Critical Review:

What are the Clinical Outcomes Associated with PEG Tube Feeding in Patients with Advanced Dementia?

Stephanie J. Rainham
M.Cl.Sc (SLP) Candidate
Western University: School of Communication Sciences and Disorders

This critical review examines the evidence regarding the negative and positive outcomes of implementing percutaneous endoscopic gastrostomy (PEG) feeding in individuals who have advanced dementia. Two observational controlled cohort studies and two systematic reviews were used in this review. Overall, the majority of evidence gathered for this review suggests that PEG tube feeding is not associated with improved survival in patients with advanced dementia. Published empirical work using observational data remains highly consistent in finding a lack of benefit for tube feeding in this population.

Introduction

Dementia is a syndrome caused by numerous progressive disorders that affect memory, cognition, behaviour, and the ability to communicate and perform activities of daily living (Alzheimer's Disease International, 2010). Approximately half a million Canadians are currently living with dementia, making it one of the most significant causes of disability among Canadians 65 year of age and older. By 2038, the number of Canadians with dementia is expected to increase to 2.5 times the current level, affecting 2.8% of the Canadian population (Alzheimer Society of Canada, 2010).

In the final stages of dementia, eating impairment often occurs (Dharmarajan, Unnikrishnan, & Pitchumoni, 2001). Individuals with advanced dementia may be indifferent to food or resist feeding. Swallowing function may be compromised in the oral phase if the individual is unable to properly manage the food bolus in their mouth and in the pharyngeal phase if aspiration occurs (Finucane, Christmas, & Travis, 1999). When oral intake cannot easily be sustained, weight loss and decreased consciousness commonly ensue (Murphy & Lipman, 2003).

Percutaneous endoscopic gastrostomy (PEG) feeding involves passing food through a tube directly into the stomach, and it is the most common method of enteral nutrition in patients who require long-term tube feeding (Sanders et al., 2000). PEG tube placement is frequently undertaken during hospitalization for an acute illness to address the aforementioned feeding problems encountered in advanced dementia, as many people believe that a failure to provide nutrition and hydration is morally wrong (Dharmarajan et al., 2001). PEG feeding has been validated and shown to improve both morbidity and mortality in specific clinical conditions, such as acute stroke with dysphagia (Sanders et al., 2000). This, along with the perception that PEG insertion is safe and simple (Galicia-Castillo, 2006), has led to an increase in the demand for PEG insertion in patients with dementia, a population in whom its role has not been evaluated (Sanders et al., 2000).

Despite data suggesting that the refusal of food and water by cognitively intact terminally ill patients does not result in discomfort, and the common observation of aversive feeding behaviours in patients with advanced dementia, it is often assumed that inadequate intake results in "distressing thirst, hunger, and hastened death" (Meier et al., 2001). Similarly, tube feeding is believed to prevent aspiration pneumonia and other infections, improve function, promote physical comfort, and prolong life (Meier et al., 2001). Given the nature of dementia, it is nearly impossible to obtain subjective descriptions of the experience from patients. In addition, although prospective randomized controlled trials (RCTs) are commonly considered to be the most reliable form of scientific evidence, there are complex ethical and practical issues around the use of these types of studies to investigate this intervention in this population (Finucane et al., 1999). It is unlikely that a sufficient number of volunteers would agree to be randomized to PEG or no PEG tube insertion (Murphy & Lipman, 2003). Thus, whether placement of a PEG tube improves or does not improve outcome in individuals with advanced dementia has been controversial.

Therefore, it is important to examine the existing research literature on the outcomes of PEG feeding in advanced dementia to determine whether this intervention is appropriate for this population, and whether its use should be recommended or discouraged. The prevalence of dementia is anticipated to rise substantially and studies need to be cautiously interpreted in order to avoid PEG insertions in patients who may reap no benefit.

Objectives

The primary objective of this paper is to critically evaluate existing literature regarding the outcomes of PEG feeding in adults with advanced dementia. The second objective is to provide recommendations for clinical practice and future research.

Methods

Search Strategy

Articles related to the topic of interest were found using the following computerized databases: Medline, PubMed and PSYCHinfo. Keywords for databases were as follows:

[(percutaneous endoscopic gastrostomy) or (PEG) or (enteral feeding) and ((dementia) or (advanced dementia)) and (outcomes)]

Additional related studies were obtained from the reference lists of the retrieved articles.

Selection Criteria

Primary studies selected for inclusion in the critical review were required to investigate outcomes of PEG feeding in patients with advanced dementia.

Data Collection

Results of the literature search yielded four articles congruent with the aforementioned selection criteria. For the primary selection criteria, two observational cohort studies and two systematic reviews were discovered.

Results

Observational Controlled Cohort Studies

Well-designed observational studies (recognized as level 2 or 3 evidence) have been shown to provide results similar to 'gold standard' RCTs (Song & Chung, 2010). Cohort studies are one type of observational study and may be prospective or retrospective in nature. Cohort studies can be used to examine multiple outcomes for a given exposure and to assess causality over time (Song & Chung, 2010). A prospective cohort differs from a retrospective cohort simply based on whether the outcome of interest has occurred at the time the investigator initiates the study (University of Michigan School of Public Health, 2010). Prospective studies provide a more systematic evaluation of the question posed.

Study #1

Meier et al. (2001) conducted a prospective observational cohort study in order to assess PEG feeding and long-term survival following hospitalization in 99 patients (64-100 years; 80% female) with advanced dementia over a 3-year period. Informed consent could not be obtained for excluded patients. Appropriate inclusion and exclusion criteria were well-defined to confirm a stable, long-term diagnosis of dementia.

The main outcome measures of this study were placement of a PEG during hospitalization and mortality after discharge, monitored every 3 months until lost to the study or the subject's death was reported. Overall, results obtained from appropriate stepwise logistic regression indicated that PEG feeding was not associated with survival, the risk of receiving a new feeding tube was high, and with or without a PEG, the mortality of these patients was 50% at 6 months. Median survival following admission in subjects receiving a feeding tube during hospitalization was 195 days as compared with 189 days among subjects who did not receive a feeding tube. Overall, no significant survival advantage was found among subjects who received a PEG during their hospitalization versus those patients discharged without a feeding tube.

This prospective cohort study was well designed as there was consistent longitudinal follow-up of the study subjects and the methods were well-described. However, almost half of the eligible participants admitted to hospital could not be recruited to the study due to the absence of a substitute decision maker. It is possible that this sample could have had qualitatively different outcomes from the one under study, as it is unclear how comparable these patients were with those who received a PEG. In addition, because this study took place at a tertiary care centre in a large city and because participants were hospitalized with acute illness, is it possible that the generalizability of the results may be limited.

Overall, this study provides compelling evidence that PEG feeding does not improve survival in patients with advanced dementia.

Study #2

Murphy and Lipman (2003) conducted a retrospective medical record review of comparable male patients with advanced dementia who either received (n=23) or did

not receive (n=18) PEG feeding. Survival was charted from the time of PEG tube insertion to a maximum of 2 years. Appropriate inclusion and exclusion criteria were well-specified.

The median survival for the PEG group was 59 days, compared with 60 days for the group who did not undergo PEG insertion. An appropriate Kaplan-Meier survival curve did not reveal any statistically significant difference in survival found between the groups. This finding supports the authors' hypothesis that there is no survival benefit to placing a PEG tube for artificial feeding in patients with advanced dementia.

This study provides level 2b evidence due to its retrospective design using a convenience sample. Limitations of this study include the small sample size, the fact that all subjects were male, and the lack of available clinical information to compare the groups (although all had advanced dementia).

Overall, the findings from this study provide highly suggestive evidence that PEG tube placement does not enhance survival in patients with advanced dementia.

Systematic Review

Review #1

Finucane et al. (1999) conducted a systematic review of the medical literature published between 1966 and 1999 examining whether any type of tube feeding can have positive outcomes in patients with advanced dementia. Appropriate search terms were reported. No RCTs were identified. The key findings were presented in a largely descriptive manner using percentages, which is helpful to clinicians, patients, and families. The review did not identify any published studies suggesting that tube feeding reduces the risk of aspiration pneumonia, malnutrition, mortality, or improves functional status or comfort in the general patient population. Specific to advanced dementia patients, no studies were identified to support the use of enteral feeding with respect to risk of mortality or the effect on functional status or quality of life.

There were some major limitations to the review. The search of the literature does not appear to be comprehensive, as only one online database was searched and search terms did not include "dementia" or "advanced dementia". Thus, the review (perhaps inappropriately) generalizes results of studies that examined tube feeding in general neurogenic or mixed populations to the care of patients with advanced dementia. The review also did not document or report a critical appraisal of the included studies and did not elaborate on any of the study designs or statistical analyses used. The review could be substantially improved with the addition of more specific search terms, more thorough documentation of search strategies, and discussion of statistical significance to accompany the raw percentages provided.

Overall, this review considered all outcomes that are important from a clinical perspective. Systematic reviews are usually considered to be level 1+ evidence but due to the methodological constraints of this review and its lack of evidence specific to dementia, it provides suggestive rather than compelling evidence that tube feeding does not offer any significant benefit to individuals with advanced dementia. Although the evidence is limited, it is generally consistent with a lack of support for the use of PEG feeding.

Review #2

Sampson, Candy, and Jones (2009) conducted a systematic review that sought to evaluate the outcomes of enteral tube feeding for older adults with advanced dementia. The primary outcomes were survival and quality of life. Search methods were clearly described and results retrieved from each source were explicitly stated. The search appears to have been exhaustive and it is unlikely that any relevant research was omitted.

The review did not identify any RCTs. It focused on 7 observational controlled cohort studies. Detailed information was provided regarding inclusion criteria and data collection and analysis, and a brief critical appraisal of each of the 7 articles was included. The results were consistent from one study to another. There was no evidence of increased survival in patients receiving enteral tube feeding, and there was no evidence of benefit in terms of nutritional status or the prevalence of pressure ulcers.

Only 2 of these studies (Meier et al., 2001 and Murphy & Lipman, 2003) were of particular interest for the purpose of the present review due to more restricted selection criteria; these were the only studies that focused exclusively on cohorts that were uniformly comprised of patients with advanced dementia, who were fed exclusively by PEG tube.

Overall, the review found that few studies measured a full range of clinically relevant outcomes, possibly due to the retrospective nature of some data collections. Sample sizes of the included studies were also found to be small.

Given that this recent review was conducted with methodological rigour, and it effectively evaluated the

literature specific to PEG feeding outcomes in individuals with advanced dementia, it provides compelling support that: 1) PEG feeding does not lead to the commonly expected beneficial outcomes, 2) there is insufficient evidence to suggest that enteral tube feeding is beneficial in patients with advanced dementia, and 3) data on the adverse effects of this intervention are lacking. Overall, the results of this systematic review suggest a need for further research and provide sufficient evidence to incite changes to clinical practice.

Discussion

The data from the studies considered in this critical review ultimately suggest that receiving nutrition via a PEG tube does not prolong survival among patients with advanced dementia. The effect of PEG feeding on other outcome measures (e.g. prevention of aspiration pneumonia and pressure wounds, and improvement in nutritional status and quality of life) in this specific population is not known due to paucity of research, and there have been no documented attempts to objectively assess discomfort or pain (Sampson et al., 2009).

Finucane et al. (1999) suggested reasons for the widespread use of tube feeding in the advanced dementia population despite this lack of evidence. Finucane et al. (1999) and multiple other sources (e.g. American Geriatrics Society, 2013; Dharmarajan, 2001; Hanson, 2013; Li, 2002) suggest that careful assisted hand feeding is the preferable alternative for patients with advanced dementia. Li (2002) and DiBartolo (2006) provide recommendations for optimizing oral intake in patients with severe dementia.

This critical analysis revealed that most of the data regarding the provision of artificial hydration and nutrition by PEG tube in individuals with advanced dementia comes from observational studies, retrospective studies, or data inferred from mixed populations (Sampson et al., 2009; Finucane, 1999; Li, 2002). The systematic reviews by Sampson et al. (2009) and Finucane et al. (1999) suggest that greater research of the effectiveness and outcomes of enteral feeding in the population of patients with advanced dementia is needed.

Conclusion

Due to the ethically contentious nature of this topic, there has been limited research in this area, with this specific population. Nonetheless, all of the currently available evidence suggests that there is no benefit to PEG feeding in patients with advanced dementia. Substantial empirical evidence does not exist to unequivocally support the use of PEG feeding in this population of patients.

Clinical Implications

Although the evidence compiled by Meier et al. (2001) and Murphy and Lipman (2003) indicates that PEG feeding does not enhance survival, this does not mean that patients with dementia should not have the right to receive nutrition via PEG if they choose to. It is important for family members of individuals with advanced dementia to be educated about the risks and lack of benefit of tube feeding, but also counseled about the terminal nature of dementia so they are aware these individuals can be comfortable without enteral feeding (Li, 2002). Tastes and sips of food combined with oral hygiene may be provided to promote comfort (Hanson, 2013).

Based on the aforementioned limitations of the current research, it is widely recommended that further research be conducted and include:

a) Well-designed, randomized controlled trials with adequate power to examine outcomes such as survival, aspiration pneumonia, and quality of life
b) Subject recruitment based on clearly defined stage of dementia and severity of feeding problems
c) Assessment of outcomes by blinded research assistants (Hanson, 2013)

Although there is undoubtedly a need for further research, the studies reviewed in this paper provide sufficiently compelling evidence to prompt consideration of changes to clinical practice and/or healthcare policy. The dramatic increase in patients with dementia anticipated over the next three decades means that discussions about placement of PEG tubes will become increasingly prevalent. With the ease of PEG tube insertion and current general expectation of positive outcomes, it is important for speech-language pathologists as primary care practitioners to seek out evidence on which to base their clinical practice.

References

Alzheimer's Disease International. (2010). *World Alzheimer Report 2010*. Retrieved from http://www.alz.co.uk/research/files/WorldAlzheimerReport2010ExecutiveSummary.pdf

Alzheimer Society of Canada. (2010). *Rising tide: The impact of dementia on Canadian society.* Retrieved from http://www.alzheimer.ca/~/media/Files/nationa

l/Advocacy/ASC_Rising%20TideExecutive%20Summary_Eng.ashx

American Geriatrics Society. (2013). *Feeding tubes in advanced dementia position statement*. Retrieved from http://www.americangeriatrics.org/files/documents/feeding.tubes.advanced.dementia.pdf

Dharmarajan, T. S., Unnikrishnan, D., & Pitchumoni, C. S. (2001). Percutaneous endoscopic gastrostomy and outcome in dementia. *American Journal of Gastroenterology, 96*(9), 2556-2563.

DiBartolo, M. C. (2006). Careful hand feeding: A reasonable alternative to PEG tube placement in individuals with dementia. *Journal of Gerontological Nursing*, *32*(5), 25-33.

Finucane, T. E., Christmas, C., & Travis, K. (1999). Tube feeding in patients with advanced dementia: A review of the evidence. *Journal of the American Medical Association, 282*(14), 1365-1370.

Galacia-Castillo, M. (2006). The PEG dilemma: Feeding tubes are not the answer in advanced dementia. *Geriatrics*, *61*(6), 12-13.

Hanson, L. C. (2013). Tube feeding versus assisted oral feeding for persons with dementia: Using evidence to support decision-making. *Annals of Long-Term Care: Clinical Care and Aging*, *21*(1), 36-39.

Li, I. (2002). Feeding tubes in patients with severe dementia. *American Family Physician, 65*(8), 1605-1610.

Meier, D. E., Ahronheim, J. C., Morris, J., Baskin-Lyons, S., & Morrison, R. S. (2001). High short-term mortality in hospitalized patients with advanced dementia: Lack of benefit of tube feeding. *Archives of Internal Medicine, 161*(4), 594-599.

Murphy, L. M., & Lipman, T. O. (2003). Percutaneous endoscopic gastrostomy does not prolong survival in patients with dementia. *Archives of Internal Medicine*, *163*(11), 1351-1353.

Sampson, E. L., Candy, B., & Jones, L. (2009). Enteral tube feeding for older patients with advanced dementia. *Cochrane Database of Systematic Reviews*, 2.

Sanders, D. S., Carter, M. J., D'Silva, J., James, G., Bolton, R. P., & Bardhan, K. D. (2000). Survival analysis in percutaneous endoscopic gastrostomy feeding: A worse outcome in patients with dementia. *American Journal of Gastroenterology*, *95*(6), 1472-1475.

Song, J. W., & Chung, K. C. (2010). Observational studies: Cohort and case-control studies. *Plastic and Reconstructive Surgery*, *126*(6), 2234-2242.

University of Michigan School of Public Health. (2010). *Cohort study (Prospective and retrospective)*. Retrieved from http://practice.sph.umich.edu/micphp/epicentral/cohort.php