

Tensions in advance care planning with dementia: Time for a good-enough laid-back approach?

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Keywords

Advance care planning, dementia, conceptualisation

Ten years ago we considered research we no longer need on dementia palliative care which includes advance care planning.¹ More recently, we have considered advances in advance care planning research,^{2,3} arguing why research into dementia-specific approaches are needed.² However, an exclusive focus on dementia could be considered to be stigmatising.^{4,5} Therefore, in this editorial, we consider the conceptualization of advance care planning in a generic versus a dementia-specific manner as a major tension. We define tensions as opposing forces that create a dilemma, making it necessary to choose, even though the choice will still involve some difficulty or strain. Tensions are inherent to the reality of advance care planning and more so, in the case of dementia. They arise around the involvement of family, the changes in people's decision-making capacity, or in communicating with people who have a disease that can take a long and rather unpredictable course.⁶ In this editorial, we reconsider what future research we need to conduct, considering the general and dementia-specific tensions inherent to engaging people in tailored advance care planning approaches. Our central argument is that the remaining tensions on advance care planning in dementia are at times unresolvable; embracing them and work from there might be more effective than aiming to solve them.

Looking back to research in the past 5 years

A PubMed search ('advance care planning' AND 'dementia') limiting to publications between 2019 and 2024 produces as many as 50 categorised as reviews among a total of 396 hits. These either focus specifically on advance care planning or address it as part of a palliative care approach. Table 1 highlights some of this literature drawing on diverse settings and dementia types as examples of how the field has progressed. Researchers have been shaping

the concept and practice of advance care planning in dementia and the research has increased the understanding of perspectives of people with dementia and their care partners (or family caregivers) on it. New approaches and models to improve advance care planning by professionals and within the family context have been developed and evaluated. Conversation analyses and other promising research methods uncover the micro-level mechanisms of advance care planning communication. Improved measurement of outcomes could steer the field even further.

Looking forward: Remaining tensions in advance care planning and how to embrace them

Advance care planning can be useful by virtue of the tensions that are inherent to it. One major tension inherent to advance care planning concerns the need to consider competing goals of care or treatment (e.g. comfort versus maximizing functioning, or versus life-prolonging goals). As not all goals are always simultaneously achievable, competing goals may need to be prioritised and choices may need to be made, either in-the-moment or in-advance (Figure 1). For

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Table 1. Research progress.

Research agenda set in 2019 editorial <i>Palliative Medicine</i> ²	How has this been addressed recently?
1. A need for dementia-specific advance care planning research	Having dementia affects the advance care planning process in various ways as laid out in 2019. ² The European Association for Palliative Care Taskforce on advance care planning in dementia conducted a 33-country Delphi study to develop a consensus definition for advance care planning in dementia highlighting what is specific for dementia, ⁶ formulate recommendations for clinical practice and identify policy and research gaps.
2. The perspectives of people with dementia and their family	Research focusing on uncovering the perspectives of people with dementia themselves and those of their family caregivers or care partners have gained traction, as have user-centred designs to develop interventions in co-creation. The research highlights a need for a holistic approach beyond addressing medical issues. ⁷ The importance of the lived experience of people, the paradoxical nature of autonomy and striving for, or letting go of control surfaces from ethnographic work and qualitative interviews. ⁸
3. Advance care planning communication research	Fundamental communication research is still limited. Analysing recordings or observations of conversations is a promising way forward; ^{9,10} especially when interpreting findings in workshops along with people with lived experience and informed by theory. ¹¹ A recent study, ¹² although not about dementia, offers an example of how new types of analyses can bring insights into how to achieve more person-centred communication in advance care planning.
4. Developing and evaluating patient-centred and family-focused advance care planning models	In multiple countries, nurse-led and multi-disciplinary models in the field of dementia are being developed and tested; also dyadic interventions for people with early-stage dementia and their family caregivers.
5. Finding ways to support 'informal' advance care planning processes	Promising tools complementary to conversations with professionals to support advance care planning by persons with dementia are embedded within a larger public health palliative care movement. ¹³ However, research in this domain is limited when it concerns dementia, while present in public education tools.
6. Dementia-specific outcomes measures for efficacy and effectiveness research	Considering that advance care planning could span a long period with numerous concrete and underlying goals, ¹⁴ evaluating its effects can be difficult. Core outcomes sets evaluating short and longer term effects have not yet been developed but would aid understandings of advance care planning as a process considerably.

example, maintaining function might threaten comfort when encouraging mobility causes pain.¹⁵ Choices people with progressive illness make, are often value-based. In many cases, there is no single optimal solution. Therefore, it makes sense to clarify what is important to the person or to clarify treatment preferences and their underlying values. Revisiting of preferences is needed in planning for an unforeseeable future considering declining capacity to express preferences.

In the case of dementia, multiple tensions in advance care planning are exacerbated adding to complexity of advance care planning (Figure 1, middle square). A major tension relates to the changes in capacity over time. Popular generic definitions of advance care planning^{16,17} have resolved this by excluding people with limited, declining or fluctuating decision-making capacity. Hence, there was a need for a definition that is fully applicable in the case of dementia. Therefore, in the recent Delphi study of the European Association for Palliative Care (EAPC), we defined advance care planning in dementia more inclusively as a process that is continued when the person with dementia becomes unable to make their

own decisions.⁶ Involving proxy decision-makers who may support, but also override, or not know patient preferences, complicates the process exactly at the point when it is crucial to understand what's important to the person. Sellars et al.¹⁸ in their review highlighted these two points (Figure 1, points 1 and 2) accepting the inevitable capacity decline and alleviating decisional responsibility as '*navigating existential tensions*' by persons with dementia and their family caregivers. Involving family caregivers is important for the process to not stop when the person's engagement diminishes. It is also important for the family caregivers themselves to understand the preferences and to consider the impact of decisions on them or on the relationship between the person with dementia and them. There is no uniform answer to the question to what extent, or when, advance care planning is a person-centred process based on individual autonomy, or a relationship-centred process inclusive of, and focused on relationships with family caregivers.

Another important tension relates to the different approaches to conceptualizing advance care planning (Figure 1, point 3): should we adhere to a generic definition

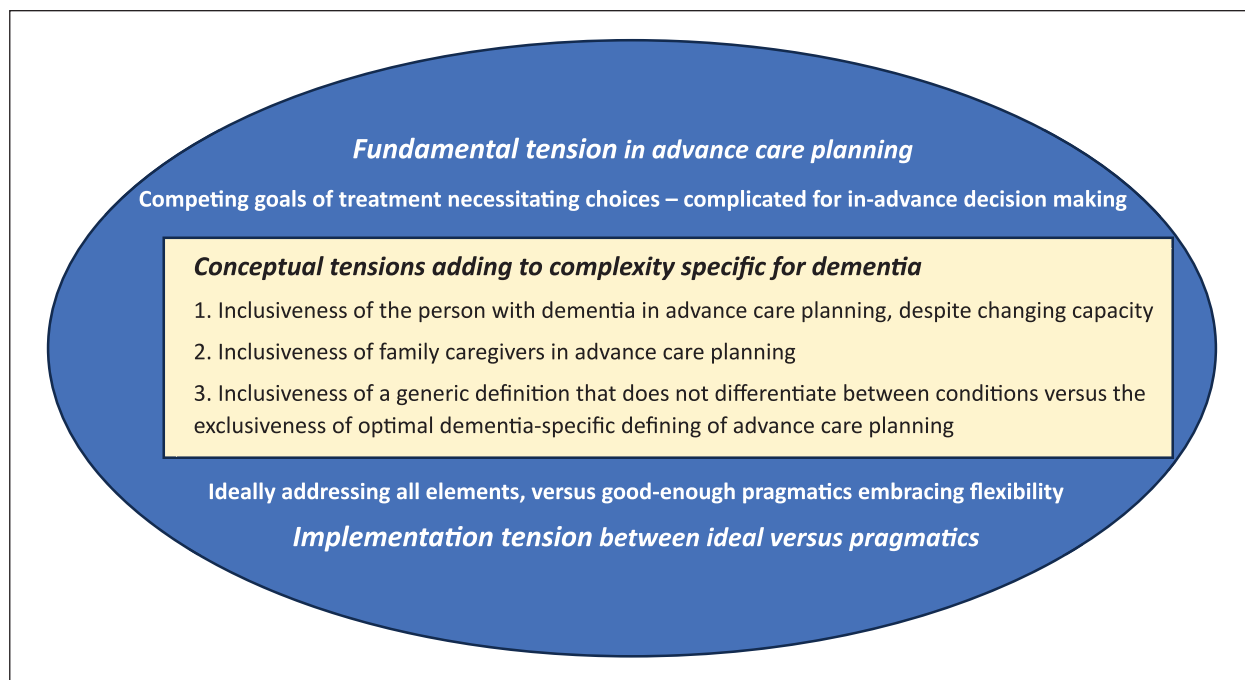


Figure 1. Challenging tensions in advance care planning: generic (blue) and dementia-specific (yellow).

that is inclusive and applies to anyone, or do we need that specific definition that mentions and applies specifically to people with dementia? People with dementia themselves have resisted an exclusive or separate focus on dementia as this might suggest inequality. A person with dementia stated: *‘to be honest with you, I think a generic definition with smaller changes for our needs is all that is required because we’re no different’*.⁵ This narrative of inclusivity is important to people with dementia, wanting to be identified as a person and not by a disease.

Finally, and from these conceptual tensions, challenges in practice emerge. Implementation challenges present themselves more as a rule than as an exception in advance care planning practice (bottom of Figure 1). In the case of dementia, Delphi panellists estimated that a median of four sessions are needed to address the necessary elements of advance care planning in the case of dementia (manuscript under review). This might not be compatible with feasible practice in many health care systems currently. It could even be seen as too prescriptive. Rather than a separately demarcated process, advance care planning is preferably integrated in a person-centred underlying approach. However, as long as advance care planning is not part of usual care, framing it as a demarcated process may be needed to ensure it happens in practice.

Being overly ambitious (i.e. wanting advance care planning to be a perfect process) may be a caveat as it risks paralysing professional caregivers. This might then lead to professionals continue to (reactively) wait for the person or family caregiver to bring up topics related to advance care planning. Thus, the numerous recommendations

made for an ideal advance care planning process with persons and their family caregivers might deter people from even getting started. A non-scripted less formal approach focussing on values and goals may be culturally appropriate in many individual cases. This shows a potentially unresolvable implementation tension between ideals and pragmatics. Should we strive to address all elements of a thorough and sensitive advance care planning process with all? As an alternative, should we opt for a good-enough practice embracing flexibility and tailoring, perhaps focusing first and foremost on conversation starters and triggers?

Conclusion

After decades of research on advance care planning and considerable progress in conceptualizing it in dementia, several fundamental tensions or strains remain. Those do not need to be considered as problematic as such, as they are inherent to the complexity of the process. Yet, particularly in dementia, changes in capacity, the importance of family caregivers, and the prolonged disease trajectory along with questions around inclusiveness, bring along potentially unresolvable tensions in what advance care planning should entail and how to engage with it. Accepting such tensions to be inherent to any complex process, leads to considering what type of engagement with advance care planning is good enough. Can we find middle ground in striving for an ideal process while preventing rushed tokenistic tick-box exercises or quick fixes? Can we find a pragmatic solution to ensure a good-enough practice? We

encourage future research to uncover how to acknowledge and navigate the tensions in advance care planning and to actively seek to identify a good-enough laid-back approach which might in the end approximate optimal practice.



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