A QUESTION OF FUTILITY? END OF LIFE DECISION MAKING IN THE UK COURTS

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Background What action should palliative care clinicians take if they feel that a medical treatment is ineffective but carers disagree? In the case of incapacitated adults in England and Wales, it is only lawful to withhold life-sustaining treatment if it is judged to be futile or overly burdensome to the individual. Disagreements as to an individual’s best interests may involve recourse to the courts.

Methods This paper reviews the case law in this area, charting 25 years of judicial decision making on behalf of incapacitated patients receiving life-sustaining treatment.

Results Recent cases illustrate a evolution; from a deference to medical decision making to a rejection of a biomedical ‘best interests’ decision-making model. Courts now show a willingness to scrutinise what clinicians mean when they invoke the term “futile” to withhold life-sustaining treatment in a person’s best interests. The UK Supreme Court’s recent narrow interpretation of futility; “ineffective or being of no benefit to the patient” has the potential to skew treatment decisions in favour of interventions that have little chance of producing a meaningful improvement in clinical condition.

Conclusion By rejecting the ‘medical’ view of futility the right of an incapacitated individual to have burdensome or minimally beneficial treatments withdrawn is now interwoven with the judicial interpretation of their best interests. Removing these decisions from the bedside adds additional complexity to end of life decision-making as clinicians may no longer know with certainty that their decision to withdraw life sustaining treatment is a lawful one.
We previously piloted ESC in several disease groups. The work demonstrated that timely supportive care improves patient experience and reduces hospital admissions.

Incorporation of ESC within experimental cancer medicine is new in the UK. The aim is to help maximise patient recruitment and retention and enhance the patient experience within the context of experimental cancer medicine clinical trials (Phase I and non-randomised Phase II clinical trials).

**Methods** A Joint clinic was set up between the Experimental Cancer Medicine Team (ECMT) and the Supportive Care Team (SCT). These clinics are staffed by consultants from each team, research nurses and fellows and a clinical nurse specialist in supportive care. Patients being considered for or currently participating in a clinical trial are offered early referral to the supportive care team for assessment and management.

**Results** The pilot project began in September 2015. To date the SCT have undertaken 132 patient consultations within the ECMT. The predominant referral has been for optimisation of pain control, which is managed with specific consideration of the restrictions in the concomitant medication prescribing within Phase I trials.

**Conclusion** The ECMT at The Christie is the first early phase clinical trials unit to adopt ESC into practice. The ESC approach is now a routine part of the ECMT assessments of trial patients. Next steps will be to measure the impact of ESC on patient experience, eligibility for clinical trials, and admission avoidance.

**P-95 THINKING AHEAD: DISCUSSING RESUSCITATION DECISIONS WITH DIVERSE COMMUNITIES**

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**Background** Improving Advance Care Planning (ACP) and increasing its equitable access is a key UK government strategy. Evidence (mainly from the USA) suggests that there are lower levels of ACP in people from Black, Asian and Minority Ethnic (BAME) communities. People from some BAME groups also seem to be more likely to desire invasive medical interventions, regardless of prognosis and impact on quality of life. The beliefs, values and needs of BAME communities in the UK have not been explored to see if the UK model of decision making around resuscitation fits for them. Also, healthcare professionals (HCPs) report that they do not feel confident in providing culturally appropriate care for BAME patients and families in this situation.

**Aims** To identify barriers and enablers to HCPs discussing deterioration and resuscitation with patients and families from BAME communities, and to identify associated HCP training needs.

**Methods** Qualitative semi structured interviews with 30 HCPs.

**Results** HCPs’ interviews identify key barriers and facilitators of resuscitation discussions including differing attitudes towards death; differing values amongst different generations of migrants; and the need to find a balance between the desire to act in a non-discriminatory way whilst respecting cultural differences. Analysis of interviews informed a set of statements regarding decision making about resuscitation, which are being used as part of a ranking exercise (using Q methodology) with members of the public.

**Conclusion** There are significant barriers for HCPs when discussing resuscitation decisions with people from BAME communities. This increases the complexity of navigating ACP and achieving patients’ preferences.

**P-96 THE MANAGEMENT OF TA – SURVEY OF NURSES WORKING IN A SPECIALIST PALLIATIVE CARE UNIT**

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**Background** National formularies recommend a step wise approach to Terminal Agitation (TA) using benzodiazepines and anti-psychotics.

Within our 21 bed specialist palliative care unit, a flowchart for management of TA was created in response to reviews where medical and nursing staff felt TA had been poorly controlled.

Four months after the introduction of the local guidelines, we conducted a spot survey of trained nursing staff to ascertain confidence toward management of TA.

**Methods** A standardised pro forma of 13 questions was used.

Staff ranked confidence with various aspects of TA management using a numerical rating scale (1 = lowest, to 10 = highest). Free text responses were collected regarding the most rewarding and challenging aspects of managing TA.

**Results** 11 of 12 nurses (all female) responded. Mean age 42 years (25 - 56), with a mean of 15 years since qualification.