Shared decision making and its role in end of life care

Rosanna Kay Frank

Abstract

Currently, 'shared decision making', which involves the multi-disciplinary team, i.e. the patient, nurse and doctor making joint decisions is advocated in many governing policies to improve the care of the dying patient. The UK population is ageing at an ever-increasing rate, which means that more people are experiencing a progressive death typical of that associated with chronic disease. These patients are suitable for participation in end of life decision making due to the pre-existing knowledge of impending death. Health-care professionals can assist the patient to achieve a 'good death' based on the patient's preferences, wishes and needs. The aim of the literature review discussed in this article was to identify the extent to which shared decision making currently exists during end of life care in the acute/hospice setting. Particular attention is paid to patient participation, the nurse's role, and the doctor/nurse relationship – factors that may facilitate or prevent shared decision making. Eighteen qualitative research papers published between 1997–2007 were reviewed and analysed, and demonstrated a strong link between shared decision making and a 'good death'. However, the research reviewed identified that although shared decision making can exist within end of life care, there are a number of reasons why this is not being achieved throughout the secondary care setting.

Key words: Decision making ▪ End of life care ▪ Hospice ▪ Hospital ▪ Patient participation ▪ Systematic literature review

As suggested by Watson et al (2005), end of life care is the medical terminology for the care given in the terminal stages of a disease or illness. It specifically refers to the end stage of the disease, when death is impending. Over the past decade, this topic has been the subject of a number of differing incentives and policies. These include *The NHS Cancer Plan* (Department of Health (DH), 2000), *Guidance on Cancer Services* (NICE, 2004), and the *End of life Care Programme* (DH, 2005b).

The drive for improving end of life care comes at a time when the population demographic of the UK is changing. The Office for National Statistics (2005) found that 16% of the population is currently aged above 65 years old and, according to the NHS Confederation (2005), this figure is projected to reach 21% by 2024. Furthermore, this demographical population accounts for 85% of the current mortality rate, of which over half die in hospital (NHS Confederation, 2005). Thus, the acute care setting must cater for the growing needs of the dying patient in order to deliver high quality end-of-life care.

Rosanna Kay Frank is Registered Nurse, North Bristol NHS Trust, Frenchay Hospital, Bristol

Accepted for publication: April 2009

Numerous researchers, such as The Debate of the Age Health and Care Study Group (1999), and Steinhauser et al (2000) have conducted studies to explore the definition of a 'good death'. These authors have developed a number of key principles which assist the patient towards having a good death (*Table 1*).

However, end of life decisions can only occur under certain provisions, as the patient must be certified as dying. This prior awareness of impending death is a typical characteristic of the slow, progressive dying process associated with chronic diseases, such as respiratory illnesses and cancer. According to National Statistics (2005), over half the dying population within the UK would fit this criterion.

End of life decisions result in many ethical dilemmas for the whole multi-professional team, as well as the patient and relatives. These complex decisions range from major long-term decisions, such as the withdrawal of treatment, preferred place of care, symptom management, and artificial hydration/nutrition, to everyday care options such as personal hygiene.

The literature review aims to identify the extent to which shared decision making occurs during end of life care, while making particular reference to:

- The factors that influence patient participation in decision making
- The nurse's role in decision making and how the nurse can facilitate patient participation throughout this process
- The inter-professional relationships between doctors and nurses, and whether this permits or prevents shared decision making.

Table 1. Factors that make up a 'good death' from the patient's perspective

- Understanding when death is approaching
- Remaining in control with dignity and privacy as death approaches
- Participating in decisions regarding the future options such as symptom management, preferred place of care when death is impending, and advanced directives plans
- Having access to quality information in which choice is offered
- Having information communicated in an effective manner
- Preparing for arrangements after death, i.e. finances, funeral plans, and written wills
- Saying goodbye to loved ones and resolving any grievances

Source: The Debate of the Age Health and Care Study Group, (1999) (cited in Smith, 2000); Steinhauser et al (2000)

Methods

First, the following key words were identified: end of life, terminal, palliative, decision making, hospital and hospice. An initial literature search was then manually conducted to develop questions and explore the issues embedded within the topic. The literature search primarily used the OVID electronic gateway to access databases, such as CINAHL and the British Nursing Index. Similarly, the Science Direct gateway was used to widen the scope of the search. Some journals, such as *Nursing Ethics*, the *International Journal of Palliative Care* and the *Journal of Palliative Care*, were manually searched in order to gain the maximum number of relevant articles.

A total of 916 studies were identified. By studying titles and abstracts, and imposing the inclusion criteria (*Table 2*), nine studies were eventually found which directly related to the topic of shared decision making in end of life care, and eight were found which made particular reference to the aims of the review (*Table 3*).

Findings

Despite end of life care receiving great attention from the DH in recent years following the publication of the *End of Life Care Programme* (DH, 2005b), there remains a lack of research relating to end of life decision making. The majority of publications that were identified originated outside the UK, in places such as Canada, Finland and Australia. The research was, however, only accepted into the review if the country of origin was of similar culture/technological level to that of the UK.

The factors that influence patient participation during end of life decision making

The literature review suggests that numerous factors can affect patient participation during end of life decisions, which can then lead to either active or passive participation (Friedrichsen et al, 2000; Royak-Schaler et al, 2006). However Carter et al (2004), Friedrichsen et al (2000) and Royak-Schaler et al (2006) found that patients who actively participated in end of life decisions often had positive experiences through the latter stages of their life, and therefore achieved a 'good death' (Smith, 2000). In contrast, Pierson et al (2002) discovered that patients who passively participate, fail to get their preferences or wishes heard, and often receive prolonged unnecessary treatment, inadequate pain relief and suffer a 'bad death'.

In order for the patient to actively participate within end of life decisions, the literature identified three key concepts to enable patient participation: communication and information-sharing with the patient; accepting prognosis and spirituality; and sense of well-being.

Table 2. Inclusion criteria determining which studies were of sufficient relevance to be reviewed and analysed

- English language
- Primary research
- Published between 1997–2007
- Patients must be palliative, terminal or at the end-of-life
- Hospital or hospice setting, NOT the community

Table 3. The research studies included in each section

The factors that influence patient participation in end of life decision-making	The nurse's role in end of life decision-making, and how the nurse can facilitate patient participation during this process	The inter-professional relationships between doctors and nurses, and whether this permits or prevents shared decision-making during end of life care
Royak –Schaler et al (2006)	Norton and Talerico (2000)	Willard and Luker (2006)
Gauthier and Swigart (2003)	Bottorff et al (1998)	Costello (2001)
Friedrichsen et al (2000)	Hilden and Honkasalo (2006)	Oberle and Hughes (2001)
Heyland et al (2003)	Martin (1998)	Hilden et al (2004)
Myers (2002)	Clover et al (2004)	Nordgen and Olsson (2004)
Sahlber-Blom et al (2000)	Johnston and Smith (2006)	

Communication and information sharing with the patient

The research reviewed found a key link between the patient's ability to participate in end of life decision making and the communication and information sharing skills of the health-care professional. Using focus groups of 24 family members of deceased patients, Royak-Schaler et al (2006) aimed to explore the communication of health-care providers during end of life care, with reference to decision making. Even where conversations occurred between the health-care professional and the patient, Royak-Schaler et al (2006) identified the presence of a number of inhibitory factors which prevented patient participation. These included doctors and nurses using poor communication techniques, creating false hope, and not sharing enough information during end of life care discussions. According to Royak-Schaler et al (2006), false hope and confusion were avoided if terms such as death and dying were used directly. Despite these findings Heyland et al (2003) found, in a sample size of 135 patients, 87 felt they had not even participated in end of life decisions with a physician, despite 72% being willing to do so. Therefore, it is clear that health-care professionals need to ensure patients have the opportunity to participate in such discussions and decisions.

Furthermore, Royak-Schaler et al (2006) found that relatives of dying patients regularly requested non-disclosure of the prognosis to the patient, fearful of causing additional distress. However, Vivian (2006) wrote an article citing the huge ethical problem this causes, as doctors are often willing to comply with this collusion. Interestingly, Heyland et al (2003) state that the majority of patients prefer to be aware of their diagnosis and feel empowered when making their own decisions. Costello (2001) and Fallowfield et al (2002) point out that not knowing the truth can often cause more anxiety, as well as directly inhibiting the involvement of the patient in crucial end of life discussions. Thus, as pointed out by Vivian (2006), patients can only answer for themselves if they are fully aware of their condition, and relatives' views should not be a reason for withholding information from the patient.

Accepting prognosis

A key element enabling active patient participation within end of life decision making is realizing and accepting that the impending death is inevitable. If the patient is in denial, patient participation during end of life discussions is unlikely (Myers, 2002; Gauthier and Swigart, 2003).

Gauthier and Swargit (2003) believe decision making at the end of life is affected by factors such as not realizing or accepting death. This study used a biographic narrative approach to explore factors that affect terminal patients when making decisions. Out of the 14 terminally ill participants, Gauthier and Swigart (2003) identified that patient acceptance was primarily based on physiological deterioration, increased dependence and personal biographical narratives, such as personal life experiences with death. Gauthier and Swargit (2003) continued to suggest that, due to the probability of their having increased experience with death, older people cope better with acceptance and making decisions, as opposed to younger patients. However, in modern society, particularly with younger patients, these narratives/experiences give the expectation that advanced technology and expert knowledge can prolong life and postpone death, resulting in false hopes of a cure, which inevitably leads to non-acceptance (Myers, 2002). This theory highlights the need for health-care professionals to be extremely clear when communicating information.

Spirituality and sense of well-being

Both Friedrichsen et al (2000) and Gauthier and Swigart (2003) discovered increased patient well-being, and/or a strong sense of spirituality contributed to patients being actively expressive when making decisions. Friedrichsen et al (2000) aimed to explore the perception terminal patients had of their own participation within clinical discussion/decisions when receiving information about the transition from curative treatment to palliative treatment. The phenomenological interviews found categories that suggest patients participated in end of life decisions by either adopting an active or passive role. Patients who anticipated the prognosis due to increasing dependence for example, and who also had a 'strong sense of well-being', tended to actively participate, opposed to patients who were 'unsuspectingly naïve' with a 'poor sense of well-being'. Gauthier and Swigart (2003) and Sahlberg-Blom et al (2000) both suggest reasons why some patients actively participate while others quietly accept others taking responsibility. They found participation in decision making reflects the person's previous experiences, views, beliefs and spirituality. Therefore, health-care professionals need to ensure patients are being managed in response to their spiritual and well-being needs as highlighted in the Liverpool Care Pathway for the Dying (DH, 2005b). However, the health-care professional must respect the patient's beliefs, or lack of beliefs, when managing the care of dying patients.

The nurse's role in decision making

The literature in this part of the review clearly demonstrates that nurses have a role during end of life decision making, either directly or indirectly. For example, the nurse can directly influence the decision by expressing the wishes of the patient to the doctors on behalf of the patient, or indirectly influence the decision by supporting/guiding the patient to encourage participation when making difficult decisions. This can, therefore, facilitate patient participation within the decision making process. The literature within this section of the review identified two key themes: the nurse-patient relationship and the sharing of power and control, and communication and assessment.

Nurse-patient relationship and the sharing of power and control

Despite a large amount of literature relating to this topic, there is little research available directly relating to the nurse-patient relationship during end of life care and decision making. However, Bottorff et al (1998), Norton and Talerico (2000) and Hilden and Honkasalo (2006) identified a key link between effective patient participation during end of life decision making and the development of a good nurse-patient relationship. During nurse-patient interactions, nurses must demonstrate that they are prepared to share power, authority and knowledge with the patient making decisions. Johnston and Smith (2006) showed that patients receiving end of life care continue to desire control, choice and autonomy.

Bottorff et al (1998) produced a qualitative study which aimed to explore the strategies nurses used to either facilitate or restrict patient participation in decision making. This was in particular relation to choice about personal care options during the terminal phase of the participant's disease. The key principles that emerged from the observations highlighted the importance of the nurse-patient relationship. Initially, the nurse must 'get to know the patient', and provide opportunities for choice regarding the care the patient would like to receive. However, as soon as the nurse exerts any form of power or dominance over the patient, as seen in offering pseudo choices (false choices) such as offering limited choice due to, for example, time restraints, true patient participation within decision making is prevented.

Martin (1998) and Clover et al (2004) explored ways to empower palliative patients to participate within decision making, but found many health-care professionals exert power over patients by either ignoring what the patient is saying or not even offering the patient the right to decide for themselves, which results in the autonomy of the patient being lost. Both Martin (1998) and Clover et al (2004) noted that even if choice was offered, patients frequently adopted a passive accepting role due to the tone/body language and time restraints in which the choice was offered.

Hilden and Honkasalo (2006) suggest that although patients may express the need for control and participation in decision making, the process was made easier with the additional input from the nurse's professional knowledge and support on the given decision. Within the study the nurse is referred to as adopting the 'supporter discourse'. It must be noted that this study presented the interpretation of 17 nurses' views regarding patient autonomy during end of life decision making. Therefore, it must be questioned if this would accurately describe the preferences of the patients. Despite this question, nurses need to be aware of the influence that they can exert by critically analysing/reflecting on the extent to which they have control over the patient.

Communication and assessment

Many researchers identified (Bottorff et al, 1998; Norton and Talerico, 2000; Hilden and Honkasalo, 2006) that successful communication was the key to promoting patient participation during end of life decisions. Fallowfield (2002) suggests clear hoenst communication is essential in palliative care, yet many health-care professionals neglect to incorporate this into their practice.

Norton and Talerico (2000) used a grounded theory study, which is a type of research design that aims to explore a theory by continually comparing and analysing the data as it is collected, to identify behaviours that facilitated end of life decision making from the perspective of the nurse, doctor and the immediate family of the terminally ill patient. Two themes became evident within the research, the first being communication, and the second being assessment. Particular reference within the theme of communication was made to being willing to communicate about the issues within end of life care, and being clear about the prognosis and options available. These were found to be essential components when facilitating patient participation.

The overall theory behind communication was that nurses could play a huge role in allowing the patient to have a ‘good death’ by offering the sharing of accurate timely information and identifying the needs/preferences of the patient due to the intimate nature of nursing. Thus with the additional use of honest colloquial language, nurses can empower patients to participate in decision making. This would, however, depend on the nurse’s willingness to engage with this process and initiate these discussions.

Similar findings were shown in a studies by Johnston and Smith (2006), and Hilden and Honkasalo (2006), which again found that nurses could facilitate patient participation by providing information to the patient/family followed by the opportunity to talk about it. Nurses could also spend time with the patient and act between the multi-disciplinary team and the patient.

Norton and Talerico’s (2000) second theme, assessment, involves the health-care professional being able to assess patient deterioration, the understanding of the patient and relatives in regards to accepting the prognosis, and the wishes and expectations of the patient/family. The nurse is also in a position to assess the patient’s capacity to participate in decision making regarding end of life wishes and preferences. This principle of assessment as highlighted by Norton and Talerico (2000) is in accordance with the Mental Capacity Act (2005), released

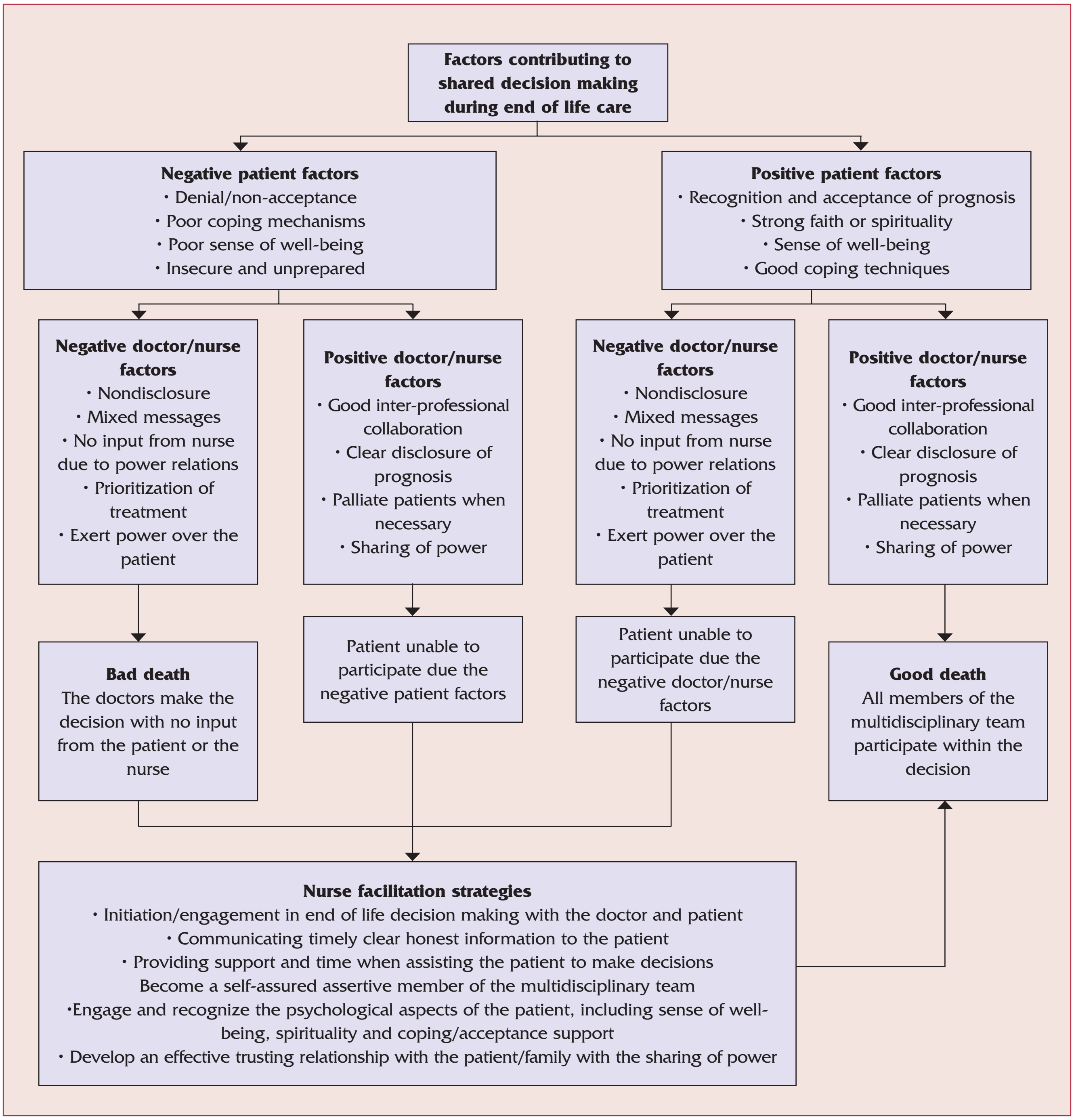

Figure 1. Diagram of factors influencing shared decision making.

in 2007. The Act covers the need for complete assessments to be carried out to judge capacity for decision making, as it will be unlawful to assume people with disabilities, such as those who are rapidly deteriorating, cannot make their own decisions.

Norton and Talerico (2000) expanded this point, by suggesting health-care professionals, particularly nurses, are in a position to assess not only when to initiate end of life discussions, but also the patient's/family's understanding or misconceptions of pending death. This principle demonstrates how nurses can facilitate shared decision making, in terms of helping the patient to achieve acceptance of death previously identified by Gauthier and Swargit (2003).

The interprofessional relationships between doctors and nurses

The evidence reviewed suggests that conflicts between doctors and nurses during end of life decision making still exist. These conflicts result from a number of key issues: prioritization of treatment, nondisclosure of diagnosis, and hierarchical and power relations.

Prioritization of treatment

Generally, considerable conflicts are caused between the nurses and doctors becuase of prioritization of treatment. Willard and Luker (2006) suggest (from the clinical nurse specialist perspective) that patients often express the wish to withdraw painful treatment and die peacefully. This is often prevented by doctors because of the paternalistic nature of the acute care setting and the view of death when withdrawing treatment being a medical failure. This caused great frustration to the clinical nurse specialists. In accordance with these findings, a quantitative study by Hilden et al (2004) found that 44% of nurses felt active treatment was ongoing for too long. This process of prioritizing treatment over the patient's wishes directly obstructs the patient's ability to achieve a 'good death', as symptom management is often poorly achieved, and the patient and family are unable to concentrate on planning and preparing for death.

Nondisclosure of diagnosis

In contrast to the above theme, once doctors had accepted/determined the withdrawal of treatment, Costello (2001) found that the paternalistic nature of some doctors within the acute care setting results in the prevention of the disclosure of the terminal diagnosis. Costello (2001) made these findings by observing the experience of dying patients for 15 months on three different care of the elderly wards. Costello found that the health-care staff and the relatives of the patient may be informed of the terminal diagnosis, but the patient is not told. The idea of 'closed awareness' (Costello, 2001), where the patient is unaware of their terminal diagnosis, will severely prevent patients from participating in shared decision making, as well as cause some nurses distress, for they have to deceive the patient by breaking the trusting relationship.

Friedrichsen et al (2000) found that while not all patients wish to have their diagnosis disclosed, others become increasingly anxious and distressed if the prognosis is not revealed. Oberle and Hughes (2001) acknowledged that this creates serious ethical dilemmas for the doctors when making decisions as they do not always know whether a patient will be better or worse off for hearing a terminal diagnosis.

Hierarchical and power relations

The literature (Costello, 2001; Oberle and Hughes, 2001; Hilden et al, 2004; Willard and Luker, 2006) discovered that a hierarchical structure and continues to exist between doctors and nurses. Oberle and Hughes (2001) conducted a qualitative grounded theory study to compare doctors' and nurses' perception of ethical dilemmas within end of life decisions. The findings revealed that conflicts arose during the decision making process as nurses are able to gain a comprehensive holistic account of the patient's wishes, yet, sometimes, doctors failed to listen to the nurses, causing great frustration. If this approach continues in the NHS, effective shared decision making during end of life care will never be transformed from theory into practice.

Oberle and Hughes (2001), however, presented a differing perspective to Costello (2001) and Wilard and Luker (2006) as to why conflicts between doctors and nurses occur. Interestingly, Oberle and Hughes (2001) acknowledged that doctors and nurses have the same moral obligations, but due to the different roles and responsibilities, conflicts occur. Oberle and Hughes (2001) developed a conceptual description of the phenomenon, which identified that doctors and nurses have the same moral obligation of preventing suffering to the greatest extent they are able to.

This was linked with the theme of uncertainty, of making decisions that will have a significant impact on the patient's life, as the study found that doctors make the decisions and nurses have to act upon them. However, difficulties occur for the doctors, as doctors have to make decisions based on the constraints around them, such as other senior doctors and high patient demand. In contrast conflicts arise for nurses as they have to support the doctor's decision when providing the care, despite having no input to that decision. Similar findings were briefly mentioned by Nordgen and Olsson (2004) who consider issues of conflict between doctors and nurses, a main one being that nurses have little input on decisions. It became evident from the literature search that this area was severely under researched, therefore limited studies are provided to support these findings.

It must also be acknowledged that Costello (2001) and Oberle and Hughes (2001) conducted these studies prior to the implementation of new major key policies – T*he End of life Care Programme* (DH, 2005b) advocates enhanced collaborative decision making. Therefore, if these policies have contributed to changing practice, the findings of the studies under review would not reflect this.

Conclusion

The evidence from the literature suggests there is a strong link between shared decision making and a ‘good death’. However, the reviewed research found that although shared decision making can exist within end of life care, there are a number of reasons why this is not being achieved throughout the secondary care setting. The factors that were found to influence the shared decision making were:

- The patient’s ability to participate, depending on the factors surrounding them
- The nurse’s role in decision making, which often proved valuable to the patient and family if the nurse was prepared to discuss the care with the patient
- The conflicts that occur between doctors and nurses, which can prevent both nurse and patient participation.

As a result of the findings, the author has developed an evidence-based model, shown in *Figure 1*, to guide nurses when assessing their role within shared decision making.

In summary, the model and conclusions demonstrate a number of implications for practice. These include the additional understanding as to why some patients participate more than others, the reasons underpinning the doctor and nurse conflicts, and theories as to how nurses can facilitate shared decision making. The additional knowledge discovered by the review discussed in this article allows health-care professionals to critically analyse and reflect upon the end of life care that is delivered within the clinical setting and the role they play in that process. Due to the variance within the key studies designs, sample and location of the study, further research is required to confirm the author’s findings, and the particular relevance to the UK. BJN

Bottorff J, Steele R, Davis B, Porterfield P, Garossino C, Shaw M (1998) Striving for balance: Palliative care patient’s experiences of making everyday choices. *J Palliat Care* **14**(1): 7–17

Carter H, MacLeod R, Brander P, McPherson K (2004) Living with a terminal illness: patients’ priorities. *J Adv Nurs* **45**(6): 611–20

Clover A, Browne J, McErlain P, Vandenberg B (2004) Patient approaches to clinical conversations in the palliative care setting. *J Adv Nurs* **48**(4): 333–41

Costello J (2001) Nursing older dying patients: Findings from an ethnographic study of death and dying in elderly care wards. *J Adv Nurs* **35**(1): 59–68

Debate of the Age Health and Care Study Group (1999) *The future of health and care of older people: The best is yet to come.* Age Concern, London

Department of Health (2000) *The NHS Cancer Plan: A Plan for Investment, A Plan for Reform.* DH, London

Department of Health (2005a) *Research Governance Framework for Health and Social Care*. DH, London

Department of Health (2005b) *The End of Life Care Programme*. DH, London

Fallowfield L, Jenkins V, Beveridge H (2002) Truth may hurt but deceit hurts more: communication in palliative care. *Palliat Med* **16**(4): 297–303

Friedrichsen M, Strang P, Carlsson M (2000) Cancer patient’s perceptions of their participation and own resources after receiving information about discontinuation of active tumour treatment. *Acta Oncol* **39**(8): 919–25

Gauthier D, Swigart V (2003) The contextual natural of decision making near end of life: Hospice patient’s perspectives. *American Journal of Hospice and Palliative Care* **20**(2): 121–8

Heyland D, Tranmer J, O’Callaghan, Gafni A (2003) The seriously ill hospitalized patient: preferred role in end of life decision making? *J Crit Care* **18**(1): 3–10

Hilden H, Louhiala P, Honkasalo M, Palo J (2004) Finnish nurses views on end of life discussions and a comparison with physician’s views. *Nursing Ethics* **11**(2): 165–78

Hilden H, Honkasalo M (2006) Finnish nurse’s interpretations of patient autonomy in the context of end of life decision making. *Nursing Ethics* **13**(1): 41–51

Johnston B, Smith L (2006) Nurses and patients perceptions of expert palliative nursing care. *J Adv Nurs* **54**(6): 700–9

Martin G (1998) Empowerment of dying patients: The strategies and barriers of patient autonomy. *J Adv Nurs* **28**(4): 737–44

Mental Capacity Act (2005) *The Mental Capacity Act and Independent Mental Capacity Advocate Service*. DH, London

Myers G (2002) Can illness narratives contribute to the delay of hospice admissions? *American Journal of Hospice and Palliative Care* **19**(5): 325–30

National Statistics (2005) *Mortality Rates in the UK*. Office for National Statistics, South Wales

NHS Confederation (2005) Improving end of life care. *Leading Edge*. Issue 12

NICE (2004) *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer*. NICE, London

Nordgren L, Olsson H (2004) Palliative care in a coronary care unit: A qualitative study of physicians and nurses perceptions. *J Clin Nurs* **13**(2): 185–93

Norton S, Talerico K (2000) Facilitating end of life decision making: strategies for communicating and assessing. *J Gerontol Nur* **26**(9): 6–13

Oberle K, Hughes D (2001) Doctors’ and nurses’ perceptions of ethical problems in end of life decisions. *J Adv Nurs* **33**(6): 707–15

Pierson C, Curtis J, Patrick D (2002) A good death: A qualitative study of patients with advanced AIDS. *AIDS Care* **14**(5): 587–98

Royak-Schaler R, Gadalla S, Lemkau J, Ross D, Alexander C, Scott D (2006) Family perspectives on communication with health care providers during end of life cancer care. *Oncol Nurs Forum* **33**(4): 753–60

Sahlberg-Blom E, Ternestedt B, Johansson J (2000) Patient participation in decision- making at the end of life as seen by a close relative. *Nurs Ethics* **7**(4): 296–313

Smith R (2000) A good death. An important aim for health services and for us all. *BMJ* **320**(7228): 129–30

Steinhauser K, Clip E, McNeilly M, Christakis N, McIntyre (2000) In search of a good death: observations of patients, families and providers. *Ann Intern Med* **132**(10): 825–32

Vivian R (2006) Truth telling in palliative care nursing: the dilemmas of collusion. *Int J Palliat Nurs* **12**(7): 341–8

Watson M, Lucas C, Hoy A, Back I (2005) *Oxford handbook of Palliative Care.* 1st edn. Oxford University Press, Oxford

Willard C, Luker K (2006) Challenges to end of life care in the acute hospital setting. *Palliat Med* **20**(6): 611–5

KEY POINTS

- Shared decision making is often difficult to achieve, especially during end of life care due to the sensitive nature of the decisions that need to be made during this type of care.
- Patient participation during end of life decision making is often prevented if limited or misleading information is communicated to the patient, the patient is in denial of the prognosis or has a poor sense of well-being.
- Nurses are in a prime position to involve the patient and relatives within end of life decisions/discussions, as they can initiate conversations to discover patients’ understanding of the prognosis, and/or any preferences/wishes the patient would like to achieve during the terminal stage of their life.
- Shared decision making is often prevented due to conflicts that occur between doctors and nurses, as patients often express the wish to die peacefully, however, due to the paternalistic nature of medicine this is often not recognized.