

**Title: Care at the End of Life – How does Policy and the Law Support Practice?**

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**Aim of the paper:**

To identify and outline the legal, ethical and moral issues surrounding end of life care.

## **Abstract:**

The End of Life Care Strategy (Department of Health [DH] 2008) was introduced in an attempt to achieve a high standard of care for patients nearing the end of life and to improve carer experience. This high standard should not depend on socio-economic status, geographical location or diagnosis. It was to ensure individuals felt supported, informed, empowered and that symptoms and issues were managed by experienced staffs that employ evidenced based practice. In addition, the service provision should involve a multidisciplinary team and have the patient at the centre of all decision making. This would be facilitated by endorsing the use of end of life care pathways (DH 2008).

These recommendations are further supported by frameworks and policies e.g. Preferred Priorities for Care (NHS 2007) Gold Standards Framework (Gold Standards Framework Centre[GSFC] 2004) in Primary Care (GSFC 2009). Healthcare professionals must also be cognisant of the legal frameworks that protect patients' and facilitate their rights to exert their autonomy e.g. Mental Capacity Act and Advanced directives (Great Britain 2005). The issues surrounding care at the end of life with respect to legal frameworks alongside ethical and moral dilemmas will be further explored within this discussion paper.

## **Summary statements**

### **What is already known about this topic**

- Policy determines that end of life care provision requires improvement
- The law supports patient choice at the end of life
- Communication breakdown effects care delivery
- End of life care is fuelled with ethical dilemmas

### **What this paper adds**

- Highlights the policy directives that specifically support care at the end of life

- Healthcare professionals can have a major impact on end of life experience for both the patient and their carers
- Clarifies the legalities surrounding patient decision making at the end of life

#### **Implications for practice and/or policy**

- Enhance patient care
- Work towards key strategies surrounding end of life care

#### **Keywords**

End of life care; legal concepts; policy; quality of care

#### **Introduction**

The term Palliative care derives from the Latin word 'Palliatus' meaning to cloak or conceal (Claxton-Oldfield 2004). Consequently the aim for the professional in delivering care at the end of life is to ensure the patient remains symptom free and to utilise knowledge, skills and previous experience to enhance the quality of care delivered. Symptom management extends beyond the physical but incorporates the spiritual, psychological, emotional and social aspects of the individual and collectively they may all contribute to the issues or symptoms presented. A holistic assessment from an experienced practitioner is essential to enable the patient to be managed effectively. This does not necessarily mean a specialist nurse or doctor but a healthcare professional that is cognisant of all the issues which may impact on the individual, who can take an extensive and detailed history and has the knowledge and ability supported by current evidence to support the patient and their carer.

#### **Background**

The goal of palliative care is focused on achieving the best possible quality of life for patients and their families (World Health Organisation 1990). Medical

palliation is the active relief of a symptom or a problem without necessarily affecting lifespan. This is just one means of managing symptoms. In a study by Skilbeck et al (2002) 57% of the 814 referrals to the palliative care team were for emotional support, consequently, informing, listening and referring the patient , where appropriate, to other members of the multidisciplinary team can all aid the best possible quality of life.

Cicely Saunders' palliative care philosophies focus on quality of life. Her insightful statement "You matter because you are you; you matter to the last moment of your life and we will do all we can to help you not only to die peacefully but also to live until you die" (Saunders 1976) has driven forward individualised care at the end of life. Palliative care perceives death and dying as normal processes rather than failures and affirms life and living but not at the expense of quality of life (National Council for Hospices and Palliative Care Services 2001).

Medical palliation utilises numerous treatments to aid symptom relief and indeed, has become more complex and included more specialists being central to the core multidisciplinary team e.g. a dietician if nutritional needs become problematic and an anaesthetist may be involved with specialist interests in alleviating enduring pain in the palliative and terminal phase of illness and can help. Treatments for enduring and bothersome symptoms may include; pharmacotherapy, radiotherapy, chemotherapy, antibiotic therapy, palliative surgery, endoscopic and percutaneous treatment/interventions (Twycross and Wilcock 2001). All this is accessed in an attempt to improve symptom control and maximise quality of life.

Other supportive mechanisms derive from the employment of specialised dieticians, psychology support services, chaplains, specialised occupational

therapy and physiotherapy service, social workers complementary therapists to name but a few (DH 2008). These specialists contribute to the comprehensive approach and service a patient symptomatic of their disease may expect at the end of life

The cognisance discussed consequently relates to understanding the resources available and current evidence/opinion/policy/frameworks in force to inform and / or regulate practice. With this approach a hope is fostered by all involved which may facilitate a new-found freedom and acceptance giving the patient and carers space and time (hopefully) to reflect and plan (Bradshaw 1996). Without this understanding and awareness patients, carers and healthcare professional may be subjected to an altogether different experience. Palliative and terminal care can be challenging however and this should be identified in order to ensure that those caring for individuals in this setting, in turn, receive support.

Oberle and Hughes (2001) conducted a qualitative study examining ethical dilemmas as experienced by medical and nursing colleagues. Participants were derived from numerous areas within an acute setting but common themes were identified as stressors and indicated moral and ethical issues at the end of life were causative factors. These dilemmas included; suffering with a moral obligation perceived to alleviate distressing symptoms, uncertainty regarding best course of action and often there were conflicts between the patient and the family, but, in addition, competing values and communication.

Communication skills and the adoption of specific strategies to ensure a cohesive team approach to care of the patient and their carer at the end of life is paramount (NICE 2004). In a community setting communication strategies may be more challenging. The multidisciplinary team involved in care may be in various geographical locations and may use different case notes which may

fragment care but also require repetition in assessments thereby exhausting both patients and their carers (DH 2008). The decision to place a patient on an end of life care pathway may facilitate a more cohesive and inclusive approach to care. The communication and coordination of care by a core team of health and social care professionals has been acknowledged as key to ensuring a high standard of service provision and, in turn, improving the quality in end of life care (Firth 2003).

The benefits of a written pathway e.g. Liverpool Care Pathway (Kinder and Ellershaw 2003) facilitate understanding within the team and the family, any wishes regarding care at the end of life, including specific decisions in relation to how and where they wish to die, planning treatment and how they wish their illness to be managed. This promotes patient autonomy and ensures they remain at the centre of all decision making. This is a vast transformation from historical approaches to care for those seen as vulnerable, now knowledge and empowerment should be firmly within the patients remit (Firth 2003). What one must be mindful of is that this is a tool to aid quality in care delivery it does not necessarily lead to high quality end of life care. Informed, educated and knowledgeable staff is a pre-requisite to high standards in end of life care.

The decision to place a patient on a care pathway may be fraught with further decision making dilemmas, 'when is the time right?' 'What if I am wrong?' This should not be a decision taken alone but a collaborative one whereby evidence has been examined and wishes respected, particularly those of the patient and perhaps the carer/family if appropriate. In order to assist practitioners to adopt the GSF approach to end of life care planning, a prognostic indicator guide has been produced to aid planning and discussions at the right time for all involved. It remains evident however, that time frames and when to discuss end of life

care may be distressing for all involved, but once choices have been made and the discussion has taken place, it may alleviate some of the underlying anxieties (DH 2008). In order to ascertain the optimum time for end of life discussion, recognising deterioration may be a valuable skill. Symptoms which may indicate a short survival time have been investigated but remain a little crude. Palmer and Fisch (2005) and Chang et al (1998) determined that dyspnoea, poor appetite and drowsiness were associated with shorter survival time and subjective symptoms had a lower predictive value for estimation of survival time e.g. level of pain

Despite extensive and methodical end of life care planning, unforeseen events may occur and calls to emergency services may be necessary. This may be the consequence of a breakdown in communication but it can lead to stress for the family and the health care professional. Difficulties can be incurred regarding last wishes, as first responders may not be able to elicit a response from the patient so become reliant on the family to relay information. They may be presented with the ethical dilemma regarding belief; do they believe what the family are saying? As a result of the National Gold Standards Framework program, a 'Paramedics factsheet' has been introduced in an attempt to inform and rationalise care delivery when it really matters i.e. the last days of life (Gold Standards Framework 2009). The aim is to reconcile the dilemmas that are presented when an emergency call has been responded to. In introducing this guidance, those responsible for driving change in palliative care service provision endeavour to bridge the gap between the gold standards of care that those in the last days of life expect and the policy and protocols that drive decision making for personnel who respond to emergency calls for help. In addition to the

guidance a clearly defined management plan needs to be available which is both cohesive and inclusive, such as the Liverpool Care Pathway (Kinder and Ellershaw 2003), with all healthcare professionals utilising it as a multidisciplinary document and if it has been used in a timely and inclusive manner, it should provide a high standard of service delivery to the point of death with the professional having kept the patient at the centre of the decision making process. It may also ensure carers and relatives receive support and information throughout their experience (DH 2008)

Managing a patient's care at the end of life is crucial and effective planning with the patient may minimise the need for emergency calls and avert undue distress for patients, carers and healthcare staff. The GSF (2009) advocates the use of; Identifying those patients who may be in the last year of life, Assessing current and future healthcare and personal needs (to include the adoption of advanced care planning strategies) and Planning (IAP). The Planning should embrace the use of the seven C's (communication, co-ordination, control of symptoms, continuity of care, continued learning, carer support, care of the dying pathway).

### **The legal perspective**

All registered health professionals have the capability of ascertaining the patient's values, attitudes and beliefs prior to any decisions being made. The timing of this may be questioned along with the appropriateness of the conversation. Needless to say, if this does not happen it can be difficult for the patient to remain at the centre of the decision making process. Article 8 of the Human Rights Act 1998 (Great Britain 1998) - respect for private and family life gives moral autonomy to individuals. Statute now supports patient autonomy further with the introduction of the Mental Capacity Act 2005 (Great Britain



2005), which was fully implemented in 2007; as this 2005 Act suggests ways in which a patient's autonomy may be supported.

Arguably the best way to ensure personal wishes surrounding care are respected is to utilise an Advanced Directive, an advanced decision to refuse treatment (Great Britain 2005 s24). It allows any patient aged 18 years and over to make a decision about a specified treatment in specific circumstances. This can be useful particularly if, at the time the decision about a specific treatment is required, the patient lacks capacity. The legal validity of an advanced directive was challenged in 1994 when it was held that a refusal of treatment could take the form of a declaration of intention never to consent to treatment or, to consent to in some future circumstance (Re C [1994]). Therefore any advanced refusal of treatment for any disorder made when the patient has capacity survives any supervening incapacity, even if the refusal leads to death.

An advanced decision can be made orally or more formally in writing with or without solicitor involvement. The Mental Capacity Act (MCA) 2005 (Great Britain 2005 s24) states that the language used in the directive should be in layman's terms and it may be revoked at any time either orally or in writing). This clearly demonstrates the need for contemporaneous, concise and logical record keeping; dissemination of such information is also imperative to support patient autonomy under moral and statutory obligations (Nursing and Midwifery Council [NMC] 2008, NMC 2009, Great Britain 2005). A failure to respect a valid advanced directive can result in a claim for battery being made against the clinician (*Airedale NHS Trust v Bland [1993]*).

In the arena of end of life care the document may be a recent one, if not recent there is a need to ensure the patient's wishes have not altered now that a terminal diagnosis has been made. It is hoped that if an advanced directive is

encouraged it is timely while the patient still has capacity. For a person to be deemed lacking capacity they must be assessed against established criteria (See Box 1).

**Box 1** Mental Capacity Act 2005 (Great Britain 2005 s3).

For a patient to lack capacity they must be unable:

- a) To understand the information relevant to the decision
- b) To retain that information
- c) To use or weigh up that information as part of the process of decision making or
- d) To communicate his decision (talking, sign language or any other means)

An advanced directive optimises the chances of empowering the patient to make it clear what care they would and would not want as they near the end of their life. Timing is vital when considering the patient may be at risk of altered cognitive function. This may present as a result of pain, disease progression or the use of therapeutic drug regimens for example.

Alternatively the patient may have nominated a Lasting Power of Attorney (LPA) to speak on their behalf at a time when they can not do so for themselves. The LPA needs explicit instructions from the patient regarding refusal of treatment, unless this occurs the LPA has to act in the best interests of the patient and can not be motivated by a desire to bring about the patient's death (Great Britain 2005 s4 (4); Dimond 2008). Alternatively, a court appointed deputy may be appointed should the patient have no other person to help with the clinician's decision making process; again this person has to act in the patient's best interests without the aforementioned motivations.

Best interests are not a tool to force an opinion about care and treatment onto another. All decisions made in the patients' best interest still have to have consideration of the patients' values, attitudes and beliefs. The aforementioned may be easy to elicit by conversing with the patient, family, carer's or nominated other. Anyone who has had or is having regular contact with the patient can contribute to this decision making process if they have been privy to the patients wishes, values, attitudes and beliefs. Articulating these to the clinicians should ensure that the patients' voice is still heard when decisions are being made in their best interests. For a health professional to act in a patient's best interests, reasonable and practicable steps have to be taken to consult with others and should consider past and present wishes as far as ascertainable (Great Britain 2005 s4 (6) (7)).

The MCA Code of Practice states any staff involved in care giving to a patient who lacks capacity should make a record of the process of working out the best interests of the patients for each relevant decision (Jones 2010). It is this that is highly suggestive of best interests, not being in the health professionals' best interests or 'what I would do if it were my decision to make'. There may be arguments raised as to why best interests are not truly representative of the patient's wishes, however, many policies and procedures do not support the legal and ethical issues that are often evident when there is a failure to manage the patient in the terminal phase of illness.

Timely discussions to encourage patients to document their care wishes surrounding refusal of treatment are paramount, documenting the plan of care in a multidisciplinary document e.g. Liverpool Care Pathway (Kinder and Ellershaw 2003) for all health care professionals to follow is essential.

### **Implications for Nursing**

There are areas of innovation which aim to drive forward service provision e.g. East and Central Lancashire Best Interests at End of Life (National Health Service [NHS] 2008). This publication provides the professional with a baseline understanding of the principles underpinning best practice and then gives the opportunity to work through example cases in order to educate the reader regarding how to apply principles of best interest to the practice situations. In addition a selection of tools has been provided to support practitioners in clinical practice. Although this relies on healthcare practitioners knowing the publications exists and being motivated enough to participate in the exercises, it appears to be an effective means of trying to reach people and improve practice which in turn should improve care for those at the end of life.

West Midlands NHS "Quality End of Life Care is Everyone's Business" (NHS 2010) was a workforce project which examined policy intervention and suggested ways to improve provision and meet targets for future end of life care. In addition there are Frameworks e.g. LCP, and policy guidance e.g. NICE (2004) which suggest best practice. Nevertheless what is evident is that consistently high standards of care at the end of life may be denied to many patients and their families.

## Conclusion

What has been established within this paper is that end of life care may involve a number of professionals in order to meet the needs of the patient and carer / relatives. A proactive approach should be adopted with clear, timely and effective communication strategies with all involved. The patient needs to remain at the centre of all decision making. When the patient is unable to make decisions for themselves then the principles of best interest or the use of an established LPA may be implemented. Health care staff may feel anxious regarding the discussions and decisions that are required at the end of life. We

should be striving to improve knowledge and skills in those involved in delivering end of life care.

One suggestion may be that further emphasis regarding end of life care should be implemented in the final year of nurse education. This should hopefully feed into current provision. In addition providing CPD training in end of life care be more available in health settings which should give all levels of staff the opportunity to enhance their knowledge and subsequently enhance their practice and the patient and carer experience.

Further research examining healthcare professionals and their perceptions surrounding advanced directives may be beneficial. In addition, examining patient perceptions surrounding end of life care discussion may benefit future patients and provide healthcare professionals with more evidence and structure for their practice.

As policies surrounding end of life care become more prolific, they should influence practice in a positive manner, providing a more uniform and informed approach to care. People should be able to live well until they die and exert their rights to autonomy but also ensure that those left behind do not feel that their loved one was subject to poor quality care provision.

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