

Advance care planning in participative social work practice

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Introduction: advance care planning's importance in social work

Advance care planning (acp), including the related concept of anticipatory care planning, are processes for finding out and recording a client's preferences for how they want to be cared for or treated by health and social care services in the future. These processes must be distinguished from care planning as part of case or care management in providing care services. Acp is an important development for achieving participatory engagement in social work practice because enables clients' preferences to emerge at a stage in clients' care careers when there is a good chance that they can realistically have impact on resource allocation in later care decisions. Existing practice tends to delay client engagement in decision-making until the point at which resource allocation decisions must be made, when the range of choices may have been reduced by preceding events. Also of significance, acp is an example of the development of well-researched practice techniques in social work with people who have long-term care needs. Providing services for such people is increasingly a social work role because populations of older people, who are likely to have increased care needs compared with a younger population, are growing in most developed countries. Existing social work practice focuses on behaviour and social change rather than theorising interpersonal practice with long-term care conditions, where most practice innovation has been concerned with care management to coordinate the provision of disparate services.

This paper starts by examining the nature and sources of acp. An important aspect of recent developments in acp is a shift from formal, rather legalistic, processes carried out occasionally, mainly to facilitate medical decision-making in the event of mental incapacity at the end of life. This practice is developing towards a more interpersonal, helping and caring process carried out to maintain continuity in help to people receiving long-term care or social work services. The second part of the paper outlines the main sources of acp practice. Finally, the third part of the paper

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identifies the potential of acp practice to improving participation strategies and to professionalise care management in service delivery of people receiving care services over long periods.

What is acp?

Acp involves 'thinking ahead' about a client's care arrangements to 'create opportunities to explore wishes and choices for the future for end of life, crisis, respite and rehabilitation needs' (LTCC-JIT, 2009, p. 9). The Scottish government distinguishes between two approaches, advance and anticipatory care planning:

Advance care planning is the term most commonly referred to in end of life care, although it does incorporate the writing of wills or 'Living Wills' now known as advance directives or advance decisions which can be done by the well person early on in life to plan for what *may* happen at the end of life. Anticipatory care planning is more commonly applied to support those living with a long term condition to plan for an *expected* change in health or social status. It also incorporates health improvement and staying well. Completion of a common document called an anticipatory care plan is suggested for both long term conditions and in palliative care. (Healthier Scotland, 2009; emphasis original)

Acp focuses on clients' preferences rather than the professional care planning that is part of care management practice, particularly in long-term social care provision in many European countries (Le Bihan & Martin, 2006). The aim of care management is to coordinate a range of care in people's homes over a long-period possibly involving different agencies and many visiting paid carers. The process involves a professional assessment to determine eligibility for services, from which a care plan is drawn up, which typically defines the needs to be met, the combination or 'package' of services to be provided and the financial arrangements. While clients and informal caregivers might be involved in the assessment, the plan that determines the care package is established by the professional (Payne, 2010).

An extensive American research review focused on end-of-life situations, suggests that many people would value acp discussions but do not have this opportunity, but that they have clear and stable views on how they would like to be treated. Many regard permanent coma, dementia, severe stroke, severe pain as worse than death and would not want life-sustaining treatments in such situations. They would reject treatments depending on how invasive and prolonged they were seen to be (Kass-Bartelmes & Hughes, 2003). Examples of groups who would benefit from acp

provision are people with dementia (Vollandes et al, 2009), heart failure (Formiga et al, 2004) and serious mental health conditions (Foti et al, 2005).

Consequently, acp is increasingly less focused on advance decisions, because it is hard to prepare for all the possible contingencies, but more on preparing people and their families for agreed 'in-the moment' decision-making at the end-of-life, in particular (Sudore & Fried, 2010) Involving informal caregivers and family members is significant in this implementation of acp in long-term care (Fried & O'Leary, 2008). This focus on family engagement and broader decision-making about care, taken up at an early stage in people's care careers, suggests that it will increasingly become an important social work role. An evaluation of an anticipatory care planning project in Scotland suggested that starting from the initial care management assessment process it was possible for social care and other practitioners to engage people with long-term conditions at an early stage in planning for the future. The plans provided support for common anticipated events, such as: carer illness; acute medical problem; acute surgical problem; slow gradual decline of multiple chronic diseases; preferred place of death and whether resuscitation is required if heart failure occurs (Gallagher & Ireland, 2008).

Scottish government policy (Scottish Executive, 2007) sees anticipatory care planning as an important aspect of shifting from health provision that is focused on acute services to a greater priority for long-term conditions. The healthcare aspect of this includes health screening, while people with long-term care needs, including social care needs, would all have individual care plans focused on helping people and their carers manage their needs better. There would also be greater support for family members and carers. Information provision is an important aspect of this development.

Sources of acp

Acp has three important direct sources:

- The process of making advance decisions in end-of-life and palliative care and, connected with this.
- The management of decision-making where people have impaired mental capacity to make care decisions for themselves.
- Planning social and healthcare services for long-term care population to ensure that they have good access to services.

Acp in end-of-life and palliative care

An important source of acp is the practice in end-of-life and palliative care of decision-making where patients are known to have an illness that has reached an advanced stage that will lead to death. As they approach death, patients may lose consciousness and then be unable to give or refuse permission for treatment or, more commonly, to make decisions not to accept treatment for their condition. The three basic choices are:

- Life prolonging care: This would involve cardiopulmonary resuscitation (cpr), that is, stimulating the heartbeat using a defibrillator, and mechanical assistance with breathing).
- Limited care: Patients would accept admission to hospital and antibiotics, but not cpr.
- *Comfort care: Patients would accept treatment only to relieve symptoms, such pain relief (Vollandes et al, 2009).*

It is usually an ethical requirement in this situation for doctors and nurses to authorise or provide treatment that they judge to be in the best interests of the patient. An 'advance decision to refuse treatment' (the British term) or 'advance directive' (the US term) expresses the patient's decisions made in case they lose their mental capacity to make the decision themselves. Many patients as they approach the end of life may also experience periods when they are unable to make decisions, for example because of advanced dementia. Sometimes particular conditions, such as motor neurone disease, affect patients' ability to communicate their wishes, even though they have the capacity to make decisions.

It is easy to misunderstand the purpose behind making provision for advance decisions. For example, some patients concerned that this offers a legal provision for physicians to assist people to commit suicide or denies care at the end of life. Thinking this through, it is important to remember that death is a natural process. At some point in everyone's life, death will take its course. Medical treatment, nursing care and possibly psychological and social support may postpone it, but in the end it must occur. Many treatments to postpone death are unnatural: they may be painful, use heavy medication that has side effects reducing the patient's quality of life. Eventually, they will lose their effect and the death will occur anyway. So the decision has to be made about the point at which treatment is more damaging than advantageous. Such a decision can only be made with full knowledge of the circumstances and wishes of the particular patient: at what point is it too painful, unpleasant or counterproductive for them? When they are unable to express a view, an advance decision can inform the medical decisions about patients' best interests.

Csikai & Chaitin (2006) review the development of advance directives in the US leading to a focus on refusal of treatment in particular circumstances. Medical advance offers a clearer picture of the typical states through which major illnesses will go at the 'end stage', permitting a clearer specification of treatments that are available for an increasing range of illnesses at different stages and which the patient might wish to refuse. This has led to a process of detailed specification of the actions refused in advance. Csikai & Chaitin (2006, p. 77) draw attention to well-established medical protocols for drawing up advance directives. These focus on clear instructions about limitations to medical treatment, particularly where it is invasive, that is, requires breaking the skin or penetrating the body. An example is the difficult decision for many people of withdrawing nutrition and hydration through tubes. Many people believe that offering nutrition and hydration leaves it open for patients to revive, whereas if it is withdrawn, patients will, in effect, starve to death. However, in many cases the reality is that patients cannot absorb nutrition and hydration through their stomach and feeding them or giving them water makes them uncomfortable (Craig, 2004). Advance directives can only be given to refuse treatment; doctors cannot be required to provide treatment that they think will not be in their patients' best interests (Samanta & Samanta, 2006). Gillick's (2006) discussion of acp in the US stresses the importance of clarifying with patients and families the risks and benefits of nutrition support in a variety of common situations as a pre-requisite to effective acp, since without this understanding an advance decision cannot be made.

An American study (Ratner et al, 2001) found that a social work visit led to very high participation in acp for end-of-life care arrangements in a community home care service, and greater compliance with patients' preferences; this makes it clear that social work skills can clarify and facilitate participation in decision-making. However, a variety of factors may affect patients' preparedness to engage with acp and using advance directives. For people with long-term conditions, end-of-life considerations are only part, and sometimes a less important part, of a wider process of changing health behaviours as people approach greater frailty and illness (Fried et al, 2009). Barnes et al (2007) found that while some patients and caregivers would like to engage in acp, others would not; also they would often prefer to deal with wider care issues, not just medical decision-making. Also, informal caregivers providing everyday support may be different from the person nominated to make decisions in end-of-life situations and decisions change over time; therefore practitioners involved in acp need to maintain a good understanding of the network of support used by patients (Dizon et al, 2009); again this is usually an important focus of social work, as compared with nursing and medical, practice. For example, an American study (Bullock, 2006)

of African Americans found low take-up of acp because their spirituality which in turn influenced their view of suffering, death and dying, the social support networks available to them leading to a feeling that documentation was not required, practical barriers to recording and transferring an advance decision document between care locations and in particular their and mistrust of the health care system all led to refusals to complete ads. Good trusting relationships between staff and clients are likely to be particularly important in creating an atmosphere in which future planning can be achieved successfully and long-term community engagement is likely to be an important aspect of building trust.

Decision-making where mental capacity is impaired

The second area where acp has developed is where a client's mental capacity is impaired, so that they become unable to make their own decisions. People's mental capacity may be impaired temporarily by, for example, a period of mental illness, or permanently, for example if they are learning disabled. Concern is also rising about people whose capacity may be progressively impaired by illness, increased frailty and particularly dementia in later life. People whose mental capacity is impaired may need others to make decisions on their behalves.

The need for such a process is related to the end-of-life services' need for acp to respond to commonplace treatment decisions at the end of life. Most legal jurisdictions make some provision for (in the American terminology) 'substituted judgment', that is another person, usually a close relative, to become a healthcare proxy, taking over decision-making for the patient. The alternative process is to develop acp to the point of producing an advance directive, while the patient still has capacity. In the US the Patient Self-Determination Act 1991 makes provision for this. These processes are hard to separate for many families because most would not take on the proxy role without discussion with the patient and consultation with other family members (Hirschman et al, 2006).

In the UK, the Mental Capacity Act 2005 has established new procedures. People may register 'lasting powers of attorney' for people to act as proxies for them in financial and welfare (including health) matters. If this has not been done, medical decisions are made in patients' best interests, if necessary with an independent representative, often a social worker if no relatives are involved, appointed to represent the patient's interests. Government guidance on implementing the Act focuses on enabling people to make decisions and maintaining that capacity by engaging them in decisions on everyday matters, for example in care homes (Department of Constitutional Affairs,

2007). This points to a developing role for social workers and care staff to build enabling practice in care homes and when people are cared for in their own homes. Social and healthcare services for long-term care populations

Building on the experience in end-of-life situations and in cases where there are mental capacity concerns, recent developments in acp focus on providing acp to wider groups, in particular people resident in care homes and receiving community social care services. Multiprofessional guidance issued by the UK Royal College of Physicians (2009) is an example of acp developing for this wider population. Its extensive review of research shows that most people are happy to discuss acp in the early stages of care in anticipation of future illhealth, acp discussions with patients with long-term conditions or as part of a broad end-of-life care management programme increase patient satisfaction. While such discussions at entry into a care home may cause upset in a period of transition it can be successfully implemented by trained care staff once the resident is settled. Acp discussions can be successfully led by a range of professionals, in the US it is often done by a social worker or nurse. Used in this way, acp is a fluid process, continuous throughout people's care careers rather than a single event leading to a document.

Implementing acp in practice

As wider acp processes have developed, practice has also been extended from the focus on clarifying potential decisions to refuse treatment where the end of life is very close to a much wider range of situations. This means that practice is drawing on the skills of many different community professionals, increasingly social workers as families and informal caregivers are drawn into the process and care homes and community settings are building acp practice.

The acp process

Shanley et al's (2009) study of Australian acp practice in care homes for older people identifies four main issues in acp practice:

- Initiation – at what point in their care career and how does a practitioner begin a conversation about future care planning with a patient?
- Scope – who is involved in the planning and what areas of care are covered?

- Follow-up – is the initial planning process referred to and used in everyday care and is the plan reviewed regularly?
- Documentation – how is the documentation kept and disseminated and does it transfer satisfactorily to new care settings with the patient?

The general answer to all of these questions is to establish the process as early as possible to cover as broad a range of topics and interests as possible and ensure that it is continuous throughout the client's care career. Authoritative guidance issued by the UK Department of Health proposed three stages:

- an informal stage of *discussion involving information giving* about patients' conditions, their likely progression and eliciting patients' concerns and personal goals in receiving care, leading to
- documentation in a *statement of wishes and preferences*, followed if necessary by
- an *advance decision to refuse treatment* (Henry & Seymour, 2008).

Initiation is important because many clients and their families are not accustomed to thinking about the kind of issues that arise in acp. Careful explanation can be enhanced by using video to support decision-making (Vollandes et al, 2009). UK Mental Capacity Act guidance (DCA, 2007: Ch 3) suggests preliminary steps before developing a document:

- Make sure that people have all the relevant information and access to alternatives.
- Communicate appropriately.
- Help people feel at ease.
- Support them while they go through the process of making decisions.

Good professional interpersonal skills are therefore crucial in introducing what may be a difficult topic for some clients. These can be enhanced by introducing an effective organisational system. It is helpful to ask routinely for people's preferences as they are assessed for the first time, or at an early stage of care. Starting at this stage promotes clients' engagement in planning as a natural process; this is reinforced by regular reference to their plans and regular review. At a later stage, asking the 'surprise' question to medical staff ('would you be surprised if this person were to die in the next six to twelve months?') enables them to integrate a holistic view the stage of an illness or disability that patients have reached and may help practitioners to decide to instigate acp processes.

A Scottish analysis extends the main elements of acp to practice with long-term conditions, covering issues such as:

- What happens if your carer becomes unwell?
- What will you do if your condition flares? How will you access help, advice and treatment?
- What would you like to happen if you became acutely unwell with...?
- Preferred place of care – home, community hospital, care home, or acute hospital.
- Resuscitation status (LTCC-JIT, 2009).

As the process moves towards documentation, it is important to consider how preferences can be best recorded. Many people prefer documents that state positively what they want to achieve, rather than directives about specific treatments in specific circumstances, but professionals find these more difficult to interpret in making treatment decisions. Therefore, the Royal College of Physicians guidance (2009) suggests maintaining a balance of expressing personal preferences in a narrative and specific advance refusals. A clear format and guidance in asking concrete questions is also important; even the most articulate people may have trouble thinking what particularly is good about their life. An agency setting up acp can find many document formats on the internet to select from by searching for 'advance care planning'.

A good Australian format for acp in care homes (Austin Health, 2007) grounds the process by starting with people's actual experience. It asks whether they have experienced or have seen other people having 'a positive or difficult experience' with care, and asking 'what could have been done better or differently?' It then moves on to ask clients about current health care needs and any values or preferences that affect their views about it, future health or care needs. Finally, it asks who should contribute to decisions about care needs in the future, or who might take them for people. An Australian prospective randomised controlled trial in this organisation of plans made up to six months before death (Detering et al, 2010) demonstrated that acp led to more patients' preferences being known and acted upon, significantly less stress, anxiety and depression and greater patient and family satisfaction. One format for community use asks concrete questions about current important aspects of life, positive preferences and dislikes if care is required in the future. Another format used in care homes asks for specific preferences in most areas of care for example, from hairdressing religious preferences (Payne, 2011, ch 2). Flexible documentation that can be kept by or disseminated among agencies involved in the patient's care or

transferred with the patient between agencies is also helpful to practitioners, clients, informal caregivers and families.

Barriers to acp

However, barriers exist in implementing acp. An American study of palliative care professionals, who might be expected to know of its value, only 35% has made an advance directive, mostly because of lack of time, although most had had conversations about their preferences with family members. Patients and informal caregivers with chronic obstructive pulmonary disease (copd) identified five barriers. One was inadequate information provision about the likely course of copd at diagnosis. Then there was a lack of consensus among professionals about who should initiate acp, how they should do it and in which setting. There were psychological connotations of comparing copd with cancer. These arise because the prognosis that the illness may lead to the end of life is better understood with cancer while copd is not understood to be life-threatening in the same way. Another problem was that acp discussions conflict with the process of focusing on chronic disease management rather than the end-of-life outcome. There was also a lack of understanding of the meaning of 'end of life' within the context of copd because it was not seen as a life-threatening condition (Gott et al, 2009). It is likely that similar factors would inhibit acp with other long-term conditions; this research suggests that it is important to shift acp away from the assumption that it operates only in end-of-life care, and transfer it more actively into long-term care situations. Relatives of older people may wait too long to have a conversation, avoid the topic or the older person may deny their increasing mental incapacity (Hirschman et al, 2006).

A well-conducted study of care homes in England (Froggatt et al, 2008) draws some of these issues together. It found that while many tried to implement acp processes, because residents were admitted when they were already very frail, a wider commitment to acp at an earlier stage from social work assessors and care home staff would have been beneficial. Where acp was attempted, there were three main principles of the process: the plan was individually tailored and led as far as possible by the resident's wishes, a wide variety of people could be involved in the process alongside the staff member documenting the plan and the resident, including relatives and external professionals involved, and the processes were incorporated into existing planning rather than forming an extra task. This meant that residents' preferences and plans informed professional planning for the future.

One of the important developments of acp in healthcare is a focus on developing appropriate participation in thinking through future plans, rather than on simply recording decisions. Examples of this trend are Henry and Seymour's guidance with its three acp processes. An extensive review of American palliative care practice (Lorenz et al, 2008) concludes that 'moderate evidence' supports advance care planning led by skilled facilitators who engage key decision makers and interventions to alleviate caregiver burden. Kielman et al's (2010) study of patient's attitudes to 'self-care' in long-term conditions suggests that patients can feel abandoned by professionals and that active engagement with them in planning programmes of care are important. Similarly, Hamann et al's (2007) study of schizophrenic patients' medication found that patients' involvement in planning for the future and shared decision-making about medication led to better long-term outcomes.

Conclusion: acp as a participative strategy in social and healthcare

This paper has explored the development of advance and anticipatory care planning. In recent years, there has been a movement away from a focus on documentation of patients' advance decisions to refuse treatment and legal protection for medical decision-making in end-of-life situations towards a broader engagement of people with long-term conditions, their families and informal caregivers in decisions throughout their care careers; however this shift is still incomplete, and in some countries there remains a focus on end-of-life care situations. The research reviewed here suggests that acp provides a good opportunity for engaging people at a difficult time of their lives and achieves increased satisfaction and better attainment of their goals in receiving care.

These developments have led to an increasing importance for acp in social work practice. This benefits clients and services for a number of reasons. First, it highlights clients' own preferences and empowers their influence within professional and social agency decision-making processes. Second, it protects human rights to freedom of decision-making through openness in professional practice, particularly about difficult issues that some people try to avoid. Third, that protection through openness is prioritised against legalistic, bureaucratic or managerial protections of clients' rights, which may be more restrictive of flexibility in meeting clients' preferences. Fourth, acp emphasises the importance in social work of its role in making arrangements for and provision of long-term care, rather than counselling or interpersonal or therapeutic problem-solving. Analysing acp therefore identifies the some of the interpersonal and human aspects of a service provision model of social work. It helps practitioners to

understand the relevance in social work practice of what sometimes seems to be 'just' an administrative or management requirement of their agency. Fifth, connected with this, examining acp also explicates practice with an important but under-explored client group, people with long-term conditions who require care for a period, rather than short change-oriented interventions which are the focus.

However, expressing preferences does not necessarily lead to clients being in control of care decisions. Often people have no choice about receiving care when they would rather not, and there are often not enough resources to meet their needs, or practitioners judge that alternative interventions are required. Nevertheless, there is evidence that acp in healthcare leads to patients' wishes being met more often than where there is no planning. There are many barriers to effective implementation of acp, in particular people's existing expectations and understanding of their condition. However, when it is offered, it is a valued intervention which also provides an opportunity for engaging family members and informal carers in care planning as well as clients. Expressing preferences helps members of the public to accept that they have been treated fairly, since practitioners have clearly listened to, recorded and given themselves the best chance of being influenced by clients' wishes. Acp permits practitioners to identify when clients' wishes cannot be met and to find ways of meeting their wishes in other ways or to some extent, rather than just accepting a status quo that they feel is unsatisfactory.

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Resumo

O planeamento antecipado de cuidados (acp) comporta processos que permitem descobrir e registar as preferências pessoais relativas a cuidados e tratamentos em situações futuras bem como diferenciar esta planificação da planificação profissional de cuidados a dirigir a um dado indivíduo. Desenvolvido a partir da aplicação de cuidados paliativos sustentados pela gravação

das decisões dos doentes referentes à recusa antecipada de tratamento, prevenindo situações de incapacidade cognitiva no final da vida, os processos de acp alargaram-se, recentemente, aos cuidados de saúde e cuidados de protecção social prolongados. Este processo tem como objectivo envolver clientes, famílias e outros cuidadores informais no sentido de se prepararem para pensar antecipadamente acerca das exigências de situações de necessidade de cuidados difíceis. A investigação demonstra que esse processo aumenta a satisfação dos clientes com os serviços e amplia a probabilidade de se verem alcançadas as escolhas de clientes e famílias. O acp é um avanço importante na teorização do serviço social relativamente às questões específicas da prestação de serviços de longa duração, quando o papel destes serviços se perspectivava apenas focalizado na gestão e coordenação dos casos. Este processo, fortalece, também, a participação dos clientes na tomada de decisão sobre os serviços sociais a adequar à sua situação.

PALAVRAS-CHAVE: ACP planeamento antecipado de cuidados, termos da prestação de cuidados sociais, participação do cliente na tomada de decisão.

Abstract

Advanced and anticipatory care planning (acp) are processes for finding out and recording clients' preferences for care and treatment in the future, and distinct from professional care planning as part of care management in coordinating service delivery. Developing from palliative care practice in recording patients' decisions to refuse treatment made in advance of possible mental incapacity at end of life, acp processes have recently extended to health and social care provision for long-term conditions. The process aims to engage clients, family members and informal caregivers in thinking ahead about managing difficult care situations. Research indicates that this increases clients' satisfaction with services and improves the likelihood of clients' and family preferences being achieved. Acp practice is an important development in theorising interpersonal social work practice in long-term care services, where the social work role has been seen as focused on management and coordination. It also strengthens clients' participation in decision-making in social care services.

KEY-WORDS: ACP Advanced and anticipatory care planning, social care provision, client's participation in decision-making.