



Goal-concordant end-of-life care: the ultimate goal for advance care planning?

Craig Sinclair^{1,2^}

¹School of Psychology, University of New South Wales, Sydney, Australia; ²Neuroscience Research Australia (NeuRA), Sydney, Australia

Correspondence to: Craig Sinclair, PhD. Neuroscience Research Australia, 139 Barker Street, Randwick, NSW 2031, Australia.

Email: c.sinclair@unsw.edu.au.

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The provision of care that aligns with a patient's goals and documented preferences, particularly in the final weeks and months of life, has been prioritized as a characteristic of effective and patient-centered care (1,2). The ideal of providing end-of-life care consistent with a patient's known preferences, or the best interpretation of these preferences, is a powerful sentiment which can unite patients, family members, healthcare professionals, funders, regulators and the broader community. It may be that this widespread support has roots in deeper historical and cultural ideology, at least within more individualist societies (3).

While goal-concordant care resonates broadly as an ideal, it has proven challenging to define, implement, and measure. These challenges start with the inherent complexities in eliciting patient preferences for end-of-life care, within historically paternalistic health systems, and contemporary societies that are increasingly socio-culturally diverse. Beyond this, even if preferences can be elicited, are these based on adequate understanding of the available options? Do they reflect the patient's authentic will and preference, or are they subject to persuasion from others (4), or the more insidious, internalized influences of ageism or other forms of discrimination (5)? Finally, are these preferences understood as context- and temporally-dependent choices or do they reflect a patient's deeper and

supposedly more stable outcome goals or personal values (6)? In short, these questions converge on the concerns of health professionals that they are acting on stable, authentic and informed preferences of their patients.

Advance care planning (ACP) has been seen as a way of grappling with some of these challenges, and has attracted increasing research interest over the past 30 years. In 2017, a Delphi consensus panel conceptualized ACP as "...a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care (7)". This panel also determined that the goal of ACP is "...to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness". In a follow up publication from 2018, 'goal-concordant care' was identified by a panel of experts as the most important outcome goal for ACP (8). However, the authors noted concerns about the difficulties in reliably measuring this outcome, and the need for further research focused on identifying and validating suitable measurement tools.

While goal-concordant care has been stated as the primary goal of ACP, this outcome is not commonly reported in ACP studies, despite the continuing acceleration of this field of research. In a 2016 scoping review, Biondo

[^] ORCID: 0000-0003-2734-2951.

and colleagues found that health systems rarely used goal-concordant care as an outcome measure when evaluating health system level ACP initiatives (9). A recent systematic review of randomized controlled trials focused on the efficacy of ACP in improving patient outcomes found that only 12 out of 132 trials assessed concordance between preferred and actual end-of-life care. Measurement of concordance was variable, and just three trials indicated beneficial effects (10). Even the description of ACP in the literature appears to downplay the focus on goal-concordant care. A manual search (unpublished) of 66 accessible, English-language papers referenced on Web of Science between July and December 2022, which referred to Sudore *et al.*'s widely cited consensus definition of ACP (7), was undertaken by the author. This process found that while 40% explicitly referred to the first sentence of the consensus definition (identifying ACP as a process of goals clarification and communication), only 17% referred directly to goal-concordant care as the primary goal of ACP. It may be that the conceptual challenges in defining and measuring goal-concordant care prove to be a barrier to its use in ACP research.

The challenges associated with conducting research on improving goal-concordant care have been widely observed, and addressed by some. Sanders and colleagues described a conceptual model and approach for measuring goal-concordant care, suggesting a range of proxy indicators, including process measures focused on the context and quality of serious illness communication, patient ratings of goal-concordance in current care, and post-death surveys of bereaved caregivers for goal-concordance in end-of-life care (11). Others have proposed measurement of clinician understanding of patient goals (12), or the automated extraction of preferences and determination of concordance from electronic health records using Natural Language Processing (13). On the other hand, recent commentary in the context of debate about the aims and value of ACP (14) has advocated for abandoning this outcome as an indicator of successful ACP (15).

In a recent study published on the *Annals of Palliative Medicine*, and against the backdrop of this ongoing debate, Malhotra and colleagues focus more directly on implementation issues (16). Their qualitative study investigates multi-disciplinary health professionals' perceptions of the challenges in providing end-of-life care consistent with patients' documented preferences. This study was integrated with the evaluation of a national ACP program in Singapore, and focused on those clinicians and

staff who had been trained and assigned roles within the program (e.g., as ACP champions or facilitators) across different sectors of the healthcare system. The data were collected through focus groups and in-depth interview, and analyzed thematically. Key themes in participant responses included conflict between honoring preferences for comfort care and extending life; difficulties associated with reflecting patients' changing preferences or medical conditions in ACP; lack of health system resources to support and honor patient preferences; barriers to retrieval of ACP documents; and rigidity of ACP documentation. Strengths of this study included the substantial sample size, with cross-sectoral data collection spanning the hospital, primary care and nursing home settings.

The authors note the important contextual considerations, such as the lack of a statutory legal framework to enforce clinical compliance with documented patient preferences in Singapore. They also note the commonly cited concerns that ACP documentation can be difficult to retrieve, and does not always reflect the patient's current preferences, which may change due to their changing circumstances or evolving medical condition. Measures to address these concerns, such as recommended annual reviews of ACP documents, were not always completed, due to resource limitations.

Perhaps the most important issue articulated by Malhotra and colleagues is that efforts to provide care consistent with documented preferences occur within the context of resource-limited health systems. This is sometimes missed when goal-concordant care is artificially construed as a sort of 'mental accounting' between patient preferences and clinician actions prior to the initiation, withholding, or withdrawal of a singular medical treatment. When a patient preference is less able to be operationalized into one specific medical decision (e.g., a desire to die at home), this implicates the work of teams of staff across different sectors of the health system, as well as family caregivers, to coordinate the range of clinical, supportive and logistical services which may be required to actualize this preference. The explicit system-wide and multi-disciplinary perspective for this study enables insights into the complex nature of this work. More broadly it suggests the need for the design of care systems which empower staff by providing time to elicit patient preferences, flexibility to be responsive to these preferences, and strategic resourcing to support the care teams who can enable the different types of care desired and expected by these patients.

While the objective measurement and benchmarking of

goal-concordant end-of-life care remains challenging (2), this study provides a timely reminder that the provision of care consistent with patient documented preferences depends on systems and organizations. System-level interventions which including developing policy; providing infrastructure for storage and retrieval of health information; designing and implementing care models; mobilizing and coordinating teams; and empowering frontline clinicians in making courageous decisions to promote goal-concordant care will all be important. More rigorously controlled clinical trials are also important, but these research studies will only rarely be able to implement and test the impact of these multi-component changes to healthcare systems. Ongoing evaluation of system-wide initiatives, informed by clear program logic and employing mixed methodologies, may yield further insights in progressing towards these goals.

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