



Worldwide the number of individuals who lack the mental capacity to participate in decisions about their own healthcare is increasing. There are now more people living longer with neurological disorders such as dementia, acquired brain injury and intellectual disability than ever before. This is due to a number of factors including advances in medical science and an increase average life expectancy. Many individuals who lack mental capacity also have feeding difficulties and may require nutrition provided through a feeding tube (known as artificial nutrition). Little is known about the decision-making process in these cases which is often complex and involves ethical and legal considerations. Researchers at the Cambridgeshire and Peterborough CLAHRC undertook a systematic review of the evidence base to determine what is known about decisions regarding artificial nutrition when individuals lack decision-making capacity.

Policy context

Capacity is a functional concept, determined by the person's ability to understand, retain, and weigh up information relevant to the decision in order to arrive at a choice, and then to communicate that choice¹. Shared decision-making between health professionals and patients is now embedded in national policy such as in Liberating the NHS (Department of Health 2010), but we do not know enough about what happens when patients lack the capacity to participate in treatment decisions. The understanding of clinical and legal aspects of capacity is still developing.

The research

The systematic review was carried out to determine who was involved in making decisions about artificial nutrition when a patient lacks decision-making capacity, and what factors are considered. PubMed, AMED, CINAHL, EMBASE, PsychINFO, and OpenSigle were searched for quantitative and qualitative studies (1990-2011). Citation, reference, hand searches and expert consultation were also undertaken. Sixty-six studies met inclusion criteria,



Key themes

- Clinical indications for artificial nutrition were similar across countries
- Quality of life was the main decision-making factor
- Prolonging life was the second most cited factor
- Patient's wishes were influential but not determinative
- Families had some influence but were infrequently involved in final recommendations
- Clinicians often felt in conflict over their role.

comprising data from 40 countries and 34,562 patients, carers and clinicians.

Findings

The findings of the review suggest that the initial trigger for decision-making is often a change in the patient's clinical condition (such as choking), but the key factor is the desire to improve the quality of life of the patient.

Implications for policy and practice

When individuals lack mental capacity, decisions have to be made on their behalf. Dynamic interactive factors, such as protecting the right to life, avoiding unnecessary suffering, and taking into account individual preferences, need to be addressed and balanced. The findings of this study will aid clinical practice and the development of decision-making guidelines for the treatment of individuals who lack mental capacity.²

References

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