Careful Hand Feeding vs Tube-feeding in Advanced Dementia: How do Caregivers Make their Decision on Mode of Feeding?

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Introduction
Eating is physically and socially important to human life. It is found that dysphagia or behavioral feeding problem is common in patients at later stage of dementia. According to Volicer et al. (1987), about half of the dementia patients failed to feed themselves within 8 years of diagnosis. Carmel (1999) reported tube-feeding was prevalent in dementia patients that 74% of patients were inserted with feeding tube as early as during their stay in acute hospital. However, it is an undoubted fact that tube-feeding had no effect on sustaining life in advanced dementia patients but would hinder quality of life adversely (Clinical, Practice, and Models of Care Committee, 2014). As advanced dementia patients cannot make the decision themselves and most patients did not have any advanced directives in managing their end-of-life care choice, this posed their caregivers to a dilemma in choosing between tube-feeding versus careful hand feeding. Owing to limited research on how caregivers make the decision on mode of feeding, this study addresses the phenomenon.

Objectives
This is an exploratory study on how caregivers of advanced dementia patients make the medical decision on mode of feeding for the patient. Also, reflection on current service model was explored.

Methodology
Subjects were recruited in Department of Medicine & Geriatrics in Tuen Mun Hospital. Four families were invited for an in-depth interview on how they made the decision on mode of feeding. The interviews were transcribed in text and interpreted via thematic analysis (Braun & Clarke, 2006) in MaxQDA system.

Result
Eight factors that caregivers would consider during their decision are summarized. This gives direction in helping medical profession to lead meeting with caregivers on
discussing mode of feeding for advanced dementia patients. The result is specific to Hong Kong local population, which may help in developing a more family-centered decision-making model on end-of-life care for advanced dementia patients and caregivers.