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Advanced Care Planning: Policy and Real Life Decision-Making?

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In the UK there is, considerable emphasis in policy and professional guidance on advanced care planning (ACP). ACP is a key pillar of the NHS End of Life Care Programme (1) to secure treatment and care consistent with patients' goals. General Medical Council guidance (2) states that doctors should encourage patients who have a chronic or life threatening condition or where loss of capacity may be anticipated, to consider preferences for future care and treatment. The 2005 Mental Capacity Act (MCA) (3) established a legal framework in England and Wales whereby healthcare decisions made in advance of loss of capacity are recognised in law (similar provision underpins the Adults with Incapacity (Scotland) Act (4) with some differences in detail). The MCA includes the right of patients who can no longer decide for themselves to refuse treatment, albeit within tightly defined conditions. Advance directives refusing treatment (ADRTs) on behalf of individuals lacking capacity are formal documents. These must be written, signed and witnessed at a time when the person has capacity to make health care decisions. They must specify which treatment(s) is to be refused and the circumstances in which it should apply. Additionally, a Health and Welfare Lasting Power of Attorney (LPA) may be made nominating someone (the attorney) to make health and care decisions, including refusal of treatments specified in the document for a patient (the donor) when s/he loses decisional capacity. The LPA must be registered with the office of the Public Guardian (on payment of a fee). The system is complex and requires knowledge and resources to navigate.

There is an enormous body of research on ACP, particularly from the United States where it has been part of the policy landscape for nearly four decades. Focus is on enabling particular groups, such as older people, those with chronic health conditions and with life threatening illnesses, to express values and treatment preferences, and to record these in formal written documents ('living wills' and advance directives). In the United States, there is a legal requirement on agencies participating in Medicare or

Medicaid (hospitals, nursing homes and home health care services) to provide advice to individuals of their rights to make healthcare decisions using advance directives. The underpinning assumption of ACP is that elicitation and documentation of preferences will ensure that medical, therapeutic and care interventions are delivered in accordance with patient choice. Considerable policy attention has been directed at increasing ACP completion, with research endeavour aimed at interventions to effect this, encapsulated in systematic reviews (5,6). Other studies have examined specific outcomes of ACP such as hospitalisation rates (7)), although these tend to be located within complex interventions of which ACP is only one component. Few studies have explored whether the care received was consistent with expressed wishes in an ACP and those that have report inconsistent findings (8, 9). Even so, completion rates for ACP are generally low and variable between countries and patient groups.

The survey on advanced care planning in this issue of *Age and Ageing* (10)) adds further evidence on the gap between policy intent and practice accomplishment in England. Conducted among a community based sample of some 2000 older people in the East Midlands, the findings evince minority engagement in any formal advance care planning process. Further, only a tiny proportion of participants (4%) had completed an ADRT that in theory would have legal force assuming it conformed to the requirements of the MCA. Even among those who had engaged in ACP, most had not discussed it with a health professional. ACP as practiced based on this survey is a process primarily pursued within the private sphere of informal close relationships. This is at odds with the policy conception of a dialogue between the individual patient and health professional to draw out, clarify and document future care and treatment preferences in advance of loss of capacity. Insofar as ACP was pursued by survey participants, it mainly took the form of a general statement of wishes which in legal terms could contribute to 'best interest' decision-making but is not incumbent on professionals to follow.

In the paper, Musa et al. simply report their findings: the gulf between how ACP is currently understood in policy and professional guidance and the views and practices of

older people as expressed in the survey, are not pursued. Yet, the dissonance between policy and practice cannot only be attributed to lack of knowledge about the process, but wider socio-cultural factors are also implicated. Three specific factors are considered below drawing on UK based empirical research (albeit limited) which touch on ambiguities in the survey findings and raise questions about the conception of ACP in policy. These are: the significance of family/close others in ACP discussions; ACP as a communication process and not a fixed event; and knowledge and engagement of professionals. They have relevance to current debate within the literature on the need for a more dynamic and systemic approach to ACP implementation.

Qualitative research with older people in the community (11,12) and among those with specific chronic health conditions (13, 14) suggests that two factors in particular shape the primacy attached to family as the arena within which end of life priorities are discussed. It is to provide guidance for close family members to obviate their distress when having to make difficult choices about end of life care at the point when the person lacks decisional capacity. In this respect, it is an expression of caring about family and intimates and the desire not to be a burden at end of life. It also reflects mutual inter-dependence between individuals in close relationships with each other. Both factors shape the level of trust placed in 'significant others' to communicate the person's interests and wishes to health professionals, and reinforce the importance of involving family/those close to the person in the advanced care planning process for best effect (9). There is some evidence as well that the conception of individuals making choices and decisions in the context of wider family/close others has particular resonance among some minority ethnic groups (11, 12, 15).

Musa et al. reported that among those who had pursued some form of advance care planning, preferences were expressed in general terms. It is conceivable that this may reflect the relative immaturity of ACP in the UK given that MCA has been operational for less than a decade. Evidence from the United States suggests that the issue is more fundamental. In one of the few longitudinal studies of ACP (16), only a small number of

individuals wished to engage in anticipatory micro-management of their own dying and death. Most desired to express more general preferences and to allow surrogate decision-makers leeway in decision making. This partly flows from the acknowledged difficulty of specifying in advance what treatments would be refused and the circumstances in which this would happen since preferences are likely to change with health status changes. It partly relates to the trust placed in close others to represent their wishes in relation to in-the-moment medical decisions.

The complexity of the legal framework and the nature of the rights enshrined in law pose a challenge for healthcare professionals to facilitate supportive and informed decision making; and for individuals to exercise choice in practice given the multiple contexts in which such decisions are made. With regard to health professionals in the UK, there is limited survey and qualitative evidence on knowledge about, attitudes to, and involvement in advance planning. First, there appears unequivocal support of ACP in principle but more variable, nuanced and sceptical views on implementation among different professionals in varied health contexts (17-20). A qualitative study with geriatricians (17) reported dissonance between support for anticipatory directives and enacting this in practice. ADRTs were not viewed as a requirement on clinicians to act, but as contributing to the clinician's 'best interest' decision-making, to be taken into account alongside the clinical context, medical knowledge and responsibilities inherent in the professional role. Similarly, an earlier survey of geriatricians views on 'living wills' predating the MCA (18), reported tensions in reconciling individuals' wishes to forgo life sustaining treatments in particular circumstances with professional and personal beliefs in sustaining life. Second, evidence suggests that knowledge about ADRTs and Health and Welfare LPAs - including their legal status - is very variable; as is actual experience in enacting advance planning. In a study of health and social care professionals in palliative and dementia services and in primary, social care and legal agencies (19), knowledge about and involvement in ACP was unevenly distributed among participants. It was more evident among solicitors and professionals in cancer related palliative care

services and least among those working in primary and community care. Third, there is lack of consensus on who should initiate and take responsibility for ACPs; and uncertainty about timing of the process particularly in respect of conditions like dementia or chronic conditions with an unpredictable course (19, 20). Clearly, if health professionals are to engage in dialogue with individuals on advance care planning and are viewed as key to implementation, there is a need for communication and knowledge based training to engage in a dialogue with patients. However, such a dialogue needs to occur not just at end of life but as part of an ongoing discussion about the illness course and treatment options at critical points in the illness trajectory.

Recent attention on systematic and dynamic approaches to ACP has contributed to the development of interventions that take into account the complexities of communication and decision-making in real life at end of life with positive outcomes (9). Notable features of the intervention pertinent to the issues posed above were: engagement of the patient and close family in discussions with a trained facilitator to understand and share values, beliefs and goals of care; systematic education of doctors; and mechanisms to ensure awareness of, access to, and use of documentation. The challenge remains as to how to embed and sustain such interventions in routine care within health systems.

Key Points

1. There is considerable dissonance between the conception of ACP in policy and enshrined in legislation and how many older people wish to convey preferences and choices at end of life.
2. Although older people place high value on a 'good death' and relieving the burden of decision-making on close family, there is little evidence that they wish to engage in the kind of detailed anticipatory planning demanded of ADRTs.
3. Notions of individual patient choice and autonomous decision-making that underpin ACP policy sit uneasily with the importance older people attach to relational decision-making involving close family and intimates and based on shared knowledge and understanding of their values, beliefs and preferences at end of life.
4. Policy and research attention needs to be directed at how to achieve a person-centred, co-ordinated and dynamic approach to ACP; embedded in professional practice and sustained in routine care delivery.

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