

Patient values informing medical treatment: a pilot community and advance care planning survey

Reference: Milnes S, Corke C, Orford NR, et al. *BMJ Supportive & Palliative Care* Published Online First: [24 Apr 2017] doi:10.1136/bmjspcare-2016-001177

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Abstract

Background: Medicine regards the prevention of death as an important priority. Yet patients may have a range of priorities of equal or greater importance. These other priorities are often not discussed or appreciated by treating doctors.

Objectives: We sought to identify priorities of care for patients attending an advance care planning (ACP) clinic and among the general population, and to identify factors associated with priorities other than prolonging life.

Methods: We used a locally developed survey tool ‘What Matters Most’ to identify values. Choices presented were: maintaining dignity, avoiding pain and suffering, living as long as possible, and remaining independent. Participants rated the importance of each and then selected a main priority for their doctor. Participant groups were a purposive sample of 382 lay people from the general population and 100 attendees at an ACP clinic.

Results: Living as long as possible was considered to be less important than other values for ACP patients and for the general population. Only 4% of ACP patients surveyed and 2.6% of our general population sample selected ‘living as long as possible’ as their top priority for medical treatment.

Conclusions: ‘Living as long as possible’ was not the most important value for ACP patients, or for a younger general population. Prioritisation of other goals appeared to be independent of extreme age or illness. When end of life treatment is being discussed with patients, priorities other than merely prolonging life should be considered.

Strengths:

This paper challenges the often-held idea that prolongation of life is the most important value to patients over priorities like maintaining dignity, remaining independent or avoiding pain and suffering. The results of this study provide a starting point to begin ACP discussions with patients.

Weaknesses:

The sample groups selected may not be representative of the community at large. The ACP group was from a single geographic area. As well, the community group was selected non-randomly via a snowball technique using social media, where the investigators emailed the survey to their friends and family. As well, the study did not keep track of how many respondents received the survey and declined to complete it in the community group. The study also sought to examine the “lay-public” and excluded physicians; however, failed to exclude other health professionals.

Relevance to palliative care:

This paper importantly spotlights the diversity of patients values and wishes, emphasizing the need for patient-centered care. The values highlighted in this paper emphasize the need for palliative care in our communities and prioritize early ACP discussion.