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Palliative care in dementia: does it work?

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The topic of palliative care in dementia has attracted increasing interest in recent years. Entering palliative+care+dementia into PubMed yields only 10 papers before 1990, the first from 1982. In contrast, there have been 100 or so papers in each of the last three years. The question we have set in this editorial is deliberately ambiguous. 'Does it work?' can be either a question about effectiveness in practice or a question about the concept of palliative care as applied to dementia and, in this regard, it's a question as to how palliative care fits in with the journey of dementia and the other models of care that may be relevant.

Conceptual

In relation to dementia, palliative care could cover a huge range from the whole course of dementia from diagnosis onwards to a much narrower focus on end-of-life care. And maybe there are points in between, e.g. as a person passes from 'living well with dementia' to the next stage, which might be regarded as that of inexorable decline.

Van der Steen et al [1] have attempted to create clearer boundaries for what we mean by 'palliative care' in dementia. They used a Delphi process to generate a set of core domains and then tested these on a wider international panel of experts. Most of these domains achieved consensus: the two which did not were about the importance of palliative care in relation to the stage of dementia and to provision of artificial nutrition and hydration. The first of these concerns reflected disagreement as to whether all dementia care should be relabelled as palliative care [2].

Another issue for palliative dementia care is that it has to compete with other terms that belong to other frameworks. Palliative care has a fairly simple conceptual basis (we allege) in that in the absence of a cure, health professionals should concentrate on relieving troublesome symptoms and avoiding unnecessary, potentially harmful, interventions. It has noble Classical roots – *primum non nocere* – that probably go back to Hippocrates.

It is closely associated with 'end of life care' or 'care of the dying' which has similar sentiments but is perhaps more closely associated with the relief of pain and bringing comfort and solace. End of life care implies a clinical milieu, even if this happens to be the person's own home.

The prevailing paradigm in dementia, however, is person-centred care, which derives from the work of Kitwood and the Bradford group. By contrast to palliative care, this arises from a reaction to the medicalisation of dementia and uses social psychology to draw attention to the perspective of the person with dementia and how the actions of those around them can shape behaviour. This model has been highly attractive for the public, the voluntary sector, and workers and academics with a psychosocial bent. It is clear how person-centred care is applicable across the whole pathway of dementia. It has enabled the voice of people with dementia to be heard, so that we now have the remarkable growth of a disability movement within dementia, with bloggers, activists, and groups such as Dementia Alliance International (<http://www.dementiaallianceinternational.org/>). Expect

further changes in the future as people living with dementia demand their rights, equality and full citizenship.

Empirical

Universal acceptance of palliative care in dementia would be easier if there was good research evidence that it delivers better outcomes than other forms of care. This is more difficult to test than it appears at first sight, for at least two good reasons.

The first of these is that, if we take the view that all dementia care is palliative care, any trial of palliative care might need to be across the whole pathway of dementia. This is unfeasible given the length of time that such a trial would have to run, not to mention some of the methodological issues as to what outcomes are desirable and at what points in the course of the dementia they should be ascertained. The second problem is that it is customary in studies of psychosocial interventions in dementia to compare the treatment of interest with 'usual care'. However, this is difficult too. Is palliative care an 'intervention'? And what is 'usual care'? And does it not already have a palliative quality? Thus, it is probably impossible to test empirically whether palliative care 'works' as a form of dementia care across the whole pathway. In practice, we duck this question by talking about a palliative care approach but it isn't established whether this adds anything to what we already do.

Palliative care can be tested if specific aspects of management, usually towards the end of life, are being evaluated. For example, it is perfectly possible to compare the outcomes of artificial nutrition with not providing it, in terms of survival, pain, quality of life and so on (see Sampson et al [3] for a review). Although, note that either arm of this trial can be regarded as palliative care so, even if one arm does better, this doesn't tell us if palliative care is effective. It is simply a judgement between two palliative care options.

Conclusion

Applying the term palliative care in dementia has some attractions and this accounts for the expansion of recent interest. However, it is a slippery concept to use as there is no agreement as to when it is best applied to dementia and there is no evidence that any thus-labelled intervention has improved outcomes. Furthermore, this may not even be an empirical question, in which case it is either a moral question ('how do we wish to end our lives?') or one of popular taste. So far, the discourse has been confined to professionals and experts and the voice of people with dementia is missing. 'Palliative' may be too clinical a word for their taste.

References

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