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Review article

Palliative care and dementia—A time and place?

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ABSTRACT

The current focus in dementia care places emphasis on the potential of people to live well with the condition. Given the historical tendency to neglect the full rights and citizenship of people with dementia, such an emphasis gives hope and optimism that there is life after diagnosis. This paper seeks to explore the potential compromise of effective preparation for the complexities of advanced illness that may be presented by this consistently up-beat message. Dementia is a life limiting condition, currently without cure. Therefore, the appropriateness of palliative care may seem obvious. Yet, until relatively recently, palliative care was seen as an adjunct to oncology in the minds of professionals and public alike. However, there is a growing recognition that specialist palliative care has much to offer people with a range of long term conditions, including people with dementia. So, whilst 'living well' is an important message—especially following diagnosis—planning for advanced dementia and dying well is equally important. The aim of this paper is to highlight policy on the living well and the palliative care approach for people with dementia. A word limited narrative literature review was conducted to explore how policies have or have not informed the literature on both messages. The findings emphasise the need for a continuum approach to dementia care, with discussion on when, where, and how can palliative care be delivered for people with dementia.

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Contents

1. Introduction

After decades of receiving little attention, dementia is now high on the health, social, education, economic, political and research agendas of the world. The exponential increase in the numbers of people diagnosed with dementia each year has served to focus the minds of societies. Nations are keen to collaborate on

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areas such as researching preventative measures, possible treatments, effective interventions and developing staff who can deliver informed and skilled care [1–3]. Educators from secondary schools, colleges, private providers and higher education institutions are providing dementia training. Governments are looking at the fiscal implications of paying for the care of nearly one fifth of their population. Research funders are promoting studies in pharmacological and non-pharmacological interventions to treat the symptoms of dementia and alleviate the distress so often experienced by people with dementia. This paper is addressing one small part of this picture; that of two major initiatives designed to enhance the lives of individuals with dementia. These are, *living well with dementia* and *palliative care in dementia*. The two initiatives are both based on best practice, yet the link between the two is not always clearly visible. So we pose the question: what is the impact on the life- and death-of someone with dementia if one of these approaches dominates the focus and direction of care provided? Both initiatives have the intentions of providing good care. However, if health and social care practitioners and/or trainers present these approaches as mutually exclusive, how do affected families begin to understand their situation, and what do educators encourage? It would seem that the answer may lie in accepting that different care approaches frequently seek the same outcomes and when that provision of support recognises the person's experience as central, synergy is possible.

2. Literature search

In order to explore the role of these approaches in dementia care policy, the authors conducted a word limited literature search.

3. Search strategy

The preferred reporting items for systematic reviews and meta-analysis [PRISMA] [4] was adopted. Two literature searches were conducted, independent of each other, using Health Source: Nursing/Academic Edition; Medline; Psychology and Behavioural Sciences Collection; Psych Info, SocIndex with full text and Cinahl complete. The first search used the key words; Living well AND dementia AND policy the second used the key words; Palliative care AND dementia AND policy. Both searches used the same limiters which were

- Full text.
- January 1999–June 2015.
- Peer review.
- Abstract available.
- Article refers to policy.

The limitation was set as the authors were aware of the voluminous return only two search words would have yielded as policy and dementia is a current topic. A search on these two words yielded 218,934 articles without limiters and 41,321 with the same limiters as the current search.

4. Results

The results of the first search (with living well) yielded 4 papers, three of which were not relevant to this paper, because they were very specific about single practices. The results were surprising as we had expected many more papers. We then used the term 'quality of life' to replace 'living well' (with 'dementia' and 'policy') which yielded 77 papers. This was reduced to 63 when duplicates and book reviews were removed. We maintained a focus on articles that referred to policy and all articles were then reviewed and screened for relevance to the subject areas, which left a total of 9 articles selected for inclusion. The results of the second search (with 'palliative care and 'policy') yielded 71 papers, which was reduced to 65 when duplicates and book reviews were removed. All articles were reviewed and screened for relevance to the subject areas with reference to policy, which left a total of 14 articles selected for inclusion (see Fig. 1 for detail). In total 24 full text articles informed this paper as did 24 policy documents.

Using the literature from the review and several relevant policy papers, this paper addresses the topic of dementia as it currently understood and goes on to explore the policy context of dementia, with reference to global strategic approaches to include living well with dementia. The paper then addresses the term palliative care and palliative care in the context of dementia care, before discussing the issues raised.

5. Current understanding of dementia

Dementia is a syndrome involving abnormal loss of neurones and damage to their complex network of connections. Most often progressive, these changes give rise to a diversity of difficulties with cognitive and physical functions. A wide range of underlying pathologies are responsible and the syndrome exists more commonly, though not exclusively, in older people [2,5]. A life-limiting condition, dementia is now understood to be associated with multiple risk factors across the whole life course [6,7]. Older people now constitute a higher proportion of the world's population and it is estimated 46.8 million people are living with dementia in 2015, with numbers expected to double every 20 years [5]. Dementia frequently has a long trajectory, its varied symptomatic pattern and progression influenced by bio-psychosocial and environmental factors [8]. These varied influences make for an entirely unique experience for each person affected by the condition. In the past people diagnosed with dementia were presented with the news they had a progressive brain disease for which very little could be done and it has taken decades to begin to address the generalised assumptions and associated stigma [9]. The uniqueness of the experience is highlighted by Clarke [10], who speaks of the different meanings the term 'dementia' has to the public, practitioners and those with a diagnosis of dementia. She poses the question, what sort of ill-health is dementia? The nature of dementia as a long term condition, as a disability or as a terminal illness will colour the manner in which it is treated and understood. The editorial resounds with this paper. If dementia is not seen as a chronic illness then services will not be geared to providing enabling strategies to live well, if dementia is not seen as a disability then services will not be geared to develop inclusive buildings and communities and if dementia is not seen as a terminal illness then services may fail to address good end of life care.

6. Policy responses to dementia

The international demographic indicates a continued rise in the expected numbers of people with dementia globally, with the sharpest increase projected in low and middle income countries, where 94% of this population are estimated to live and be cared for at home [5]. Projected numbers of people with dementia in low income countries is particularly dramatic with a rise of 239% from current levels indicated [5]. Dementia has been identified as a global health priority and many countries have developed specific national dementia strategies [2]. Korea, for example, has developed several key policies in the last 10 years, and the Korean government has described itself as declaring 'War on Dementia' [11]. A working party was set up by Alzheimer Europe in 2007; this addressed a spectrum of care with clear recommendations for end of life care for

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