Robinson, L., Hughes, J. C., Daley, S., Keady, J., Ballard, C., & Volicer, L. (2005). End-of-life care and dementia. *Reviews in Clinical Gerontology*, 15, 135–148.
Sampson, E. L., Gould, V., Lee, D., & Blanchard, M. (2006). Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Ageing*, 35, 187–189.

Advance Care Planning: An opportunity for person-centred care for people living with dementia

CATHERINE EXLEY *Newcastle University, UK*

CLAIRE BAMFORD *Newcastle University, UK*

JULIAN HUGHES *Northumbria Healthcare NHS Foundation Trust, UK*

LOUISE ROBINSON *Newcastle University, UK*

Abstract Many people want to be able to plan ahead, so that if in the future they cannot make decisions or do things, their wishes will be known. This is called Advance Care Planning (ACP). Although it is part of official NHS policy (NHS End of Life Care Planning), ACP is hardly ever done, and it may become more difficult once a person has memory problems. In the UK, there is very little research into ACP. By the time someone has signs of dementia, families often become involved. We are uncertain how this affects ACP and the views of the person with dementia, particularly with the new Mental Capacity Act which allow families to comment on health, as well as financial, issues. Our study will be exploring the area of ACP, especially in dementia, by

- looking at the experience of other countries through a systematic review of the existing literature;
- finding out what people who have carried out ACP in this country think through interviews and focus groups;
- considering what factors might help professionals to encourage the process of ACP in practice; and
- looking at how ACP might be done better for people with dementia.

The ultimate aim of our study is to produce guidance on ACP for both people with dementia, their families and health care professionals.

Keywords Advance Care Planning; dementia; end of life care; older people

Introduction

The key aim of the United Kingdom (UK) End of Life Care Strategy is to ensure that people's individual needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon wherever possible; integral to this is the process of Advance Care Planning (ACP) (National Health Service – End of Life Care Programme, 2007). ACP involves eliciting 'the person's preferences regarding both the type of care they would wish to receive and the setting or location in which they wish to be cared for'. Potential outcomes may include: an 'advance statement' – patient preferences for future care and where it is delivered; an 'advance decision' – patient refusal of certain treatment in specific circumstances and granting another individual a Lasting Power of Attorney, that is the ability to make treatment decisions on their behalf should they lose the capacity to make their own decisions.

In practice, ACP usually involves a series of discussions between a patient and their professional carers, and sometimes family carers. It is a dynamic process of recoding people's preferences and choices, and should be reviewed as an individual's condition changes. In particular it is necessary to ensure that there are systems in place which enable everyone who may come into contact with an individual to be aware of the existence of their ACP and the wishes documented in it. One way to achieve this might be to hold the document electronically so that all those with a legitimate reasons i.e. health and social care professionals, can access it readily. Although ACP is integral to the NHS End of Life Care Programme (2007), it is not yet fully integrated into everyday practice, and factors which facilitate the successful introduction of ACP within routine care need to be defined (Davison & Simpson, 2006). Although ACP in the UK is policy driven, there is a dearth of empirical, UK-based research on ACP particularly in dementia care, although findings from international research may be helpful (Jezewski et al., 2007).

ACP is not only important in palliative care (National Council for Palliative Care, 2006; NHS End of Life Care Programme, 2007), but can also be seen as a key component of person-centred care in dementia (Hedley & Hughes, 2006; Hertogh, 2006; Hughes & Robinson, 2006; Hughes et al, 2007; Kitwood, 1997). In the UK, national guidance on dementia care (National Institute for Clinical Excellence and Social Care Institute for Excellence, 2006) stipulates that ACP should be discussed with the person with dementia whilst he/she still has mental capacity. This is particularly relevant with the full implementation of the Mental Capacity Act (DoH, 2005) where Lasting Powers of Attorney now include health and welfare in addition to financial issues. However, the incidence of advance care directives in dementia is low (Mitchell et al., 2004), this may be because the timing of ACP is difficult in dementia given the protracted length of the illness. Existing studies have shown that many older people, especially those with dementia, are accompanied to medical consultations by family carers and value such involvement in their care (Fortinsky, 2001). However, older people tend to be less involved, and less assertive, in consultations involving family members (Greene et al., 1994). Carers themselves report that people with dementia become increasingly marginalised in medical consultations (Beisecker et al., 1997)] and in decision-making (Hirschman et al., 2004). 17]. However, carers themselves are often protective of the person with dementia and keen to be involved in clinical discussions and decision making (Bamford et al., 2007), which can be problematic as research suggests that the views of proxy decision-makers are different to those of the older people themselves [Seckler et al., 1991). In the field of ACP generally, and specifically in relation to people with limited mental capacity, there is a need to explore how to facilitate a person-centred approach to ACP in circumstances where patients, such as those with dementia, may wish to involve their families (Mezey et al., 1996).

Advance Care Planning in Dementia: A new research study at Newcastle University

Newcastle University has secured funding from the National Institute of Health Research for Patient Benefit programme to carry out a research project to address the current gaps in the evidence base of ACP. Our study objectives include:

1. to synthesise existing evidence from a range of countries on ACP in dementia care;
2. to identify the factors which facilitate/inhibit the process of ACP within the NHS;
3. to identify the professional competencies and training required to implement ACP;
4. to explore how ACP can be implemented in the context of loss of mental capacity, specifically focusing on people with dementia;
5. to develop guidance for healthcare professionals, patients and carers regarding the process of ACP in dementia care.

The project is made up of a series of interrelated studies. In the first study, we aim to identify and evaluate examples of ACP in dementia care from other countries, via a literature review, in order to inform UK practice (Jezewski et al., 2007).. We will include a variety of studies but we are keen to identify any actual examples from practice and any evidence of their effectiveness and acceptability (Dixon-Woods et al., 2004; Robinson et al., 2007).

In the second study, we will explore the views and experiences of NHS health professionals on the implementation of ACP in the UK in order to identify the factors which facilitate its introduction and also the barriers which may impede it. We are also going to identify the professional skills required for the successful implementation of ACP. Through focus groups, we will talk to a group of primary and secondary care health professionals in one area in the North East of England, where ACP was introduced in 2007. In this area, the ACP process is facilitated by healthcare professionals, who have received training (NHS End of Life Care Programme, 2006), and is for any patient defined as having a life-limiting illness and at risk of dying within 1 year; within UK primary care, these will be patients whose names are currently listed on the practice palliative care register. We are especially interested in their views as to how to carry out ACP with people with memory problems who may lack capacity to make decisions, such as in dementia.

The third part of the study will focus purely on those involved in dementia care. We will use both interviews and focus groups to gather the views of people with dementia, their carers, and professionals involved in dementia care on the content, process and timing of ACP in dementia. We shall also ask whether they consider the generic ACP documents currently used in the NHS End of Life Care Programme could be used in the context of people with loss of mental capacity. We will be seeking to recruit with people with mild dementia and their main family carer but will also be talking to legal professionals and advocacy groups as well.

Our final task will be to consider all the findings from the three studies in order to develop guidance, and hopefully educational tools, for implementing ACP in the context of dementia. The guidance would also identify who is best placed to facilitate this process and the skills and competencies required. We will also seek the opinions of some of our study participants (legal, health and social care professionals and people with dementia and their carers) on our recommendations and will of course refine them to incorporate their views.

Conclusion

Although integral to NHS End of Life Care Policy (NHS End of Life Care Programme, 2007), there is a lack of UK-based research on the process of ACP, both in general and in the specific area of mental incapacity such as occurs in people with dementia. Through this project, we hope to identify if, and how, ACP is currently carried out in NHS practice and how, by whom and in what situations the process can best be discussed with people with dementia. ACP has been implemented with some success in other countries and we hope to identify some examples of good practice like this in order to inform UK practice. ACP has the potential to allow people with dementia and their families the right to choose their care, we just need to find out how be we can help them to do this.

References

Bamford, C., Hughes, J., Robinson, L. (2007). Improving patient-centred care for people with dementia in medical encounters. *Gerontologist*. 47(1),158–159.

Beisecker, A. E., Chrisman, S. K., & Wright, L. J. (1997). Perceptions of family caregivers of persons with Alzheimer's disease: Communication with physicians. *American Journal of Alzheimer's Disease*. March/April, 73–83.

Davison, S. N., & Simpson, C. (2006). Hope and advance care planning in patients with end stage renal disease: Qualitative interview study. British Medical Journal, 333, 886–889.

Department of Health (DoH). (2005). The Mental Capacity Act. [cited 14 November 2006]. Available from: http://www.dh.gov.uk/PublicationsAndStatistics/Bulletins/ChiefExecutiveBulletin/ChiefExecutiveBulletinArticle/fs/en?CONTENT_ID=4108436&chk=z0Ds8/

Dixon-Woods, M., Agarwal, S., Young, B., Jones, D., & Sutton, A. (2004). *Integrative approaches to qualitative and quantitative evidence*. London: NHS Health Development Agency.

Fortinsky, R. H. (2001). Health care triads and dementia care: Integrative framework and future directions. *Aging and Mental Health*. 5(Suppl. 1), S35–S48.

Greene, M. G., Majerovitz, S. D., Adelman, R. D., & Rizzo, C. (1994). The effects of the presence of a third person on the physician–older patient medical interview. *Journal of the American Geriatrics Society*. 42, 413–419.

Hedley, K., & Hughes, J. C. (2006). Aspects of holistic terminal care in severe dementia. In Hughes, J. C. (Ed.), Palliative care in severe dementia. London: Quay Books.

Help the Aged, The Peer Education Project Group. (2006). Planning for choice in end-of-life care. Educational Guide. [cited 14 November 2006]. Available from: www.helptheaged.org.uk/NR/rdonlyres/6C50EADE-2AB7–4025–9368–6787B5A23F08/0/planning_for_choice_in_endoflife.pdf

Hertogh, C. M. (2006). Advance care planning and the relevance of a palliative care approach in dementia. Age and Ageing. 35(6),553–555.

Hirschman, K. B., Xie, S. X., Feudtner, C., & Karlawish, H. T. (2004). How does an Alzheimer's disease patient's role in medical decision making change over time? *Journal of Geriatric Psychiatry and Neurology*. 17, 55–60.

Hughes, J. C., Jolley, D., Jordan, A., & Sampson, E. L. (2007). Palliative care in dementia: Issues and evidence. Advances in Psychiatric Treatment. 13, 251–260.

Hughes, J. C., & Robinson, L. (2006). General practice perspectives: Co-ordinating end-of-life care. In Hughes, J. C. (Ed.), Palliative care in severe dementia. London: Quay Books.

Jezewski, M. A., Meeker, M. A., Sessanna, L., & Finnell, D. S. (2007). The effectiveness of interventions to increase Advance Directive Completion Rates. Journal of Aging Health, 19, 519–535.

Kitwood, T. (1997). Dementia reconsidered: The person comes first. Buckingham: Open University Press.

Mezey, M., Kluger, M., Maislin, G., & Mittelman, M. (1996). Life sustaining treatment decisions by spouses of patients with Alzheimer's disease. *Journal of the American Geriatrics Society*. 46, 144—150.

Mitchell, S., Kiely, D., & Hamel, M. (2004). Dying with advanced dementia in the nursing home. *Archives of Internal Medicine*. 164, 321–326.

National Council for Palliative Care. (2006). Exploring palliative care for people with dementia. A discussion document. London: NCPC.

National Health Service – End of Life Care Programme. (2007). Advance Care Planning: A Guide for Health and Social Care Staff [cited 23 March 2007]. Available from: http://www.endoflifecare.nhs.uk/eolc/acp/

National Institute for Clinical Excellence and Social Care Institute for Excellence. (2006). Dementia: Supporting people with dementia and their carers in health and social care. London: NICE/SCIE

National Health Service. End of Life Care Programme. (2006) [cited 14 November 2006]. Available from: http://www.endoflifecare.nhs.uk/eolc

Seckler, A. B., Meier, D. E., Mulvihill, M., & Paris, B. E. (1991). Substituted judgment: how accurate are proxy predictions? *Annals of Internal Medicine*. 115(2), 92–98.

Robinson, L., Hutchings, D., Dickinson, H. O., Corner, L., Beyer, F., Finch, T., et al. (2007). Effectiveness and acceptability of non-pharmacological interventions to reduce wandering in dementia: A systematic review. *International Journal of Geriatric Psychiatry*, 22, 9–22.

CATHERINE EXLEY
Newcastle University, Institute of Health and Society, 21 Claremont Place,
Newcastle upon Tyne NE2 4AA, UK.
[catherine.exley@ncl.ac.uk]

CLAIRE BAMFORD
Newcastle University, Newcastle upon Tyne NE2 4AA, UK.
[c.h.bamford@ncl.ac.uk]

JULIAN HUGHES
North Tyneside General Hospital, Northumbria Healthcare NHS Foundation Trust.
[j.c.hughes@ncl.ac.uk]

LOUISE ROBINSON
Newcastle University Institute of Health and Society, 21 Claremont Place,
Newcastle upon Tyne NE2 4AA, UK.
[a.l.robinson@ncl.ac.uk]

Changing practice in dementia care for people in care homes towards the end of life

CATHERINE EVANS *University of Hertfordshire, UK*

CLAIRE GOODMAN *University of Hertfordshire, UK*

Abstract This paper reports on the background and design of an innovative study seeking to develop and test a dementia specific approach to palliative care for older people in care homes, entitled *Evidence-based interventions in dementia towards the end of life* (EVIDEM EoL). The study uses a two-phase prospective design. Phase I intends to explore and document characteristics and support needs for people with dementia in care homes towards the end of life. Data from phase I