



## Introduction

- To choose the nutrition strategy in patients with a need of enteral feeding is a major decision for carers, specially in children<sup>1</sup>. Parents often feel **they receive poor and inadequate information** to make the decision of switching from oral (OF) to enteral tube feeding (ETF)<sup>2</sup>. Moreover, there's a difficulty with reconciling their preferences<sup>3</sup>.
- Adequacy of information is a potentially modifiable component that can reduce decisional conflict among patients and families<sup>4</sup>. Decision-making is influenced by personal beliefs and values<sup>5</sup>. **Effective involvement of parents/carers**, such as with decision aid tools, **improves knowledge and reduces decisional conflict**<sup>6,7</sup>.

## Objective

- To identify the characteristics of feeding options that may influence the parents/carers' decision-making process of switching from oral to enteral tube feeding and that should be included in a Patient Decision Aid to achieve shared decision-making.

## Methods

- Systematic search in electronic databases** [Medline/Pubmed, ISIWOK, Cochrane Library] to identify publications written in **English or Spanish** on patients' or surrogate decision-makers' preferences about ETF.
- European and North-American articles and congress communications** published between January 1st, 2005 and June 6th, 2016 were selected.

## Results

- A total of 7 publications were included in the systematic review. Five of them were original articles, one a systematic review and one a congress communication. [Figure 1, Table 1](#)

Figure 1. Flow chart of literature search



Table 1. Summary of the selected publications

Author, year, country (level of evidence <sup>8</sup> )	Study design / Sample	Items
Savage TA 2005, USA (4)	Case report / carer of a pediatric patient requiring EN	4, 5
Brotherton et al. 2007, UK (2c)	Qualitative study / families or caregivers of elderly patients requiring EN	4, 6, 7, 12 Feeling of shame
Planas et al. 2007, Spain (2c)	Qualitative study / patients or family or caregivers of adult patients requiring HEN	6
Hunt F 2007, UK (5)	Narrative review / families or carers of pediatric patients requiring EN	5, 7, 8, Patient discomfort
Mahant et al. 2011, Canada (2a)	Systematic review / families or carers of pediatric patients requiring EN	1, 2, 4, 5, 7, 9, 12, 13
Snyder et al. 2013, USA (2c)	Decision aid about feeding options for patients with dementia	1, 2, 3, 4, 5, 6, 7, 10, 11, 12, Respect patient wishes
Oliveira et al. 2016, Spain (*)	Exploratory observational study / patients or family or caregivers of adult patients requiring EN	2

\* Not enough information available to assess the methodological quality  
 EN: Enteral Nutrition; HEN: Home Enteral Nutrition

- Thirteen items which may potentially influence the decision-making process of switching from OF to ETF were identified. [Figure 2, Figure 3](#)

Figure 2. Items identified in the literature

### 3 items perceived as ETF benefits

- Time needed to feed:** when OF is a tedious task, ETF reduces effort and time for feeding. More time is available for emotional bonding activities.
- Complete nutrition:** regulation of caloric and water intake, and weight maintenance.
- Survival:** extension of patient's life by means of a complete nutrition.

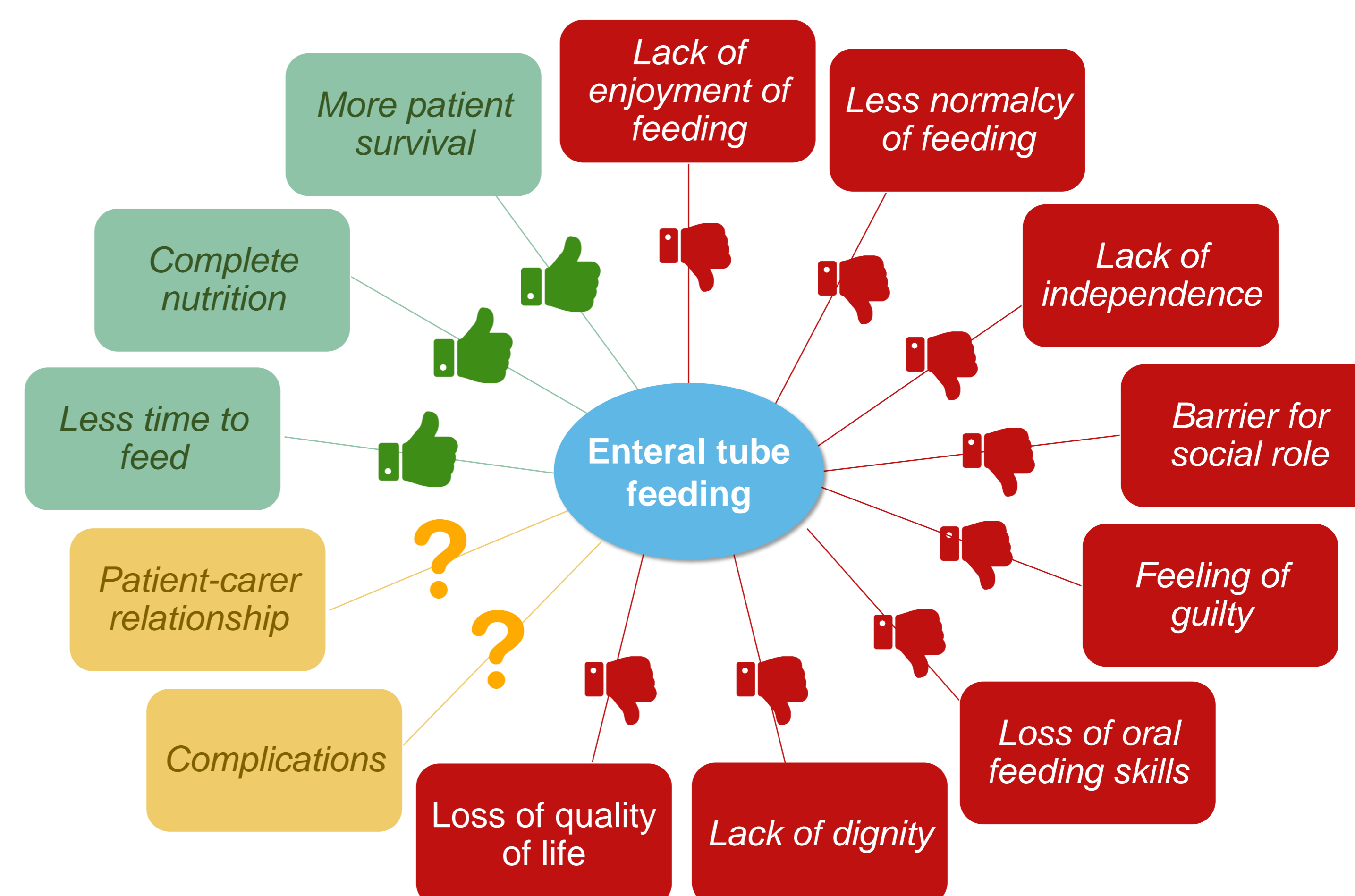
### 8 items perceived as ETF disadvantages

- Enjoyment of feeding:** OF is perceived as one of the few pleasures of the patient.
- Normalcy of feeding:** ETF is perceived as artificial.
- Independence:** ETF is perceived as a dependence sign.
- Appearance-social role:** dependence on ETF instruments, reduced mobility and aesthetic aspects could influence the social activity of the patient and be a barrier for family/carers.
- Feeling of guilty:** impossibility to feed by mouth is perceived as a failure.
- Oral feeding skills:** concern about permanent loss of ability to eat.
- Dignity:** the tube is perceived as a negative factor for patient dignity, especially in patients with reduced mobility and quality of life.
- Quality of life:** ETF is perceived by decision makers as a reduction of patient's quality of life.

### 2 items with unclear outcome in the decision-making process

- Complications:** both OF and ETF present associated complications. ETF complications are perceived as larger than OF complications.
- Patient-carer relationship during feeding:** represents an emotional connection between them but sometimes OF is perceived as a stressful situation.

Figure 3. Carers' perceptions about ETF that influence the decision-making process



## Conclusions

- Most of the potential factors identified are perceived by family and carers as disadvantages, which may contribute to delay the switch to ETF. These results highlight the need to develop a decision aid tool aimed to clarify these aspects and to facilitate the decision-making process.