

Developing a European Model of Palliative Care for Dementia:

Nathan Davies¹, Steve Iliffe¹, Jill Manthorpe² and Sam Ahmedzai³

¹UCL, Research Department of Primary Care and Population Health, Royal Free Campus, Rowland Hill St., London, NW3 2PF

²Social Care Workforce Research Unit, King's College London, Aldwych, London, UK

³Department of Oncology, The Medical School, Beech Hill Road, Sheffield



Background

With an ageing population, people living with dementia is expected to continually rise to 81 million affected by 2040¹ and 115 million worldwide by 2050². Generally, as the disease progresses, memory and other cognitive deficits become worse, together with a loss in mobility, self-care abilities, poor nutrition, and a breakdown of skin. In the final stages, it is common to have urinary tract infections, skin ulcers, pneumonia and many other complications. As a progressive and eventually fatal illness, a palliative care approach for dementia is generally accepted as the best option.

Over the past decade there has been increased attention and research into dementia and end of life care³. However, there is a general lack of research in this field⁴.

Despite the growing number of people with dementia and the fact that many palliative care services now care for non-cancer patients, people with dementia are rarely referred to such services⁵. Palliative care and models of care are well established and have long been used within cancer. However, this is still underdeveloped within dementia. Transferring these models of care directly from cancer may be inappropriate⁶ and they may not be successful in dementia.

Aim

The aim of the IMPACT study was to gain an insight into palliative care for dementia across Europe. We developed a model of palliative care for dementia which is suitable for European health care systems. The model was used to identify and aid the implementation of quality indicators in this field.

Method

Design: A mixed methodology was used to enable the triangulation of data to develop an understanding of palliative care for dementia and a model to fit this.

Participants: Thirty-nine interviews were conducted with professionals such as general practitioners, nurses, researchers, care home managers and policy leads. A further focus group was conducted consisting of six professionals from micro, 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., on:

- 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 **policy documents** about palliative care and dementia were examined including documents such as , in the UK, the End of Life Care Strategy, & the 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 five European countries. Four open questions were used. These include what aspects of palliative care for dementia professionals would wish to improve on and what they would want to export to another country. 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.

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

Results

Synthesising the results of literature reviews, policy documents and interviews with subject matter experts, the research team developed a generic model of palliative care, into which quality indicators could be inserted.

Palliative Care Model of Dementia

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.

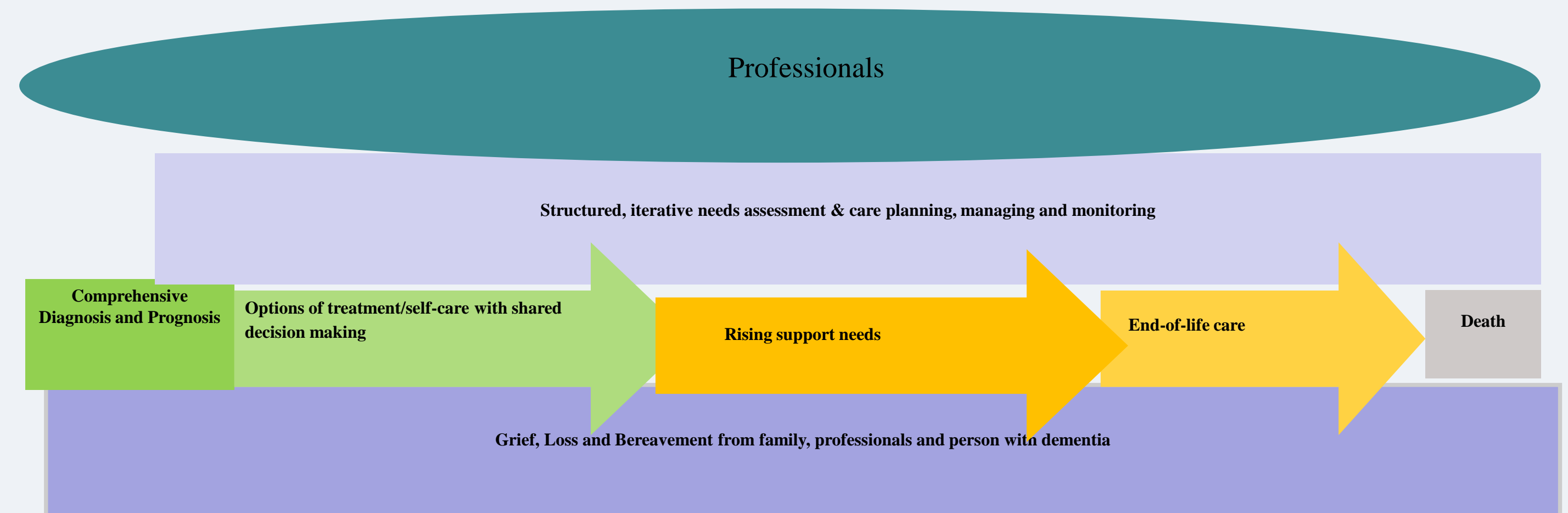


Fig 1. The basic model of palliative care in dementia.

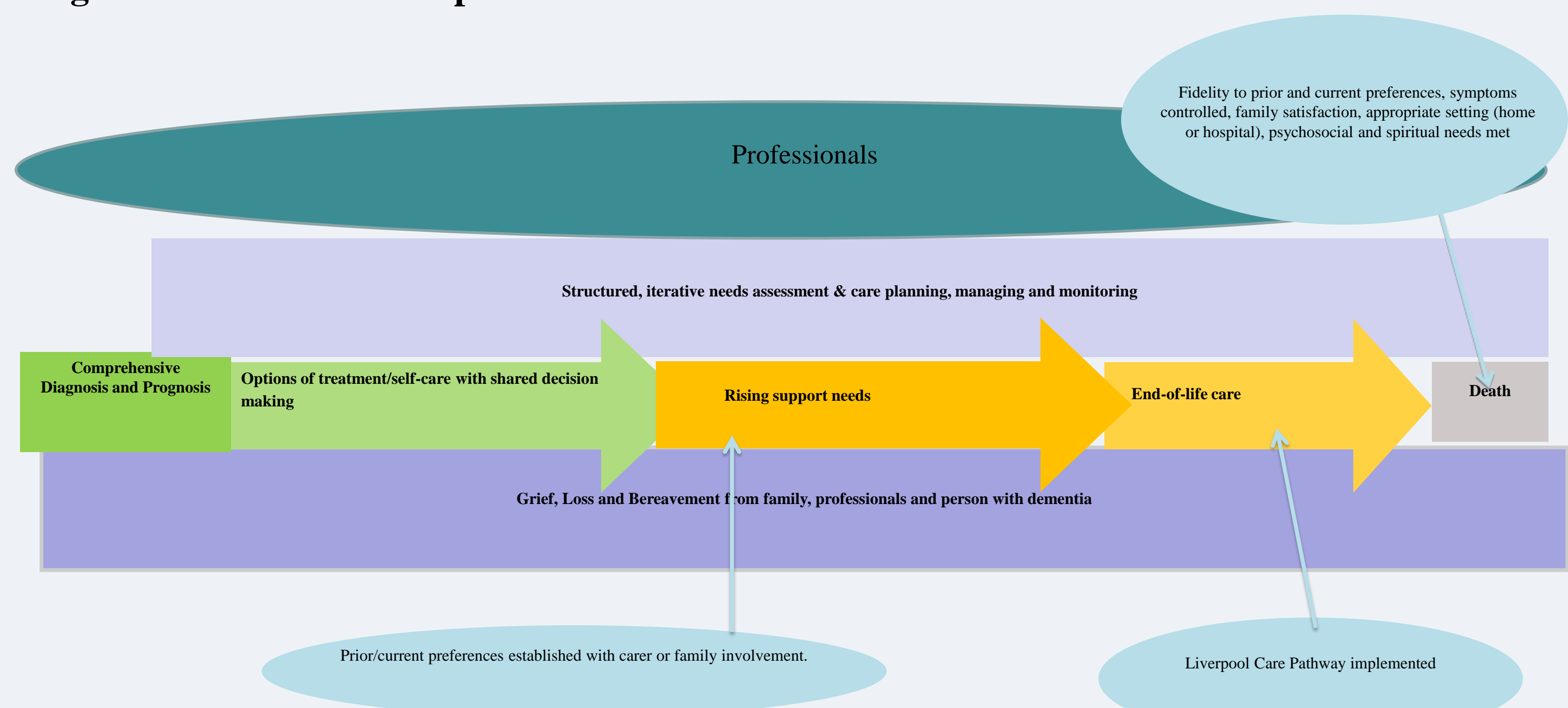


Fig 2. Quality indicators of good end of life care and of a good death related to outcome in dementia.

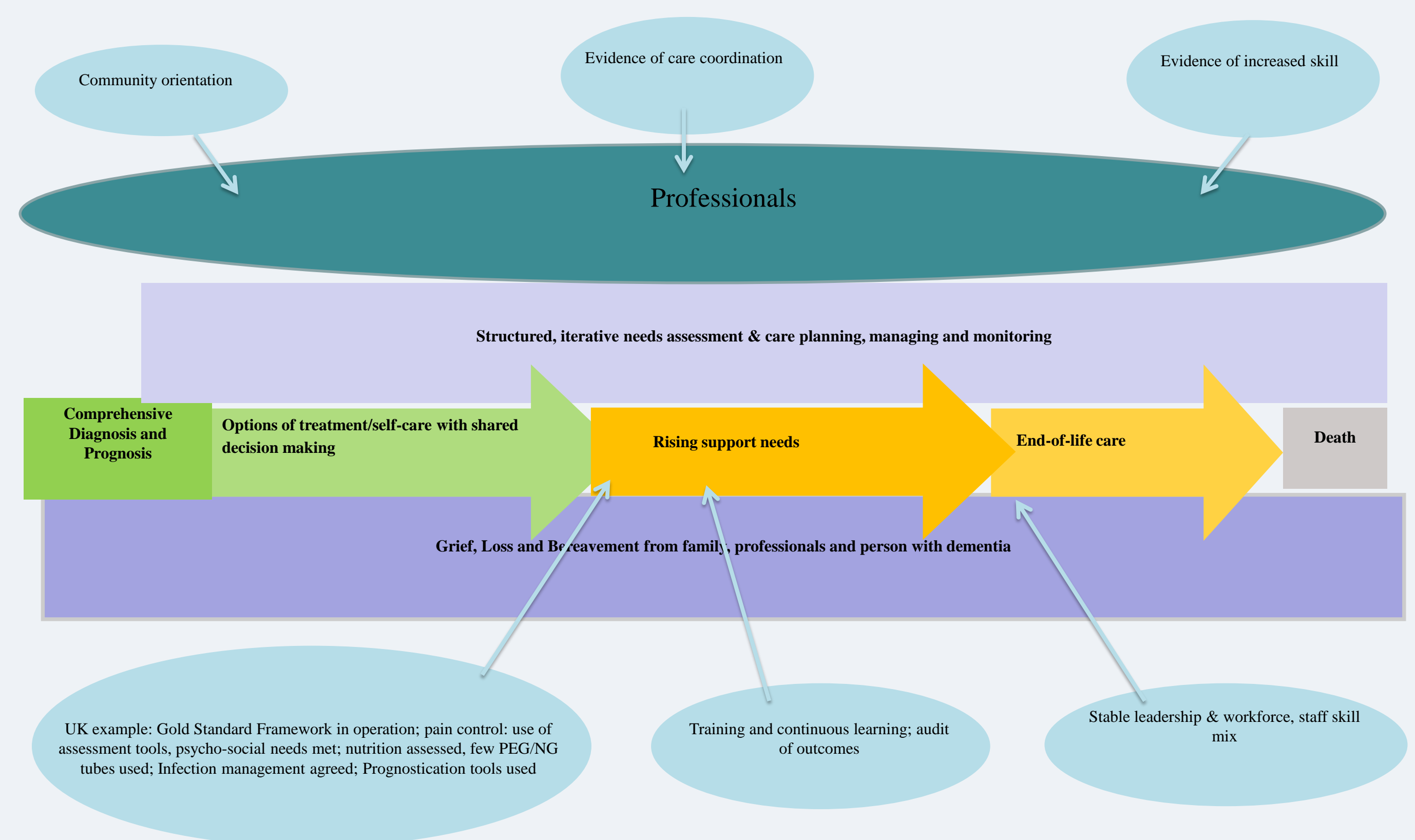


Fig 3. Quality indicators of good palliative care related to structure in dementia.

Conclusions

It has been possible to collaborate across European countries using mixed methodologies to produce a complex model of palliative care which can aid the development and implementation of quality indicators relevant to dementia.

References

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