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Measuring impacts of value to patients is crucial when evaluating palliative care.

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To the editor: The inclusion of preparation for death and managing affairs in the end of life instrument designed by Borreani et al. (1) to elicit preferences about dying is commendable. Of note, few quality of life (QOL) measurement tools contain or adequately assess this patient-valued domain. Given the importance that patients place on these issues, it is possible that evaluations of palliative health care interventions, including comparative effectiveness and cost-effectiveness analyses, could easily misinterpret the net benefit of such interventions without inclusion of this domain as an outcome measure. Better assessment methods that incorporate preparation for death and managing affairs are needed.

At a service level, if evaluation measures used in clinical practice or research do not adequately highlight patient-valued domains, service provision may also fail to focus on complex issues, such as preparation for death, and seek to focus only on managing

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physical symptoms, limiting the potential impact of palliative care on identified patient-valued outcomes.

The high value placed on the ability to prepare for death and manage affairs by people at the end of life has been clearly demonstrated. Having ‘financial affairs in order’ was rated ‘important’ or ‘very important’ by 94% (320/340) of people with advanced chronic illness randomly selected from the national Veterans Affairs database in the United States (US) (2) and for 87% (349/434) of older Canadian patients with a 50% probability of survival for six months, ‘completing things and preparing for life’s end’ was ‘very’ or ‘extremely important’ (3). Therefore, quantifying the impact of palliative care involvement on this domain in clinical research is crucial, although few measurement tools administered in this setting have attempted to do this.

In a recent systematic review by Zimmermann et al. (4) examining the effectiveness of specialized palliative care teams, only one study (8%) used a QOL measurement tool specific for a palliative care population. However, this tool did not explicitly include preparation for death (5). Similarly, the measurement tools administered in the remaining 11 studies, including the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (6) and the Medical Outcomes Study Short Form (SF-36) (7) did not explicitly include this domain. Research into patients’ values at the end of life has grown considerably since these tools were initially constructed and some of the more recent palliative care specific measurement tools do include preparation for death, although the focus first tends to be on health-related domains such as symptoms or functional status (8) (9).

Research that seeks to define the relative benefits of different models of care for end of life, including palliative care, is used by health systems around the world, such as

Medicare in the US, to inform decisions regarding the funding and provision of palliative care services. The data needed to inform such deliberations should include the outcomes most valued by patients themselves. It is crucial that the impact of interventions on important patient-relevant domains, including preparation for death and managing affairs, is systematically captured. Otherwise, a sub-optimal model of measurement could lead to missed funding opportunities for valuable palliative care programs or interventions may be inappropriately supported. Once these impacts are captured, robust analysis of multiple patient-valued domains is available to evaluate complex interventions like palliative care that span in-patient, out-patient and community care across a large number of providers (10).

It is vital that clinicians and researchers choose appropriate tools to measure important patient-relevant aspects of QOL, including preparation for death and managing affairs. Such data can drive clinical practice to ensure opportunities are optimized for patients and evaluation studies are better informed. There are numerous QOL and health-related QOL measurement tools available to assess comparative effectiveness and cost-effectiveness of health care interventions in clinical research. The desire to choose a well-established, robust tool that has been used many times before and produces generalisable data should not outweigh the need to systematically capture the impact of interventions on patient-relevant aspects in palliative care. The article by Borreani et al. (1) is a timely reminder that continuing development of palliative care specific QOL measurement tools is required, particularly given the apparent paucity of tools that include preparation for death and managing affairs as components.

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