



PROMOTING INFORMED DECISION MAKING AND EFFECTIVE
COMMUNICATION THROUGH ADVANCE CARE PLANNING FOR
PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS.

SHORT REPORT

Principal Investigator: Kevin Brazil

Co-Investigators: Chris Cardwell; Mike Clarke; Peter Hudson; Katherine Foggatt; Dorry McLaughlin; Peter Passmore; and, W George Kernohan.

Research Fellows: Gillian Carter and David Scott

Funded by: HSC R&D Division; Public Health Agency; and, The Atlantic Philanthropies.



This report can be cited as: Brazil K, Cardwell C, Clarke M, Hudson P et al (2017). *Promoting Informed Decision Making and Effective Communication through Advance Care Planning for People with Dementia and their Family Carers: Executive Summary*. Belfast: Health and Social Care Research and Development Division, Public Health Agency for Northern Ireland.

Contents

<u>EVIDENCE BRIEF</u>	3
Background	5
Aims and Objectives	6
Methods	7
Personal and Public Involvement	8
Findings	9
Conclusion	13
Practice and Policy Implications / Recommendations	15
Pathway to Impact	16
References	17
Acknowledgements	19

EVIDENCE BRIEF

Why did we start?

Advance Care Planning (ACP) is a process of discussion between patients, health care providers and, those closest to them. ACP aims to clarify a patient's preferences for their future care in the event that they lose capacity to make decisions for themselves. If a patient has not clarified their wishes in advance, often, family members are asked to make difficult and emotive choices about whether or not to proceed with life sustaining treatments. Although guidelines suggest that ACP should commence as early as possible, evidence shows that most nursing home residents with dementia do not have an advance care plan. Hence, this study sought to identify the key components of an ACP intervention, develop an evidence-based family focused intervention, and evaluate its impact on the families of nursing home residents with dementia.

What did we do?

We developed and tested an ACP intervention that comprised the following 'key' components: a trained ACP facilitator; family education; family meetings; documentation of ACP decisions; and, orientation of GPs and nursing home staff to the intervention. This study employed both quantitative and qualitative methodologies. The quantitative component comprised a paired cluster randomised controlled trial. Outcomes of interest included: family carer uncertainty in decision making; family carer satisfaction with nursing home care; psychological distress among family members; quality of death; and, administrative outcomes. The qualitative component of the study examined the experience of family members as a best interest decision maker and their experience of participating in the ACP process. In addition, we also interviewed nursing home managers and the ACP facilitator in order to assess their experiences and perceptions of implementing the intervention.

What answer did we find?

There was evidence of a reduction in decisional conflict among carers who received the intervention when compared to the usual care group. There was also evidence of a statistically significant improvement in family carer satisfaction with nursing home care. No statistically significant differences were noted between the two groups on measure of psychological distress. Although we found an increase in Do Not Resuscitate (DNR) orders and a reduction in both hospital admissions and deaths in the intervention group, this difference was not statistically significant.

Qualitative findings revealed the feelings of burden experienced by family carers and the sense of premature loss they felt as a direct consequence of their relative's dementia. Many carers reported having a limited understanding of dementia and had mixed experiences of using healthcare services. Nursing home managers recognised that a major barrier to implementing ACP was the lack of dementia knowledge demonstrated by both family members and nursing home staff as well as time and resource constraints.

What should be done now?

Education is essential to allow family carers to contribute to or make informed best interest decisions on their relative's behalf. Our study demonstrated that it is feasible to implement an ACP intervention in dementia care nursing homes with effective outcomes. ACP should be integrated into 'usual care' within nursing homes and should be supported by other healthcare providers such as GPs. Overall, we identified a need to increase dementia knowledge among both family carers and nursing home staff.

Background

Dementia is increasing in prevalence and becoming one of the leading causes of death worldwide (Ferri et al, 2005). The World Health Organisation (2012) predicts that the number of people living with dementia will double every 20 years, with 7.7 million new cases reported worldwide each year. This will have a major impact on patients, their families and society as a whole.

Dementia is a progressive and largely irreversible clinical syndrome of the brain which can lead to disturbances in: memory; orientation; thinking; comprehension; the capacity to learn; calculation; judgement; and, communication difficulties (World Health Organisation, 2012). Dementia usually progresses through three stages (early, middle and late) where health and functioning deteriorate over time. The majority of people experience dementia as a consequence of Alzheimer's disease which accounts for approximately 60-70% of cases.

As it progresses, dementia requires complex care and, in its later stages is associated with high levels of dependency which may require a nursing home admission. As the syndrome progresses many patients will require specialised care and may be transferred to acute hospitals for aggressive and burdensome treatments that provide few long-term benefits to the patient (Gillick, 2000; Mitchell et al, 2004; Lamberg, 2005). From both an ethical and clinical standpoint, understanding when a treatment becomes futile for someone with dementia is highly contested. The decision, of whether to treat physical complications in patients with severe dementia is generally answered by family members (acting as best interest decision makers) supported by doctors. Making these decisions is made more challenging if the patient's wishes regarding their future health care have not been stated in advance. Person-centred care and the patient's right to self-determination are key ethical principles in healthcare. However, due to the nature of dementia, patients will eventually lose capacity to express such preferences. Advance Care Planning (ACP) is a process designed to help determine a patient's wishes regarding their care (NHS End of Life Care, 2008; NHS Improving Quality, 2014; Seymour et al, 2010). However, given its importance, the prevalence of ACP among patients with dementia is low (Laakkonen et al, 2008; Godwin and Waters, 2009).

ACP is a process of discussion between a patient, health care providers and those closest to them about their future care preferences in the event that the patient loses the capacity to make decisions for themselves (Royal College of Physicians, 2009). Ideally, an ACP document is created when the person is capable of making an informed choice about their future care and is enacted only when the person is no longer able to express their wishes. It acts as a guide to help best interest decision makers and doctors make informed choices about someone's care. The best interest decision maker's role is complex and can place a significant burden on family members or other caregivers who have to make these decisions. They may be required to make many difficult and emotionally burdensome choices about whether or not to proceed with life sustaining treatments at a time when they feel unprepared to make such decisions (Caron, et al, 2005; Sachs et al, 2004; Livingston et al, 2010) or to contribute to these decisions (Macmillan Cancer Support and The Public Health Agency, 2013). Regrettably, given the relative importance of ACP in the dementia population, the available research demonstrates that the provision of ACP for persons with dementia is poor (Godwin et al, 2009).

To help family carers participate in best interest decision making and contribute to or make informed decisions about the patient's future care they need information to help them understand the course of dementia, possible complications and, the availability of therapeutic options (Arcand et al, 2013). Hence, the purpose of this study was to develop a family focused ACP intervention and evaluate its impact on family carers who had a relative with advanced dementia residing in a nursing home.

Aims and Objectives

The aims for this study were to:

- Identify and articulate the components of a family focused ACP intervention.
- Develop and trial an ACP intervention.
- Evaluate the effectiveness of the ACP intervention with family carers in nursing homes.
- Interview carers to examine their experience of providing care to a significant other with dementia and their views on the ACP intervention.

- Interview nursing home managers and the ACP facilitator to determine their views on ACP, the intervention, and, to identify barriers and facilitators in implementing the intervention.

Methods

This study employed a mixed-methods design with both quantitative and qualitative components. The quantitative component comprised a paired cluster randomised controlled trial. This methodology was employed as ACP was introduced at the nursing home level (rather than at individual level). The primary outcome was family carer uncertainty and difficulty in making decisions about the care of the resident as measured by the Decisional Conflict Scale. Secondary outcomes included family carer satisfaction with nursing home care (measured by the Family Perceptions of Care Scale) and psychiatric morbidity (as measured by the 12-item General Health Questionnaire). These measures were completed by family members who had been identified as best interest decision makers for the nursing home resident with dementia. Participating relatives received a questionnaire and stamped addressed envelope via mail. These measures were completed at baseline and again, six weeks later.

In the qualitative component of the study we evaluated several elements. Interviews with family carers provided an opportunity to understand the lived-experience of family carers who were required to act as a best interest decision maker for family members who no longer had the capacity to make decisions about their future medical care. The interviews with nursing home managers and the ACP facilitator focused on two major themes: how have the components of the ACP intervention helped or hindered the provision of care in their nursing home and, recommendations on how to implement the program and overcome potential barriers to its future use.

A review of nursing home records was undertaken during the six-month period following the intervention. This data was collected by administrators from participating nursing homes who were able to extract it from routinely recorded information (e.g. number of hospitalizations,

emergency transfers to hospitals (A&E), ambulance calls, place of death and, care received in the nursing home or hospital).

Personal and Public Involvement (PPI)

This study benefited significantly from the involvement of PPI representatives. The design and implementation of the study recognised the important role played by service users, carers and the public. The research team established an advisory committee which comprised professional and lay representatives from the voluntary sector, nursing home providers, clinicians and decision makers engaged in dementia care and palliative care portfolios. The advisory committee worked closely with the research team throughout the study. Through consultation with current carers, past carers and professional colleagues we were able to provide opportunities for our PPI partners to contribute to the development of the intervention as well as shape the methodology employed and the outcome measures used. The input of service users and their families was essential in helping to interpret results, determine the effectiveness and acceptability of the intervention and, inform the future development of the intervention.

Prior to the study's launch, all family carers of nursing home residents were invited to attend engagement events in participating nursing homes. These meetings gave potential participants an opportunity to meet the research team, discuss ACP, discuss the study methodology and, gain an understanding of what participation in the study would entail. In all, 24 engagement events were completed by the chief investigator.

At the conclusion of the study, all participants who had completed a baseline questionnaire were provided with documentation detailing the study's findings and inviting contact with the chief investigator if they wished to further discuss the study and its findings. Similar documentation was provided to healthcare professionals in participating nursing homes.

Findings

Quantitative findings

Twenty-four homes were randomised and participated in the study. Baseline questionnaires were sent to 657 family carers. The overall response rate was 30% (197/657), a 36% response rate was recorded in the usual care group and a 24% response rate in the intervention group. In the intervention group 67 family carers completed questionnaires at baseline and follow-up while 98 family members in the usual care group completed questionnaires at both time points. The majority of respondents were daughters whose parent had moderately severe to severe dementia. ACP meetings were completed with 67 intervention group carers; on average, these meetings lasted one hour. ACP facilitator time allocated to each family averaged 130 minutes, this included administration, face-to-face contact, telephone calls, drafting an ACP and liaising with nursing home staff.

Typically, family carers identified preferences for their relative's care which included: being kept pain free and in comfort; non-essential medication should be discontinued; their relative should be allowed to die within the nursing home; religious support should be provided; and, nursing home staff to provide emotional support in the family's absence. Family carers also wanted to be consulted on decisions to transfer the patient to hospital; to avoid life prolonging measures if there was no possibility of improving quality of life; and, if a Do Not Resuscitate (DNR) order had been completed by the resident, that their wishes would be honoured.

In terms of outcome measures there was evidence of a significant improvement in total mean scores on the Decisional Conflict Scale (DCS) favouring intervention group participants (-10.5, 95% confidence interval -16.4 to -4.7; p<0.001). There was also evidence of differences between the intervention and usual care groups on all subscales of the DCS.

In terms of psychological distress there was little evidence of a difference between the intervention group and usual care group on total General Health Questionnaire (GHQ) score.

There was evidence of a statistically significant improvement in the total mean Family Perceptions of Care Scale (FPCS) among participants who received the intervention compared to the usual care group (8.6, 95% CI 2.3-14.8; p=0.01). This change in total score was largely driven by significant improvements in the subscales relating to 'Family Support' and 'Communication'.

We also examined routinely recorded statistics relating to the number of DNR orders completed in the participating nursing homes, reductions in hospital admissions and deaths recorded during the study period. While there were differences in favour of the intervention group none of these were statistically significant.

Qualitative findings – the views of carers

An overarching theme of 'Transitions of Care' was found to reflect the experience of family carers. This theme comprised four sub-themes: The impact of caring for someone with dementia; differing levels and sources of support; knowledge and understanding; and, experience of the health care environment.

The impact of caring for someone with dementia.

This theme related to the personal impact of caring and coping for a relative and dealing with the experience of being a decision maker for someone with dementia. Carers believed that the chronic and progressive nature of dementia impacted on their experience as they slowly 'lost' the person they once knew. The stress and guilt associated with this premature feeling of loss led to significant levels of mental and emotional exhaustion among carers who were unsure how to cope in these circumstances. As one carer stated; "*She's in this horrible limbo state, and has been for a long time, where she's neither dead nor alive*". Carers reported that they believed they were failing their relative as they were no longer able to care for them at home and this feeling of failure was compounded when they were forced to have their relative placed in a nursing home. This transitional period seemed particularly difficult for carers who reported that once their relative was established in the nursing home their fears and anxieties were reduced. This

was largely due to carers recognising that their family member was cared for, and were now living in an appropriate environment where they were safe, happy, and reasonably content.

Differing levels and sources of support

Family carers discussed the levels of formal and informal support available to them and how effective these supports had been in helping them to provide care for their relative. Carers valued the support of extended family members and friends though often family carers reported that they felt isolated. In some instances family carers believed that dementia and its associated symptoms had contributed to strains within their family and the end of friendships; “*People came, kept calling for a little while and then, one by one, they faded away*”. Carers valued the communication and support they had received from nursing home staff however, they noted that due to staff turnover in nursing homes that this was a source of support that they could not rely on. Carers reported mixed experiences when discussing the support that they had received from formal healthcare providers. Some family carers reported a lack of continuity in service provision which contributed to a sense that some health care professionals were unfamiliar with their circumstances. Carers also reported that they were unaware of potential sources of support as often, information sources were not clearly ‘signposted’; “*..there isn't an advice centre you can go to and have a chat...where do you go? It's not Citizen's Advice, it's not Cruse bereavement...*”.

Knowledge and understanding

This theme illustrated the level of understanding and competence family members and health care professionals demonstrated regarding dementia and also the systems and processes which were in place to help them improve their knowledge. Overall, family members reported that they had limited understanding of dementia and its prognosis. Providing education that would allow family members to understand and anticipate the disease’s progression was seen as a key requirement. Family members also felt that many members of nursing home staff had a limited understanding of dementia. This lack of knowledge among both carers and nursing home staff contributed to a reluctance to initiate discussions about end-of-life care. Carers acknowledged

that for many, discussing end-of-life care was an uncomfortable topic though, for those who had participated in end-of-life discussions, there was acknowledgement that it made planning their relative's future care much more easy.

Experience of the health care environment

Carers discussed their relative's experience of hospitalisation. In the main hospitalisation caused significant stress for carers as their relative experienced disorientation or heightened confusion. Again, carers reported that general hospital staff lacked knowledge about caring for someone with dementia and other inpatients would react inappropriately to patients exhibiting symptoms. Carers also believed that, on many occasions, hospitalisation was unnecessary; "*whenever they have a problem, it's all so easy to ring the out-of-hours doctor, who ships them up to A&E,somebody from out-of-hours who doesn't want the responsibility*".

Qualitative findings – the views of Nursing Home Managers and the ACP Facilitator

Interviews with nursing home managers revealed several themes relating to the acceptability and feasibility of implementing an ACP intervention within the nursing home. In terms of acceptability managers recognised that family members had little knowledge of dementia and required additional education and support to allow them to participate in ACP. In some instances managers reported that a lack of knowledge among families acted as a barrier to end-of-life discussions as nursing home staff did not want to upset relatives by discussing the prognosis. Managers also recognised that many nursing home staff would have to further enhance their knowledge and skills if they were to successfully engage in ACP with family members; in particular they would need to enhance their knowledge of dementia and their communication skills in order to engage successfully with family members. There was recognition that the model of ACP employed in this study was key as it had created a set of conditions where family members could access information, gain an understanding and engage in conversations which allowed them to candidly talk about their fears and concerns about their relative's dementia. This process had allowed them to understand and contribute to the ACP process in a way which had facilitated shared decision making; "*It gives reassurance to families, they know where we are going, and it*

gives reassurance to us that we also know the families wishes and the patient's wishes going forward. I think it benefits both parties a lot".

In terms of feasibility, nursing home managers recognised that implementing ACP would require a change in working culture within the nursing home and staff would need to be sufficiently motivated to gain the additional knowledge and skills required to undertake ACP. Managers also recognised the variety of skills and experience within their staff team and felt that some staff may be better able to undertake ACP than others; "*Some nurses...through experience are much more comfortable with doing it [end-of-life discussions] so it's sort of trying to get everybody up to that level*". Managers also believed that in order to undertake ACP, their staff would have to be able to build trusting relationships with families and be able to actively listen to their concerns. Although managers had positive views about facilitating ACP within the nursing home they recognised that this would require additional training for their staff teams which would be difficult to source and releasing staff for training or to engage in ACP activities would be difficult as they have very tight resource constraints; "*You're working on limited staff. You're up against it with staff absences and stuff and, with the best will in the world and the best staff in the world...would it ever be done? I think you need to have one person focusing on it all the time*".

Conclusion

The paired cluster randomised controlled trial indicated that it is feasible to implement an ACP intervention within a dementia nursing home and to achieve positive outcomes. This study illustrates the importance of improving dementia knowledge among both family members and nursing home staff. Improved education for family members is vital as often, as their family member enters the later stages of dementia, they have to make difficult decisions about their relative's care. Improving knowledge about dementia and its prognosis will help family members weigh up the potential benefits and burdens associated with available treatment options. Clinicians and policy makers should also recognise the importance of communication between formal healthcare providers and family carers and should seek to improve communication with family caregivers. Furthermore, ACP needs to be integrated into routine nursing home care and

should involve other formal care providers such as the resident's GP and nursing home staff. In conclusion, it should be recognized that the approach pursued in cultivating and supporting sustainable ACP expertise will be shaped by broader nursing home conditions and should be accounted for in practice and policy deliberations. The qualitative element of the study aimed to explore the experiences of family carers responsible for decision making on behalf of a relative living with advanced dementia and Nursing Home Managers' views on implementing an ACP intervention. Findings have implications for practice and education and suggest the need to develop family carer psychoeducational care interventions, with embedded facilitated peer support, to help prepare this population for contributing to or making best interest decisions. Given the global impact of dementia (World Health Organisation 2012), and the fact that most people with dementia receive end of life care in nursing homes (NICE, 2006; Mitchell et al, 2004), the findings of this study have implications for similar nursing homes internationally.

Key findings for further investigation are to hold goals of care decision-making earlier in the dementia disease trajectory; recognition of the influence of family dynamics; improve knowledge to facilitate informed decision-making, and, communication with and between staff.

Recommendations for Practice and Policy

This study identified a range of recommendations for policy and practice. Some of the key recommendations are summarized here:

- Dementia should be recognized as a terminal illness. This should inform the development of all policies relating to dementia care.
- In order to facilitate the timely completion of end-of-life care plans we need to increase awareness about ACP among the general population.
- There is a pressing need to improve knowledge about ACP among health care professionals who work outside acute hospitals and palliative care.
- There is a need for policies which will help to facilitate the development of effective partnerships between staff based in the community, primary care, palliative care and the nursing home sector.
- Nursing homes should have an explicit policy to guide the provision of end-of-life care for residents with dementia.
- Where possible, nursing home residents with a diagnosis of dementia should not be moved at a crucial point in their care.
- A range of education programmes and tools have been developed to help nursing homes deliver improved end-of-life care. However, these programmes need to be evaluated, particularly in relation to people with dementia and their families.

Pathway to impact

The importance of ACP is acknowledged in many policy documents however, current evidence suggests that the completion of an ACP, particularly among those with dementia is rare. We engaged in a collaborative research process where Patient and Public Involvement and consultation with a major provider of private nursing home care was key to formulating the research questions and developing the intervention. This process was undertaken to ensure the relevance of the project to policy makers, service providers, residents with dementia and their families, both locally and further afield.

To ensure our findings reach an appropriate audience we have engaged on a series of knowledge translation activities including: reporting findings to participants; providing summary findings to nursing home managers and staff; publishing papers summarising the study in academic journals (Brazil et al, 2017a; Carter et al, 2017; Brazil et al, 2017b; Carter et al, 2016; Brazil et al, 2015); and, presenting findings to healthcare providers and NHS Trusts in an effort to promote collaboration between the research team, healthcare professionals and, the policy and practitioner community.

We were also mindful of the national and international significance of our study and engaged in a series of conference presentations to disseminate our findings widely amongst academics and professionals.

In addition, as a direct result of this study and our dissemination activities, staff in the Belfast Health and Social Care Trust are engaging with the research team with a view to using an updated version of the 'Comfort Care at the end of life for persons with Alzheimer's disease or other degenerative diseases of the brain – a guide for carers' booklet as a decision aid to help family carers contribute to or make best interest decisions for older people with dementia. The Comfort Care Booklet has been amended to suit the Northern Ireland population and can be accessed here:

<http://www.research.hscni.net/sites/default/files/Comfort%20Care%20Booklet.pdf>

REFERENCES

- ARCAND. M., BRAZIL, K., NAKANISHI, M. and ET AL, 2013. Educating families about end-of-life care in advanced dementia: acceptability of a Canadian family booklet to nurses from Canada, France, and Japan. *International journal of palliative nursing*, **19**, pp. 67-74.
- CARON, C., GRIFFITH, J. and ARCAND, M., 2005. End-of-life decision making in dementia: The perspective of family caregivers. *Dementia*, **4**, pp. 113-136.
- FERRI, C.P., PRINCE, M., BRAYNE, C., BRODATY, H., et al. (2005). Global prevalence of dementia: a Delphi consensus study. *Lancet (London, England)*, **366**(9503), pp. 2112-2117.
- GILLICK, M.R., 2000. Rethinking the role of tube feeding in patients with advanced dementia. *The New England journal of medicine*, **342**(3), pp. 206-210.
- GODWIN, B. and WATERS, H., 2009. 'In Solitary Confinement': Planning End-of-Life Well-being with People with Advanced Dementia, their Family and Professional Carers. *Mortality*, **14**(3), pp. 265-285.
- LAAKKONEN, M., RAIVI, M., ELONIEMI-SULKAVA, U., TILVIS, R. and PITKALA, K., 2008. Disclosure of Dementia Diagnosis and the Need for Advance Care Planning in Individuals with Alzheimer's Disease. *Journal of the American Geriatrics Society*, **56**(11), pp. 2156-2157.
- LAMBERG, J.L., PERSON, C.J., KIELY, D.K. and MITCHELL, S.L., 2005. Decisions to Hospitaize Nursing Home Residents Dying with Advanced Dementia. *Journal of the American Geriatrics Society*, **22**(2), pp. 201-208.
- LIVINGSTON, G., LEAVEY, G., MANELA, M. and ET AL., 2010. Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *British Medical Journal*, pp. 341.

MACMILLAN CANCER SUPPORT and THE PUBLIC HEALTH AGENCY. 2013. Your life and Your Choices: plan ahead. 1st edition. MAC14376.

MITCHELL, S.L., KIELY, D.K. and HAMEL, M.B. 2004. Dying with Advanced Dementia in the Nursing Home. *Archives of Internal Medicine*, 164(3), pp. 321-326.

NATIONAL INSTITUTE OF HEALTH AND CLINICAL EXCELLENCE, 2006. Dementia: Supporting People with Dementia and their Carers. London: NICE.

NHS - HEALTH EDUCATION ENGLAND, 2014. *End of Life Care for All (e-ELCA)*. London: NHS England.

NHS IMPROVING QUALITY, 2014. *Capacity, care planning and advance care planning in life limiting illness: A Guide for Health and Social Care Staff*. London: NHS England.

ROYAL COLLEGE OF PHYSICIANS, 2009. *Concise Guidance to Good Practice: A series of evidence-based guidelines for clinical management*. Twelve. London: Advance care planning National Guidelines.

SACHS, G.A., SHEGA, J.W. and COX-HAYLEY, D., 2004. Barriers to Excellent End-of-Life Care for Patients with Dementia. *Journal of General Internal Medicine*, 19(10), pp. 1057-1063.

SEYMOUR. J., ALMACK, K. and KENNEDY, S., 2010. Implementing advance care planning: a qualitative study of community nurses' views and experiences. *BMC Palliative Care*, 9(4).

WORLD HEALTH ORGANISATION, 2012. *Dementia: A Public Health Priority*. Geneva: World Health Organisation.

Acknowledgements

This project was supported by the Health and Social Care Research and Development Division, Public Health Agency for Northern Ireland and The Atlantic Philanthropies. We are very grateful for the support provided and, in particular the guidance and assistance of Dr Gail Johnston. We would also like to express our thanks to all the families and health care professionals who participated in this study, this work would not have been possible without their support.