Learning from international models of advance care planning to inform evolving practice in England

RESEARCH FINDINGS

Physician leadership and involvement in advance care planning (ACP) are key; recommendation by a physician was the most important factor influencing take-up. But physicians do not have the time to deliver ACP support single-handedly

Nurses, particularly those involved in chronic disease management, and social workers can play key roles. Social workers have facilitation and counselling skills, work with families and are able to conduct challenging conversations efficiently

The growth of palliative care social work and increasing involvement of social workers in the care of people with chronic disease and at the end of life present new possibilities for their involvement in ACP

Team-based approaches align well with new multi-disciplinary models of care and allow for coordinated approaches

While supporting individuals is important, some of the aims of ACP can be promoted through public education, public health, group facilitation approaches and community-based interventions

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BACKGROUND

Advance care planning (ACP) has been promoted in policy as a way of improving the quality and appropriateness of care and making better use of resources.

It is a voluntary process of reflection and discussion, usually undertaken with a health or care professional, about goals and preferences for future care. These are usually documented so they can be shared and inform care in the event of loss of capacity.

In research, ACP has been associated with fewer emergency admissions, hospitalizations, burdensome treatments and hospital deaths, reduced hospital costs, greater concordance of care with preferences and improved carer satisfaction. However, evidence about implementation and resources needed to deliver ACP support is lacking.

STUDY AIMS

- examine how participating organisations staff their ACP support provision and identify opportunities, barriers and models for involving different health and care professionals

- identify organisational aims for providing ACP support and explore leaders' perspectives on the economic case

- explore experiences of public demand for ACP support and identify factors that are thought to influence this

- explore significant areas of resource use, particularly staff time, for delivering ACP support and gain insights into how high-quality ACP support can be provided efficiently and at scale.

Methods

This qualitative study was conducted in twelve international health and care organisations with extensive practical experience of delivering system-wide ACP support (see Box 1). These are based in the United States (US), Canada, Australia and New Zealand, countries which all have well-developed ACP policy.

In-depth qualitative interviews were conducted with purposive samples of system leaders, specialist ACP staff, physicians, and other clinical and non-clinical staff (average 13 per system). Interviews were audio-recorded with permission and data analyzed thematically using NVivo software.

FINDINGS

OPPORTUNITIES AND BARRIERS FOR ENGAGING HEALTH AND CARE STAFF

With no clear professional lead role, ACP is commonly thought of as 'everyone's job' with the potential contributions of different types of professional outlined only broadly in policy and guidance.

In this context, the research team explored how ACP support was staffed in each of the participating health and care systems, identifying the opportunities and barriers for involving different health and care professionals.

Most organisations had a full-time ACP coordinator responsible for strategic coordination and development of ACP support. This role, alongside active and sustained senior management support, helped to embed provision of ACP support. In two systems where coordination was led by physicians with full-time clinical roles, sustaining momentum was more challenging.

Some organisations had dedicated ACP facilitators. They could act as role models, help to normalise ACP conversations and show that such conversations are feasible and acceptable. Some clinicians appreciated having them to refer to and their independence was valued. However, ACP conversations conducted by dedicated facilitators were not always well-integrated with the rest of a person's care and, if entirely physician-led, over-reliance on dedicated facilitators was not considered sustainable or scalable.

Physicians were often supportive, sometimes taking on leadership roles for ACP and acting as champions. However, many did not refer patients to trained staff, where available, or facilitate ACP conversations themselves. The main reason was lack of time. Other barriers included the potentially erroneous belief they were already having these conversations, poor skills and confidence and concerns about fragmenting discussions about goals of care. Encouraging physician ownership was considered important for integrating and sustaining provision of ACP support but, where expert clinicians were scarce, ACP could become limited in scope and occur late in the illness trajectory.

Nurses embedded in chronic disease management were well placed to deliver ACP support, but needed protected time and support from physicians. Social workers had good facilitation skills, notwithstanding some concerns about de-skilling, and were thought to facilitate ACP conversations efficiently. However, they could also lack time, especially in busy clinic environments, and needed more clinical support than nurses.

Box 1: Organisations involved in study

United States	
Gundersen Health	A physician-led, not-for-profit healthcare system; birthplace of Respecting Choices, an evidence-based ACP model for person-centered decision making
Dartmouth-Hitchcock	A non-profit, academic health system, providing ACP support using the Honoring Care Decisions ACP programme (based on the Respecting Choices model)
Wisconsin Medical Society	A physician member association supporting 32 participating health organisations to implement the Honoring Choices ACP programme (based on the Respecting Choices model)
Sharp Healthcare	A not-for-profit, integrated regional health care system, providing ACP support in collaboration with the Coalition for Compassionate Care of California
Canada	
Northern Alberta Renal Program	Renal programme in Edmonton, Alberta, providing integrated ACP support using an approach based on Conversations Matter
Fraser Health	One of six publicly funded health care regions in British Columbia, providing ACP support in community, acute and residential care based on materials developed provincially and at Fraser Health Authority
Australia	
Austin Health	A publicly-funded health service in Melbourne, providing acute, sub-acute, mental health and ambulatory services, providing ACP support using materials developed locally and as part of Advance Care Planning Australia
Northern Health	A publicly-funded provider of acute, sub-acute and ambulatory specialist services in Melbourne, providing ACP support using the 'A-C-P in three steps' approach developed within Northern Health
Barwon Health	A publicly-funded, large regional health service, providing acute, sub-acute, elderly care, community health and mental health services, with ACP support delivered across secondary and primary care using materials, including MyValues, developed in Barwon Health
Albany Health	A regional primary and secondary healthcare system, providing ACP support using forms developed by the Western Australian government and piloting systems for communication and access of ACP documents
New Zealand	
The Canterbury Initiative	A District Health Board initiative, delivering change and quality improvement initiatives across community, primary and secondary care and providing ACP support using materials developed by the Canterbury Initiative and by the National ACP Cooperative, New Zealand
Auckland District Health Board	A regional health authority overseeing community, primary and secondary care, providing ACP support using material developed by the National ACP Cooperative, New Zealand

Care homes were a challenging environment, with low skill staff, high staff turnover and sometimes weak links to external health services. Inreach teams of palliative care physicians and nurse practitioners provided some ACP support. In US systems, spiritual care advisors provided ACP support, particularly in hospitals. Volunteers played an important role in community education.

PERSPECTIVES ON THE ECONOMIC CASE

The economic case for investing in ACP support was multi-faceted. Leaders expected ACP support to help limit unwanted and low-value treatments. They also expected it to deliver quality benefits, by preparing patients and families for future health deterioration and the decision-making likely to accompany this and by improving communication with care providers. At an organisational level, it was thought to reduce the risk of complaints and possible legal challenges from bereaved families and to support health and care staff by reducing crisis-driven decision-making, potential conflict with families and experiences of moral distress.

FACTORS INFLUENCING PUBLIC DEMAND FOR ACP SUPPORT

Respondents said that consumer research pointed to high levels of in principle support for ACP and that those who undertook ACP were generally highly satisfied. However, demand varied from setting to setting; sometimes demand was higher than the capacity of organisations to respond to it while, in other cases, people frequently declined ACP conversations, failed to respond to repeated invitations or did not show up to appointments. The reasons for this were not always clear, but suggested that demand was unsettled. The lack of a user-led political lobby for ACP was also noted.

Demand was also limited by poor public understanding of health- and

care-related decision-making. People did not always understand why ACP was necessary or what choices might be involved. Misunderstandings about disease progression and medical treatments were common, and some were concerned about not being able to change their mind or of ACP influencing their care negatively. Organisations aimed to address these gaps in understanding in the course of ACP conversations, and through public education and community outreach.

Recommendation from a physician was the most important influence on whether people chose to undertake ACP. Other facilitating factors included experience of close relatives or friends dying, a hospital admission or health crisis and patients' desire to limit the burden on their families. People also naturally varied in how much they wanted to plan; some were keen, while others put it off or saw it as too difficult, preferring to leave decisions to others.

There were differing views on the relevance of race, religion and culture; some identified cultural and religious taboos whereas others thought service mistrust issues or how ACP was presented were more important barriers.

RESOURCE USE IN THE DELIVERY OF ACP

Organisations had good information about the costs of specialist ACP staff, materials, training courses and community-based activities. Costs associated with senior management support, quality improvement teams, accommodation for ACP conversations, facilities, administration costs and the time of health and care staff spent in training and delivering ACP support were less readily identifiable.

Training ranged from brief online modules to two-day workshops, and could be a significant, ongoing cost where large numbers of staff were involved. Challenges of ensuring benefit from wide-ranging training

investments were identified in several systems. Responses included having most staff introduce and refer, while limiting the number of staff fully trained to facilitate ACP conversations. Others limited training length, offering follow-up training as needed. ACP training was also sometimes incorporated into continuing professional education.

Depending on complexity, 30-90 minutes was considered appropriate for an effective ACP conversation, potentially spread over multiple shorter discussions, with briefer discussions later on for reviewing ACP decisions. It was noted that this was not all new work; ACP systematized conversations that were, or should, already be occurring. The main factors influencing conversation length were thought to be the skills and experience of facilitators and participants' informational and educational needs. Conversation tools had limited effect on conversation length. The serious Illness Conversations Guide© (Ariadne Labs 2015) was sometimes used helping busy physicians, particularly in acute settings, have 15–20 minutes goals of care discussions. However, intended for advanced illness, these needed to build on earlier education and ACP discussions.

PROMISING MODELS FOR DELIVERING ACP SUPPORT EFFICIENTLY AT SCALE

Drawing upon findings from the study as a whole, promising approaches for the efficient delivery of high-quality ACP support were identified:

- Team-based provision allows physicians to retain involvement while more time-consuming aspects are completed by less costly but skilled staff such as nurses and social workers. This approach aligns well with new models of care such as patient-centred medical homes or, in England, multi-specialty community providers and primary care homes

- Some staff specialized in ACP conversation, having it incorporated into their work role and/or having some work re-allocated. Experienced staff are able to conduct conversations more efficiently and in-depth training can be better-targeted

- ACP conversations were sometimes 'broken down' into multiple shorter conversations, for example, in chronic illness and other routine care. However, sufficiently uninterrupted time is needed to raise and discuss potentially complex or emotional issues and care must be taken to ensure that ACP does not get 'squeezed out' or become too fragmented or 'gappy'

- Some organisations had successfully used, or were considering, decision aids, particularly for common interventions that were poorly understood. These can simplify conversations, support non-clinicians to facilitate ACP conversations and ensure people receive consistent information

- Group facilitations were led by trained facilitators, usually nurses or social workers in community and clinical settings. Many preferred this approach, benefiting from the wider discussion and feeling less need to pre-commit to making a written plan. Even where people do not complete documents , they are likely to be better prepared for later decision-making

- Online videos, community events and public education can help to prepare people for later decision-making. Subsequent ACP conversations are also likely to take less time. However, encouraging participation from those traditionally less likely to engage with public education initiatives is important.

CONCLUSION & IMPLICATIONS

This study was pragmatic and exploratory, mapping key issues for policy, practice and research. It provides a rich descriptive overview of how ACP support is resourced and delivered in twelve international health and care organisations with well-established, system-wide provision and identifies a range of issues and themes, as well as promising approaches for providing high-quality ACP support efficiently and at scale.

The findings highlight the importance of physician leadership and involvement, but physicians do not have the time to deliver ACP support single-handedly, nor should they for good quality care.

Nurses, particularly those involved in chronic disease management, and social workers can play key roles.

Social workers, in particular, have facilitation and counselling skills, work with families and can conduct ACP conversations efficiently.

The growth of palliative care social workers and the increasing involvement of social workers in the care of people with chronic disease and at the end of life presents new possibilities for their involvement in ACP.

Team-based approaches align well with new multi-disciplinary models of care, for example, multi-specialty community providers and primary care homes.

The study also identified information and education as key aspects of ACP support. While individual conversations are important, educational needs may also be addressed using, potentially targeted, public education, public health and community-based interventions. These may also be an effective way of targeting education and support for carers, including those of people with dementia.

FURTHER READING

Dixon J, Knapp M (2019) Delivering advance care planning support at scale: a qualitative interview study in twelve international healthcare organisations, *Journal of Long-term Care*. pp. 127–142.

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National Institute for Health and Care Excellence (2019) Advance care planning. A quick guide for registered managers of care homes and home care services www.nice.org.uk/Media/Default/About/NICE-Communities/Social-care/quick-guides/advance-care-planning-quick-guide.pdf

The School for Social Care Research was set up by the National Institute for Health Research (NIHR) to develop and improve the evidence base for adult social care practice in England in 2009. It conducts and commissions high-quality research.

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