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Autonomy and choice in palliative care: time for a new model?

Fiona Wilson, Christine Ingleton, Merryn Gott & Clare Gardiner

Abstract

Aims. This paper will examine understandings of autonomy and choice in relation to palliative and end-of-life care and identify implications for nursing practice.

Background. Autonomy in relation to patient-centred care and advocacy has been identified as a key component of palliative and end-of-life care provision internationally. Understandings of autonomy have emerged in an individualised framework, which may be inadequate in supporting palliative and end-of-life care.

Design. A critical discussion paper.

Data sources. Seminal texts provide a backdrop to how autonomy is understood in the context of palliative care. An overview of literature from 2001 is examined to explore how autonomy and choice are presented in clinical practice.

Implications for nursing. A model of autonomy based on a 'decision ecology' model may be more applicable to palliative and end-of-life care. Decision ecology aims to situate the individual in a wider social context and acknowledges the relational dimensions involved in supporting choice and autonomy. Such a model recognizes autonomy around wider care decisions but may also highlight the everyday personal aspects of care, which can mean so much to an individual in terms of personal empowerment and dignity.

Conclusion. A 'decision ecology' model that acknowledges the wider social context, individual narratives and emphasises trust between professionals and patients may support decision-making at end of life. Such a model must support autonomy not just at the level of wider decisions around care choice but also at the level of everyday care.

Keywords: autonomy, choice, decision ecology, decision-making, end-of-life, ethics, nursing, palliative care

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Introduction

Nurses and doctors are bound by professional codes of practice, which emphasize patient autonomy. Medical practice aims to support patient best interest, whereas nurses are advised to support autonomy as patient advocates. The International Council of Nurses (2012) promotes a Code of Ethics, which emphasizes the nurse's role in information giving to support informed consent. It is also highlighted in the UK Nursing & Midwifery Council's (Nursing & Midwifery Council 2008) code of practice, which states clearly that nurses must act as advocate for those in their care and support people's rights to be fully involved in care decisions. However, a recent review of care in a UK hospital (Francis 2013) has stimulated debate around the role of nurses in supporting patient autonomy and a review of this concept is timely. The terms 'end-of-life' and 'palliative' care are contested internationally (O'Connor 2010); however, this paper will define the term 'palliative' to include the period from non-curative support with an emphasis on quality of life to a terminal care as end-of-life approaches (National Council of Palliative Care UK 2012). Palliative care will be the primary focus of this paper; however, given that palliative care needs are being recognized in different settings including the acute sector (Gott et al. 2013), this discussion will be relevant to a range of contexts.

Background

Patient choice and autonomy are emphasized in the World Health Organisation report on palliative care and older people, which states that 'however complex a person's problems or uncertain their future may be, autonomy is a

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key human right and maintaining this must be a core ethical

value for society and healthservices' (Davies & Higginson

2004 p. 18). Patient choice is heavily promoted in the

NHS end-of-life strategy for England: promoting high quality

of care for all adults at end-of-life (Department of

Health 2008a). This document cites the word 'choice' 45

times in an attempt to promote engagement in planning for

end of life and to involve individuals in care decisions.

Other providers of end-of-life care including UK Charities,

Macmillan and Marie Curie Cancer Care organizations also

champion facilitating choice and involvement in

decision-making by patients.

Data sources

Seminal texts including Beauchamp and Childress (2001),

Randall and Downie (1999) and Woods (2007) provide a

backdrop to how autonomy is understood in the context of

palliative care. An overview of literature from 2001 is

examined to explore how autonomy and choice are

presented in clinical practice.

Discussion

Autonomy: an individualized model

Choice and autonomy are regarded as essential components

of palliative care delivery internationally (Lau & O'connor

2012, Brogaard et al. 2013). For this reason, it is worth

tracing the concept of autonomy in prominent ethical

frameworks before exploring the practice of autonomy in

palliative care nursing.

Western understandings of autonomy are based on an

individualized model, which focuses on individual selfdetermination,

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with etymological origins in the Greek

meaning ‘self-rule’ (Beauchamp & Childress 2001, Skilbeck & Payne 2005, Woods 2007). Such a definition of autonomy is linked to the rise of individualism and enlightenment in Western culture. Gubrium and Holstein (2002, p. 6) suggest that the age of enlightenment and the demise of absolute monarchy challenged the notion of the self as a subject and instead emphasized individual rights at a political and individual level. Only once the individual is recognized as an autonomous being do the concepts of free will and choice begin to be recognized.

Western understandings of autonomy are based on the writings of John Stuart Mills (1806–1873) and Immanuel Kant (1724–1873). Kantian definitions of autonomy are linked to concepts of liberty and freedom but constructed in a moral framework, which asserts that individuals are due autonomy, but must also respect the autonomy of others. Kantian approaches can be described as ‘obligation based’ (Beauchamp & Childress 2001, p. 348) and rest on an assumption that the individual is capable of rational reasoning to do that which is morally right. Mill’s approach recognizes freewill and morality but assumes a negative logic; in that, autonomy is freedom from interference from others, including state agencies (Woods 2007, p. 84).

The philosophical writings of Mills and Kant inform two broad approaches to autonomy and inform utilitarian and neo liberal standpoints (Woods 2007, Beauchamp and Childress (2001). Utilitarian perspectives are largely based on Kantian logic and focus on rational balancing of happiness and pleasure and maximizing benefits. This is not a hedonistic approach as the individual gains intrinsic value (pleasure) from undertaking a morally correct action.

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Beauchamp and Childress (2001) link such an approach to

the notion of justice where the individual rights are

balanced against wider societal responsibilities.

Neoliberal perspectives focus on self-determination and

are perhaps the most dominant approach in Western healthcare

ethics (Randall & Downie 1999, Beauchamp & Childress

2001). Liberalist autonomy is based on rights both

negative and positive. Negative rights assume the position

that an individual can exercise the right not to do something

(e.g. refusal to undergo chemotherapy as part of an advance

care plan), whereas positive rights refer to the right to receive

goods or services (e.g. free hospice care in a welfare system).

It is argued that neoliberal positions tend to focus on the negative

right and incorporate the idea that individual autonomy

rests on non-interference from others. This logic is expressed

in current debates supporting the individual's right to euthanasia

and freedom from unwanted medical intervention, for

example, the UK case of Tony Nicholson, (BBC News 2012)

and the US case of Terry Shiavo (Payne et al. 2008).

In exploring the different approaches, it is clear that

definitions of autonomy are shaped by interpretations of

morality and ethics. Beauchamp and Childress (2001) provide

a framework for exploring ethics in health practice;

autonomy; justice; maleficence; and beneficence. However,

ethical decision-making remains fraught with tensions particularly

when different interests are to be balanced. A

dying person whose condition is deteriorating may be adamant

in their wish for support at home, but the availability

of services may place responsibility on relatives, which may

be detrimental to their health. Despite Beauchamp and

Childress's (2001) framework, the reconciliation of different

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tensions, therefore, remains challenging.

Autonomy and the challenge of an individualized approach

Woods (2007) argues that individualized understandings of patient autonomy arose as a challenge to traditional and paternalistic models of medical practice. However, rather than a challenge to medical practice in palliative care, Woods (2007, p. 78) argues that patient autonomy actually complements a non-curative speciality where a person-centred, holistic approach is desirable. Randall and Downie (1999) suggest that palliative care should offer a consensus approach to decision-making described as 'preference autonomy'. 'Preference autonomy' is described as a medic (health professionals are defined as medics in this text) and patient interaction where 'the patient's informed choice as a self-determining and self-governing being is respected, as is the professional's choice of suitable treatments based on professional knowledge and skills' (p. 212). What Woods (2007) and Randall and Downie (1999) appear to be proposing is a more open dialogue between health professionals and patients around informed choice. Although open dialogue might facilitate discussions on care, there are, however, constraints. Supporting autonomy requires that patients have willingness, knowledge and understanding to interpret choices, as well as the ability to make rational decisions. This presents challenges, including when and how knowledge is presented and understood (Richards et al. 2013).

Tensions in supporting the 'informed patient'

Informed consent is a contemporary feature of health care enshrined in the NMC Code of conduct (2008, p. 3), which

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states that ‘nurses must ‘uphold people’s rights to be fully involved in decisions about their care’. Most nurses would recognize, however, that giving information is not straightforward and presents the potential for adverse outcomes if poorly enacted. There are, for example, ethical dimensions to information giving. Gardiner et al. (2010) cite that the process of informed consent in research must comply with the ethical remit ‘to do no harm’ but this is difficult to address when understandings around terminology may differ between lay and health professional. Beauchamp and Childress (2001, p. 89) similarly suggest that how information is given shapes (mis) understandings. Options are often presented as probabilities or delivered using analogy, which can be misleading and distort understandings. An added challenge is recognizing when to initiate conversations around end-of-life.

Gardiner et al. (2011, p. 56) notes that a key recommendation of the End-of-Life Care Strategy for England (2008) is that ‘death should become an explicit discussion point when patients are likely to die within 12 months’. Recognizing if death is likely within 12 months can be difficult for health professionals, particularly in non-cancer conditions such as chronic obstructive pulmonary disease, where there is often a less clear journey of beginning and end (Gardiner et al. (2011). Opportunities to discuss care preferences are, therefore, not always initiated or timely, particularly if health professionals are uncertain in recognizing when such discussions might be appropriate (Gott et al. 2009). Recognizing the transition from curative to palliative care and when to broach discussions particularly in conditions with an uncertain disease trajectory is, therefore,

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difficult (Gardiner et al. 2011).

The timeliness of information giving is then a key consideration.

For example, it may be considered maleficent

to overwhelm a patient with information at a point when they may be unwilling or unable to understand information.

Illness can threaten control and identity (Beauchamp & Childress 2001) and the need for information and response to information can differ over a period of adjustment.

This is captured in several theories around adaptation including Sprangers and Schwartz (1999) 'response shift' theory, which argues that changing circumstances can lead to a review of expectations and choices; what might seem untenable or conversely desirable is no longer following a period of transition. An example in palliative care is the well-documented shift in preference around place of death, the closer someone is to actually dying (Townsend et al. 1990). This process of transition is similar to the theory of biographical disruption (Frank 2002 and Bury 2005) where individuals regroup following a period of disjuncture. Little et al. (1998) also describe a transitional state of 'liminality' where the individual enters a 'black box', with an uncertain outcome in terms of self-identity and management of illness. Those with palliative care needs, undergoing an embodied process of transition and loss of control or identity may experience a psychological and physical inability to engage with information and make decisions (Bradley 2011). Richards et al. (2013) similarly argue that despite an emphasis on 'open awareness' around prognosis, patients do not always desire this. Giving information is, therefore, sensitive and requires a balance of when and how to offer information to maintain,

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rather than eliminate autonomy. It also requires that

health professionals, particularly nurses, are sensitive in recognizing and supporting transitional responses to information.

Hope and autonomy

The ethical imperative to ‘do no harm’ in information giving may link to a desire on the part of healthcare professionals to support hope. Beauchamp and Childress (2001, p. 286) state, ‘for prognosis, professional norms reflect the values of truthfulness, accuracy and empathy, along with the therapeutic value of hope for patients.’ Supporting hope as a coping mechanism, however, is problematic and Frank (2009) describes how ‘false hope’ can detract from opportunities for veracity in communications. A BBC Radio 4 broadcast (12th May BBC Radio 42008) illustrates this point in the narrative of the wife of the deceased Nick Clarke (a BBC journalist) where she discusses how hope seemed so important but actually reduced opportunities for honest conversations, which were later recognized to be important. Beauchamp and Childress (2001), Randall and Downie (1999) and Greener (2007) suggest that the emphasis on an individualized model of autonomy fails to give adequate recognition to the problem of how to facilitate information giving and choice whilst balancing the ‘risk’ of losing hope.

Greener (2007) questions the desire of patients to make clinical decisions and suggests that patients may prefer instead to be advised by health professionals with their perceived concomitant expertise. Individual patient autonomy is recognized as requiring competency (Department of Health 2005) but in palliative care, this can be reduced or intermittent as disease progresses and mental capacity is

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reduced or altered. For this reason, there is an emphasis in the end-of-life care strategy (2008) on advanced care directives or care planning using documentation such as the Preferred Priorities of Care (Department of Health 2008a,b). Participation in care decisions can become onerous at end of life and tensions can exist between wanting control and wanting to be cared for (Seymour et al. 2004). Seymour et al. (2004) also identified that older people regarded trust and continuous dialogue as essential in delivering end-of-life care rather than a formal plan. This may account for the low use of such initiatives in the UK and Harris and Fineberg (2011) suggests that most patients have no written plan despite the recommendations of the UK National End of Life Care Programme (2008). Frank and Anselmi (2011) report similar trends in the USA where less than a quarter of Americans have completed advanced care directives.

Autonomy and the nursing role

Battin (1994) suggests that as deterioration occurs, patients may be less concerned with wider decisions around care such as place of care and more concerned with comfort and the immediate physical relief of pain. At this point, patient autonomy is vulnerable but can be supported by attending to the personal aspects of care, which can mean so much to an individual in terms of maintaining control. Montgomery and Little (2011) describe such an approach as enabling 'patient agency'. This concept is based on Giddens' work (Montgomery & Little 2011, p. 3) and defines patient agency as engagement in care but also as 'recipients of others' agency (e.g. by being affected by others' actions during the course of treatment'. Bradley et al.

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(2011), for example, cite that agency and patient-centred

care can maintain self-esteem care where social interactions

and choice around what to disclose, eat, where to sit

and so forth are important psychosocial factors in maximizing

a sense of control. Montgomery and Little (2011)

also capture narrative accounts where patient agency is

subtly undermined by care; for example, a patient accepts

a naso-gastric tube, which is uncomfortable and asks

whether it can be removed and is unaware that its insertion

was precautionary and not a necessary part of care.

The Francis (2013), which explored poor practice in a UK

hospital trust, would also support that patient-centred care

must be mindful in attending to all aspects of care to support

autonomy. Nurses must, therefore, demonstrate mindfulness

in attending to not only the 'big' decisions but also

in demonstrating a more holistic understanding of autonomy,

which supports patient agency and identity in everyday

care.

In terms of 'bigger' decisions around autonomy, Randall

and Downie (1999, p. 35) argue that the primary

focus of medical practice is to act in the patient's best

interest and this may lead to decisions contrary to patient

autonomy (for example, ceasing chemotherapy, which is

no longer therapeutic despite patient demand). Randall

and Downie (1999, p. 75) legitimize this approach arguing

that health professionals are best placed to assess care

options given both knowledge and professional practice.

However, the recent media attention surrounding the

implementation of the Liverpool Care pathway (Press

Association 2012) suggests that in practice, patient autonomy

can be overruled or ignored and this is of public

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concern.

Whether nurses are empowered to challenge or contribute to ethical decisions around care is questionable (Hyland 2002, Schwartz 2002, Frank 2009). In terms of supporting information giving, key texts such as Randall and Downie (1999) and Beauchamp and Childress (2001) give very little recognition to the nursing role in decision-making and information giving. Hyland (2002) argues that in practice, nurses are often involved as intermediaries to support and explain information but rarely lead key interactions. The nurse role in supporting patient autonomy and choice may be impeded by a medical hierarchy where nurses are expected to support decisions, but may not be expected to engage in decision-making processes. As a result, Frank (2009) suggests that nurses themselves may not recognize a role in supporting patient autonomy and may not be equipped or empowered to participate in discussions around choice and care. There are also criticisms of the concept of nurses as ‘patient advocates’ including concerns around paternalism, lack of empowerment, little education around the concept of advocacy as well as the potential for inter-professional discord as this concept sets nurses apart from the team (Hyland 2002, Schwartz 2002). Nevertheless, the UK Nursing & Midwifery Council (Nursing & Midwifery Council 2008) cites the nurses ‘professional duty to act in the patients’ best interest, particularly with regard to consent for care. Lack of a democratic and inter-professional approach to supporting patient care may lead to an over reliance on the medical model. This may be to the detriment of patient autonomy and supports a passive nursing practice.

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Autonomy and power

Although the End-of-Life Care Strategy for England (2008, p. 18) argues that a key objective is to ‘ensure that people’s individual needs, priorities and preferences for end-of-life care are identified, documented, reviewed, respected and acted upon wherever possible’, the autonomous patient may be thwarted by social context and the inability to exercise power. Murphy (1998, cited in Sheldon & Thomson 1998) explores critically the discourse in interactions between health professionals and patients through the theories of Foucault and Habermas. Murphy (1998) suggests that patient and health professional interactions are driven by ‘expert’ professional discourses where the patient’s voice may be lost.

Economic and structural factors also impinge on patient autonomy and particularly in a healthcare market that is limited and rationed. Cohen (2011) discusses how the body and caring have become a site of labour relations and that given the current ‘austerity’ measures and emphasis on efficiency savings, this applies even in the context of palliative care. Randall and Downie (1999) suggest that there is little conflict of interest for professionals and decisions are made on clinical best practice. However, the mantra to support care provides significant hospital savings, as stated by a recent Marie Curie (2012) document on service design, which reports that ‘with nearly two-thirds of people in England expressing a preference to die at home, providing services outside the hospital setting greatly enables patient choice’. According to QIPP estimates, reducing hospital admissions could also save £180 m a year.’ This would suggest that clinical decision-making is influenced by cost considerations

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and therefore De Vries et al. (2012) and Eagle

and de Vries (2005) suggest that clinical decision-making is indeed shaped by rationing limitations. Greener (2007), therefore, questions the whole notion of an expert, selfdeterministic patient given the constraints in service provision.

Individuals who struggle to access services or whose decisions are shaped by professional definitions of patient 'best interest' may fail to make decisions (particularly if altruistic) may explain why some patients do not engage in decision-making, but have a 'learned helplessness' with regard to care decisions (Battin 1994). Battin argues that such passivity can contribute to the failure to engage in future care plans and therefore it is sudden crisis or deterioration, which triggers changes in treatment and options rather than patient wishes and health professionals are obliged to direct decisions. Therefore, early support of individuals in exploring care choices must be developed to avoid crisis decision-making.

Early support requires the building of relationships and trust not just in a health context but also in a network of trust (Giddens cited in Murphy 1988). Patient and professional interactions are multiple and, in the UK, typically take place in a large NHS system and across third sector and other providers. Although palliative care may involve fewer and more intimate relationships between clinicians and patients, Hardy's (2011) work suggests that patients nevertheless receive care from a wide range of health and social care professionals that can be confusing. Seymour et al. 2004 and Broome et al. (2012) note that trust is crucial in the context of supporting older people and their carers as they negotiate services in social and healthcare systems.

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Where there are several people involved in providing care, then developing trusting relationships is increasingly challenging when facilitating discussions around care preferences.

Recognition of the importance of building trusting relationships may be embraced through a reconceptualizing of autonomy in a decision ecology framework.

A new model of autonomy: decision ecology?

Woods (2007) argues for a communitarian model of autonomy, which derives from societal understandings around shared values and relationships. Such an approach repudiates the emphasis on neoliberal and utilitarian individualized approaches. Zelderloo (2009) suggests that the reality of people's lives is one of interdependency. Woods (2007) and Broom and Kirby (2012) similarly argue for recognition of the relational aspects of autonomy to include a contextualized and community-focused understanding. Broom and Kirby (2012) also argues that acknowledgement of the social systems, which operate around individuals, may enhance conversations by honestly acknowledging the uncertain and hypothetical nature of patient choice and future care. It would seem that what is important is recognition not just of the principles of maleficence, justice and beneficence but of the wider cultural and social networks where people exist and the discourses, which are available to patients, families and health professionals.

Factors including gender, ethnicity and age shape inequalities and also shape access to resources. In terms of gender, Biggs (1998, p. 285) highlights that women tend to be carers in the family context and therefore it is often women who care for the dying. As women tend to live longer, they may, in turn, find that their dying experiences are shaped by reliance

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on state resources. Venkatasalu et al. (2011), in a study

involving South Asian understandings around end of life,

suggests that gender and ethnicity can intersect and whilst

family-orientated approaches to decision-making are preferred

in the South Asian community, women's autonomy

can be undermined depending on their position in the family.

Dialogues around choice and care should, therefore, take

into account the gendered nature of dying and care with support

in place to ensure access to services and support.

Worth et al. (2009) in a UK study of South Asian Sikh

and Muslim participants argues that due to cultural misunderstandings

and language, some ethnic groups experience

barriers to receiving care. Venkatasalu et al. (2011)

highlights that ethnicity also shapes decision-making and

choice and reflects similar findings, for example, Bito

et al. (2007) exploring Japanese approaches to decisionmaking

focus on family-orientated decision-making as

opposed to an individualized model of autonomy. Similar

findings are explored by Bellamy and Gott (2013) where

older ethnic groups in New Zealand preferred a collective

and family-orientated approach to decision-making. Lau

and O'connor (2012) also found that cultural (mis)understandings

between health professionals and different ethnic

groups undermined autonomy in accessing services. Nurses must be aware of the need to engage in culturally

sensitive practice, particularly in palliative care where

middle class, white and Christian values tend to predominate

(Howarth 2007) despite the shift to a multicultural

demographic. Failure to understand and respect wider

belief systems may impact on the care experience (Frey

et al. 2013).

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Access to care is also shaped by age and Gomes et al.

(2011) exploring local preferences and place of death in the UK highlight that the numbers of older people dying in hospices is low, but numbers dying in the hospital setting are high despite hospice being a preferred place of care by older people. Thomas et al. (2004) suggests that factors, such as complexity of disease, social support and service provision, may shape the discrepancy between choice and outcome in older people and Gardiner et al. (2011) argue that palliative care needs are often overlooked in older people. With the ageing of populations in developed countries it is important that the experience of ageing and dying is supported by a model of autonomy that addresses issues of equality and equity in care provision.

Assumptions around caring contexts may also constrain patient autonomy and choice. For example, a common assumption is that family carers provide informal care; however, Broom and Kirby (2012) suggest that choice occurs in social support networks that are not necessarily based on kinship relationships and instead social networks reflect neoliberal shifts in society. Broom and Kirby (2012) identified that older participants in their study were aware of being a burden, particularly as traditional family networks were supplanted by individualized discourses where work obligations and economic structures eroded traditional family care giving relationships. Instead, a wide range of social networks including neighbours, friends and informal support often supported older people. Lavoie et al. (2011) suggest that autonomy around care decisions is likely to be shaped by availability and willingness of carers and therefore demographic shifts and shifting networks will impact on care options. Recognition

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of the social context, which surrounds patients, will be

important in understanding the choices available and identify constraints of choice. Nurses must engage with those in their care to support individuals and those who care for them.

A decision ecology

Biggs (1998) suggest that individualized models of autonomy fail to recognize the social relations where individuals are embedded and a sole focus on the individual is unrealistic.

An understanding of autonomy that moves away from a purely individualized model offers the potential to explore how autonomy might be supported on a broader level, which encompasses both the interpersonal dimensions and wider factors. Broome et al. (2012) offer an alternative framework, which attempts to look at both individual and meso-level elements of choice and autonomy and describe such an encompassing approach as 'decision ecology'. This concept was developed in an exploration of decision-making in the care of older people and foregrounds notions of awareness of the whole individual, particularly their narratives, social capital and relationships, as well as service provision.

The decision ecology model aims to include recognition of the importance of building trust between older people and the care agencies around them. It also aims to acknowledge the realities and availability of service provision in discussions and to review understandings of risk by practitioners to maximize agency and autonomy.

Although this is in the context of older people and social care, there is nevertheless resonance with how autonomy and decision-making may function in palliative care.

How nurses engage in decision ecology depends on the relationships nurses develop with those in the interprofessional

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team and patients in their care. Hyland (2002) and

Frank (2009) suggest that nurses must aim to interact as equal partners in the interprofessional team and should envisage that they are able to support patient choice. Richards et al. (2013) identify that whilst medics may initiate end-of-life discussions, it is nurses that deliver care and must work interprofessionally with the team and patient and family to explore communication and autonomy needs, which may differ between individuals. Key areas of focus to support a decision ecology in palliative care need to provide a framework for recognizing transitions to palliative care and how to initiate discussions around care, which are timely, sensitive to transitions and flexible. Building the foundations of relationships, which engender a trust in the care systems and personal trust, is important (Seymour et al. 2004) and such relationships must engage with the social context and resources available to the individual. It is also important to explore the interrelationship of the factors of ethnicity, gender and age in shaping experiences of end-of-life care. Greater recognition of the nurse's role in autonomy is also important and this must operate not just at the level of interprofessional discussion around care but also around the minutiae of care that can support patient and carers feelings of self-agency and control.

Implications for nursing practice

Quite how to achieve an approach such as that described by Broome et al. (2012) warrants further debate, but Richards et al. (2013) suggest that nurses must contribute to wider discussions around care and practice in a way, which is mindful and engaged. Perhaps, Beauchamp and Childress (2001, p. 34) are correct to suggest that the 'qualities of

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discernment and compassion should underpin practice, a process of ‘phronesis’ around insight, judgement and compassion and suggest that ‘generally the person of discernment is disposed to understanding and perceive what circumstances demand in the way of human responsiveness.’

How one can develop such qualities is debatable, but it would seem that a deeper understanding of the concept of a ‘decision ecology’ rather than an individualized approach to autonomy may offer a better framework for supporting decision-making in palliative care.

Conclusion

An individualized approach to autonomy fails to recognize the complexity of decision-making including the cultural and social relations, which shape patient agency. To support patient agency, nursing practice must begin to engage in wider understandings around autonomy at different levels: both at the level of contributing to discussions around care decisions and supporting individuals through timely and sensitive information giving processes, which recognize transitional processes, but also to focus on the everyday aspects of care, which can make a difference to patient autonomy.

Nursing practice must engage in exploring new ways of supporting patient agency around both the ‘big’ decisions, but also in the everyday aspects of care that support an individual in terms of personal empowerment and control.

The approach described by Broome et al. (2012) where the social context, individual narratives, care networks and building of trust are considered in the decision-making process may offer a useful model.

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