

**DEMENTIA COLLABORATIVE RESEARCH CENTRE –
Consumers, Carers and Social Research****Interim Report**

Project Title Older people who receive enteral nutrition via gastrostomy tubes: a population-based study of incidence, indications and outcomes.

Researchers Dr Janine Calver, Associate Professor Barbara Horner

This study explored population-based estimates of the incidence, indications and outcomes (survival and rehospitalisation) of all older Western Australians who had a feeding tube inserted over a 10-year period. A retrospective cohort study design was employed using de-identified data from two computerised administrative databases that have been probabilistically linked by the WA Data Linkage Unit: the Hospital Morbidity Data System (HMDS) and the Mortality Registrar.

Enteral tube feeding is a form of artificial nutrition that provides nutrients, hydration and sometimes medication to the body on a long-term basis (> 1 month) via an access route other than the mouth. It is often used to treat or forestall malnutrition and its sequelae (e.g., pressure sores, infection, and death) in older people with seriously debilitating or terminal diseases who have an impaired swallowing mechanism and a functioning and accessible gastrointestinal tract. This procedure is an option for people with dementia where there are concerns about hydration and nutritional status.

The controversy associated with feeding tubes extends beyond clinical complications and presents challenges for staff and family carers. Apart from having uncertain benefits, there are considerable risks associated with feeding tubes. These risks include peristomal infection, leakage, tube removal/displacement/migration, bleeding, gastric mucosal overgrowth or ulceration, aspiration, metabolic and biochemical complications (e.g., refeeding syndrome), gastrointestinal side-effects (e.g., nausea, abdominal cramps, constipation, diarrhoea), microbial contamination and infection of feed, and death. Additionally, the decision to insert (or remove) a feeding tube is frequently provided by a surrogate who may not be fully informed of the risks or is potentially motivated by expectations and beliefs quite different to the patient or indeed others who feel they should have some say in the care of their loved one. Whilst advance care directives (also called a living will or health care power of attorney), made whilst the patient is decisionally capable, are intended to overcome some of these difficulties, they rarely anticipate all possible scenarios, they are not necessarily legally binding (e.g., in Western Australia), and they can be difficult to access when the patient transfers between care settings. This report provides some preliminary findings.

Demographic characteristics

A total of 2,023 older people (≥ 65 years) underwent gastrostomy tube (GT) placement for the first time, 1994-2004. Significantly more men ($n = 1,103$, 54.5%) than women ($n = 920$,

45.5%) had the procedure ($\chi^2 = 16.5541, p < 0.0001$). The age of GT placement ranged from 65.0 to 101.6 years, with a mean of 78.0 years (95% CI, 77.7 – 78.4).

Baseline diagnoses at the time of first GT placement

The indications for GT placement, based on the primary diagnosis of the index (first) GT record, are summarised. Cerebrovascular disease was the most common indication for GT placement (n = 622, 30.7%), followed by symptoms, signs and ill-defined conditions that predominantly involved dysphagia and pneumonitis due to solids and liquids (n = 304, 15.0%).

To improve our understanding of the morbidity profile of GT recipients beyond a single, primary diagnosis, we calculated the Charlson Comorbidity Index for each person, based on a 12-month inpatient look-back period of all diagnosis fields, inclusive of the index GT record. Over one half of GT recipients had a known history of cerebrovascular disease (n = 1017, 50.3%) at baseline. The prevalence of paraplegia or hemiplegia, malignancy, congestive heart failure, dementia, chronic pulmonary disease, and diabetes without complications, all exceeded 10%. The mean score on the Charlson Comorbidity Index was 2.7 (95% CI 2.6-2.8, range 0-12) out of a maximum possible score of 33. Of the 227 (11.2%) people known to have dementia at the time of GT placement, almost half also had cerebrovascular disease (n = 108, 47.6%), and 32 (14.1%) had Parkinson's disease. Using a 12-month inpatient look-back period, an additional 64 cases of MND and 88 cases of Parkinson's disease were also identified, bringing the total case counts to 147 (7.3%) and 105 (5.2%) respectively. GT placement for people with Huntington's disease and multiple sclerosis was rare (n= 14 over 11 years).

Mortality outcomes after GT placement

The proportion of deaths for the entire cohort at 7, 30, 60, 180 and 365 days were 5.5%, 16.6%, 26.3%, 41.1% and 54.1%, respectively. Almost one fifth of the cohort (n = 380, 18.8%) did not survive the index hospitalisation. Mortality outcomes were poorest for people who had a known history of metastatic solid tumour at the time of GT insertion. One quarter did not survive the first 30 days following the procedure, and three quarters did not survive one year. People with a known history of motor neurone disease had the second highest 12-month mortality (72.1%). The presence of dementia at time of GT placement did not significantly affect mortality outcomes, as determined by a Cox proportional hazard model that adjusted for age, sex, year of GT placement and Charlson Comorbidity Index (HR = 1.06, 95% CI 0.87-1.28).

Practice implications

The final report on this study will further explore the data and discuss the organisational and practice considerations that arise from the analysis. Although PEG tube placement in nursing home residents with advanced cognitive impairment seems to have declined in the US since 1996, significant provider and state-to-state variations remain within Australia. Quite apart from health factors, the decision to place feeding tubes is influenced by organisational factors such as size, location, casemix staff (e.g., availability of registered nurses), operational status and financial incentives. For example, it has been argued that the use of feeding tubes in institutionalised patients with advanced dementia is motivated by cost-saving, because hand feeding by staff is too expensive and time consuming. Such practice issues need to be considered further.