

Health-related quality of life in patients who utilise home enteral nutrition in Australia/New Zealand

Summary of Survey Results

Dr Mercedes Hinchcliff



UOW
AUSTRALIA

Introduction

This research project was conducted by ausEE President and UOW Academic, Dr Mercedes Hinchcliff in 2023. This study delved into the utilisation of Home Enteral Nutrition (HEN) across Australia and New Zealand.

The primary objectives of this project were threefold:

- To assess the overall quality of life for individuals who rely on tube feeding.
- To gain a deeper understanding of the usage patterns of feeding tubes and formulas within both adult and paediatric populations.
- To identify and comprehend the unmet needs within these communities.

Being the first project of its kind in Australia, it has generated valuable data that we hope will pave the way for enhanced support and greater awareness for the affected community.

Background: According to the Non-admitted Patient Care report (2014–15) issued by the Australian Institute of Health and Welfare, the most common non-admitted patient services were those patients requiring home enteral nutrition (HEN) or tube feeding. There were 1.1 million service events recorded. According to the Feeding Tube Awareness Foundation (2022), there are over 400 conditions which could require a feeding tube, but the majority of those patients are not adequately meeting their minimum dietary requirements (Gastroenterology, 2022). Some prevalent examples of needing a feeding tube are dysphagia, Crohn's disease, poor growth or an eosinophilic gastrointestinal disease.



The research design was an online anonymous questionnaire, distributed throughout Australia and New Zealand with the help of numerous support organisations such as ausEE Inc.

The results identified gaps in care, costs, social acceptance, mental health and supply issues.

Preliminary Findings

Overview

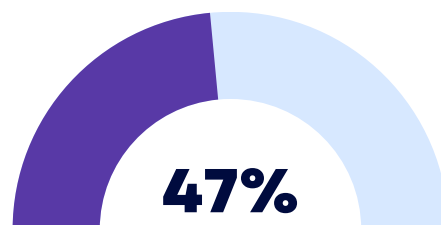
The survey yielded a total of 158 completed responses. Of these, 91 were from participants who were carers of those tube-fed, while 67 were from those who were tube-fed themselves. This grouped the respondents into two groups: paediatric and adult.

The majority of paediatric and adult patients had their tubes inserted with public hospitals (86% and 74% respectively), while the remainder had them placed in private hospitals. Half of the paediatric group used a G-tube (gastrostomy) button, while the other half used a G-tube PEG (percutaneous endoscopic gastrostomy) or NG-tube (nasogastric). For the adults, the most commonly used feeding tube was a GJ-tube (gastrojejunal) (24%), followed by a fairly even distribution of G-tube button, G-tube PEG, J-tube (jejunal), NG-tube, and NJ-tube (nasojejunal). 52% of the respondents had been tube-fed for under two years, while the remaining 48% had been tube-fed for more than three years, with 23% having been tube-fed for over six years.



Financial Pressure

Surprisingly, almost 47% of the participants surveyed received zero government financial support in terms of carers payment, health care cards, etc., while 41% spent over \$200 a month on supplies. This identifies a clear gap in support for families potentially struggling to cope with higher medical costs. For those who did receive support, it was the carer group predominantly, mainly carers payment and/or allowance. For this group, no other form of financial support was identified.

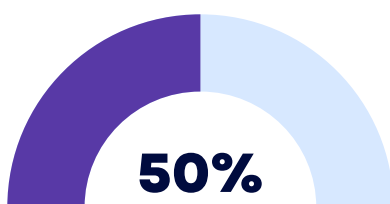
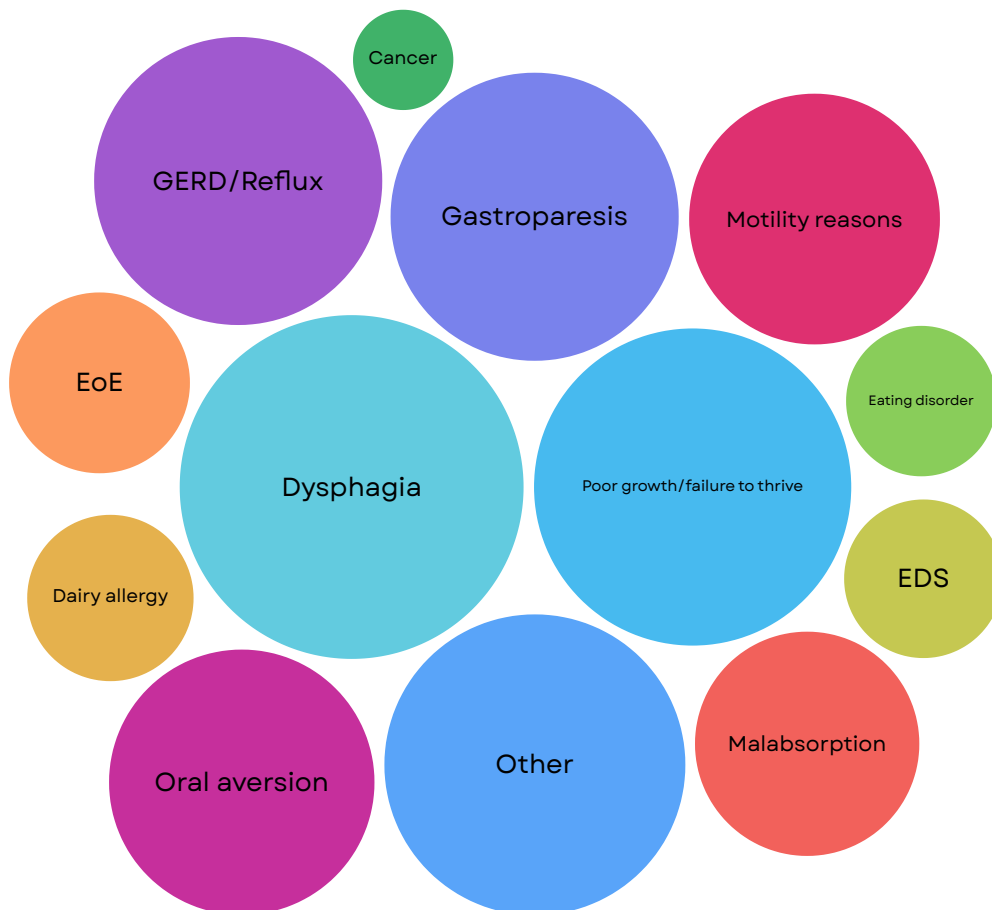


received zero government financial support in terms of carers payment, health care cards, etc.

Preliminary Findings

Overview

Hundreds of conditions were mentioned as to why the respondents needed a feeding tube, and the majority had more than one condition, with the average being between 2-3 per person. The most frequent conditions identified (in order of prevalence) were swallowing difficulties, poor growth/failure to thrive (paediatric), Gastroparesis, GERD/Reflux, oral aversions (mainly paediatric), motility issues, malabsorption and eosinophilic oesophagitis (EoE).



receive 100% of their nutrition from their tube

Over half of both groups receive 100% of their nutrition from their tube, with 25% receiving over 75% of their nutrition from the tube. This highlights the extent to which this community relies on tube feeding for their overall nutrition.

Social Impact on Adults

The positive implications of tube feeding are evident, as a significant majority of adults (73%) express an improved sense of health, and an even larger proportion (80%) report feeling well-nourished following the insertion of the feeding tube. Moreover, many individuals acknowledge the crucial support of their family networks during this process.

However, the challenges faced by adults reliant on tube feeding underscore a notable crisis within this population. Socially, concerns are revealed, with most restricting their social engagements to those that do not involve food. Notably, nearly half of the individuals attempt to conceal their feeding tubes from friends, indicating fear or shame surrounding potential judgment from their peers. Additionally many feel excluded from their social circles, while half experience depression and anxiety solely attributed to the presence of the feeding tube.

81%

Social Fears

Restrict their social engagements

50%

Social Stigma

Try to conceal their feeding tubes from friends

60%

Exclusion

Feel excluded from their friends

50%

Mental Health

Experience depression and anxiety

Well-being - Adults

Physically, tube feeding introduces several challenges, with most participants reporting skin irritation, their struggles with disrupted sleep, and the physical discomfort the tube brings, such as dry mouth, stomach heaviness, and acid reflux. The emotional toll is further emphasised, as almost all respondents express a yearning for the sensory aspects of eating, including chewing and savoring food.

Additionally, many individuals express heightened concerns and worries about their overall health since initiating tube feeding. Body image becomes a prominent worry for many of those responding as well, underscoring the psychological impact of this medical intervention.

Work-related challenges are prevalent, as nearly all reported limitations in their professional capacity. Furthermore, many find it difficult or impossible to adhere to normal meal times, adding an additional layer of complexity to their daily lives. Lastly, those who receive over 90% of their nutrition from a tube, miss the feeling of chewing food.

Skin Irritation



Worry about their body image



Disrupted Sleep



Report challenges at work



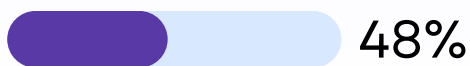
Physical Discomfort



In-ability to adhere to mealtimes



Heightened concerns about health



Miss chewing food



Well-being - Paediatric

In the case of our paediatric respondents (or carers responding on behalf of), the results present a more optimistic outlook, suggesting that the community is generally more accepting of children and adolescents with feeding tubes compared to adults.

Encouragingly, the majority of paediatric participants do not attempt to conceal their feeding tubes from friends and do not feel excluded (80%). Notably, a smaller percentage (22%) reported experiencing anxiety and depression, a significant departure from the higher rates observed in adults. This unexpected finding challenges previous research suggesting potential social stigma associated with tube feeding for children. It may be attributed to the robust support provided by parents or caregivers, who themselves report higher rates of social exclusion and isolation (50%) and often need to take time off work (50%) to care for their child or dependent.



On another positive note, paediatric respondents report improvements in their physical health (74%), maintenance of a healthy weight (76%), enhanced ability to monitor nutrition (89%), and a sense of being well-nourished (73%). These findings indicate that, for this demographic, tube feeding is yielding the intended positive effects.

However, mirroring their adult counterparts, a significant majority of paediatric respondents report skin irritation (60%) and physical discomfort (71%) from feeding tubes. Nonetheless, a considerable proportion (60%) claim to sleep well with their feeding tubes.

Free-response

One of the last questions on the survey asked participants to name anything that could help make their lives easier. Several themes emerged from the responses. Those being:

- Greater need for social acceptance
- Cost reduction and financial support and funding
- Free and easier to obtain dressings
- A supportive backpack to carry feed and pump
- Greater community awareness
- Access to different supplies
- Improved clinician education
- Consistent availability of formula and consumables
- Shorter wait times for replacement tubes
- More support groups available
- Being able to get a surgical tube sooner
- Formula in a bag/pouch rather than a bottle so it doesn't have to stay upright all the time (like in a bag)
- Streamline ordering system, online or an app to manage/track supplies and order products accordingly



Summary

In summary, individuals reliant on tube feeding experience notable positive effects on health and nutrition, accompanied by crucial family support. However, pervasive challenges encompassing social, emotional, and physical aspects underscore the complexity of this population's experiences. The high prevalence of social limitations, emotional distress, and physical discomfort emphasises the need for comprehensive support and understanding. Recognising these challenges is essential for healthcare providers, researchers, and society at large to develop targeted interventions, policies, and social awareness campaigns that can enhance the overall well-being and quality of life for individuals undergoing tube feeding. This understanding is vital to fostering a more inclusive and supportive environment for those facing these complex challenges.

Feeding Tube Awareness Week

4-10 February

#FTAW2024



ausEE Inc.

a charity dedicated to improving lives
affected by an eosinophilic disease



**UNIVERSITY
OF WOLLONGONG
AUSTRALIA**



www.feedingtubeaware.com.au