Feeding Intolerance in a Patient with Advanced Parkinson's Disease and Vascular Dementia: Lessons Learnt

Dr Michael Warren Lim, Dr Jeffrey Jiang Song En

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INTRODUCTION

Mdm N is an 80-year-old Chinese female with advanced Parkinson's Disease (PD) and vascular dementia (VaD) who was admitted to a community hospital for management of her sacral ulcer. She was bed-bound and non-communicative and had been initiated on nasogastric tube (NGT) feeding since 2009. Over her prolonged inpatient stay for wound care, numerous difficulties were encountered in her NGT feeding requiring frequent adjustment of her feeding regime. This led to difficulties with her long-term placement even after her sacral ulcer had healed.

Through this case, we illustrate the challenges encountered in patients on long-term tube feeding (TF), measures that were taken to optimise her nutrition and how these challenges had a bearing on her long-term care.

PATIENT'S REVELATION

“Doctor, why do my mother's feeds keep getting stopped? She is getting skinnier every day!” Mdm N's son asked as yet another syringe of milky undigested feeds was aspirated from her NGT.

Case History

Mdm N has been bed-bound, non-communicative and dependent in her Activities of Daily Living (ADLs) since 2015 due to advanced PD and VaD. Her PD symptoms were noted since 2006 when she developed bradykinesia, increased muscle rigidity, constipation and recurrent falls causing progressive functional decline. She was also noted to have cognitive impairment from 2006 and was diagnosed with VaD after work up by a neurologist.

Her functional status continued to decline from 2006 despite treatment with levodopa and galantamine for PD and VaD respectively. She was wheelchair-bound by 2008 and subsequently bed-bound and ADL-dependent by 2015. Oropharyngeal dysphagia was noted after a subcortical stroke in 2009, and she was started on enteral nutrition (EN) via nasogastric tube (NGT) feeding and has been on regular dietician follow-up since then. Her medical history and functional status are summarised in Figure 1.

Dr Michael Warren Lim
Resident, Department of Family Medicine,
National University Health System

Dr Jeffrey Jiang Song En
Registrar, St Luke's Hospital

Figure 1: Summary of Mdm N's Medical History and Functional Status

Her past medical history included previous trans-sphenoidal resection and radiotherapy for a non-functional pituitary adenoma in 2000 following which she required lifelong thyroxine and hydrocortisone replacement. Her other medications include levodopa-benserazide (Madopar), esomeprazole and lactulose.

Throughout this, her family had been highly supportive of her care. She was looked after at home by her husband, her youngest son and adomestic helper together with support from dietetics services in adjusting her feeding regime. An Advance Care Planning (ACP) discussion was previously planned during a previous admission in another institution in 2017 but did not take place due to the absence of some family members.

From October 2017, she was noted to have intolerance to her EN as manifested by high Gastric Residual Volumes (GRV), requiring various trials of more concentrated feeds to decrease feeding volume while meeting her caloric and protein requirements.

She was admitted to an acute hospital in February 2018 for a large unstageable sacral ulcer and was subsequently transferred to a community hospital for wound care. She was noted to be persistently intolerant of her EN as evidenced by high GRVs despite frequent adjustments of her feeding regime.

Physical Examination

Mdm N was a 49kg woman who was cachectic and dehydrated. Her vital signs were normal. She was able to open her eyes occasionally but unable to communicate through words or gestures. Her abdomen was soft, non-distended and non-tender without any palpable masses. Bowel sounds were normal and no succussion splash could be elicited. On neurological examination, she had flexion contractures of both upper and lower limbs with lead-pipe rigidity and cogwheeling tone in both upper limbs. Examination of the skin noted a deep 5.3 x 4.6 cm unstageable ulcer on the sacral region with erythema of surrounding skin. Additional areas of redness were noted over bony prominences at the left hip and both heels.

Medical Issues

1. Intolerance to EN manifested by high GRVs, likely due to gastroparesis from advanced PD causing malnutrition
2. Large sacral ulcer
3. Advanced PD and VaD complicated by oropharyngeal dysphagia requiring NGT feeding

Social Issues
1. Mdm N’s family was increasingly burdened by her care requirements despite their best efforts. The family’s search for a Nursing Home (NH) was also hindered by feeding difficulties which most NHs were unable to handle.

GAINING INSIGHT
In managing Mdm N, the following questions arose:
1. Why was Mdm N unable to tolerate her EN?
2. How can we optimise Mdm N’s nutrition despite the issues encountered with her EN?
3. What are the long-term care options for Mdm N?

MANAGEMENT
1. Why was Mdm N unable to tolerate her EN?
Gastrointestinal dysfunction is frequently observed in patients with PD and includes symptoms such as drooling, dysphagia, impaired gastric motility (gastroparesis) and constipation\(^1\). In Mdm N’s case, it was postulated that her feeding intolerance was due to gastroparesis, which is thought to affect between 70–100 percent of patients with PD\(^2\). Gastroparesis manifests as nausea, reduced appetite, early satiety, bloating, vomiting and weight loss\(^3\). These symptoms are thought to worsen in advanced PD\(^4\). In addition to hindering nutrition, gastroparesis in PD is also known to interfere with levodopa pharmacokinetics by decreasing small intestinal absorption and contributing to motor fluctuations\(^5\).

Reversible causes of gastroparesis were excluded – her thyroid function tests, fasting glucose and electrolytes including calcium and potassium were normal. Structural causes of gastric outlet obstruction were considered, for which a referral to a gastroenterologist was sought for further work up.

2. How can we optimise Mdm N’s nutrition despite the issues encountered with her feeding?
Mdm N was managed by a multidisciplinary team including medical, nursing, dietetics and medical social work staff. A family conference was organised to understand the family’s Ideas, Concerns and Expectations (ICE), to determine the goals of care and to conduct Advance Care Planning (ACP). In view of the patient’s frail premorbid state, the family was keen to optimise the patient’s nutrition, facilitate sacral ulcer healing and maximise the patient’s comfort. Invasive investigations and management were not desired. The patient was referred to a gastroenterologist and invasive work up including oesophagogastro-duodenoscopy (OGD) was considered to exclude anatomical causes of high GRV, but in view of the goals of care this was not pursued. While post-pyloric feeding via nasojejunal tube(NJT) insertion and percutaneous endoscopic transgastric jejunostomy (PEG-J) were options for the treatment of refractory gastroparesis\(^6\), they were also not in line with her goals of care. As domperidone was unsuccessful in improving the patient’s feeding tolerance, on the gastroenterologist’s advice, a trial of metoclopramide was successful in lowering GRVs and a decreased frequency of skipped feeds. The patient was monitored closely for the worsening of Parkinsonian features while on metoclopramide, given its potential to worsen Parkinsonism.

More expensive energy-dense feeds were required to maximise protein and calorie intake while minimising feed volume. Due to her intolerance of bolus NGT feeding, the decision was made to switch the patient over to continuous NGT feeding via enteral pump with some success. Her NGT feeding regime during the admission is summarised in Figure 2.

Nursing staff assisted with wound care, feeding and regular monitoring of GRV. As the patient was taking levothyroxine, continuous NGT feeding had to be interrupted before administration of levothyroxine to avoid interfering with its absorption\(^7\). With nutritional optimization and meticulous wound care, the patient’s sacral ulcer healed after several months in our institution.

3. What are the long-term care options for Mdm N?
Most NHs are not able to handle the nursing workload of continuous NGT feeding, thus limiting her placement options. The family was also unable to handle the burden of caring for her at home despite maximal support. The options for placement are outlined in Figure 3. Due to Mdm N’s high care requirements, she was placed in a Chronic Sick Unit (CSU).

During the Advance Care Planning (ACP) discussion, it was noted that Mdm N herself did not express any preferences for her care, and that the last verbal communication the family has had with the patient was 12 years prior to her current admission. The content of the ACP discussion included the family’s preference for place of care and extent of interventions in case of deterioration, as outlined in Figure 4.

DISCUSSION

Optimising nutrition in a malnourished bed bound patient with pressure ulcers
Mdm N is at high risk for developing pressure ulcers as she is bed bound and underweight. Her frequent interruption of EN due to intolerance caused a protein-calorie deficit which is an additional risk factor\(^8\). Optimising nutrition, meticulous wound care, pressure offloading and treatment of superimposed infection are key interventions to facilitate ulcer healing\(^9\). Patients with wounds have a caloric requirement of 30–35 kcal/kg/day (increased to 35–40 kcal/kg/day\(^{10–11}\) in underweight patients) and a protein requirement of 1.2–1.5g/kg/day. Mdm N’s gastroparesis posed a considerable challenge in achieving this target, requiring a combination of gastrointestinal prokinetic agents, low-volume energy-dense feeds and continuous NGT feeding.

Gastric residual volume (GRV) monitoring and enteral feeding (EN) intolerance
Mdm N was monitored regularly for signs of feeding intolerance, including abdominal distension, vomiting, diarrhoea and dehydration. Our institution’s protocol is to measure GRV prior to each feed, with feeding held if it exceeded 100mls. In Mdm N’s case, the frequent occurrence of a high GRV led to omissions of bolus NGT feeds or delays in continuous feeding, causing difficulties in achieving nutrition targets.

Mental Health Update

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Despite being widely used as a marker of gastric emptying and hence aspiration risk, the effectiveness of GRV monitoring has been questioned. Numerous studies on patients receiving EN in a critical care setting found GRV to be a poor marker of aspiration and pneumonia risk\(^a\), while trials of delivering EN without GRV monitoring showed no difference in rates of pneumonia while allowing increased feeding volumes\(^b\,c\). Based on this evidence, the latest American College of Gastroenterology Clinical Guidelines recommended against routine GRV monitoring\(^d\).

In Mdm N’s case, a strategy observing for clinical signs of feeding intolerance without monitoring GRV may increase the success of EN. However, it is yet to be determined if these findings are applicable to patients with a neurological cause of gastroparesis and in a general ward setting.

The use of tube feeding (TF) in patients with advanced dementia

Mdm N has been fed via NGT since 2009 due to the perceived aspiration risk of feeding orally. The question arises of whether this practice is in line with her disease trajectory and overall goals of care. The weight of evidence shows that TF does not prevent and may even increase the chance of aspiration pneumonia\(^e\,f\) and is associated with increased risk of pressure ulcers\(^g\,h\,i\) and mortality\(^j\,k\,l\). Most guidelines do not recommend the use of TF for older adults with advanced dementia\(^m\,n\).

Given that Mdm N’s family has become accustomed to feeding her via NGT, her present difficulties with feeding even on her NGT and the near-term goal of healing her sacral ulcer, the option of withdrawing NGT feeding was not considered. However, should her condition continue to deteriorate, the option could be brought up as part of her ongoing review of her goals of care.

Right-siting of patients with complex care requirements

Mdm N’s need for continuous NGT feeding requires round-the-clock monitoring and specialised nursing care which most nursing homes (NH) are not equipped to handle. The team thus had limited options in obtaining long-term placement for the patient. With Singapore’s rapidly ageing population\(^o\), the proportion of patients with long-term care needs is set to increase. Among them will include patients with complex care requirements including tracheostomy care, enteral pump management and non-invasive ventilation. Currently, most of these patients are cared for in Chronic Sick Units (CSUs). It is conceivable that the demand for complex nursing care will increase, requiring additional CSU places or the expansion of the capabilities of existing NHs.

Advance Care Planning (ACP) for patients with progressive neurodegenerative disease

Mdm N’s case illustrates the importance of ACP in patients with progressive neurological diseases such as Parkinson’s disease and dementia. With the increasing prevalence of such conditions, all doctors should be equipped to initiate ACP discussions when appropriate. Patients with such conditions tend to deteriorate gradually over years, making it difficult to identify the right moment to initiate ACP discussions\(^p\). Significant friction can hinder effective discussion on goals of care, arising from factors including avoidance of discussing end of life issues, difficulties in prognosticating survival\(^q\,r\,s\), uncertainty and conflicts of opinion between patients and their caregivers\(^t\) and the loss of patients’ mental capacity. Nevertheless, it is critical for doctors to actively overcome this friction and seek out appropriate moments to initiate the ACP process with these patients to improve end of life care, patient and family satisfaction and reduce stress and anxiety in surviving relatives\(^u\).

CONCLUSION

Mdm N’s case highlights the complexity of caring for bed bound elderly patients with multiple comorbidities, in particular the difficulty in meeting nutrition targets in patients with gastroparesis due to chronic neurological disease. Inputs were required from a multidisciplinary team, including doctors, nurses, dieticians and medical social workers. Ultimately, her care was optimized in an individualised approach in line with her family’s goals of care, with the complexity of her care requirements requiring her eventual placement in a Chronic Sick Unit.

REFERENCES

Figure 2: Mdm N’s NGT Feeding Regime

<table>
<thead>
<tr>
<th>Date</th>
<th>NGT Feeding Regime</th>
<th>Volume (mls)</th>
<th>Calories (kcal)</th>
<th>Protein (g)</th>
<th>Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 Aug 2018</td>
<td>Continuous NGT feeding Nepro HP* 440ml @ 30ml/h over 13h Water 500ml over 5 flushes</td>
<td>940</td>
<td>800</td>
<td>36</td>
<td>High GRV noted, multiple omitted feeds – decision to try continuous NGT feeding</td>
</tr>
<tr>
<td>17 Aug 2018</td>
<td>Continuous NGT feeding Nepro HP* 500ml @ 35ml over 15h Propass 1 scoop 4x/d Water 500ml over 5 flushes</td>
<td>1000</td>
<td>1030</td>
<td>65</td>
<td>Volume increased as feeds tolerated</td>
</tr>
<tr>
<td>20 Aug 2018</td>
<td>Nepro HP* 550ml over 5 feeds Propass 1 scoop 4x/d Water 250ml over 5 flushes</td>
<td>800</td>
<td>1121</td>
<td>69</td>
<td>Switched to bolus feeding due to resource limitation</td>
</tr>
<tr>
<td>21 Aug 2018</td>
<td>Resource 2.0** 480ml over 4 feeds Water 400ml over 4 flushes</td>
<td>880</td>
<td>960</td>
<td>40</td>
<td>Switched to Resource 2.0 due to high GRV noted</td>
</tr>
<tr>
<td>3 Sep 2018</td>
<td>Resource 2.0** 480ml over 6 feeds Water 600ml over 6 flushes</td>
<td>1080</td>
<td>960</td>
<td>40</td>
<td>GRV threshold for holding feed increased to 100mls</td>
</tr>
<tr>
<td>13 Sep 2018</td>
<td>Continuous NGT feeding Resource 2.0** 480ml @ 30ml/h over 16h Water 400ml over 4 flushes</td>
<td>880</td>
<td>960</td>
<td>40</td>
<td>Continuous NGT feeding resumed due to high GRV and suboptimal tolerance</td>
</tr>
<tr>
<td>1 Oct 2018</td>
<td>Continuous NGT feeding Nepro HP* 440ml @ 25ml/h over 18h Water 350ml over 4 flushes</td>
<td>790</td>
<td>800</td>
<td>36</td>
<td>Feeding rate and volume decreased due to high GRV and suboptimal tolerance</td>
</tr>
<tr>
<td>17 Oct 2018</td>
<td>Continuous NGT feeding Resource 2.0** 480ml @ 27ml/h over 18h Water 250ml over 4 flushes</td>
<td>730</td>
<td>960</td>
<td>40</td>
<td>Changed to Resource 2.0 due to lower cost</td>
</tr>
</tbody>
</table>

Nutritional content (per 100mls)
*Nepro HP (Abbott Laboratories) – Energy 182 kcal, protein 8.1g
**Resource 2.0 (Nestle Health Science) – Energy 200 kcal, protein 8.3g
Figure 3. Placement Options for Mdm N

**Option 1: Home Care**
- Requires family to buy enteral pump and receive caregiver training on enteral pump operation
- Requires caregiver to monitor round-the-clock for any issues with feeding
- Home nursing support for NGT care

**Option 2: Nursing Home (NH)**
- Requires family to buy enteral pump
- Few NHs in Singapore are able to care for patient on enteral pump
- Requires specialised nursing care

**Option 3: Chronic Sick Unit (CSU)**
- Limited availability of beds in Singapore
- More expensive than NH (although subsidies available)

Figure 4. ACP Discussion with Mdm N’s Family

<table>
<thead>
<tr>
<th>Advance Care Planning Discussion with Mdm N’s Family</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Preferred Place of Care</strong></td>
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<tr>
<td><strong>Feeding Method</strong></td>
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<tr>
<td><strong>Extent of Intervention in case of Deterioration</strong></td>
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<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td><strong>Preferred Place of Death</strong></td>
</tr>
</tbody>
</table>
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The submission should comprise of the following:
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Authors are advised to ensure the anonymity of study subjects and patients by removing any and all information that could compromise their privacy from the submission.

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• The title should be concise and highlight the key elements of the article.
• Include on the title page first name, qualifications, present appointments, type and place of practice of each contributor.
• Include name, address, handphone number and email address of the first author to whom correspondence should be sent.
• Insert at the bottom: name and address of institution or practice from which the work originated.

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• Structured – Organise the abstract according to the following headings:
  1. Introduction – states the purposes/aims of the study/investigation
  2. Methods – describes the selection of study subjects/experimental animals, observational and analytical methods
  3. Results – provides specific data and its statistical significance, if possible
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Key Words

• Add, at the end of summary in alphabetical listing, keywords of up to 5 in number which will be used for article indexing and retrieval under Medical Subject Headings or MeSH. MeSH is the NLM controlled vocabulary thesaurus used for indexing articles for WPRIM and PubMed. Please refer to www.nlm.nih.gov/mesh/for details.

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The text should have the following sequence:

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• Methods (whenever applicable e.g. original article, review article): Specify the study's main and secondary objectives—usually identified as primary and secondary outcomes. Identify methods, equipment (give the manufacturer's name and address in parentheses), and procedures in sufficient detail to allow others to reproduce the results. Give references to established methods, including statistical methods; provide references and brief descriptions of methods that have been published but are not well known. Describe new or substantially modified methods, giving reasons for using them and evaluate their limitations. Include numbers of observations and the statistical significance of the findings where appropriate.

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Describe the selection of the subjects clearly, including eligibility and exclusion criteria and a description of the source population. If the study was done involving an exclusive population, for example in only one sex, authors should justify why except in obvious cases, (e.g., prostate cancer). Authors should define how they determined race or ethnicity and justify their relevance.

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Identify precisely all drugs and chemicals used, including generic name(s), dose(s), and route(s) of administration. Identify appropriate scientific names and gene names.

  • Drugs must be referred to generically; all the usual trade names may be included in parentheses.
  • Dosages should be quoted in metric units.
  • Laboratory values should be in SI units with traditional unit in parentheses.
  • Do not use patients' names, initials or hospital numbers to ensure anonymity.

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Provide data on all primary and secondary outcomes identified in the Methods Section. Extra or supplementary materials and technical details can be placed in an appendix where they will be accessible but will not interrupt the flow of the text, or they can be published solely in the electronic version of the journal.

Give numeric results not only as derivatives (for example, percentages) but also as the absolute numbers from which the derivatives were calculated, and specify the statistical significance attached to them, if any. Restrict tables and figures to those needed to explain the argument of the paper and to assess supporting data. Use graphs as an alternative to tables with many
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Title
- The title should define the key focus of the case study.

Case Presentation:
- The author(s) will provide a pertinent summary of the medical and/or psychosocial issue pertaining to the health or disease management of the case. It should cover the situation and relevant background of the case. Author(s) should conceal the identity of the subject and/or related or accompanying personnel: abbreviation should be used instead, if necessary.

Diagnoses / Problems identified
- The assessment of the diagnoses / problems identified will constitute a problem list and will serve as a focus for the management of the case. If the case was a diagnostic dilemma, the author(s) should showcase the diagnostic challenges and their work in narrowing to the correct diagnosis and/or differential diagnoses.

Management of the case
- This section covers the approach to the management of the case by the author(s).
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Literature review on latest evidence / guidelines (related to diagnosis and/or management)
- The author(s) should provide a literature review of current evidence / guidelines, if any, of the basis of the case's diagnosis / management, or to highlight the gaps of knowledge if such evidence is lacking.
- The author(s) will provide a concise summary of the lessons learnt from this case study.

Clinical Practice pointers (up to 3)
- The author(s) will suggest ways to apply the new knowledge in clinical practice or to highlight the limitations of its applications, if any.

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Title
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Patient's revelation: What happened?
- The author(s) will provide a concise description of the setting on which the subject raised their medical or psychosocial issue pertaining to their health or disease management. It should cover the background, encounter and interaction of patient with the healthcare professional (doctor, nurse or allied healthcare professional). Author(s) should conceal the identity of the subject and/or related or accompanying personnel; abbreviation should be used instead, if necessary.

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- The issue(s) raised by the patient should be framed into question(s). The question(s) will constitute a problem list and will serve as a focus for the management of this subject.

Study the management: How do we apply in our clinical practice?
- This section covers the approach to the management of the subject by the author(s). The author(s) should provide a literature review of current evidence, if any, of the basis of the subject's management, or to highlight the gaps of knowledge if such evidence is lacking. The author(s) will suggest ways to apply the new knowledge in clinical practice or to highlight the limitations of its applications, if any.

Conclusion
- The author(s) will provide a concise summary of the lessons learnt from this case study.

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Correspondence & Enquiries should be addressed to:
The Honorary Editor, The Singapore Family Physician
College of Family Physicians Singapore
College of Medicine Building
16 College Road #01-02
Singapore 169854
Tel: 6223 0606 Fax: 62220204
Email: editorialoffice@cfps.org.sg

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