

Dying with Dementia: a Challenge for Palliative Care Now and in the Future



Morrer com Demência: um Desafio para os Cuidados Paliativos Agora e no Futuro

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Dementia is identified as the most significant health problem in the world because of its prevalence and impact on individuals, families and economies. It affects nearly 36 million people now and the number will double by 2030.¹

Palliative care, with its previous emphasis on care for patients with cancer, is increasingly reaching out to help a wider community of the dying, including those dying with dementia.²

Dementia has a similar prevalence in Portugal as in the UK and it may be appropriate to explore how people with dementia can access dementia care, especially towards the end of life, wherever they are living, whether at home, in hospital or in the nursing home.

Although there are differences in healthcare provision between the two countries, many of the principles of patient centred care in dementia may well be universally applicable as a guide to good practice.

Background

The modern hospice movement traces its origins to the pioneering work of Cicely Saunders in London. Her mission was to bring relief from pain to people dying from cancer or related conditions and the early history of hospices has been strongly linked to cancer.³

It has become clear that the palliative approaches to incurable, progressive, distressing conditions exemplified by cancer, can be extended with benefit to a range of other conditions. These include neurological disorders, muscular dystrophies, heart failure, respiratory failure, diabetes and more.⁴

This approach, with its roots in the UK, is now applied in many countries around the world, including Portugal.

Current and future needs of the dying

Calanzani et al report to inform of the predictable need for specialist palliative care internationally over the next 10-15 years delivered interesting findings. Death is displaced to late life: 36% of those dying are aged 85 years or older, by

2035 the proportion will be 50%. Most deaths in very late life are, and will be, due to cancer or to dementia. One in three people dying aged 65 and older die with dementia.⁴

Fifty percent of people aged 85+ say that a specialist palliative care unit would be their preferred place to die, yet people in this age group, including those with dementia, are least likely to be admitted there at present.⁵

Dementia

Although dementia does occur amongst relatively young people it is strongly associated with later life. Once an individual has developed dementia it will stay with them until they die. It will contribute as a cause of death and modify the experience of dying even when other conditions such as cancer, heart disease or stroke are seen as the main terminal event.²

The clinical syndrome of dementia

Dementia derives from an underlying organic disorder of the brain. In most instances this is degenerative and progressive. Death may be a direct consequence of the degenerative condition which is characterised by progression of symptoms from memory impairment, often complicated by non-cognitive symptoms and behavioural change. From 'soft' physical signs such as dysphasia, dyspraxia and agnosia, to 'harder' symptoms including falls, incontinence, swallowing problems and inanition. The terminal phase of dementia may include immobility, contractures, decubitus ulcers, recurrent infections and may be associated with behaviour which appear to indicate distress and be unresponsive to most approaches to reassurance.^{6,7}

Death with dementia

Some people with dementia die at home or during admission to hospital for other illnesses. Many others survive to die within care homes, nursing homes or other long-term care facilities.⁵

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The terminal phase of care for people with advanced dementia is often less than optimal as symptoms of distress may remain unresolved, sometimes with no appropriate attempt to ameliorate them.⁷

Pain may not be recognised because individuals cannot describe it but behave in a way which is puzzling or even frightening to observers. People with dementia with objectively painful conditions are less likely than others with the same condition to receive adequate analgesia. 'Behavioural problems' have been shown to be more greatly helped by analgesics than anti-psychotic medicines.⁸

Some patients are admitted repeatedly to acute hospital for assessment followed by ill-informed, inappropriate life-sustaining therapy which serves to prolong suffering, add to confusion and distress and may be associated with the development of additional complications such as decubitus ulcers, MRSA or other problems.⁹

Where the problem starts

Problems have been related to a failure to recognise dementia: less than half the predicted prevalence is known to family doctors or registered by them; and to failures of ownership or continuity of care: while death at home persists as the declared preferred outcome by many and adopted with little question by policymakers, the reality is that 60% of people with dementia have moved into care before dying. Transitions to such long-term, terminal placements are often mediated via a period in acute hospital. Sadly this may result in the benefits of knowledge and mutual respect achieved by primary care over many years being lost in the relocation to another place and into the hands of new medical and nursing staff.^{7,9}

Palliative Care and Dementia

Interest in developing palliative care services for people in the end stages of dementia is growing.¹⁰ Most published reports relate to work in the USA and UK: a review of 200 papers yielded by a Medline search to Hospice AND Dementia from August 2006 – June 2014 included only 23 from other countries: France (8 reports); Germany (4); Canada (4); Japan (2); Holland (2); and Israel, China and Spain with one each.

Where palliative care services for people with dementia have been established they result in improvements in care, greater confidence and satisfaction amongst relatives and represent better use of resources; but, which models are most effective and most cost effective is not certain.¹⁰

Models of care - an example

We have been most impressed with the St Christopher's initiative led by Victor Pace which demonstrated that a small and inexpensive service could produce disproportionately

effective benefits. A small team is led by a Specialist Nurse in Dementia with palliative skills and supported by the rest of the Palliative Care team, including physicians and a psychiatrist. The team mainly gives advice but will see individuals where this will be helpful, in whatever location they are living. It is well recognised that a change in place of residence, especially into the acute hospital environment, can precipitate a decline in cognitive function in patients with dementia.

The Dementia Specialist Nurse helps support patients and families to remain in their home or care homes, without necessitating admission to inpatient units. St. Christopher's also provided education, training and advice in care homes, general hospitals and the community.¹¹

Our experience

Willow Wood Hospice have adopted the essential elements learned from St. Christopher's and replicated and extended the findings in the North of England. Our rate of contact has been roughly 80 per annum, extending palliative approaches to many who are not yet near to death but encountering difficulties. For some patients and families, help preparing plans for future care has been all that has been required. We work in collaboration with other professionals in the delivery service; of education, training and support, caring for people with dementia in care homes, hospital and the community.¹²

Reflection

Palliative care must change to respond to the challenge of helping a wider community of the dying, including those dying with dementia.¹³

The inclusion of dementia in the portfolio of Palliative Care was pioneered in the USA. It is beginning to be explored in units such as ours in Ashton-under-Lyne, in the UK and there are reports from other parts of Europe. Within each country, the details of development will depend upon the context, the strengths, weaknesses and ambitions of existing providers; but everywhere the relevance of dementia to the profile of people dying is growing ever more significant.

We hope that this report of our experience and reflections from the UK will be of interest and encouragement to the Palliative Care movement in Portugal.

CONFLICT OF INTERESTS

The authors declare that they have no conflicts of interest.

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