Life Before Death - Conversations, Preferences and Action

Dear Sir,

The extent to which people think about dying, talk about it, plan for it and make their preferences for end of life care known are issues which are increasingly important in the public domain, in clinical care and the research literature. In 2015 ‘Which?’ published a report entitled ‘Dying Better: The consumer experience at the end of life’. In every sense, and properly so, discussion on end of life care is presently a mainstream societal issue.

Docherty et al’s research (vol 109, 5) provides important insights about perceptions of an Irish sample of people with metastatic carcinoma. Their ambivalence around the concept of palliative care and end of life care is shared by many Irish people. In Ireland, palliative care and hospice organisations have started to run public awareness campaigns about the nature and impact of palliative care, its applicability across the lifespan, and its link to social and psychological rehabilitation, as much as end of life care (e.g. Palliative Care Awareness week in Ireland, 2015). Doherty et al rightly identify the evidence-based benefits – including survival time – associated with early palliative care involvement. This message needs to be communicated both to health care professionals and into the public domain, so that those who will benefit can themselves request appropriate advice and services.

Participants in Doherty’s study indicated reluctance to talk about dying, associating it with loss of hope. Irish Hospice Foundation population surveys established consistently that people have clear preferences for their end of life care, yet these preferences have not yet been systematically converted into a range of actions (from discussing wishes, writing preferences in advance healthcare directives, and seeing these realised). As directed by health & social behaviour change models, we consider consistently enabling such actions, supporting them professionally, and rendering them socially ‘normal,’ are key to supporting increased positive attitude and personal involvement in shaping end of life experiences – over years, months and days.

O’Shea et al have previously reported on acceptability of discussing and recording end of life preferences using ‘Think Ahead’. The Think Ahead tool is a citizen-led initiative, which includes a section on Advanced Healthcare Directives (http://www.thinkahead.ie/), and is designed in the context of the Assisted Decision-making (Capacity) Act (December 2015). This Irish research establishes acceptability of ‘Think Ahead’ in primary care. A further study on feasibility and acceptability of use of Think Ahead with frail patients/ those identified as increased risk of dying in the short-term is in press at the BJGP.
Promoting autonomy and engaging in ‘life before death’ are necessary and positive developments. There remains unmet need in developing legislative, health and social systems, and our education infrastructure to enable these to become a reality for all citizens.

Yours,

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References: