

## **Introduction**

This assignment will explore ethical, legal and professional issues surrounding advanced directives. The writer will attempt to objectively critique the literature relating to the study area and its relevance to issues of justice and diversity. The assignment will employ the four principles of health care these being, justice, autonomy, beneficence and non-maleficence. Considerations of the findings of the review, the implications for practice and the impact on care provision will be discussed and a conclusion containing a reflective summary of the process of enquiry considering how the writer's individual values, beliefs and attitudes have been challenged.

## **What is an Advanced Directive?**

Advanced directives are a way for patients to exercise their right by preparing for a time when they may lose their capacity to make or communicate a decision and allows a competent adult to indicate which treatments they would or would not want to have at the end of life, if they were to become seriously ill and were then unable to state their values and wishes (Davis, Aroskar, Liaschenko and Drought 1997) see appendix. When making an advanced directive a person is asking the medical profession not to give them certain medical treatment. (Dimond 2002).

## **Legal, Ethical and Professional Discussion**

In 1976 Joe Quinlan asked a US Court to allow him to make a legal decision for his daughter and allow her to be taken off a ventilator. This dealt with ability of an individual to appoint someone to speak on their behalf if they became incapacitated, known as a proxy decision. Kennedy and Grubb 2000 & Tingle and Cribb (2002) consider that in English law a patient can appoint a person to act as their advocate for medical decisions. However once the commissioning party is no

longer deemed competent in making decisions, the power of the advocate is withdrawn (General Medical Council 2005).

In 1990 a US court granted Cruzan the right to have gastrostomy feeding discontinued, after the court recognised she had made a verbal advanced directive refusing medical treatment. This case addressed the right for a healthy individual to have an advanced directive recognised. This then led to the Patients Self-Determination Act 1991, this Act validates the existence of advanced directives and states that patients must be asked if they wish to make an advanced directive on admission to hospital (Humphrey 2003). At the present time the UK does not have anything similar to the Patients Self – Determination Act 1991.

In the United Kingdom common law recognises advanced directives, but there has been no Act put through Parliament, to set out a law related to the enforcement of advanced directives (McLean 1996). Dimond (2002) clarifies common law and says each case before the court relates to what has gone before; precedents are set by previous cases and are used to argue judgement in similar situations. Once the advanced directive has been signed and witnessed and the doctor believes to the best of their knowledge that this is the patient's wish. The doctor can rely on it in court were there any repercussions related to their failure to provide treatment for that patient (General Medical Council (2005). Three particular cases have established this precedent, in terms of the doctor being bound by consent. These being Miss T [1992], Airdale NHS Trust v. Bland [1993] who did not have an advanced directive and C adult refusal of treatment [1994] (Kendrick and Robinson 2002).

Advanced directives have gained importance as a result of the publicity surrounding difficult cases, prompting the BMA and the RCN to issue guidance for

doctors and nurses. Kendrick, Clarke and Flanagan (2002) consider the impact this has had on the health care service and discuss how the National Health Service is increasingly asking for the law to be changed or clarified and what should be done to enable them to collaborate more with patients and medical staff when faced with an end of life issue. The writer feels it is important not only to respect a patient's choice but also to have empathy with that patient and their family. The nurse should be aware that when considering ethics, empathy is not just about understanding what the patient and their family are going through it is also about building trust with any involved.

The British Medical Association (2000) has issued a Code of Practice related to advanced directives to aid with legal clarification. They say the advanced directive must meet with certain criteria; the person must be over eighteen they must be competent, meaning that the individual understands the effects of refusing treatment, that the person was not wrongly encouraged to make the advanced directive and they must also consent to it. There must have been no cancellation verbally or in writing since being drawn up. Fry and Johnston (2002) acknowledge the patient must be in a position for which the directive applies and the patients will be at some stage unable to make the decision for themselves.

### **Justice**

According to Thompson, Melia and Boyd (2000) ethical justice is the demand for universal fairness and that this can only come about through the respect for the rights of individuals. Tschudin (2003) argue that the complexity of justice or fairness makes it harder to exercise an individuals right and that in times of emergencies ethical decisions may be based on the information available and for the greater good, not for what is right for the person at that point in time. Justice is about attempting to respect all people equally and to provide equal treatment; this is what is fair and just.

According to the Code of Conduct (2004) nurses must understand the values that individuals have and respect them even if it goes against their personal beliefs and values. Being able to do this for individual patients would allow each one to receive the justice they deserve by delivering individualised health care, rather than treating each patient the same. All patients are diverse they possess individual values and beliefs patients should be given choices as to how they want to be treated at the end of their life. Doctor and nurse may act using professional judgment and believe they are delivering equality of justice to their patients. Nevertheless nobody could truly state what an individual would choose, in a situation where they were faced with the choice of life sustaining treatments but were incapacitated.

Patients should understand that the advanced directive must clearly state when and at what point they would want the doctors to implement their directive and state clearly what treatment the patient would or would not be given. What one individual finds acceptable treatment at the end of their life another may not. Therefore preference on such things like not to have food and hydration through a tube, although withdrawing feeding could be considered by some to be a cruel way to die of thirst, others would not want to prolong their death. Being put on a ventilator at the end of life would be unacceptable is also another dilemma as some would rather be left to die. Ventilation is a problem because patients have come out of comas after many years and families might hold on to a glimmer of hope not wanting to let their loved one go without a fight, but what is written in the patient's advanced directive should be held to be the doctor's first priority.

One problem that may arise out of making a living will is that a person could have changes in preference over time. The directive may become inconsistent with the patients revised views about quality of life or other outcomes. BMA (2000) identify patients do not have the right to refuse basic nursing care such as provision for warmth, management of symptoms that distress the patient such as pain, vomiting and dyspnoea as well as personal hygiene needs. Nursing a patient for whom these symptoms were not sufficiently relieved, could inflict an intolerable load on nursing staff and people close to that patient, causing an unfair stressful situation.

The Nursing & Midwifery Council (2004) stipulate that nurses have a duty of care to patients within their professional role and that they are accountable for their own practice to treat patients as individuals. Therefore it is important for nurses to have guidance when dealing with advanced directives. When nurses work closely with patients and their families they develop trust and understanding and they can become aware of any fears and hopes the patient could have about future treatment. The nurse can explore with the patient any concerns and correct misconceptions they may have. The nurse can provide the patient the opportunity to participate in their own care planning, by discussing advanced directives or by writing down expressed wishes in nursing notes.

Nurses can become the patient's advocate giving them a voice and helping to avoid any interventions not acceptable to them. Respecting the patient choice is a part of justice in being allowed to have a dignified death without unnecessary medical intervention. Nurses need to be aware that people may never truly appreciate how they will feel or desire to have medical treatment when the time comes. Nurses need to be conscious to ensure that people do not make an advanced directive because they feel a burden on their families, society and medical resources. It is important that a patient who wants to make an advanced

directive do so with a professional fully able to help them understand what making the advanced directive implies. Patients need to know that the advanced directive can be withdrawn at any time (British Medical association 2000).

### **Autonomy**

The Royal College of Nursing (2005) stresses that the primary duty of a nurse is to work to restore the optimum degree of autonomy for the patient, that is compatible with what has been lost as a result of disease, injury or mental illness. A duty of care exists to educating people enough so that they make autonomous decisions. The RCN (2005) promotes advanced directives as a medium for patient advocacy, they state that many people who are not afraid of dying fear that they will be kept alive, in pain and in circumstances that they would not value. Where people to have their advanced wishes known, this could give them consolation in knowing that they can continue to have autonomy and be in control of their own lives, when they are no longer able to explicitly express or implement it. A challenge that the medical profession are faced with is that they must maintain an understanding of their patient's values and preferences.

Hinchliff, Norman and Schober (2003) support respecting patient autonomy is a primary principle of western medical ethics, it is not the event of signing the actual form but the continuation of doctor and patient communication and relationships based on understanding and voluntary decision-making. Just as patients have the right to give informed consent or to refuse medical treatment, they have the right to choose or refuse potentially life sustaining medical treatment, even if it goes against medical opinion. A patient's hygiene needs must be met as the patient could contract opportunist infections, which would have the potential to contaminate others as well as worsening their own health.

In this instance Dimond (2002) recognises that personal autonomy cannot override the potential for harm to others.

Olick (2001) considers there may be times when the autonomy of a patient could be questioned for example, if it is suspected that a decision has been made upon a belief that is false. A patient who is diagnosed with terminal disease may not fully understand what mental or physical condition they might be in at the end of their life, or they may have been miss informed by friends, family or the internet. When that time comes the patient may think their condition to be fair all considering. When the time comes they may decide they have a good quality of life even though they are ill. The patient's preferences or expectations of what they want from life could be different or have changed from when they were fit and well. Their views may have changed and they perhaps now decide they are more comfortable than what they had imagined they would be. There could also be advances in medicine that were not thought of when the directive was written.

### **Beneficence and Non-maleficence**

Beauchamp and Childress (2001) state the principle of beneficence involves the concern for the patient's best out come and highlights the moral importance of doing good. The question of best interest is not simply just a physiological one. When a patient is unable to make an autonomous choice health care professionals have a duty of beneficence, to act for the best interest of the patient. However, Fry and Johnston (2002) identify this is normally measured in relation to a personal view of what would be best for the patient. What the doctors consider best for the patient may be in retrospect what the patient would deem best if they were able to autonomously make the decision for themselves.

Doctors may feel that they should do whatever is in their power to preserve a patients life. But considerations should be broader than that of just medical risks

or benefits, it should include religious and cultural needs and beliefs of the patient. If these were considered it would imply the duty of best interest lie in, what would be appropriate in the context of that particular patient's life. By acting in beneficence way the nurse helps to increase the power of the patients and to further their own importance, by giving them a voice. However, it is important that the nurse has a history of the patient's values and wishes.

Davis, Aroskar, Liaschenko and Drought (1997) look at the principle of non-maleficence being the avoidance of harm. In assessing whether to give invasive treatment or not, consideration should be given regarding the harm that the treatment may cause to the patient and compare this against any benefits. McCormack (1998) state that the duty of preventing harm should take priority over providing the patient with benefits. Fry and Johnston (2002) recognise that this could extend to respecting the patients advanced values and wished at the end of their life. Therefore the nurse should weigh up the side effects of treatments such as antibiotics or extensive mouth care when being fed other than orally.

### **Culture and Diversity**

The influence of culture on Advanced Directive can be difficult to understand and when nursing patients of different ethnic groups. The family should be involved in helping the health providers to understand the diverse need of the individual patient. Henley and Schott (1999) recognise the concept of autonomy and informed consent may vary among different cultures. Helman (2000) consider that many Asian cultures believe that family members should be spared from having to make their own end of life decisions and it is perceived as unnecessarily cruel for a doctor to inform the patient directly of a terminal illness. Holland and Hogg (2001) even recognise that some Asian adults are often expected to care for their ageing parents. This may leave the family with a sense of obligation, to influence a decision for advanced treatments to sustain life. This may lead to



elderly Asian patients continuing with treatments they would otherwise have choose to terminate, but for the emotional comfort of their family.

Were an advanced directive is to be discussed with cultures other than that of the medical professionals an interpreter should be used to aid with understanding of all concerned. This would be of more benefit if the interpreter had a medical background and understood the consequences of refusing treatment, so there are no misinterpretations. Holland and Hogg (2002) appreciate most Asian cultures permit the use of life support and disconnecting equipment could be seen as causing death. However some believe that treatments should not be given just to prolong a person who is going to die anyway. Holland and Hogg (2002) go on to explain in some religions the use of life sustaining equipment and medication is unacceptable if the doctor see it as useless, in this situation switching off life support is seen as merciful.

Nurses should consider justice and diversity in relation to providing care for different cultures and take into account the NMC (2004) Code of Conduct which states that care is to be provided irrespective of race, culture, age, gender, social class or political belief. The NMC (2004) Code of Conduct advocate nurses are responsible for their standard of practice and the care they provide. This involves making sure different cultures understand and are educated about their rights to have or not to have medical treatment.

**Conclusion and Reflection**

After considering advanced directives the writer reflected that it is not only vital that they have some legal backing for both patient and doctor. They are part of any ethical decision making process. Knowing this should promote shared management with medical staff and the family enabling all patients to feel that they are part of any decision making process, when in a time of immense change in their lives. This has lead the writer to believe that rather than making advanced directives with emphasis being on just patient rights, consideration should be made so that the patient has the right people around them when making the directive. An Advanced Directive can give the patient a voice in the process of deciding about future medical treatment; it can aid medical professionals when deciding on the best interests of their patients, by providing them with a reflection on the patient's individual values of what life means to them. Due to a wide variety of cultural values medical professionals should be aware of listening to family members as well as spirituals associates connected to them.

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