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 157, 275 in 2010 and 75 million worldwide in 2008. In 2006 over 5 million people were diagnosed with cancer and 1,703,000 died of cancer. With people living longer, it is thought that 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 organically developed for cancer, further improvements are needed, for example contiguity 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 if treated for Alzheimer’s and Parkinson’s. As patients live longer, they have more time to be diagnosed with other diseases which require palliative care. This is an on-going piece of research where additional participants will be interviewed to inform the continued development of a model of palliative care for dementia and cancer. The interviews have so far revealed a variety of themes containing what constitutes a model of palliative care for cancer and dementia.

Aim

The aim of the current research is to gain an insight into palliative care for dementia and cancer across Europe. Using this information we aim to develop a model of palliative care for dementia and cancer which is suitable for European health care systems. The model will be used to identify and aid the 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.

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 included what aspects of palliative care professionals would wish to improve 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 continued development of a model of palliative care for cancer and dementia. The interviews have so far revealed a variety of themes containing what constitutes a model of palliative care for dementia and cancer. The interviews have so far revealed a variety of themes containing what constitutes a model of palliative care for cancer and dementia. The interviews have so far revealed a variety of themes containing what constitutes a model of palliative care for cancer and dementia.

Conclusion

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