Outcomes of percutaneous endoscopic gastrostomy in children with severe neurological disabilities

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Introduction
Development Disabilities Unit (DDU) in the Caritas Medical Centre is the largest hospital-based clinical unit in Hong Kong providing residential and rehabilitation services to children with severe neurological disabilities (GMFCS level 5). Percutaneous endoscopic gastrostomy (PEG) has been shown to be safe in short term and effective in improving nutrition in children with neurological disabilities1, but Hong Kong data was sparse. One study reported the mortality rate of 11%, 21%, 27% and 39% after 1, 2, 3 and 13 year after PEG placement2. Mortality was regarded as due to comorbidities and underlying etiologies of disabilities rather than the procedure2.

Objectives
To study the long term outcome of PEG in a cohort of severe neurologically disabled children retrospectively

Methodology
From 1998, PEG was placed in DDU children who required long term tube feeding. 24-hours esophageal pH studies were performed before PEG and within one year after PEG, and when patient had clinical deterioration or new occurrence of gastroesophageal (GE) reflux symptoms. Abnormal GE reflux index was defined as greater than 4%. The children were followed every three to six months. Data were censored at the end of June, 2012 or the last recorded date (discharge or death). Body weight, episodes of vomiting, chest infection, gastrointestinal bleeding and date of discharge or death were extracted from patient records. The body weight at baseline and each follow up years were recorded. The pre-operation and the post-operation GE reflux index of the patients were compared by paired T-test.
Result
Eighteen patients (13 boys) had PEG performed from 1998 to 2009. The median age was 15.7 (range: 5.0-18.8) years. Mean body weight before PEG was 19.7 ± 4.0 kg. Mean weight gain was 2.41 kg (0-10.5 kg) one year after PEG (table 1). Median follow up patient-days was 2801 days (234 to 3939 days). Pre-PEG reflux index was 2.2 ± 2.3%, mean long reflux >5 minutes was 2.1 ± 2.2; mean longest reflux was 12.3 ± 12.2 minutes. For post-PEG pH study, the mean reflux index was 3.8 ± 3.8% (P<0.005), number of long reflux >5 minutes was 1.8 ± 2.4 (P=ns), longest reflux times was 12.6 ± 22.64 minutes (P=ns). Four deaths occurred. Two children died of respiratory failure due to degenerative brain disease (0.6 year and 2.6 year after PEG respectively). Two children developed worsening dystonia and recurrent aspiration pneumonia. They died of respiratory causes 2.0 and 9.9 years after PEG. Mean survival was 9.31 ± 0.92 (95% CI 7.50, 11.12) post-operative years.