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Review article

# The basis, ethics and provision of palliative care for dementia: A review

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## ABSTRACT

Interest in palliative care for people with dementia has been around for over two decades. There are clinical and ethical challenges and practical problems around the implementation of good quality palliative care in dementia. This narrative review of the literature focuses on the rationale or basis for services, some of the ethical issues that arise (particularly to do with artificial nutrition and hydration) and on the provision and implementation of services. We focus on the most recent literature. The rationale for palliative care for people with dementia is based on research and on an identified need for better clinical care. But the research largely demonstrates a paucity of good quality evidence, albeit particular interventions (and non-interventions) can be justified in certain circumstances. Numerous specific clinical challenges in end-of-life care for people with dementia are ethical in nature. We focus on literature around artificial nutrition and hydration and conclude that good communication, attention to the evidence and keeping the well-being of the person with dementia firmly in mind will guide ethical decision-making. Numerous challenges surround the provision of palliative care for people with dementia. Palliative care in dementia has been given definition, but can still be contested. Different professionals provide services in different locations. More research and education are required. No single service can provide palliative care for people with dementia.

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## 1. Introduction

It is probably safe to say that the idea of palliative care for people with dementia is here to stay. It certainly seems like a good idea. But what exactly does it mean? What it must mean is something practical, something that actually makes life better for people with dementia and for their family carers. So it may seem strange, therefore, if this review is motivated in part by philosophical (rather than practical) concerns. But if it is not clear what palliative care for people with dementia means, it will be hard to assess whether or not it is successful.

Of course, it is open to anyone to stipulate a meaning. It seems reasonable to stipulate, for instance, that palliative care for people with dementia is all about pain relief. We can then look at how pain is assessed in dementia (where particular challenges arise when the person is no longer able to communicate) and how it is treated. But the notion of palliative care for people with dementia seems much broader than just pain relief. So, what is it? And how do we put it into effect?

If such questions provide part of the background motivation for this narrative review, its focus will be on three specific areas. First, we shall consider the rationale for palliative care for people with dementia; secondly, we shall review some of the ethical issues that arise; and, thirdly, we shall look at the actual provision or implementation of palliative care for people with dementia. It is timely to consider these specific objectives because a good deal is being written about palliative care in dementia and there is increasing research in this area, but we need to be sure that we know what we are talking about. The risk is that we try to set up services that are doomed to failure because they do not have a secure basis.

So, in the discussion of the results of our review, we shall deliberately focus on some background concepts. Throughout, however, we have had in mind that clinical work is also, at one and the same time, ethical work. Questions of right and wrong or good and bad are never irrelevant to clinical practice. This is no more evident than in questions around palliative care for people with dementia [1]. Hence, whilst in the central section of our review we shall address questions to do with ethics directly, there are also ethical components to our consideration of both the rationale for and the provision of palliative care for people with dementia.

## 2. Methods

### 2.1. Sources of information

We searched Medline, AMED, EMBASE and PsychInfo separately.

### 2.2. Search terms and limits

The search combined the terms “palliative”, “care”, “dementia”, “ethics”, “provision”, “service”, “model” and “rationale” in different combinations.

The search was limited to publications between 2002 and 2015, involving humans, but any type of document was accepted (i.e. clinical trial, meta-analysis, observational studies, pragmatic clinical trials, controlled clinical trials and reviews). We also set the age limit to 65 years and older.

### 2.3. Selection criteria

The inclusion criteria were that the papers should be relevant to the rationale for, the ethical issues concerning, or the implementation of, palliative care for people with dementia. We were keener to include reviews, rather than multiple small studies of the same type of intervention or approach. We looked for papers which overtly suggested ethical issues.

The exclusion criteria were pragmatic in that we tended to exclude papers which were less up-to-date or which related to findings or themes we had already encountered. We were less concerned to include opinion pieces, although much of the literature includes opinions. We did not give much attention to papers referring to ethical issues published before 2011, i.e. which would have been included in the review of ethical issues in dementia care produced by Strech et al. [2].

### 2.4. Synthesis

After an initial scoping search of the literature, we met to discuss the more detailed search strategy and started to focus on the areas of interest to us (rationale, ethics and implementation of palliative care). Papers were selected on the basis of their abstracts. After the full literature search was complete, we met to discuss the papers extracted and the nature of the themes that were emerging. The selected papers were read in full and a narrative account of the main findings or conclusions of the papers was prepared. We identified, through discussion, the overall themes to emerge from the extracted papers and, in the light of clinical practice, we reached our conclusions.

## 3. Results

### 3.1. The rationale for palliative care for people with dementia

It is easy to state the rationale for palliative care for people with dementia. As the population ages, there are increasing numbers of people with dementia and they do not receive good quality palliative care, even though dementia is increasingly recognized to be a terminal condition. Thus, a social science review of the literature some years ago highlighted themes such as person-centered care, grief, agitation, pain, education, decision-making, spirituality and dignity and concluded that, because of the projected increase in the numbers of people with dementia, palliative care was going to become more relevant [3]. Harris, similarly, highlighted the relevance of palliative care to dementia—since it is a progressive, life-limiting condition with complex needs—but also recognized that these palliative care needs are poorly addressed for people with dementia [4]. In particular, there is a lot of evidence that people with advanced dementia receive inadequate treatment in some ways (e.g. insufficient pain relief), whilst also being subject to burdensome investigations and treatments in other ways (e.g. hospitalization which serves no useful purpose) [5]. The symptom burden at the end of life for people with dementia has frequently been assessed to be similar to that of people with cancer, emphasizing the need for palliative care; and this has been found in a variety of countries [6,7]. Pneumonia, febrile episodes and eating problems are frequent complications in patients with advanced

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