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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

dementia and they are associated with high six-month mortality rates [6]. Symptoms described in the last two days of life for people with dementia include severe weakness, fatigue, confusion, loss of appetite, anxiety, shortness of breath and pain [7]. And thinking about palliative care in dementia, which includes difficult decisions about withdrawing or withholding food and fluids or even antibiotic medication from people in the severe stages of the condition, “amply demonstrates the extent to which clinical decisions are often ethical decisions”, where “The ethical imperative must be to maintain or improve the quality of life, even at its end” [5].

Sampson found in her review of the literature in 2010 that antibiotics, fever management policies and enteral tube feeding were all in use in advanced dementia despite little good evidence that they were effective at improving quality of life or other outcomes [8]. More research is required on almost every aspect of palliative care for people with dementia. For instance, prognostic indicators of death remain imprecise, despite considerable effort by researchers [9]. Despite increasing interest, as recently as 2005 Sampson and colleagues could find little evidence to support a palliative care approach for people with dementia [10]. Five years later, van der Steen could find little evidence to support the effectiveness of specific treatments, despite encouraging trends [11]. She did find consensus-based guidelines in support of advance care planning, continuity of care, along with family and practitioner education; assessment tools for pain, prognosis and family evaluation of care had also been developed [11]. Birch and Draper reviewed the literature and found four key themes to explain why delivering effective palliative care to people with dementia was a challenge: difficulties around defining the terminal phase, issues around communication, medical interventions and the appropriateness of palliative care interventions [12]. Challenges to the provision of palliative care services for people with dementia were also highlighted in a study of five European countries, which were about communication, integration, funding, processes and time [13].

What does all of this tell us about the rationale for palliative care for people with dementia? Having established that people with dementia can have complex symptoms in a context of terminal decline, the literature goes on to suggest that it is both difficult to establish an evidence base for palliative care in dementia and difficult to establish clinical services. Things become more difficult when special groups are looked at, such as those with intellectual disabilities [14]. When families are asked there is a variety of views, from some feeling that invasive and aggressive therapies are warranted to those who opt for palliative techniques [15]. Meanwhile, consultants involved in palliative care for people with dementia believe a new model of generalist-led dementia-specific palliative care is required [16]. And the need for improved coordination and provision of services is recognised [17]. So the rationale is based on an identified need for good clinical care and, in addition, on research which largely, however, demonstrates a paucity of good quality evidence, even if specific interventions and non-interventions can be justified in particular circumstances. Nonetheless, it has been possible for quality indicators to be developed [18]; and for experts in the field to define palliative care for people with dementia [19].

3.2. Ethical issues

Strech et al. carried out a systematic review of the English and German literature between 2000 and 2011 [2]. From 92 references, they found 56 ethical issues relating to clinical dementia care. Many of the more general issues relate directly to end-of-life care. For instance, there were issues to do with giving adequate amounts of information in the right manner and to do with involving relatives. Not involving patients in decision-making is another example of an ethical issue relevant to palliative care. Numerous ethical issues arise in connection with

advance care planning [20]. Strech et al. were able to identify some specific situations relevant to palliative care [2]. One example is the use of antibiotics; another is tube feeding.

Gauthier and colleagues have also reviewed the literature, looking at past, present and future ethical issues in the diagnosis and management of Alzheimer's disease [21]. End-of-life care featured in their review, where they highlighted the unnecessary suffering which can occur in the absence of appropriate palliative measures. They emphasised the importance and difficulty of prognostication and the need for advance care planning or substitute decision-making for people who have lost capacity to make decisions for themselves. In a cross-cultural comparison of ethical issues in dementia in Kerala (India) and The Netherlands, the authors highlighted the influential role of advance directives in The Netherlands as compared to Kerala [22]. They also emphasised how the legal and social setting in The Netherlands influenced physician decision-making concerning end-of-life issues compared to Kerala. Gauthier and colleagues, when discussing unnecessary medical interventions, state that “a key example is the delivery or artificial nutrition and hydration” [21]. They cite studies which have shown that feeding tubes do not “improve functional status, quality-of-life, or life expectancy while being associated with dysphagia, aspiration pneumonia, and malnutrition” [21].

Rather than attempting to summarize all of the ethical issues captured by Strech et al. [2], here, we shall focus more precisely on the issue of artificial nutrition and hydration. Relatively little literature relevant specifically to ethical issues emerged in our search. But the issue of artificial nutrition and hydration is related to the broader theme of futility. Gusmano has highlighted how there can be disagreements about the meaning of futility [23]. This can lead to poor care, with policies and politics in the United States (at least) tipping people in the direction of active treatment, even where there is strong evidence that palliative care would be more appropriate.

Most authorities agree that there is compelling evidence against the use of tube feeding to prolong life and prevent aspiration in people with severe dementia [24]. This was the finding of a Cochrane review some years ago [25]. Nevertheless, some doctors and families continue to overestimate the benefits of tube feeding, which means that good communication is vital [24,26]. Schwartz et al. argue against the use of feeding tubes for people with advanced dementia and provide an algorithm and checklist to aid decision-making [27]. But they also emphasise that the goal is advance care planning or a timely consensus amongst all those involved in the person's care if he or she is unable to make decisions for him or herself. They state:

“The autonomy of the patient or surrogate decision maker should be respected and considered above all other ethical principles. Emphasis should be placed on functional status and quality of life. Cultural, religious, social, and emotional sensitivity is essential in the process” [27].

Others have picked up this theme and emphasised the importance of the unique values of the individual [28]. Alsolamy usefully sets out an Islamic view on artificial nutrition and hydration for terminally ill patients [29]. It is emphasised that Islamic rules would support the principle that injury and harm should be prevented or avoided, but at the same time the withdrawal of futile treatments would be permitted. Although feeding is part of basic care, if there is the risk of shortening life, causing more harm than benefit, or acting against an advance directive, then feeding would not be obligatory [29]. Harwood, in a useful paper on feeding decisions in dementia, has written as follows:

“There is a variety of alternative ethical frameworks and approaches that are relevant in dementia which emphasise relationships, communication and narrative. The ethics of care, perspectivism, discourse and narrative ethics highlight the uniqueness

of situations, vulnerability, and caring as a disposition. The ethical solution is the one that creates and maintains healthy relationships. A given situation is unlikely to yield a single ‘correct’ answer, since the right course of action will depend on beliefs and preferences that vary, with, amongst other things, culture and religion” [30].

Ethical issues in dementia care, particularly at the end of life, are complex; but they are best tackled by good communication and by keeping the well-being of the person with dementia firmly in mind [31].

3.3. The implementation of palliative care for people with dementia

Issues around the implementation of palliative care for people with dementia remain, of course, ethical. But there are particular challenges. These have been highlighted as follows: the division of labour amongst different practitioners; the structure and function of care planning; the management of increasing risk and complexity; boundaries between disease-modifying treatments and palliative care and between palliative and end-of-life care; as well as the process of bereavement [32]. An important conceptual issue is to do with the timing of palliative care: when should it begin and what are the prognostic indicators [33]? We have already alluded to the importance of advance care planning, but it turns out there is a reluctance to engage in this process [34]. Education of staff is clearly important, not only to improve advance care planning, but also to manage symptoms and decrease distress amongst patients and families [35].

Many people with dementia will die in care homes. A Cochrane review of interventions to improve palliative care for older people living in nursing care homes found few studies [36]. However, they showed some promising results, with less discomfort, a higher referral rate to hospice services, fewer hospital admissions, an increase in Do Not Resuscitate orders and documented discussions about advance care planning [36]. Engaging general practitioners (GPs) to hold case conferences in nursing homes is a good way to facilitate advance care planning [37]. Again, good communication helps. A prospective, randomised trial compared structured conversations about end-of-life care for family members of those living with advanced dementia in nursing homes with a control group who received only social contact via the telephone [38]. The intervention group showed more satisfaction and were more likely to agree to palliative interventions.

One of the complexities in thinking about palliative care for people with dementia is that people live and are looked after in a variety of settings. Group homes, for instance, have been studied in Japan, where the availability of medical staff, the physical set up and staff education all tend to lead to more progressive policies concerning end-of-life care [39]. Part of a progressive policy would include the need to rationalize medication at the end of life, but this has been the subject of relatively little research [40], despite the evidence of inappropriate medication being used for people with advanced dementia [41]. Given the variety of places where people with dementia live in the community, it is surprising that relatively few studies have looked at interventions and outcome measures concerning end-of-life care in the community where most people live and die [42]. Some would advocate hospice care [43]; and it may be that specialist units for people with advanced dementia and behaviour that is challenging should be regarded as akin to dementia hospices [44]. But many people with dementia living in care homes, for instance, can be given good quality palliative care by a dedicated GP [45]. An alternative or complementary model is to have a specialist palliative care nurse, supported by a palliative care team, providing input to care homes. This has been shown to improve the quality of palliative care in a way that is both effective and cost efficient [46]. Multidisciplinary teams can be used to sup-

port families if they wish to care for their relatives at home with advanced dementia [47]. It remains difficult, in the UK at least, to support people with dementia to live and die in their own homes, although innovative projects have shown that it is possible [48].

4. Discussion

4.1. Significance of results

The literature records that there is a clinical need for good quality palliative care for people with dementia. Research further demonstrates that there are important areas which need to be considered in detail. Meanwhile, the implementation of interventions to improve the quality of palliative care for people with dementia is piecemeal and the research base for any particular intervention is thin. Nevertheless, the ethical imperative for good quality palliative care for people with dementia is obvious in a field where every type of intervention (or non-intervention) carries moral significance.

The fact that this is the situation after many years of writing and research provides, perhaps, grounds for a pause in our thinking. There is a compelling rationale for palliative care in dementia given the prevalence of the disease and the ways in which it presents. Not only are there issues to do with the recognition and treatment of pain, but also behaviour that is challenging is itself an area of specialism. The need to reduce unnecessary hospital admissions, to identify and stop futile treatments, whether this be resuscitation, the use of antibiotics, the inappropriate use of other drugs at the end-of-life or the use of artificial nutrition and hydration, makes advance care planning seem like a panacea. But the evidence is that it remains difficult to do. Meanwhile, we struggle to improve communication with those living with dementia as well as with their family and close carers. Much is written about person-centered and holistic care with attention to the individual's biological, psychological, social and spiritual needs.

The truth is that there cannot be a single service providing palliative care for people with dementia. Dementia means too many things and is seen in too many settings, so there cannot be a single service to meet the complexity of needs that arise for people with dementia. They may, after all, die under the care of the orthopaedic team or in the coronary care unit. What is certainly required is knowledge and experience of dementia. What is also required is knowledge and experience of end-of-life care. Our brief review of the literature demonstrates some of the frustration that palliative care in dementia has not moved further. Perhaps it will do so; but perhaps it will not be possible to achieve anything like a service that can provide an overview of dementia care at the end of life.

4.2. Limitations of the study

This has been a brief review of the literature, using a limited search strategy and a pragmatic selection of the literature upon which to comment. Nevertheless, general themes have emerged which seem congruent with our wider awareness of the relevant literature. It could be said that palliative care in dementia is still in its infancy as a discrete discipline and that further research will help to clarify its overall scope and effectiveness. Indeed, there is no doubt that specific areas can be defined as pertaining to palliative care in dementia [19], so there is a job to be done to improve knowledge in these areas. And yet, we cannot say interest in palliative care for people with dementia is an invention of the current century [49,50]. Furthermore, the conceptual problem of pinning down exactly what palliative care in dementia means and how it is different from good quality person-centered dementia care remains.

5. Conclusion

In 2004, Purtilo and ten Have published *Ethical Foundations of Palliative Care for Alzheimer Patients* [51]. In his review of this, Tom Arie commented that, “the word ‘palliative’ in the title (and throughout) seems to be there chiefly to emphasise that in Alzheimer’s all care is palliation; the book is really about the ethics of care for people with dementia” [52]. The notion of *palliative* care in dementia is a useful heuristic: it directs our search and allows us to discover something about the nature of the care we should be offering. There is, after all, a rationale for a type of dementia care which recognizes that dementia is a life-limiting condition, is holistic, involves the person’s family and close friends, focuses on symptom control and quality of life, which pays attention to autonomy and to open, sensitive communication. But this can reasonably be called good quality, person-centered dementia care.

The clinical implication of this is that we need to improve dementia care overall. It is an argument against the over-emphasis on early diagnosis. The care of people with dementia needs to cover the full course of the condition (*palliare* means, after all, to cover). We need good quality, person-centred dementia care, which will include adequate liaison with end-of-life specialists when the time is right. Meanwhile, research should continue into the areas where care, knowledge and skill remain deficient. There is no more needy aspect of care in dementia than the area of behaviour which is found challenging. To regard this as the focus of palliative care in dementia would not be sufficient, but it would change how we conceptualize such behaviour and, perhaps in a necessary way, how we conceptualize palliative care.

Author contributions

Dr Fariba Mahin-Babaei declares that she helped to conceive the form of the review, that she designed and participated in the literature search, that she wrote an initial draft of the paper, contributed to the final draft and that she has seen and approved the final version. She has no conflicts of interest.

Dr Jamal Hilal declares that he helped to conceive the form of the review, that he designed and participated in the literature search, that he contributed to the final draft of the paper and that he has seen and approved the final version. He has no conflicts of interest.

Professor Julian C Hughes declares that he helped to conceive the form of the review, that he advised on the design of and contributed to the literature search, that he wrote the final draft of the paper and has seen and approved the final version. He has no conflicts of interest.

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