DECISIONS REGARDING ARTIFICIAL NUTRITION FOR THOSE AT RISK OF LACKING CAPACITY: A SYSTEMATIC REVIEW

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Background In many countries, artificial nutrition is frequently used when individuals are approaching the end of their lives; however, it rarely used in the UK. Many patients for whom artificial nutrition is considered are approaching the end of life and at risk of lacking capacity. For these vulnerable patients, decision-making is emotive and challenging.

Aim To review the international literature concerning decisions about artificial nutrition for individuals at risk of lacking capacity due to dementia, intellectual disability or acquired brain injury (ABI). Key research questions: a) Which factors are being considered? b) Who is involved in the decisions?

Methods Searches of PubMed, AMED, CINAHL, EMBASE, PsychInfo and OpenSIGLE were undertaken for articles in English between 1990 and 2011 containing original empirical data. Hand searches were undertaken of key journals and articles. Information was extracted and analysed using NVivo and a narrative synthesis of emergent themes undertaken.

Results Sixty-seven relevant studies were retrieved: 75% included information about dementia patients, 42% ABI and 6% intellectual disabilities. The majority of studies were based in the USA (46%). The findings revealed that indications for artificial nutrition are embedded within the personal circumstances of the patient and the contextual environment of the treatment. Key decision factors include: prolonging life and quality of life, interpretation of behaviour and family/surrogate wishes. The key decision points for each patient group are modelled.

Conclusions The majority of the international literature relates to end of life care and dementia patients. The results show that decisions about artificial nutrition do not happen in isolation. The wide variety of studies identified, the large number of different persons involved and the diversity of decisions involved indicate that artificial nutrition is not a single decision but a decision process which is embedded within context. Implications for UK practice and policy are discussed.