

## A PITSTOP FOR A LIFE IN THE PITS: THE CARE OF THE SEVERELY DEMENTED IN A COMMUNITY HOSPITAL

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### ABSTRACT

We describe a case of an elderly lady's journey with severe dementia through a community hospital. Community hospitals play an important role in transitional care for elders with complex needs and their families to recalibrate the goals of care and optimise function after tumultuous stays in acute hospitals. We explore how the community hospital helped to break the vicious cycle of re-hospitalisation of our patient despite her dismal disease trajectory and address the complications of feeding difficulties and high caregiver burden. We also share practical advice on how a stay in a community hospital added value to the long-term care of similar elders.

**Keywords:** Dementia, Feeding Difficulties, Value-driven care

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### INTRODUCTION

HMA, an 85-year-old Malay lady with severe Alzheimer's Dementia, was admitted to the community hospital for rehabilitation after being hospitalised for a stable head injury following a fall at home.

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### MEDICAL HISTORY

HMA's past medical history includes severe Alzheimer's dementia, with a mini mental state examination score of 11 out of 30, ischaemic cardiomyopathy with previous percutaneous coronary intervention, and 2D-echocardiogram showing an ejection fraction of 25 percent with multiple regional wall motion abnormalities, diabetes mellitus, hypertension, hyperlipidaemia, osteoporosis, hypothyroidism, bilateral cataracts, and Bell's palsy.

### SOCIAL HISTORY

HMA was a homemaker with three children (refer to **Figure 1**). She lived with her eldest daughter and her family in a 4-room HDB flat with a lift landing for many years and depended on her daughter for her daily sustenance, with her medical bills covered by both her and her daughter's Medisave. She was pre-morbidly wheelchair bound and required assistance for all her basic activities of daily living (bADLs).

### ASSESSMENT: WHAT HAPPENED?

#### History of Presenting Complaint

HMA's fall for which she had presented to the acute hospital was mechanical in nature and unwitnessed. This occurred after she took a few steps in her toilet but failed to grab hold of a support in time.

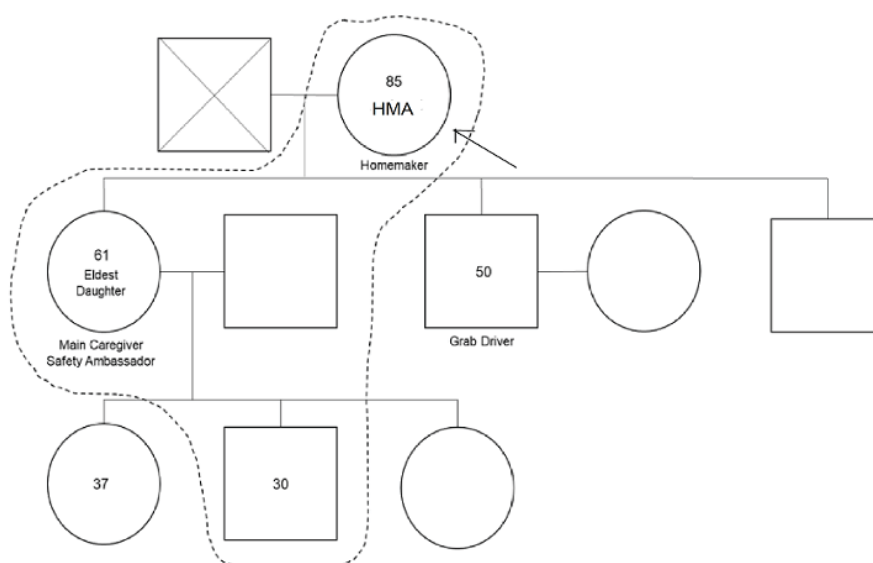


Figure 1: HMA's genogram

## Physical Examination

On admission, HMA was orientated to person and place, but not to time. Her blood pressure was 144/93 mmHg with no postural drop. There was no pallor, but her oral mucosa was dry. Cardiovascular, respiratory and abdominal examinations were unremarkable. There was a left lower motor neuron facial nerve palsy consistent with an old Bell's palsy and a global motor weakness score of 3 out of 5. Skeletal review was negative for bony tenderness or injuries.

Functional assessment conducted by the in-house therapists revealed that HMA had poor standing balance and was only able to sit unsupported for 30 seconds. She required moderate assistance from two persons for her to ambulate three metres using a rollator-frame. Her attention and memory were impaired and she was unable to follow one-step instructions consistently. She also had moderate oropharyngeal dysphagia from cognitive impairment, resulting in poor oral intake and requiring constant supervision in feeding.

## Investigations

Investigations upon admission to the acute hospital revealed signs of malnutrition as HMA was found to have low serum potassium (3.1 mmol/L [N:3.5-5.1]), inorganic phosphate (0.52 mmol/dL [N: 0.94-1.50]), and albumin levels (34 g/L [normal: 0.94-1.50]). Computer tomography of the head showed age-related involutional changes and there was no intracranial haemorrhage.

## DISCUSSION AND FOCUSED LITERATURE REVIEW

HMA's problem list spanned biomedical and psychosocial domains.

HMA's overriding medical problem was her severe progressive Alzheimer's dementia complicated by moderate oropharyngeal dysphagia, predisposing her to aspiration and infections. She did not possess the mental capacity to decide upon medical matters. She also had poor oral intake complicated by deranged electrolytes, starvation ketosis, and malnutrition. Her dementia led to poor communication and engagement, causing social isolation while in the community hospital and poor participation in rehabilitation with the allied health professionals.

Second, HMA had a high risk of fragility fractures with four episodes of previous falls on a background of severe osteoporosis. Her high risk of fractures was further predisposed by her impaired cognition and safety awareness from her dementia.

Third, she had a high cardiovascular risk profile due to her multiple chronic diseases of severe ischemic cardiomyopathy, diabetes mellitus, hypertension, and hyperlipidaemia.

Lastly, HMA's psychosocial issues include a substantial burden of caregiving, requiring moderate assistance by two people for her bADLs. Her daughter faced high caregiver stress due to being the lone caregiver while earning only a modest income. Moreover, there was no previous documentations of end-of-life discussions with HMA and her family members. This might have contributed to additional stress for HMA's carer should HMA acutely deteriorate.

## RECOMMENDATIONS

The community hospital is run by family physicians who believe in holistic, patient- and family-centric, and sustainable value-driven healthcare. The root cause of HMA's complex issues was her severe irreversible Alzheimer's Disease. We explored how the community hospital aimed to address HMA's severe dementia and its biomedical and psychosocial complications.

### I. How should the medical team establish goals of care in the face of dementia and dismal prognosis?

HMA had no advanced care plans in place and lacked capacity due to her severe dementia. She was initially transferred to the community hospital with the aim of improving her functional, swallowing, and nutritional status before she could return home, supported by day care services when her daughter goes to work. However, HMA's rehabilitation progressed minimally as she had engaged poorly during therapy. This required re-assessment of HMA's goals of cares. Under the Singapore Mental Capacity Act, it is stated that a person is unable to make decisions for oneself if one is unable to understand, retain, weigh, and communicate information relevant to the decisions.

The team approached HMA's daughter sensitively on the overall goals of care. Although HMA did not previously express any wishes about resuscitation should she suddenly deteriorate, her daughter recalls that her mother could not bear the thought of prolonged suffering from repeated medical interventions (e.g., strong intravenous treatment and blood taking, let alone intubation). As such, her daughter agreed to shift her end-of-life plans from a curative and restorative stance to an approach of comfort care and accepted the medical team's recommendation on the extent of care during deterioration. She declined further resuscitation and extraordinary life support upon cardiovascular collapse and artificial feeding should her appetite further worsen. She trusted the doctors to decide on her mother's best interests and institute judicious investigations and management, which would relieve her mother's suffering. She also felt assured that the team had not given up on her mother and wanted her to spend her remaining life with much dignity and with minimal suffering.

## **2. What are the practical steps to help an elderly with high care needs and her caregivers?**

HMA had persistent electrolyte abnormalities from poor oral intake, despite intravenous correction and oral supplementation. Her weight decreased drastically while in the hospital and she was fatigued most of the time, either lying down in bed or sitting on the geriatric chair and staring into space.

Thus the medical team first optimised HMA's medical status. Unnecessary blood taking was stopped and the team focussed on encouraging adequate oral intake by scheduling regular fluids. Her statins and diabetic medications were discontinued as her oral intake was poor. The team also reduced the monitoring of her capillary blood sugar and adopted less stringent goals for her sugars, blood pressure, and fluid restriction. The team targeted a blood pressure of below 150/90 mmHg, fasting sugar of between 4-9 mmol/dl, random sugar of 4-14 mmol/dl, and a fluid target of 1.5 litres per day. The team also instituted oral hygiene so as to reduce the risk of macro-aspiration. These helped to relieve the carer's burden of chasing strict targets and focus the care on keeping HMA comfortable.

### **Dietary and Speech Management**

The speech therapist engaged her in swallowing exercises such as lip strengthening and stretching exercises, while supervising her intake of soft diet consisting of mainly porridge, minced meat, and pureed fruits. After the initial slow progress where HMA constantly refused oral feeds, the dietician explored with HMA and her family her previous preferences for food, and noticed ice cream was one of her favourite foods. The dietician then trialled innovative supplements in the form of Propass ice cream and Glucerna popsicles, which were well-received by HMA. This dramatically improved her intake of soft diet foods. On good days, she took as much as 700 to 800 millilitres of soft foods, an improvement from her 200 to 300 millilitres at the start of her admission, and the food modification helped to increase her joy in feeding.

Anorexia in elderly is a regular feature of patients with dementia, with up to 40 percent of dementia patients experiencing clinically significant weight loss in their lifetime.<sup>1</sup> Reasons included reduced energy intake, diminished gustatory perception, or dysphagia as result of dementia.<sup>2,3,4</sup> Pharmacological options for dementia, namely acetylcholinesterase inhibitors, are also associated with weight loss.<sup>5</sup> Weight loss in dementia is detrimental as it is linked with higher mortality, institutionalisation, and poorer functional status. Recommendations for encouraging oral intake in patients with dementia is therefore important, especially in ageing populations, to prevent these. This can be instituted through oral supplementations and modification of other lifestyle factors, such as experimenting with new

diets or introducing pleasant environments around meals. While acetylcholinesterase inhibitors remain a mainstay for cognitive enhancement in dementia, other alternative drugs such as memantine can be considered for severe dementia, as it comes without the side effects of severe weight loss.<sup>6</sup>

### **Physiotherapy and Occupational Therapy**

The focus on the therapy sessions conducted by the allied health professionals was to maintain HMA on her current function and range her joints to prevent contractures. Caregiver training sessions and home modification were planned such that her daughter learnt how to perform safe transfers, toileting, and showering assistance. She was eventually deemed competent in ambulating HMA in a rollator-frame with minimal assistance and felt supported from the practical advice given by the therapists.

### **Social Recommendation**

The discharge care plan hinges upon adequate financial and caregiver support and the provision of caregiving services. HMA's daughter agreed to continue to be the main carer for HMA at night and during the weekend, underwent caregiver training, and was given a list of private care service providers as part of contingency planning. After considering various care options, her daughter chose an Integrated Home and Day Care package, where HMA would be able to have the flexibility of getting care services in both her home and in a day care centre. She preferred this as she felt that HMA could benefit from the comprehensive set of nursing, medical, and rehabilitative services that the package afforded for her mother.<sup>7</sup> More importantly, being either at home or at the day care allowed HMA to be surrounded by her loved ones constantly, which HMA would have wanted. The monthly fees of \$900 from these services would be covered by various financial subsidies. The medical social worker applied for Medifund assistance for medical bills and tapped on available subsidies to alleviate their financial burden, such as the Pioneer Generation Disability Scheme, which provide local elders coping with disability some financial assistance for their daily expenses.

## **3. What can we learn about the role of community hospital in the current healthcare climate for patients with dementia and poor prognosis?**

HMA is one of many elders with complex needs, of whom care by a lone healthcare provider may be insufficient. A multidisciplinary team comes in strategically to holistically tackle all the patient's needs with constant reviews and realignment of goals of care with stakeholders.<sup>8</sup> Similar to a pitstop in a high-intensity Formula One race, the community hospital positions itself as a bridge for the acute hospital and long-term community-based care, where the medical team works tirelessly to restore, rehabilitate, and readapt patients and their family before safely releasing them back to life's challenges. To prevent rehospitalisation, the team aims to

formulate water-tight plans with consultation of the patient and the family so that all possible loopholes are covered, and contingency measures are in place should the primary plan fail to deliver.

In Singapore, the prevalence of patients living with dementia (PWD) is 1.26 percent and is expected to increase with time.<sup>9</sup> Ageing in place with dignity is a goal that the healthcare system should aim towards where healthcare and social enterprises can seamlessly combine efforts to support PWD. Currently, the COVID-19 pandemic has overwhelmed community-based services such as dementia care centres and nursing homes, with extremely long waiting lists. The responsibility of caring for PWDs should be inched back towards caregivers and families, which require reinforcements such as carers, external care providers, and case-managers.<sup>10</sup> The community hospital plays that active role in seeking possible care models, such as the Integrated Primary Care for at-risk elders (IPCARE) model of providing continued case-management support and multidisciplinary resources to General Practitioner (GP) partners, patients, and caregivers of PWDs to age in place in the community.<sup>11,12</sup> This model enables GPs to provide comprehensive and continuing care for elders with complex issues, in keeping with Singapore's vision for every resident to have a personal family doctor for all his/her care needs.

That being said, caregiver stress for PWDs remains a very pertinent and unsolved issue permeating our society. Caregivers of PWDs perform numerous daily tasks, helping with activities of daily living, and managing behavioural symptoms of disease such as aggression and wandering, and these take a toll on caregivers. They report 27 hours more care per month on average (92 hours versus 65 hours) than caregivers of people without dementia, and twice as many of these caregivers indicate substantial emotional, financial, and physical difficulties, with a 30 percent higher prevalence of depression among these caregivers.<sup>13</sup> There are many ways to support these caregivers' health and wellbeing by relieving the negative aspects of care, but perhaps we have not tapped enough on our local services available. These include help from AIC and various Dementia Support Groups in Singapore, which seek to provide respite for caregivers regularly and to provide psychotherapeutic support through therapists and counsellors.

## CONCLUSION

Community hospitals function as a pitstop for elders, where patients and their families recalibrate care goals and discharge plans after tumultuous stays in acute hospitals. This contributes to a sustainable healthcare system to break the vicious cycle of readmissions despite often dismal disease trajectories. Beneficiaries such as PWDs can receive patient-centred multidisciplinary care with a lasting legacy in their disease trajectory to age in place beyond their hospital stay.

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## LEARNING POINTS

- In an ageing population, a growing number of elderly patients with complex needs can no longer be looked after by a single medical professional. A multi-disciplinary team is essential to tackle all aspects of care for our patients.
  - Community hospitals transition the care of elderly patients from their acute hospital stays back to the community. Similar to a pitstop in a race, community hospitals aim to restore, realign, and readapt patients and their families before releasing them back into the community.
  - In community hospitals, one should aim to discharge patients back to the community and to prevent readmissions. For discharge care plans to be water-tight, our patients require good caregiver and financial support.
  - In our current era of long waiting lists for institutionalised care, it should be encouraged that families care for their elderly families. These can be assisted by the many and sometimes untapped social services in place.
  - We need to look after our caregivers as caregiver stress currently remains an unsolved issue. Respite care and psychotherapeutic support remain some of the ways we should encourage caregivers to seek help in.
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