Northern Ireland Assembly

Queen's University Belfast

The Open University

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Knowledge Exchange Seminar Series (KESS)

PROVIDING END OF LIFE CARE FOR DEMENTIA – TOWARDS A MODEL OF BEST PRACTICE IN PRIMARY CARE

KEY MESSAGES

- General Practitioners (GP) are in a pivotal position to initiate and adapt care for an individual living with dementia. Dementia being insidious in onset makes if challenging to diagnose, however, GPs as gatekeepers to other health services should be able to recognise the early signs of dementia and refer the patient to specialist services to perform the necessary tests and make the diagnosis. Nonetheless **GPs have expressed limited confidence in their assessment and knowledge of dementia.**
- **Health Care Professionals (HCP) and family carers have difficulty in recognising dementia as a terminal illness**; however integrating a **palliative care approach** early in dementia care would be beneficial due to the uncertain course of the disease in combination with the inability of the individual living with advanced dementia to communicate about decision-making and end of life care choices.
- Whether GPs feel they have satisfactory dementia training and a sufficient level of multidisciplinary HCP support to provide care, including end of life care, for their patients living with dementia, is questionable. This alongside a perceived dementia knowledge deficit for HCP and the public; resource shortfalls; conflict with and within families; and poorly integrated team care, together have a **detrimental impact** on providing appropriate care at end of life.
- Generating a personalised shared care and support plan to outline treatment goals, can facilitate holistic care. Advance Care Planning (ACP) is such a mechanism which facilitates communication and decision making, wherein people can plan for a time when they can no longer make decisions for themselves. However, ACP usage in primary care is low. Optimal timing of these discussions should be determined by the patient and family carers' readiness to face end of life choices, but should also accommodate the readiness of the GP. Such discussions can be enhanced by educational strategies for the patient and family carer to enable shared decision-making, but also training for the GP to provide optimal patient and family-centred caregiving. **Emphasis on enhanced education and training is essential to improve communication and integration across all health disciplines**.
- A shared care model for integrated GP services between primary care, emergency services, secondary care and social services is critical to improve access to quality palliative care and to foster system integration – **a necessity to provide best practice end of life care for dementia.**

CONTEXT

Dementia is a life limiting disease without curative treatments (1). The most common cause of dementia is Alzheimer's disease which accounts for over 50% of cases, vascular dementia accounting for 20% and the remainder including Frontal Lobe dementia and alcohol related dementia (2).

When a person has dementia the brain nerve cells are damaged and die faster than normal without replacement (2). It is a worldwide health issue with 35.6 million cases reported in 2010, a number expected to double by 2030 (3). In 2011 it was believed that 19,000 individuals were living with dementia in Northern Ireland (NI), however only 11,000 of these were on the GP dementia register (2). As the population in NI ages, dementia is becoming a major public health and societal issue - a significant burden that the health care system will have to meet.

A GP is predominantly the first HCP to be contacted by an individual living with dementia. As gatekeepers they are well placed to recognise the early signs of dementia and to enhance access to the necessary range of professionals and diagnostic tests (such as that found in memory clinics) required to address the complexities of diagnosing a dementia in the early stages (2, 4). Such early identification can help to ensure the appropriate interventions are commenced and has been known to be beneficial, often leading to improved outcomes for the individual and their family (5). To achieve this GPs need a good knowledge of dementia, and to be aware of the importance of early diagnosis, however research of mental health services for older people in NI has demonstrated that less than half of GPs surveyed believed they had enough training to diagnose and manage dementia (6).

Traditionally the palliative care community have focussed on care for advanced-stage cancer patients (1). However, it has been increasingly recognised that good quality end of life care should be an integral part of care provided for individuals living with chronic illnesses including dementia (7). Adopting a *palliative approach* is one innovation that has the potential to promote anticipatory planning (including ACP) and promote enhanced end-of-life care (8). This has been recommended to include: early care guidance directed at the needs of the individual living with the life-limiting condition and their families to ensure their needs are met throughout the illness trajectory; adaption of palliative care knowledge and expertise to allow individualised assessment of care needs by any healthcare professional; and employment of a palliative approach through integration within healthcare systems in which the evolving end-of-life care needs are recognised and addressed (9).

When comparing the disease trajectories of cancer patients with that of dementia, it can be seen that cancer patients potentially experience a substantial decline in functioning in the last months/weeks of life, whereas with dementia there may be a prolonged 'dwindling' and severe disability may persist for years (10, 11). As such the European Association for Palliative Care (EAPC) have produced a white paper defining the optimal palliative care in older people with dementia by describing 11 core domains and 57 recommendations (1), within this work a model to highlight dementia progression and suggested prioritizing of care goals (Figure 1) was produced.

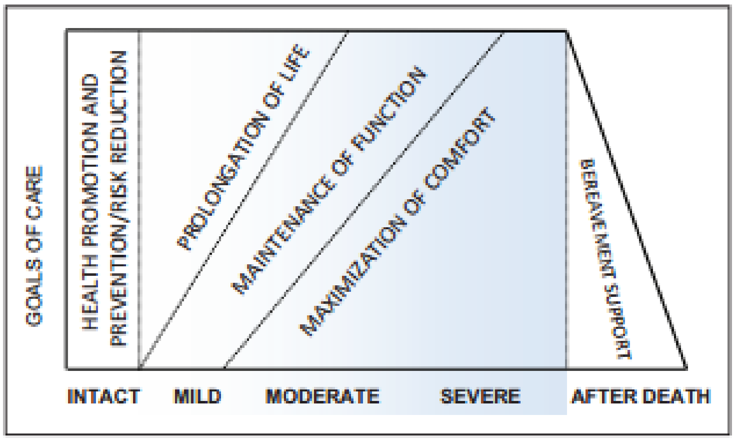

Figure 1. Dementia progression and suggested prioritizing of care goals (1, p.206).

The figure demonstrates the changing care goals and priorities throughout the dementia trajectory, highlighting the complexity of needs of the person living with dementia. Consequently the implementation of a model of shared care to enhance the delivery of care needs is essential to provide effective end of life care for dementia.

IMPLICATIONS FOR PRACTICE

There are two specific themes to highlight the implications for practice:

- **Enhanced education is a strong agenda**

Interventions to promote GP's knowledge and skills are crucial to match complex requirements of dementia, which has significant implications for educators and clinicians. Research has demonstrated an insufficient basic and post-qualifying training in dementia (5), and in Europe certain barriers to treatment may be founded in a poor awareness of the complexity inherent in the recognition, care and management of dementia (12). Additionally, physicians need to be more knowledgeable and proactive with respect to their approaches to ACP for patients with dementia, (13) in order to effectively engage with family carers in dementia care (14). As such, education of the healthcare team was highlighted as a core domain in the white paper by the EAPC for the optimisation of palliative care in dementia (1).

It has also been recognised that public education is essential to improve community and professional awareness to promote empowerment for the ageing population (15). The suggestion of practice-based learning to assist evidence based guideline implementation has been welcomed (16). Recommendations of educational support for GPs concentrating on epidemiological knowledge and disclosure of the diagnosis in dementia have been highlighted (17), but, overall, knowledge transfer in dementia not only involves healthcare professionals and academics but also the general public and consumers. This would require educational strategies directed towards patients and family carers to enable shared decision-making with the GP for optimal timing of ACP discussions, and systematic approaches for improved public dementia awareness (14). With an insufficient understanding of the dementia diagnosis or future implications comes an additional burden for the carer (2). One potential recommendation is the use of the booklet 'Comfort Care at the end of life for persons with dementia' (Box 1) adapted from Arcand et al.(18), previously showing a high level of acceptability (19, 20) and identified as a best practice instrument by the World Health Organisation European Office (21). The booklet is currently being used in a large randomised controlled trial involving 25 care homes in N. Ireland, in which Professor Kevin Brazil (Queen's University Belfast) is the principle investigator. Early evaluation of this booklet from individual interviews and family conferences with family carers, care home managers and with the study's ACP facilitator, have welcomed it. It was believed that the booklet allowed family carers a deeper understanding of what to expect in the final stages of the disease, and provided in a question and answer format, the carers felt the booklet offered the options available to them for end of life care and believed it answered all their pertinent queries, many claiming they wished they had been able to access it earlier.

- **A Shared Care Model**

Substantial multidisciplinary support is essential to meet the needs of the dementia population and their carers. It is argued that at the core of good clinical practice is good interdisciplinary team work, but poor communication and inadequate integration with other HCPs can impinge any palliative care offered to individuals living with dementia (22). As such a personalised shared care plan can facilitate access between primary care, emergency services, secondary care and social services - all crucial elements to realize a shared care model (23). Further, due to the central role of GPs they are in a commanding position to identify early signs of dementia and to enhance access to the range of professionals (24). However, this would require effective two-way communication and integration with other healthcare professionals, as no individual medical speciality has the expertise to manage the multifaceted range of mental, physical and social problems that accompany dementia (25). Consequently, an integrated and holistic team approach to dementia is needed to improve patient outcomes (26, 27), highlighted in Domain 4 of the EAPC white paper (1).

Seamless dementia care hinges on the full integration of all parties involved. Conceivably any programme to promote collaboration, co-ordination and continuity of care will be pivotal to successful dementia care (22). To improve communication, effective interdisciplinary collaboration and the delivery of good quality palliative care requires the implementation of a model of shared care (28). A good death with dementia has been defined as one without pain and being surrounded by loved ones, (7), these are not complex goals but ones that require co-operation, communication and integration by and between allied health professionals (27).

Box 1. Comfort Care Booklet Contents

Section 1. The Natural Evolution of Dementia

- What is the Path Leading to the End of Life Like for Those Suffering from Dementia?
- What can caregivers do when the sick person can no longer eat or drink?
- What can the caregiving team do when the patient develops pneumonia?
- Should the individual with this problem be transferred to a hospital?
- Do doctors always carry out cardiopulmonary resuscitation?

Section 2. Decisions about the end of life

- Who makes medical decisions at the end of life, the doctor or the patient's representative?
- What is the role of the patient's representative in the decision making process?
- What to do in case of conflict or doubt?
- If it is decided not to resort to curative treatment, does this mean that the patient is left on their own?
- Under such circumstances, are religious authorities in agreement with the decision to withdraw or not provide life-prolonging treatment?

Section 3. Relief of Symptoms

- What are the most frequent symptoms at the end of life?
- How does the caregiving team look after breathing problems?
- Should the patient be given antibiotics when they have an infection?

Section 3 (cont): Relief of Symptoms

- How are secretions controlled when they cause difficult and noisy breathing?
- Is it helpful to provide oxygen?
- What are the signs of pain in someone who is unable to express themself?
- How can pain be relieved?
- Can morphine kill the patient?
- How can anxiety or agitation be relieved?
- Is it necessary to administer other medications or to verify blood pressure, temperature, blood sugar levels, and so on?
- How does the patient feel when he or she is no longer drinking or eating?
- Should intravenous fluids be started?
- What to do if the person *already* has a feeding tube?
- How long will a person who is no longer drinking or eating live?

Section 4. The Final Moments

- How should you behave with someone who appears to be unconscious?
- What are the final moments like?

Section 5. After the Death

- What happens after death?

SUPPORTING EVIDENCE FROM A RECENT STUDY CONDUCTED IN NORTHERN IRELAND

In autumn 2013 questionnaires called "Care for Dementia Patients at the End of Life" were mailed to GPs across NI (14, 22, 29, 30). The questionnaire explored GPs' perceptions on palliative care for individuals with dementia, the items included were based on the domains of care for patients diagnosed with dementia that were developed by experts and ratified by the EAPC (Box 2).

The sample was based on GP practices that had more than 30 registered dementia patients. They were identified by using the Quality & Outcomes Framework along with the Business Services Organisation Practice and GP lists to provide a list of all GP practices that fulfilled the criteria to be included. Altogether the sample comprised 340 GPs representing 174 practices with each receiving a personal self-complete postal questionnaire.

Data from Sections A, B and D were inputted and managed using specialist computer statistical analysis software, SPSS, and the free text from Section C was organised and analysed using qualitative data analysis software NVivo.

RESULTS

A total of 138 responses were received, giving a response rate of 40.6% (138/340), representing 60.9% of surveyed practices (106/174). Of these responses, 133 provided fully complete and viable surveys, and 84.2% of respondents provided between one and four perceived barriers for Section C.

The demographics of the GP respondents were: 57.4% male and 43.6% female; their average age was 49.3 years old and their average time in practice was 24.7years. Of these respondents, 57.4% spent less than 10% of practice time providing clinical care in the care home with, 39.5% spending 25-49% of time. The majority of respondents (48.4%) visited a care home patient at least weekly, and 46.5% stated they had cared for one to four dying dementia patients in the previous year, 5% had cared for more than 20.

Box 2: Survey items contained in the “Care for Dementia Patients at the End of Life” instrument

Section A:	24 statements on perceptions of dementia as a terminal illness, communication, Advance Care Planning (ACP), and decision-making. A five point Likert scale, ranging from strongly disagree to strongly agree, allowing the respondent to express their level of agreement with each statement.
Section B:	Catalogued domains of palliative care in dementia and asked for respondents’ perceived importance of these aspects of care, the significance of each domain as a barrier in clinical practice and the challenge of addressing the barriers to implement the domains of care.
Section C:	Respondents’ perceptions of up to three of the most significant barriers to the provision of palliative care in dementia, and potential solutions to address those barriers (open-ended).
Section D:	Respondent characteristics.

In response to their level of agreement with statements describing ACP about future care at end of life for dementia:

- GPs were divided on the statement that ACP should be initiated at the time of diagnoses and if it should be reviewed on a highly frequently basis
- Just over half agreed with the statement that an Advance Directive was essential when a patient was not able to participate in treatment decisions
- Most respondents (82.7%) felt the GP should take the initiative to introduce and encourage ACP
- Most respondents (52.6%) felt that family members should not simply agree with the GP on the goals of care
- Their responses were widely distributed on their judgment of the success of the ACP process when family members have difficulty in understanding the limitations and complications of life sustaining therapies or if they could not accept their loved one’s prognoses.
- Most respondents (90.2%) reported that there should be an agreed format for ACPs
- Most respondents (79.7%) felt GPs needed training to improve their knowledge to successfully involve families in caring for dementia at the end of life.

Based on the analysis of Section C, five key themes were identified as main barriers to providing good quality palliative care in dementia (Table 1). These recognised the perceived lack of knowledge and understanding about dementia within the family, healthcare and public domains. Logistical, financial and time management barriers were also noted to have a negative effective on dementia care alongside concerns of inappropriate medical treatments with complexities of assessments and prognostication stemming from a lack of enhanced education and training for HCP. A disjointed team was blamed for the breakdown of communication between GP practices and community support leading to a poor interdisciplinary team approach to care. Finally inadequacies of appropriate social support for family carers and the challenges of discussing the dying process with them were seen to impede the palliative care process. Suggested solutions to these barriers had a heavy emphasis on enhanced education and training (including public awareness campaigns), being the inertial point to the improvement of communication and integration across all healthcare disciplines for the subsequent implementation of appropriate and seamless care.

Table 1. Themes and subthemes of the analysis of survey Section C - the perceived most significant barriers to the provision of palliative care in dementia

Theme	Subthemes	No. of perceived barriers provided by GPs
1. Lack of knowledge & understanding	▪ Level of family/carer understanding ▪ Recognition that dementia is a palliative condition by HCPs, families and the public ▪ HCP understanding, education & training ▪ Level of public understanding	84
2. Limited availability of resources	▪ GP resources – practice & time pressures ▪ Access to community staff & resources ▪ Funding	59
3. Mismanagement of appropriate care	▪ Inappropriate medical treatments, interventions & hospitalisations ▪ Difficulty of assessments, diagnosis & prognosis ▪ Lack of standardised guidelines & information	62
4. Poor interdisciplinary team approach	▪ Team communication, integration & access to specialist support ▪ Continuity of care	52
5. Family support & involvement	▪ Family, carer & patient support ▪ Family resistance & disagreements	39

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