

## **Exploring the role of the District Nurse in facilitating sensitive and individualized Advance Care Planning.**

This article discusses the advantages and risks of the current policy related to Advance Care Planning (ACP). It highlights that District Nurses are well-positioned to influence both a sensitive and individualised approach to ACP, and can advocate for appropriate outcome measures to evaluate the success of ACP policy. The challenges to DNs in facilitating ACP and strategies to overcome these challenges are identified.

### **What is ACP?**

ACP is a process of discussion between a person with advanced progressive disease and their professional carers, which explores both a person's preferences and wishes about future treatment and care at the end of life (Thomas 2011). The ACP is a key tenet of the End of Life Care Strategy (DH 2008), and has been described as a cornerstone in improving end of life care (Thomas 2011). End of life care in this article refers to care given to people approaching the end of their lives from advanced progressive disease.

### **Healthcare policy and ACP.**

Involving people with decision making has become a key measure of the quality of care given to people at the end of life (The Choice in End of Life Care Programme Board (CELCPB) 2015). The commitment to supporting people's choice about how to have a good death is embedded in healthcare policy (NHS 2013, DH 2008, DH 2010,). This drive to widen people's participation in healthcare choice is a reflection of a wider healthcare policy which recognises the importance of individuals' engagement with health related decisions not only in terms of successful outcome (Griffin et al 2004), but also in terms of satisfaction (Goodrich and Cornwell 2008).

The centrality of this commitment to involve patients in end of life care decisions was underlined in the development of 'One Chance to Get it Right' document (Leadership Alliance for the Care of the Dying People LACDP 2014), which includes the priority that:

'the dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants' (p 20).

The CELCPB (2015) identified that although many people wish to have the opportunity to be involved in decision making, a significant number have not been given such opportunity. This organisation has developed a blueprint to increase the number of people engaging in ACP; it suggests that simply asking the question 'What is important to you' will increase opportunities for people to engage in ACP.

## **Risks related to ACP policy**

There is some evidence that this emphasis on ACP is leading to HCPs initiating conversations insensitively (Kleebauer 2014), and the media has picked up on the policy initiative of introducing ACP to over 75 year olds (NHS England 2014) with reports of people receiving phone calls from practice nurses to discuss their 'Do not attempt cardiopulmonary resuscitation' (DNACPR) preferences (Borland 2014). The law states that people must be offered the chance to be involved in such decisions (Freeman 2014). However, best practice identifies that decisions regarding DNACPR should be part of a broader discussion about future care and treatment preferences (Resuscitation Council UK 2014). Reports regarding insensitive initiation of ACP such as leading with telephone DNACPR discussions are a cause for concern and need further exploration. It is possible that using DNACPR discussions to lead the ACP process maybe due to HCPs anxieties about breaching the law regarding including patients in DNACPR discussions. It is vital that ACP policy, which is designed to empower patients, does not lead to enforced and tactless discussions.

The risks of harming patients by shifting responsibility regarding health care decisions towards them have been reported. For example, Dartington (2010) reports that such a shift may lead to a denial of patient vulnerability, which may result in missed opportunities to benefit from the authority, competence and experience of HCPs and others in the caring professions. He goes on to argue that caution needs to be applied, and models of care that, increase patient involvement may not adequately take into account either inequalities in education or cultural differences.

Patient participation in care must always focus on the patient's interests; traditional models of 'patient- centred care' have been criticised for allowing for engagement, but not delegation of care (Thorinsottier and Krisjansson 2014). There is a danger of interpreting the concept of choice in such a way as to assume that everyone wants to be engaged in decision making about their health. Relating this to ACP, there is evidence that it is not universally acceptable (Macpherson 2012, Horne et al 2006) and that the facilitation process needs to allow for patients to decline interventions, and engagement in decision making (Randall and Downie 2010). Person- centred ethics, which embrace humility, listening, communication and courage, are fundamental to sensitive facilitation of ACP, and any application of a rules based ethical code is likely to be damaging (Baughman & Aultman 2014).

## **District nurses strategically placed to ensure sensitive, individualised ACP**

### *Relationship*

Increasingly people are dying in their usual place of residence (DIUPR) (DH 2012), indicating that nurses working in the community setting will have a leading role in facilitating ACP discussions. Although HCPs experience difficulties in deciding who leads on ACP (Gott et al 2009,) there is evidence that nurses working in community settings recognise that they are

strategically placed to facilitate ACP (Seymour 2010), and that building relationships is key to the process (Baughman et al 2014, Boot and Wilson 2014).

Thorinsottier and Krisjansson (2014) argue that a human connection is the antecedent to the delivery of care, and empowers patients to express their wishes. This connection facilitates respect and recognition and thus empowers the patient to accept or delegate responsibility for decisions. The authors argue that a move towards self-managed care, whereby patients are expected to take a lead role in coordinating and directing their care, may diminish the importance of relationship within care. The expertise of the DN in establishing relationship has long been established (Luker 2000), and the essence of good palliative care provision by the DN is the establishment of relationship with both patients and their families (Often 2015), indicating that DNs are well placed to take a lead role in facilitating ACP.

#### *Integrated care*

The separation of social and health care has been identified as a threat to the ability of the DN to build relationship and provide continuity of care with advanced progressive disease (Often 2015). There is however a renewed focus on developing integrated health and social care, a model which is thought to support individualised coordinated care (Humphries and Wenzel 2015). The centrality of an integrated approach to the success of end of life care has been recognised (National Palliative and End of Life Care Partnership 2015). However, further funding is recommended to underpin this development (CELCPB 2015.) Marie Curie have developed a model which supports integration and improved communication between all community service providers caring for people at the end of life. They report an increase in the DN's ability to meet family expectations (Marie Curie 2012), suggesting that integrated care delivery may offer DNs an alternative framework in which they have the information and time to coordinate individualised care including ACP.

#### **Challenges DNs face when facilitating ACP.**

##### *Workload pressures.*

HCPs should anticipate caring for people who will have a range of preferences relating to engagement with ACP. As DNs have the opportunity to develop relationships with patients they could assume a guardianship role in ensuring that patients have the right to exercise choice, either to be involved in ACP or to delegate responsibility to the HCPs caring for them. However, there are challenges related to timing of these conversations (Griffiths et al 2015), and DNs have reported that finding both the time (Seymour 2010) and the right moment for the patients (Griffiths et al 2015), so that ACP is patient-centred and culturally sensitive (Burt et al 2008), can be difficult. In addition to the complexity of the timing the

increasing workload pressures due to increasing numbers of patients in the community and staffing shortages (Queen's Nursing Institute QNI 2014) threaten the DN's guardianship role.

### *Targets driving the agenda*

DN team leaders and managers need to be aware that these workload pressures will undermine the ACP process and that ACP targets may risk patient safety. Documentary evidence of ACP completion is not a measure of good care. The Liverpool Care Pathway, (LCP), which was withdrawn in 2013, is an example of the disparity between outcome measures and user experience. The audits of the LCP demonstrated improvements in end of life care, although RCT data was lacking (Philips et al 2011). However, the audit measures did not expose some of the distressing experiences that families reported in relation to the LCP, which were reported in the LCP review (Neuberger 2013). The widespread implementation of the LCP by bureaucrats with little understanding of the implications has been blamed for the poor practice associated with the LCP (Currow and Abernethy 2014). Against a background of workload pressures in the community, the current policy to drive forward widespread ACP implementation could lead to a parallel situation developing.

There is very little research evidence on how ACP frameworks and documentation influence process. However, there is a tendency for ACP to focus on DNACPR orders, rather than the more complex communication process (Brinkman & Stopptenbery et al 2014), and form filling may be a barrier to facilitating sensitive discussions (Moore and Reynolds 2013). Further research is needed to explore how documentation and frameworks influence practice, and to what extent ACP policy supports the development of human connection and individualised patient-centred care as opposed to a mechanism that offers a more rigid engagement with decisions about DNACPR and Preferred Place of Care. As identified above Dartington (2010) highlights that models of care, which assume patients are both willing and able to be involved in all aspects of their care, puts the most vulnerable of patients at risk.

Electronic care coordination frameworks have been introduced to facilitate the sharing of information e.g. Electronic Palliative Care Coordination System (EPaCC). EPaCC records patient's choice of place of care at end of life, and is an effective way of sharing information between HCP across settings (Hayes et al 2014). There is evidence that when this information is recorded there is an increase in DiUPR (DH 2012). This is seen as a key indicator of quality of end of life care (DH 2012). The improvement in the number of DiUPR when preferred place of care is recorded demonstrates the importance of involving people in decision making, and in recording this information. These figures are encouraging, but caution needs to be applied when interpreting the data. The figures do not reflect to what extent patients were involved in decision making, or how they experienced the process. Qualitative data is more useful than outcome measures when exploring patient experience (Dartington 2010, Goodrich and Cornwell 2008).

## **Implications for practice**

### *An alternative approach to the measurement of success*

Pawson and Tilley (2004) argue that while policy-makers share their vision it is the imagination of the practitioners and participants which are crucial to the success and ultimate shaping of the policy. They go on to point out that interventions do not work in the same way for all people and in all circumstances. When implementing ACP policy it is important that this principle is not forgotten when attempting to measure the strategies to increase the number of people who are offered the opportunity to engage in ACP. Realist evaluation which explores how engagement works, the context in which it works and the pattern of outcome measures, and which involves monitoring across a range of measures (Pawson and Tilley 2004) is likely to give more honest and informative information about ACP strategies rather than the simplistic data collection evaluations.

District Nurse leaders, who are well positioned to understand the complexity of implementing ACP policy and have insight into profile of the population they serve need to advocate for a realist evaluation of ACP implementation. They can demonstrate their understanding of what patient-centred care means by ensuring not too much weight is given to the current ACP measures. Although they may be helpful indicators of some outcomes, they should not be considered as sensitive measures. Service leaders must ensure that target setting and the monitoring of ACPs do not lead to a 'form filling' culture where data such as DNACPR status recordings are interpreted as equating to a satisfactory outcome in terms of ACP.

### *Team culture*

Having time to build relationships helps facilitate individualised and appropriately timed discussions (Boot and Wilson 2014), and is an essential resource for the DN. The pressures on DN time has already been highlighted (QNI 2014). The culture of the DN team needs to recognise the importance of spending time building relationships and facilitating end of life conversations. Workload pressures on the team may be one of the biggest challenges to facilitating patient-centred ACP.

### *Staff development*

Sensitive communication is fundamental to facilitating the ACP process (Baughman et al 2014, Boot and Wilson 2013). There is evidence that Clinical Nurse Specialists are more likely to facilitate discussions ((Jeong et al 2012), perhaps reflecting that traditionally Specialist Nurses have had more opportunity for training in both end of life care (DH 2008) and communication (Wilkinson 2008) Mandatory training models using simulation training have proved successful in improving cancer specialists' confidence in managing difficult conversations (Wilkinson 2008, Fallowfield 2002). With the focus on increasing care in the

community a similar approach to DN communication skills is needed. Evidence suggests that training DN using a model on how to deal with emotional distress improved DN confidence at talking to patients with cancer (Griffiths 2014). Further research is needed to explore communications training models related to ACP for DNs. The policy of driving forward ACP needs to be matched with a willingness to invest in staff development relating to ACP and communication skills and a framework for addressing this has been identified (CELCPB 2015).

### **In conclusion**

The policy to engage people in decisions about their care is embedded into health care policy, and extends to encouraging and empowering people to be involved in decision making regarding their care at the end of their lives. DNs are uniquely placed and have a key role in facilitating sensitive ACP. However, the workload pressures in the community are a threat to the delivery of excellent care. The developments in integrated models of care may offer an opportunity for improved communication and continuity of care for patients, which may support DNs in finding the time to fully engage with ACP. DN service leaders need to develop a culture which supports the continued development of skilled staff, and an environment which provides temporal space in which to do this.

Measuring the success of a policy of empowerment needs to reflect the complexity of the intervention. Simple data collection will not reflect the diversity of care needs or the contexts of delivery, and will not identify any negative impacts of implementation. A more detailed and sophisticated evaluation is required to ensure that at a time of vulnerability people are given the opportunity to receive sensitive and skilled care meeting their individual needs. DN leaders can take a lead in advocating for, and developing, appropriate evaluation strategies, and ensuring that targets do not lead to a culture of target-led ACP.