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Complexity and gaps: the high-hanging fruit of dementia and palliative care research

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Healthcare teams have been looking after people dying from the dementias for aeons. But research on dementia and palliative care has only emerged as a specific field in the last thirty years. It was back in 1986, that *JAMA* published a paper on the development and evaluation of the first dementia-specific hospice programme aimed at comfort (1). Since then, many more researchers from all around the world have entered the field. We are grateful to all those who submitted papers for the current special issue. The submissions we received showed the breadth and innovative nature of the work that is being done. The selection we now publish demonstrate the richness of that work and confirm the international nature of the research endeavour.

Reviewing the papers published in this issue (as well as those submitted), or published elsewhere recently, we would make two observations. First, that the work still to be done is becoming more complex; and, secondly, that some important areas are relatively under-represented. Both observations could be summed up by saying that the low-hanging fruit has been harvested! The high-hanging fruit that remains is marked by its complexity and is required to fill the gaps in research that persist.

Nevertheless, we are able to publish both quantitative and qualitative studies that demonstrate sophisticated methodology and include at least one negative trial (Boogaard et al., this issue). For we need to know what works and what does not. A general point is that the importance of education and of multidisciplinary input is obvious. The need for more work in the area of dementia and palliative care is shown by a recent Cochrane review in which only two studies were eligible for inclusion (2). It is pleasing, therefore, to have had a good response to the call for this special issue.

Part of the complexity is conceptual: there are misconceptions about dementia and palliative care. Changing conceptions is a complex business. We would highlight four misconceptions. First, dementia is still not regarded as a terminal condition and, therefore, palliative care is seen as irrelevant (see Chen et al., McInerney et al. and Poole et al. in this issue). These papers indicate that this is true for the general public, as well as family and professional carers. This goes some way to explaining why it is so difficult to implement advance care planning (ACP) in dementia. Of course, there may be other reasons why people avoid ACP, ranging from existential angst to plain uncertainty about what to plan for (which is evident in Poole et al. this issue). And yet we see evidence (Verreault et al. and Brazil et al. this issue) that information about both end of life issues and ACP are helpful for the families of people with dementia.

The second misconception is that dementia is regarded as being no different from other conditions from which people die. Sometimes this is true, but people with dementia and their caregivers also have specific palliative care needs before and during the dying phase. In the White Paper developed for the European Association for Palliative Care (EAPC), optimal care for people with dementia was defined in terms of 11 domains and 57 specific recommendations (3). Many of these would have similar salience in other conditions, but some are specific to dementia, such as prognostication or dealing with uncertainty around the course of the disease.

Thirdly, there is a problem of fit. Dementia seems not to fit in the palliative or hospice model of care. In some countries, this may be because people with advanced dementia cannot consent to this sort of care, but it may also be because palliative services are not set up to accommodate some of the behavioural issues associated with dementia. Further, palliative care is not seen as falling within the remit of psychiatry or other medical specialities. Hence, we continue to seek a panacea: a perfect palliative service for people with dementia. Is there such a thing? Or is it (see Broady et al. and Schmidt et al. in this issue) that the needs of people with dementia and their families are so individual and multifarious that one service is unlikely to provide everything that is required? Unless, of course, the service facilitates or coordinates as much as provides care. Elsewhere, at least in the UK, there is evidence that services with strong leadership, which are nurse-led and linked to other palliative care services, can provide appropriate support to people dying with or from dementia (4). And we also know there is evidence that some specific palliative programmes can be useful (2, 5). Nursing homes may be able to provide hospice-type care and avoid hospital admissions for this population (6), but this may need specific programmes along with specific training and strong multidisciplinary teamwork.

A fourth misconception is that palliative care is exactly the same as dementia care, that palliative care is already being performed as part of normal care for people with dementia. Whilst it is true that a palliative care approach could be employed in all chronic, terminal conditions such as dementia, (a) it is not always evident; and (b) it remains true that specialist palliative care is required for complex symptoms, which are common in dementia as shown by some of the papers we publish here.

There are particular issues that seem relatively neglected in current research. The importance of this is shown by the symptom burden that still exists for people with dementia at the end of their lives (see Sampson et al. this issue). For example, although much work has been done on assessment tools for pain, relatively little has looked at how pain is treated in dementia and the link between assessment and treatment (but see Pieper et al. this issue). Pieper et al.

also explore the complicated relationship between pain and agitated behaviour, which surely needs further work. Pain and agitation were found to be ‘common and persistent’ by Sampson et al.. Looking at the medical symptoms highlighted by Sampson et al. (aspiration, dyspnoea, septicaemia and pneumonia), none of the studies we present in this special issue deals with interventions for these problems. It might be said that the treatments for such conditions are standard and not worthy of further discussion. Even if this were true, we still need reflection on the ethical quandaries that surround these and other issues in palliative care and dementia.

A final thought about gaps in the research literature: ACP is mentioned throughout this special issue, but it raises unanswered questions. For instance, are advance care plans actually effective (7)? How specific might they be whilst still being effective? And should they be encouraged to include, for example, refusal of hand-feeding, even if staff feel this is in the best interests of the person with dementia, when he or she can no longer eat independently (8)? Along with outcome studies, we need more qualitative data to provide the nuanced account of people’s needs, as in Poole et al. and Schmidt et al. in this issue. We also need to look more closely at palliative care for people living with dementia in their own homes, especially because the desire to remain at home can often be an expressed wish in an advance care plan.

In the blog written to accompany the call for submissions for this special issue on dementia and palliative care (https://eapcnet.wordpress.com/2016/12/14/palliative-care-in-dementia-call-for-papers-for-a-special-issue-of-palliative-medicine/), we emphasized the importance of relationships. The importance of relationships remains evident in many of the papers presented here. Research evidence must be enacted in the context of good relationships.

Going forward, good quality care for people with dementia at the end of life will continue to depend on the nature of such relationships, which need to be embedded in the relevant systems of care.

[Word Count: 1291]

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