Improving Palliative Care in Dementia and Cancer: Organisation of Palliative Care – IMPACT Study

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Background

Palliative care is a national priority within the UK, following the publication of the End of Life Care Strategy. This is reflected internationally within several other similar key publications and national strategies. In the UK the overall death rate for cancer was 137, 2% in 2010 and 7.5 million worldwide in 2010. In 2006 over 3 million people were diagnosed with cancer and 1,702,000 million died of cancer. With people living longer, it is thought this will be the biggest contributing factor to the expected increase in the number of cancer diagnoses. As the number of cancer patients rises there will be an increased need for palliative care. Despite palliative care being originally developed for cancer, further improvements are needed, for example continuity of care across settings.

Within this ageing population, there is also a trend of people living longer with dementia which is expected to continue to rise. In 2010 it is estimated that 157,275 in 2010. However, there is a general lack of research in this field and more research is needed for these groups of people.

The existing literature surrounding palliative care was examined including documents such as the End of Life Care Strategy, End of Life Care Strategy: promoting high quality care for all adults at the end of life. London: DH, 2008. The five European countries: France, Italy, The Netherlands, Germany and the UK. These were supplemented by the use of vignettes. The vignettes described clinical cases based on existing literature. They were used to elicit and aid the implementation of quality indicators in this field. The research leading to these results has received funding from the European Union’s Seventh Framework Programme FP7/2011-2015 and is co-financed by Greece (co-funded by the European Social Fund and the Greek national resources) and Spain under the co-financed agreement between ESF and Spain (08/10/013654).

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Palliative Care Model of Dementia and Cancer

Based on the themes and responses generated thus far from the interviews together with existing literature and literature reviews, the following model of palliative care has been developed. This is a model which will continue to develop and will aid the development and successful implementation of quality indicators.

Method

Design

A mixed methodology was used to enable the triangulation of data to develop an understanding of palliative care for dementia and cancer with a model to fit these.

Literature reviews

- Consensus conferences
- Recruit analysis
- Interviews

Participants

Fifty-four interviews were conducted with professionals from palliative care such as general practitioners, nurses, researchers, care home managers and policy leads. A further focus group was conducted consisting of six professionals from macro, meso and macro levels of health care services. Interviews took place within five European countries including the United Kingdom, Germany, the Netherlands, Italy and Norway.

Procedure

1. Three literature reviews of indexed peer-reviewed publications were conducted. These are:
   - Palliative care services for people with dementia: a synthesis of the literature reporting the views and experiences of professionals and family carers
   - Palliative care for people with dementia: a review of reviews
   - Evaluating educational initiatives to improve palliative care for people with dementia: a narrative review of the evidence

2. The existing literature surrounding palliative care was examined including documents such as the End of Life Care Strategy, National Dementia Strategy.

3. Face to face structured interviews or telephone interviews where face to face was not possible, were conducted with national experts in the five European countries. Four open questions were used. These include what aspects of palliative care professionals would wish to work on and what they would want to export to other countries. The interviews were supplemented by the use of vignettes. The vignettes described clinical cases based on existing literature. They were used to enhance the understanding of behaviour and attitudes in this area. Interviews were recorded for transcription or captured using contemporaneous note taking.

4. Two consensus conferences of experts from palliative care, cancer and dementia using a nominal group technique will be conducted to evaluate and refine the model of palliative care for dementia and cancer.

Analysis

Recorded interviews were transcribed verbatim and together with the notes, will be analysed using thematic analysis.

Results

Interview Themes

This is an on-going piece of research where additional participants will be interviewed to inform the continuous development of a model of palliative care for dementia and dementia. The interviews have so far revealed a variety of themes containing what currently work well for people dying with dementia and what would be recommended to other countries. These include:

- Skills of staff
- Need for a structured system/pathway
- Diagnosis/Prognosis/Recognition of dementia
- Communication between professional disciplines and settings
- Advanced Care Planning
- Coordinator/case manager

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Fig 1. The basic model of palliative care in dementia and cancer.

Fig 2. Quality indicators of good end of life care and of a good death related to outcome.

Fig 3. Quality indicators of good palliative care related to structure.

Conclusions

It is possible to collaborate across European countries using mixed methodology to produce a complex model of palliative care which is capable of aiding the development and implementation of quality indicators. This model will then be used to develop and implement quality indicators to improve palliative care for dementia and cancer.

References


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