Balance of lifetime remaining to anticipated suffering behind
10.1136/eb-2015-102124

Phillipa Malpas
Department of Psychological Medicine, FMHS, University of Auckland, Auckland, New Zealand

Correspondence to: Dr Phillipa Malpas, Department of Psychological Medicine, FMHS, University of Auckland, Private Bag 92019, Auckland 1142, New Zealand; p.malpas@auburn.ac.nz


Implications for practice and research
- Uncertainty about the dying trajectory may manifest itself in a desire of patients to control the dying process.
- A desire for a hastened death should not be interpreted literally as a death wish.
- Further research exploring what dying patients need at the end of life is recommended.

Context
Despite tremendous advancements in palliative and hospice care over the past several decades, some patients facing their own mortality express a desire for an assisted death. Pestinger and colleagues explore the motivations of patients who express a desire for an assisted death in a country that prohibits euthanasia and physician-assisted suicide. The aim of this study was to explore the subjective world of experience of patients who had an advanced condition with a view to better understand their motivations for a hastened death.

Methods
This qualitative study recruited potential inpatients from three hospitals in Germany. A patient who had requested a desire for a hastened death was eligible to participate if they: had an advanced incurable condition; were aged over 18 years; were competent; and could consent to the study. The study used a modified form of Grounded Theory due to the small sample size. Confirmation of interview material was gained from analyses of six patient interviews in other study sites as a substitute for theoretical sampling. Saturation was reached at 12 individuals once it was determined that no new information was being revealed. Participant’s face-to-face interviews were audio-taped.

Findings
Three central motivational themes emerged from thematic analysis: self-determination, agony and time. Participants also provided a rich tapestry of anticipated situations to be avoided at the end of life. Self-determination was characterised by a desire for control over the circumstances of one’s current state. Agony was as much a psychological state as a physical one with patients concerned about past painful experiences and their fears around future losses. Time emerged as a central theme—for some patient’s time passed too slowly, for others they had too much time to contemplate their situation—this permeated all interviews.

Commentary
As populations rapidly age in most countries around the world and more people live with, and die of, chronic rather than acute conditions, understanding what matters to patients at the end of life and how that translates into practice has never been more important than it is today. Advances in palliative and hospice care have transformed the provision of medical treatment and care at the end of life, yet some patients express a desire for a hastened death that may be challenging for health professionals involved in their care. Patients’ desire for an assisted death could be understood as an invitation for a conversation and not a literal request for help to die.

This study clearly and powerfully illuminates the patient’s voice as he or she navigates the end of life and the dying trajectory. Fear of the unknown, the impact of loss of one’s interests and activities, leaving family with decision-making which can lead to a sense of thankfulness but also guilt and the fear of losing one’s self-esteem and control, contribute a compelling picture of the importance and significance of skilled and informative communication at the end of life. A therapeutic relationship grounded in trust and affection and one that provides certainty to vulnerable patients may provide a sense of security and relief. Such rich and encompassing relationships may mitigate the desire for a hastened death and reassure patients of being cared for until the very end of life.

This study highlights the motivations and vulnerabilities of those facing their own mortality, the implications this has for health professionals working with people who are dying and the importance of being heard at the end of life.

Competing interests None declared.

References