

The attitudes and experiences of patients with advanced malignancy receiving home enteral nutrition – a qualitative study

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One of the primary goals of palliative care is to maintain or enhance a patient's quality of life⁽¹⁾. Studies that have considered the impact of home enteral feeding (HEF) on patients' lives describe significant burdens such as a sense of loss associated with not being able to eat, the discomfort and inconvenience of HEF and a negative effect on body image^(2–4). This study investigated the impact on the lives of people with advanced malignancy, receiving home enteral feeding (HEF), where treatment was palliative; and to consider if patients nearing the end of their lives differed in their perceptions of HEF compared with other patient groups.

A qualitative approach was taken, using semi-structured interview. An interview guide was prepared based on themes identified by other studies which examined quality of life and home enteral feeding and comprised questions regarding the support received from healthcare professionals, feed and equipment providers, participants' feelings concerning the feeding tube, the effect on everyday life and that of their family, and whether they derived any benefit from HEF. The interviewee's responses were either recorded or written according to their ability to communicate orally. They were then transcribed and analysed using a grounded theory approach.

Eight people consented to participate, though three were subsequently unable to take part owing to deterioration in their condition. The study population ($n = 5$) comprised patients with head and neck cancer ($n = 4$) fed via a gastrostomy tube, and oesophageal cancer ($n = 1$) fed via nasogastric tube. Three were completely dependent on HEF; two used HEF to supplement their oral intake.

The small study population meant saturation of the data was not achieved; however, the following themes emerged.

Positive themes	Negative themes
Good support from health professionals	Discomfort and pain on tube insertion
Good support and service from feed and equipment suppliers	Restrictions placed on choice of clothing
Felt HEF gave them the strength and energy to maintain a social life and carry out daily activities	Loss of the pleasurable aspects of eating, HEF was described as 'nutrition without satisfaction'
Felt empowered to find their own strategies for managing their feeds	Complications of HEF included nausea, diarrhoea, tube blockage and belching
Saw HEF as essential to their survival	

For patients with advanced malignancy compared with patient groups already studied, the main difference was that it was recognised that some of the reduction on the quality of daily life could be attributed to the cancer and its treatment rather than HEF itself. Also that the impact of HEF on daily life assumes less importance as individual's priorities change towards the end of life. In conclusion, the role of HEF in the palliative management of patients with advanced malignancy is worthy of further study, particularly, to investigate its effect on functional status.

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