable ONS. In collaboration with the nurses, ONS was served in various ways to improve intake: chilled, warm, frozen into ice popsicles, served with medications, and prioritising ONS over plain water.

C. Family Engagement and Psychoeducation

Family conferences were held during Madam C's admission to establish the family's ideas, concerns, and expectations, and discuss goals of care to optimise oral intake and nutrition. The patient's husband and two younger daughters were concerned about starvation, and were initially resistant to ONS because they were worried it would worsen her diabetes control.

Her family was briefed about the course of patient's dementia and different treatments instituted at each stage of her condition, which allowed them to clarify any questions or misconceptions. Allowing the family to accompany Madam C at mealtimes in hospital during her episodes of food refusal also helped them to understand the fluctuating nature of the patient's oral intake. They were also more receptive towards the interventions and ONS when they witnessed her clinical improvement.

Pharmacological Intervention

As the patient persistently spat out her medications, medication reconciliation was performed. Non-essential medications, metformin (in view of euglycemia), melatonin (no sleep disturbances), and cholecalciferol (minimal ambulation) were stopped. Mirtazapine 7.5 mg ON was started for low mood and poor oral intake, and increased to 15 mg ON a week later. Madam C tolerated it well without side effects. Her oral intake improved subsequently, in conjunction with non-pharmacological interventions.

OUTCOME

Upon discharge from the community hospital, Madam C regained 67 percent of the weight she lost and was 46.9 kg. A memo was written to the NH, to allow family members to visit and bring food for Madam C. Two months later, Madam C was reviewed at a follow-up appointment in the community hospital clinic. The NH nursing manager reported that care staff were following instructions from the memo and as a result, Madam C was eating well and she was now at her baseline weight of 50.1 kg.

DISCUSSION

Anorexia of Ageing

Anorexia of ageing is defined as decreased appetite and/or food intake in older adults. It is a multifaceted clinical condition influenced by physiologic changes with ageing, medical conditions, and social factors.¹ Olfactory impairment and reduced number and sensitivity of taste papillae result in food being less tasty. Reduced gastric relaxation from reduced gastric fundus compliancy leads to delayed gastric emptying and earlier feeling of satiation.² Many neurotransmitters that decrease food intake (anorexics) were observed to increase with ageing in animal studies, although cholecystokinin is the only hormone confirmed to have increased satiating effect in older adults.³

Comorbidities such as depression, chronic organ failure, and conditions leading to physical impairment cause pathologic anorexia of ageing. Food refusal is one of the BPSD symptoms in dementia, particularly AD, as observed in Madam C. The biologic mechanism pathways of how dementia causes feeding problems are unknown, but dysphagia and altered processing of olfactory stimuli are postulated to result in anorexia in patients with dementia. Medications that affect taste and appetite may also induce anorexia, hence medication review is important, especially in older adults where polypharmacy is common. Social isolation and repetitive menus in long-term care facilities also contribute to reduced appetite and food intake in older adults.⁴

Optimising Nutrition in Patients With Dementia

Individuals with dementia often fall into a vicious cycle of malnutrition and nutritional problems such as food refusal, loss of function, olfactory and taste dysfunction – which is related to frailty – sarcopenia, and other age-related diseases and changes.⁵ In institutionalised settings, it is recommended that nutritional interventions for older adults should be individualised as part of a multimodal MDT intervention to ensure adequate nutrition intake, improved clinical course, and quality of life.⁶ Hence, family conferences were also held to manage caregivers' expectations and provide education on optimising nutrition for Madam C.

Current guidelines recommend using ONS to improve nutritional status by increasing the intake of energy and

protein in individuals with dementia.^{5,7} However, individual preferences were also taken into consideration, as Madam C used to dislike milk prior to her diagnosis of dementia. Hence, functional food and food with higher caloric content was offered instead. Studies show that individualising feeding routines, environments, and social interactions for patients with dementia have positive outcomes. The “Grazer Programme” provides practical steps in managing unintentional weight loss associated with cognitive decline by reducing distractions, increasing sensory cues, and using finger foods to improve oral intake.⁹ Caregivers can also use direct hand (caregiver holds utensil to provide food) or underhand (caregiver holds utensil and places it under patient’s hand) feeding techniques as meal assistance to improve oral intake in patients with dementia.¹⁰

Four broad strategies were employed to optimise Madam C’s nutrition.^{11,12}

- Firstly, through history obtained from family members, Madam C’s baseline personality traits, needs, and preferences were established.¹³
- Secondly, meal fortification strategies were employed: nourishing fluids, high calorie, and high protein food items were prioritised over other food items. Her favourite food items were offered to her⁸ and dietary restrictions were ceased.
- Thirdly, MDT employed assisted techniques to encourage eating. For example, providing finger foods and freezing ONS into popsicles that Madam C could hold and self-feed.
- Lastly, environmental modifications were made to enhance meal-time experiences.⁷ Madam C’s family was allowed to be present during mealtimes and bring home food that Madam C was familiar with. When possible, Madam C also ate in a communal meal setting to encourage oral intake.

Food refusal in patients may also be managed according to the severity of their food refusal attitudes. Each patient’s feeding and swallowing abilities should be assessed before determining a suitable diet texture, fluid consistency, and nutritional value. Patients who refuse meals but consume snacks may trial high caloric supplements, while tube feeding (TF) may be considered in patients who refuse to eat in all circumstances. However, studies show that TF does not improve survival in patients with advanced dementia, and there is significant risk of complications like pressure ulcers.¹⁴ Most guidelines also do not recommend TF for older adults with advanced dementia.¹⁵ In our patient, although her family was concerned about starvation with food refusal, they were against initiating TF as the discomfort might cause her to pull the tube out and repeated insertions might be traumatic should she become agitated. This was a shared decision between the healthcare team and family, which is in line with the recommendations.

Assistive devices or modified feeding equipment such as utensils with bigger handles, plates with raised edges, and cups with spouts or built-in straws may also allow older adults to retain their ability to feed themselves.¹⁶ Strategies to tackle food refusal based on severity and food refusal attitudes are further explained in **Table 1**.¹⁷ Such strategies may be employed by family physicians working in various care settings.

Medications in Dementia

There are no medications with marketing approval for the treatment of BPSD in dementia, although anti-depressants and anti-psychotics are often used as off-label treatment.¹⁸ Research shows that mirtazapine, a noradrenergic specific serotonergic anti-depressant, is effective in alleviating agitation and preventing further weight loss. Mirtazapine is preferred over other anti-depressants as it is less likely to cause drug-drug interactions and adverse side effects.¹⁹ For Madam C, mirtazapine’s “side effects” of increasing appetite and anxiolysis helped improve oral intake and reduced her agitation.

Table 1: Suggested Strategies to Tackle Food Refusal

Severity	Food Refusal Attitudes	Strategies
Low	Patient only eats if fed by specific people	Allow team & family to help during meal times to suit patient’s preferences.
	Patient refuses meals but consumes snacks	Introduce oral nutrition supplements into the diet. Stimulate appetite by offering foods of different colours or textures.
Moderate	Patient has ineffective chewing	Cut food into smaller pieces or change to soft diet.
	Patient has swallowing response but refuses food	Observe timings that patient responds to. Trial different stimulation (e.g., non-verbal cueing, visual cueing, syringe-feeding).
Severe	Patient refuses to eat in all circumstances	For consideration of careful hand-feeding and informing family members of the risks of aspiration. Tube feeding and intravenous infusions should only be considered based on family members’ cultural beliefs after discussion with the MDT.

Megestrol, a progestin used to treat anorexia in unexplained weight loss, is associated with slight weight gain in AIDS and cancer patients.²⁰ Although megestrol appears to improve appetite in older adults in some settings,²¹ no significant weight gain has been observed.²² With significant adverse effects such as thromboembolic events reported, usage in patients with dementia should be evaluated on a case-by-case basis.¹⁶

“De-prescribing” – stopping unnecessary medications or medications with limited benefits – in patients with advanced dementia can improve quality of life and reduce side effects such as drug-drug interactions.²³

Family Engagement

Addressing family concerns was crucial in managing Madam C's feeding difficulties. Many Singaporean Chinese believe that their loved ones would starve to death without food, and considered it unfilial if feeding was not initiated.²⁴ Therefore, accompanying their loved ones during meals maintains this sense of normality. Family bonding is also achieved as eating together at a large dining table is an expression of social support, group cohesion, and identity in the Chinese culture. Studies show that psychoeducation of family members²⁵ with provision of practical, specific instructions²⁶ can help caregivers better cope with food refusal behaviour in patients with dementia. Through engaging Madam C's family during mealtimes, Madam C's appetite improved and her family was also more receptive of the fact that her oral intake may fluctuate on different days.

Lastly, when patients are institutionalised or discharged to community home care team, continuity of care can be achieved through handovers to corresponding professionals prior to discharge. Subsequent family physician clinic reviews can also be paired with dietitian and speech therapist assessments, where ongoing family engagement can be incorporated to optimise long-term management. Future interventions can consider establishing guidelines for closer collaborations between institutions to bridge the gap in caring for individuals with dementia and food refusal.

CONCLUSION

Madam C's case highlights the challenges in caring for patients with dementia with food refusal behaviour and managing family's expectations. Personalised care in line with the family's goals was required to optimise management before she was eventually discharged well to a dementia nursing home. The various pharmacological and non-pharmacological strategies listed in the paper can be applied across various healthcare settings.

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LEARNING POINTS

- **A personalised approach should be used to address feeding difficulties in patients with advanced dementia.**
- **Modifying diet texture, fluid consistency, feeding techniques, and environmental factors can assist in overcoming food refusal.**
- **Psychoeducation of family members with provision of practical, specific instructions can help caregivers better cope with food refusal behaviour.**
- **Follow-up with multidisciplinary team members upon discharge from community hospital settings allows provision of longitudinal care for patients and continuous support for caregivers.**