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**Title:**

UK end-of-life care services in dementia, initiatives and sustainability: results of a national online survey

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## **Abstract**

**Background** People living and dying with non-cancer diagnoses including dementia, have poorer access to generalist and specialist palliative care than people with cancer, and experience worse outcomes in terms of pain and symptom control, and quality and experience of care. In the United Kingdom, the National Council for Palliative Care (NCPC) ran a national survey services for end-of-life care for people with dementia (2008) in which sixteen services were identified, and reported on case studies and examples of good practice. We updated the NCPC survey to review progress in previously identified services, identify factors that lead to sustainable services and identify new initiatives in this area of care.

**Methods** An online survey was developed and piloted before use. Initiatives were contacted via targeted (N=63) and open call invitations. The survey was made up of five sections. Quantitative data were analysed using descriptive statistics.

**Results** Fifteen services responded. They engaged in a wide range of activities predominately providing direct care (80%) and workforce development/ advisory or educational activities (87%). Results suggest that sustainability of services is reliant on clinicians with a leadership role and wider system support through funding mechanisms and a minimum level of integration within normal service provision.

**Conclusions** Recent initiatives are largely built on the expertise of the nursing profession (with or without input from medical consultants), and driven mainly by both the charity and hospice sector. This has generated a potential new model of care provision in end of life in dementia care, "Hospice-enabled Dementia Care".

## INTRODUCTION

People living and dying with non-cancer diagnoses including dementia, have poorer access to generalist and specialist palliative care than people with cancer, and experience worse outcomes in terms of pain and symptom control, and quality and experience of care [1]. Barriers to providing end-of-life care for people with dementia include health care professionals' and families' awareness of the terminal nature of dementia and associated attitudes towards end-of-life treatment (e.g. hospitalisation, tube feeding, resuscitation), and an uncertain illness trajectory [2 3] which makes it difficult to meet needs and plan care, potentially leading to inappropriate or reactive care. This is compounded by the negative impact of hospital admissions tied to lack of skills and resources in acute settings; lack of dementia specific expertise among health and social care staff; lack of communication and coordination between care agencies, primary and secondary services including out-of-hours services [4 5].

Prior to the implementation of the United Kingdom's national dementia strategy in 2009 which made little mention of end of life care [6], the National Council for Palliative Care (NCPC) ran a national survey of local practice in end-of-life care for people living and dying with dementia. Sixteen services were identified and reported on in a compendium of case studies and good practice examples [7]. The recent Prime Minister's challenge on dementia sets a strategic framework to deliver major quality improvements to dementia services, pledging that people with dementia and their carers receive co-ordinated, compassionate and person-centred care towards the end of life, including access to high quality palliative care from health and social care staff trained in dementia and end of life [8]. As part of the Supporting Excellence in End of life care in Dementia (SEED) research programme (<https://research.ncl.ac.uk/seed/>) and in association with the NCPC, we updated the 2008 survey to review progress in previously identified services, identify factors affecting sustainability of services and identify new initiatives in this area of care.

## METHODS

An online survey was developed using OPINIO (Version 6.9), a web-based tool which provides a framework for authoring and distributing surveys. The survey was piloted with members of the SEED research group and ran from beginning of October 2014 to end of February 2015. The survey consisted of five sections covering (i) general information regarding the service (i.e. title, contact information and location), (ii) service activities and referral criteria, (iii) team size and composition, (iv) situation, funding mechanisms, sectors of operation, as well as (v) dissemination and evaluation activities.

Over sixty services which were set up specifically to provide end of life care to people with dementia (N=63) were purposively sampled, via targeted email invitation. This included respondents to the NCPC 2008 survey; services identified via professional networks of the SEED research group (i.e. the NCPC Working Group and the Health and Care Champion Group for the PM's Dementia Challenge); Gold Standard Framework accredited care homes registered to provide dementia care and awarded Beacon status; Integrated Care Pioneer Sites and other services identified via web-based searching using search terms including "dementia", "end of life", "palliative", "service" and "innovation". Open call invitations were posted in the NCPC News Roundup, the National Care Forum newsletter and Practice Forum, the UK edition of ehospice, the January 2015 issue of the Old Age Psychiatrist Magazine, the Admiral Nursing Network and via social media (i.e. Twitter). We distributed flyers advertising the survey at the NCPC's 9<sup>th</sup> Annual Conference on Dementia and End of Life. Targeted email and open call invitations, and flyers contained a brief description of the SEED programme and link to the survey.

## **ETHICS**

The study did not involve human subjects and ethics committee approval was not required.

## **RESULTS**

Fifteen respondents representing discrete service initiatives responded (see Table 1 for summary of their main characteristics). Two-thirds of returns were received in response to the 63 targeted email invitations (16%), and one-third in response to open calls. Only one initiative is located outside of England, in Wales. Remaining initiatives are concentrated in the South East and North of England.

The funding and organisation of services are mixed with no clear pattern of funding or provision identifiable. Forty per cent (n=6) of initiatives are run by the National Health Service (NHS). The same proportion (i.e. 40%) is hospice-based, and remaining initiatives are charity-led by organisations including Dementia UK. Respondents reported engaging in a wide range of activities (see Table 1). These include (i) direct care for people with dementia and/or their families/carers (80% of initiatives identified), (ii) informational and educational support for families/carers of people with dementia at the end of life (66.6%), (iii) workforce development including advisory and educational activities (86.6%), (iv) tool, framework and/or pathway implementation and/or development (60%) and (v) development of mechanisms for care coordination, for example, training and provision of care coordinators or development of strategies and/or policies for joint working across palliative and dementia care (60%). 80% of initiatives engage in either (i) virtually all types of activity described above (ii) or all activities described above except direct care services. In other words, since 2008 current initiatives have either

forgone or are extending the clinical delivery model, in favour of practice and/or workforce development approaches.

**Table 1 Main characteristics of identified initiatives (N=15)**

<b>Situation</b>	
National Health Service	40.0%
Hospice sector	40.0%
Charity sector	20.0%
<b>Funding</b>	
Trust (Mental Health, Acute, Health and Care)	40.0%
Clinical Commissioning Group/Regional Innovation Funding	33.3%
Hospice sector	40.0%
Community/Voluntary/Charity sector	26.6%
Independent care sector	13.3%
<b>Staffing</b>	
<b>Direct care</b>	
Nursing incl. Registered Nurse (Palliative care, Mental Health); Clinical Nurse Specialist (MacMillan, Admiral, Palliative Care); Advanced Nurse Practitioner, Nurse Consultant	86.6%
Medical Consultant incl. Old Age Psychiatry, Psychological Medicine, Palliative Care, Geriatrics	33.3%
Allied Health Professional (Occupational Therapist, Physiotherapist) and Complementary Therapists	33.3%
Social worker	26.6%
Care worker and care assistant	20.0%
Counsellor	6.6%
<b>Educational</b>	
Educationist	20.0%
<b>Service management/development/commissioner roles</b>	
Strategic (Chief Executive) and Administrative (incl. project manager) support	20.0%
Commissioner	6.6%
<b>Activities</b>	
Direct care (e.g. care planning and review)	80.0%
Informational and educational support for families/carers of people with dementia at the end of life (e.g. educational resources and/or training)	66.6%
Workforce development (e.g. educational resources, programmes and/or training)	86.6%
Tool, framework and/or pathway development and implementation	60.0%
Development of mechanisms for care coordination (e.g. training and/or provision of care coordinators; development of strategies and/or policies for joint working across palliative and dementia care)	60.0%

Over 85% of initiatives relied on nursing professionals, from nurses and mental health nurses; Clinical Nurse Specialists (i.e. Palliative care, Macmillan and Admiral); Advanced Nurse Practitioners and Nurse Consultants. Medical consultants (i.e. Old Age Psychiatry, Psychological Medicine, Palliative Care and Geriatrics) and Allied Health Professionals (i.e. Occupational Therapists and Physiotherapists), were also involved to a lesser extent, each group providing expertise in 33.3% of services identified. The majority of services (73.3%) were multidisciplinary, with remaining services mainly relying on nursing input only.

The majority of services (73.3%) receive funding from just one source; remaining services receiving funding from two or more sources. The majority of services receive public funding via a Trust (40%) or are partially or fully commissioned (33.3%). Forty percent of initiatives are either totally or partially funded by the hospice sector. Over 65% of services evaluate their activity. Outcomes evaluated include patient and service outcomes such as completion of ACP documents, place of death and number of unscheduled admissions to hospital (40% of services), service user satisfaction (40%), educational outcomes, i.e., numbers trained and staff confidence measures (26.6%) and economic evaluation (20%). Most services publicise their practice either at conferences (53.3% of services), through publications (13.3%), or via inclusion as case studies or in surveys (13.3%).

Five out of eight direct care services identified in 2008 were still existed in 2015 (four out of eight responded to the present survey). Those services running seven years later are either part of statutory services (i.e. part of normal service trust provision) or are commissioned (i.e. reported receiving CCG funding), and benefit from leaders from within the UK end-of-life in dementia practice community, who have been recognised for their contribution to the field in both theory and practice through either awards or selection as demonstrator sites in major research, or who are heavily involved in advancing end-of-life care practice in dementia at a strategic level.

## **DISCUSSION**

Despite the increased policy attention and funding accorded to people living and dying with dementia since the 2008 survey, the present survey did not identify an equivalent expansion of activity or reach in dementia-focused end of life care services. Initiatives surveyed appear to concentrate on practice-level issues in end-of-life care in dementia through the development of tools, frameworks for assessment and management and care pathways which may address the uncertainty of the illness trajectory. There is also ongoing investment in educational and advisory activities to remedy the lack of skills and

expertise in the workforce. These results suggest that many of the barriers to delivering excellent end-of-life care in dementia remain. The initiatives we identified are largely built and rely on the expertise of nursing professions (with or without input from medical consultants) and supported via hospice and charitable organisations. These may indicate a new model of care provision in end of life in dementia care, referred to as “Hospice-enabled Dementia Care”[9].

Our results are similar to those obtained in 2008 (i.e. fifteen examples of local practice versus sixteen). This survey provides a snapshot of how services are supporting people dying with dementia since the 2008 survey, but the relatively small sample size and our purposive sampling frame limits the extent to which findings can be generalised. New services and models of care are constantly developing and it would be useful to repeat this survey, with a wider sampling frame of all generic palliative care services, collecting data on the numbers of people with dementia that they care for. Sustainability of initiatives appears to be attributable to funding mechanisms and integration of the service as part of normal service provision. Continuity of leadership at a more individual level [10] is also important, as has been highlighted elsewhere [11]. We identified pockets of service provision supported by piecemeal funding but the challenge remains how to ensure this is achieved for all people who would benefit from such care.



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## **COMPETING INTERESTS**

None declared

## **CONTRIBUTORSHIP STATEMENT**

SA, CG, LR and ELS made substantial contributions to the conception or design of the work. SA and ELS the acquired, analysed and interpreted the data. SA, CG, LR and ELS drafted the work and revised it critically for important intellectual content. SA, CG, LR and ELS gave final approval of the version to be published and agree to be accountable for all aspects of the work.

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