

Supplement with Editorial van der Steen and Goodman, for online only.

Box 1. Research we do not need on the care of people with dementia at the end of life

Research we do not need	Reason	Example of research we do not need	Research we do need
<b>(1) Theory: more or less?</b>			
a. Research with implicit underlying assumptions that lack an explicit theoretical framework	<p>There is a tendency to think that the value and basis of palliative care interventions are self-evident. We need to be clear whether research is:</p> <ul style="list-style-type: none"> <li>• exploratory</li> <li>• has implicit hypotheses based on clinical/ experiential knowledge or</li> <li>• has an explicit theoretical framework of the impact of cognitive impairment, co-morbidities, family involvement and setting</li> </ul> <p>A-theoretical research limits what can be learnt from other settings and patient groups and building up of theory.</p>	<p>The uncritical application of models of palliative care (e.g. for cancer patients) to populations with chronic-progressive disease</p> <p>Development of tools with item selection based on implicit clinical experience</p> <p>Research on the use of one-time advance care planning (ACP) discussions that either does not recognize the pragmatic reasons that drive their use or fails to consider how an ACP intervention fits with existing practice and how care is planned and provided over time</p>	<p>Theory development for specific populations and settings iteratively informed by findings</p> <p>Comparative research that draws on a good understanding of the similarities and differences with cancer care, but also other chronic-progressive disease</p> <p>Research on how to overcome barriers to initiate and continue a process of ACP and the role of living wills in this</p>
b. Research developing theories that are not applied in practice	Missed opportunities for development, both of theory testing and practice development	Research that has developed theories of spiritual care without work demonstrating its application	How the integration of spiritual care principles within existing palliative care approaches affects outcomes
<b>(2) Research design: uni or multi dimensional?</b>			
a. Descriptive research in a single setting with no direct comparator (unless a country with no prior research in this area)	We know that symptom burden may be high and about suboptimal palliative care provision to people with dementia	Research that describes the shortcomings of existing palliative care provision to people with dementia	Descriptive research comparing over time directly with other settings, health care systems or countries, using the same measures. This includes an evaluation of how to embed change into existing practice and the cost consequences

<p>b. Complex interventions failing to identify effective ingredients of an intervention and linked barriers and facilitators</p>	<p>Palliative care interventions will always be multi professional and multi component. It is problematic if this is not systematically considered within the design and analysis. Findings may be uninterpretable or not very informative if implementation fails in part. Also in practice we will need to balance compliant flexibility versus full fidelity and adherence to interventions if we are to avoid cookbook palliative care</p>	<p>Testing of multi component interventions where their differential effect is not assessed or discussed</p> <p>Studies that either have no comparison or use “usual care” only as the comparator</p>	<p>Adequately powered studies employing sophisticated research design and analyses that consider how innovation and new models of service delivery can be normalized into everyday practice. It should allow for assessing effective elements through analysing degree of implementation, mediating factors, specific barriers and facilitators</p> <p>Directly comparing two slightly different palliative care interventions with usual care. Research with more arms and head-to-head comparisons are needed</p>
<p>c. Research in highly selected or restricted samples including restriction to stages that many people with palliative needs may never reach. Narrow focus on terminal stages</p>	<p>It will not teach us how to provide palliative care to the many people with dementia who may also have palliative care needs, nor about the sensitive issue of how to shape palliative care in earlier stages</p>	<p>Research on people dying from dementia that excludes people who are dying with dementia or sudden deaths</p> <p>Research limited to people with advanced dementia only</p> <p>Research with inclusion and conclusion at times convenient for the research but not anchored in the trajectory of the disease</p>	<p>Research that analyses the disease trajectory in multiple ways, considering also the developing of additional health problems, and other longitudinal changes. It considers changes reported in the literature for the wider population as well (e.g. older people).</p> <p>Sampling that reflects the care setting and range of palliative care needs encountered. Studies should include at least moderate dementia and patients not perceived as dying soon; arguably, decision making is the most complex in this stage. Effects of interventions on patient and family may also be different in different stages, and studies should be adequately powered for planned subgroup and moderator analyses</p>
<p><b>(3) Implementation: based on evidence?</b></p>			
<p>a. Research aimed at innovation that does not consider drawbacks or unintended consequences or</p>	<p>Optimism bias relates to distorted evidence</p> <p>We then lack evidence of generalizability, which is important because, for example,</p>	<p>Advance care planning interventions ignoring individuals’ resistance to looking ahead and an emphasis on the pleasures of living in the moment</p>	<p>Research aware of possible unintended consequences, e.g., through the use of theory (in the case of advance care planning, on psychological coping strategies)</p>

<p>is not replicated</p>	<p>interventions may not work as well if carried out by others in other places or with other budget limitations</p>	<p>Interventions that demonstrate potential but do not demonstrate how they can be replicated in different settings or embedded into everyday practice. For example, complex interventions that rely wholly on additional funding and the creation of new services and roles, if shown to be effective risk not being replicated in research and risk not being implemented or compromised because it is not possible for services to replicate the level of provision</p>	<p>Research that takes replication seriously and includes analysis of costs and what needs to be in place for the intervention to become normalised</p>
<p>b. Palliative care research that does not learn from other disciplines or models of service delivery</p>	<p>There is considerable overlap between the objectives of chronic disease management, person centred care for people with dementia and palliative care particularly for older frail populations</p>	<p>Research that is not multi-disciplinary or does not consider research (or theory, see (1)) with similar populations e.g. people with multiple morbidities, people with learning disability</p>	<p>Research identifying the overlap with other disciplines or models of service delivery</p> <p>Research that acknowledges models of care that have tested methods of providing continuity of care and ensuring patient and carer involvement over key points of transition and the disease trajectory</p>
<p>c. Research that remains unpublished due to a focus on “positive” results.</p>	<p>Selective reporting results in publication bias and overestimation of effects of interventions, and reporting of results confirming expectations more generally, which in turn results in distorted evidence</p>	<p>Results that are not written up because, for example:</p> <ul style="list-style-type: none"> <li>• the intervention “did not work” (consequently there is no learning to inform development of future interventions and results that are published are overstated)</li> <li>• the sample size is blamed for not achieving “significant” results</li> <li>• the results are not promoting a palliative approach (intellectual conflict of interest)</li> </ul>	<p>Do publish seemingly less interesting or unexpected findings, with full report of limitations to learn from, even if in a journal for negative findings or on your own website</p>