PATIENT AUTONOMY AND MEDICAL PATERNITY: CAN NURSES HELP DOCTORS TO LISTEN TO PATIENTS?

Sarah Breier-Mackie

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Nurses are increasingly faced with situations in practice regarding the prolongation of life and withdrawal of treatment. They play a central role in the care of dying people, yet they may find themselves disempowered by medical paternalism or ill-equipped in the decision-making process in end-of-life situations. This article is concerned with the ethical relationships between patient autonomy and medical paternalism in end-of-life care for an advanced cancer patient. The nurse’s role as the patient’s advocate is explored, as are the differences between nursing and medicine when confronted with the notion of patient autonomy. The impetus for this discussion stems from a clinical encounter described in the following scenario.

Scenario

Mr X was admitted to the oncology ward with a primary diagnosis of multiple myeloma for which he received a bone marrow transplant. This was complicated by stage 4 graft versus host disease (GVHD) and cytomegalovirus infection. Mr X’s response to aggressive chemotherapy was poor and he suffered intractable nausea, vomiting, diarrhoea, rectal bleeding and extreme abdominal pain for over three months after the transplant. He was then diagnosed with sepsis secondary to ischaemia of the bowel and was found to be gancyclovir resistant. During this time Mr X became progressively weak yet remained lucid and, despite aggressive treatment, continued to deteriorate. He spoke with nursing and medical staff about his wish for cessation of the treatment. His children were supportive of his wishes and conveyed these to the medical staff. They requested their father to be transferred home with hospice care or to a palliative care setting. The medical team rejected this request, explaining that there were still other treatments they wanted to try that may alleviate the GVHD. Mr X and his family reluctantly com-
plied, yet the patient did not respond to the other treatments and was rendered severely ill owing to the drugs’ side-effects and catheter sepsis. Both the patient and his family became frustrated and angry. Their request for palliation was finally granted a week later when Mr X deteriorated suddenly and returned home with full hospice support. He died peacefully, surrounded by his family, a mere 24 hours later. After his passing, Mr X’s family stated at a follow-up bereavement visit by home hospice staff that they felt angry and cheated over their father’s prolonged suffering in hospital and could not understand why the doctors did not listen to him.

Introduction

Nurses are directly involved with patients such as Mr X on a day to day basis and, while clinical decision making has been seen traditionally as the responsibility of the doctor, the consequences of those decisions fall largely on the nurses who are caring for such patients. Although there is an obligation to carry out the doctor’s orders when decisions are medically orientated, there is no evidence that doctors are any more qualified in ethical decision making than nurses.1 Others argue that there is no reason why doctors should have a monopoly over ethical decision making.2 Nurses have a professional obligation to act in the best interests of their patients3 and if they are to take part in the analysis of ethical issues they need to be well versed in the practical philosophies underpinning the ethical debates on end-of-life care in order to contribute effectively. Consideration of the ethical principle of autonomy forms the basis of this article.

Futility and the end of life

Defining medical futility is significant in the efforts of clinicians and ethicists who seek to identify the limits of patient autonomy. In general, the nursing literature has not contained much discussion about nursing’s role in facilitating respect for patients’ preferences at the end of life. For example, although an extensive amount of medical research has been carried out on the utilization and efficacy of advance directives, there has been little nursing research on any aspect of advance directives, with some important exceptions.4–6 This raises the question of who should be involved in making the decision that the patient’s condition is medically futile. Given nursing’s greater degree of presence at the bedside and a key role in patient communication, more discussion and enquiry are needed in this area.

Futile treatment at the end of life is not a new predicament. In its original encounter it was experienced most often by patients as undesired care.7 Efforts to extend the education of health care professionals about a patient’s right to be self-determining and the securing of legal protection for this right have done much (primarily in the USA) to mitigate this problem. Similarly, the high-profile ethical debate of physician-assisted suicide has done much to fuel efforts to improve end-of-life care.8 Nurse advocates who inform and alert their health professional colleagues to thorough consideration of the patient good beyond mere physical well-being have also been helpful.
It is first necessary to recognize the two different consequences of beneficial health care: improved physical well-being and improved overall well-being. Although medicine suggests the physical benefits of treatment interventions, only the patient or those who know the patient best can determine if such medical care is improving and enhancing the patient’s overall well-being. This latter determinant is a subjective measurement. Using these distinctions, medical care can be classified as follows: (1) not futile: beneficial to both physical and overall well-being; (2) futile: nonbeneficial to either physical or overall well-being; (3) futile from the clinician’s perspective: considered valuable by the patient, or by his or her proxy, but not clinically indicated; and (4) futile from the patient’s perspective: clinically indicated but not considered valuable by the patient, or by his or her proxy. It is the last point that is the focus of this discussion. Despite this component being partially resolved by an increased emphasis on patient autonomy in recent years, plenty of anecdotal evidence abounds to the contrary. This assumption leads us to a compelling question: Are health care providers obligated to comply with patients’ wishes? or, more candidly: Are nurses obligated to comply with doctors’ wishes and ignore patients’ wishes and sanction further aggressive treatment by their provision of such treatment?

Autonomy analysed

Western health care systems have long considered autonomy as an important ethical principle in directing clinical decisions. Patient autonomy has been promoted significantly in declaring the moral and legal right of competent individuals to make decisions about the course of their dying, in improving methods for the expression of their preferences, and in better understanding of the family’s role and experience in decision making. Highly publicized court cases, including the Karen Quinlan, Nancy Cruzan (USA) and Tony Bland (UK) cases, have brought professional and public recognition to the question of the patient’s voice in medical decision making about aggressive treatment in terminal conditions.

It is useful here to undertake a brief analysis of the predominant discourse within this argument. The term autonomy has its foundations in the Greek words _auto_ (self) and _nomos_ (rule, legislation, or determination). The term _autonomia_ originally described Greek city-states that were independent of external control, whereby citizens set their own governing laws rather than being subjected to laws imposed by an outside source. Gillon defines autonomy in its most literal sense as being ‘self-rule’ or the capacity to think, decide and act on the basis of such thought and decision, unhindered and independently without fear of reprisal. Rubin explains that self-rule, or autonomy, contrasts with other-rule, or heteronomy. Rather than being ruled by another, autonomous individuals develop and act on their own life plan.

Encumbrance with one’s right to choose one’s own goals and ends, or the imposition of another’s rule instead, subjects an autonomous individual to a heteronomous life. When doctors attempt to substitute their judgement for that of their patients, they are attempting to substitute autonomy with heteronomy. Within the clinical context, this is traditionally the disparity between patient autonomy and medical paternalism. The ‘overriding’ of a patient’s autonomous
preferences, decisions, or actions out of a concern for the patient’s welfare constitutes medical paternalism. Conversely, the principle of patient autonomy necessitates the empowering of patients through the provision of information. It is often in connection with the choices that patients wish to make about controlling the end of their lives that doctors find patient autonomy most problematic.  

Patients who are confronted with the autonomy/paternalism dichotomy, are often unable to verbalize their needs or wants to their doctors, either because they are intimidated by the doctors’ perceived power, or because the doctors lack the time to listen to their concerns. Nurses, however, as patients’ advocates, are ideally positioned to assist the patients and their families to clarify their needs and desires.

Nurses’ role in futile treatment decisions

Once cure of illness and/or restoration to ‘health’ are no longer realistic, the decision to modify the treatment plan so that either stabilized functioning or a comfortable dignified death results is indispensable. In an ideal world, the patient, the family, and the health care team are in agreement about the goal for continued treatment or what constitutes continued treatment. Unfortunately, however, this is often not the case. The opening scenario alludes to an all too common situation whereby clinicians are allowed to decide upon futility, that is, to subordinate patient autonomy to physician autonomy or, as described by Nuland, to the paternalism of doctors. Ideally, the decision either to proceed with or to withdraw aggressive treatment should be one of negotiation between all parties. Others maintain that the parties should try to reach an understanding of treatment expectations as early as possible, before the patient reaches the terminal stage. Such expectations include, but are not limited to, what care would be deemed futile, and what care falls within acceptable limits for the patient, the family, the doctor and the institution. It is by reaching this understanding via negotiation that nurses can play a critical role in effecting a just outcome. Nurses are in a unique position to initiate discussions regarding patients’ preferences for treatment and quality of life. The intent of such nurse-driven negotiation is to ensure that everyone works together to secure the best possible outcome for the patient, not that any one person or party asserts their assumed authority.

Historically, nurses have situated patients and their values at the centre of care. The futility debate accentuates the pressing need for professionals to introduce into ethical discourse and clinical treatment decisions a sense of who the patient is and the values that underlie the patient’s (and/or the proxy’s) demands for treatment or refusal of treatment. Equally pressing is the need for an honest evaluation of the variables influencing both patient and doctor determination of when a given treatment justifies the risk of suffering and the allocation of both scarce and costly resources. Nurses are well placed to bring the realities of patient autonomy to the ethical discourse, as well as contributing significantly to the burden/benefit discussion that should always be present in such scenarios.
Patient knows best

Much of the bioethics literature in general, particularly the futility literature, presupposes that, in conflicts between patients and doctors, patients are more authoritative in evaluative matters that have direct consequences for their lives and bodies and doctors are more authoritative in exacting technological matters. Following this general assumption, many contributors to the futility literature have suggested that patients are in the foremost position to decide on therapeutic goals and to determine whether or not they are worth achieving.17–22 Correspondingly, they are in a prime position to evaluate, interpret and contemplate available medical information and to make evaluative judgements about whether a particular treatment modality is appropriate and worth trying.10 This is generally accepted as true because only patients know how much risk they are willing to take and can judge particular benefits.23 More importantly, patients alone live with the outcome of medical interventions. From this perspective they are consequently best situated to recognize when treatments are futile for them, that is, are not worth trying. At the very least, they should be significantly involved in making such determinations. However, it occurs seldom that patients are considered to be sufficiently authoritative to make judgments about the probability of a treatment’s success in achieving their desired goal.10

Doctor knows best

A basic assumption is that when it comes to data collection and its interpretation and evaluation of relevance for a given patient, doctors are the more expert. On that account, many have argued that doctors are in the best position to detect authoritatively when treatment goals can or can not be accomplished.24–28 It is also argued that doctors possess the knowledge, expertise and authority to recognize when they are confronted with either physiologically viable or futile treatments. Accordingly, it is ultimately the doctor’s responsibility to review the clinical facts and to recognize when treatment modalities will be futile in accomplishing specified goals.10,29 The obvious disparity between the ‘patient knows best’ and the ‘doctor knows best’ arguments essentially forms what is the autonomy/paternalism dichotomy.

Us and them: do doctors and nurses consider patient autonomy differently?

In an ethnographic study by Robertson,30 nurses and doctors viewed patient autonomy differently. Although they were reported to share a commitment to the liberal and utilitarian concepts of the principle of autonomy, nurses emphasized patient autonomy while doctors were more likely to emphasize beneficence via treatment provision. The key professional goals of nurses were daily care and helping patients to live as normally and independently as possible. These goals were sought through ongoing relationships whose sustenance necessitated the demonstration of character virtues. The most important goals of doctors were
systematic problem solving, improving organ function, and research. For doctors the priority was the technological imperative, essentially the improvement of organ function.\textsuperscript{30} An exception to this assumption is the recent efforts of the medical profession to move away from the biomedical model to a more holistic model, as, for example, in Pellegrino’s ethics of caring.\textsuperscript{31}

Much anecdotal evidence exists about the differences in caring priorities in addition to those research findings noted above. Robertson\textsuperscript{30} explains that this emphasis of nurses regarding patient autonomy is secondary to the fact that nurses’ most salient professional goal (patient normality and independence) is defined by patients’ abilities. This relationship is established through the daily and nightly care of the ever-present nurse rather than via the episodic consultative nature of typical patient–doctor contact.

Assuming the role of patient advocate when conflict develops between patients and doctors means taking the ‘middle ground’ and uncovering what it is that truly underpins the patient’s (and/or the proxy’s) requests as well as the factors that give rise to doctors’ professional discomfort about these requests. Patient advocacy also means uncovering the factors that make health professionals uncomfortable about those demands for treatment.\textsuperscript{32} Unfortunately there is not always a satisfactory resolution of the conflict until these factors are identified.\textsuperscript{7}

Nurses, however, can intervene and provide much needed clarity in the identification of such conflict variables. This kind of intervention is enhanced by nurses gaining skills in mediation.

It is essential for nurses to develop the necessary communication skills, including interpersonal competence and group process adeptness. Related to this, the American Nurses Association code of ethics\textsuperscript{33} and standards of clinical nursing practice\textsuperscript{34} oblige nurses to be patient advocates. Similarly, in the UK\textsuperscript{3} as well as in Australia,\textsuperscript{35} nurses share a responsibility to inform the public and to contribute to public debate on ethical issues. Skills development in effective interpersonal communication in problem-solving groups should therefore feature strongly at unit or ward ongoing education level, if not within all nursing curricula.

To assume successfully the role of mediator, nurses must know the patient and their proxies, otherwise their effect as advocates is futile in itself. Central to nurses’ contribution to the interdisciplinary team is the nurse–patient relationship. It is this relationship that empowers nurses to speak with authority regarding the effects of the illness on the patient. As Taylor\textsuperscript{7} explains, it is a triple assessment of the current health state, the influence of this state on the person, and the influence on the person’s ability to achieve meaningful life goals, that distinguishes nursing from medicine. By virtue of this assessment, nurses are able to discuss futility from the patient’s perspective and elucidate why some patients (and/or their proxies) are requesting the withdrawal of treatment that doctors consider appropriate. This discussion may also open up opportunities for suggesting strategies for clarifying unrealistic expectations of both treatment provider and treatment recipient. In order to fulfil this mediating role effectively, nurses must also be both reactive and sensitive to professional and societal factors that promote conflict. For example, bias and discrimination can always influence clinical decision making.\textsuperscript{7} More problematic may be the need to separate surrogate suffering from patient suffering to guarantee that treatment decisions such as its
provision or withdrawal are based on the interests of the patient rather than on those of the surrogate, especially when the surrogate is the primary caregiver.

End-of-life care and autonomy

The unanimous efforts to improve end-of-life care that are now burgeoning in the USA are focused on better provision of palliative care. These efforts are reflected in the recent progress of institutional futility policies: the ‘Last acts: care and caring at the end of life’ initiative of the Robert Wood Johnson Foundation, and the EPEC project (‘Education for physicians on end-of-life care’) of the American Medical Association. Similarly, in the UK a recent British Medical Association publication demonstrates a raised awareness in the complexity of end-of-life care. Finucane, however, exposes the shortfall of end-of-life care by claiming that some dying patients do suffer unnecessarily because doctors lack the skills, temperament, or motivation to provide good palliative care:

This is a serious failure. An ardent focus on technical aspects of symptom control, however, could distract broader efforts to improve care of those near death. Symptom control is often not the most difficult aspect of management. In caring for a severely, progressively ill patient, what may be the most difficult is moving through the transition from gravely ill to fighting death to terminally ill and seeking peace, shifting the goals of treatment from cure or longer survival to preservation of comfort and dignity.6

Elisabeth Kübler-Ross wrote that ‘death is still a fearful, frightening happening and the fear of death is a universal fear even if we think we have mastered it on several levels’. Most readers may agree that this is still the case, with many doctors espousing much of that fear. This fear is not helped by the fact that the majority of medical curricula, regardless of their geographical margins, offer little education for would-be-doctors on end-of-life care or the actual process of dying itself. Nurses, on the contrary, deal regularly with the realities of the active process of dying. These realities – be they physiological or the complex personal, spiritual and emotional actualities – are not new to the majority of nurses, especially those working in clinical environments such as oncology, palliative and hospice care, critical care, emergency departments and geriatric care facilities, to name just a few. Nurses are also ‘there’, that is, on the ward, at the bedside, 24 hours a day, providing continuous care rather than the segmented consultative care that is so characteristic of the practice of hospital medicine. Yet it is not only the doctor who may be unprepared to deal with ‘death’ but also the patient who is in a state of dying. This may be the greatest difficulty that nurses deal with in empowering patients’ right to self-determination in futile treatment decisions.

As Fox and colleagues claim, dying patients who receive hospice care and their families are more satisfied with the care than those who are cared for elsewhere. This reflects the skill, compassion and dedication of the people working in the hospice environment, predominantly nurses. The doctor’s central task in caring for seriously ill persons who are near to death is to accompany and guide these patients, who generally do not want to die, through the critical transition of being ill to dying. Several of the following tasks are therefore important: giving the best estimate of prognosis; identifying situations where palliative care may supplant the desire for aggressive treatment; and at times giving permission...
for a patient or loved one to agree to forgo treatment. A patient–doctor relationship based on continuing communication, truth telling and an awareness of the experience of the patient and loved ones is paramount to good care of the dying. However, the establishment of such a relationship may require encouragement of the nurse to step in and ‘get the ball rolling’. The foundation for such a relationship is to understand and respect a patient’s desire for all aggressive treatment to stop, even if this goes against the doctor’s commitment to fight the disease and preserve life at all cost. Encouragement, support, fidelity, virtue and realism remain the cornerstones of good care for the dying. Yet even with these considerations and with impeccable technical expertise in symptom management, patients, doctors, nurses and family members are likely to continue to struggle with the decisions that must be made as patients enter the active stage of life’s final outcome.

Avoiding a medicalized death

The care of people who are dying has been greatly affected by the process of ‘medicalization’ of contemporary society. It is often problematic for doctors to shift their care from restorative intervention and aggressive management of disease and focus it on a pattern of care where primacy is granted to the quality of life. Within hospitals this transition to palliative care is a frequent area of tension between medical and nursing staff. In a study by Singer and colleagues on patient perspectives on quality of life, participants were afraid of ‘lingering’ and ‘being kept alive’ after they could no longer enjoy their lives. Quality of life concerns seemed to fuel this fear; many were terrified of becoming a ‘vegetable’ or living in a coma. These participants adamantly denounced ‘being kept alive by a machine’. They wanted to be ‘allowed to die naturally’ or ‘in peace’. Ufema directly encouraged nurses to ask patients what they want, claiming that people know what is best for themselves, right up to the moment they die. Such claims do not fit comfortably within the technological imperative of medical treatment, yet the above study identifies five domains of quality end-of-life care from the patient perspective that challenge such an imperative: to receive adequate pain and symptom control; to avoid inappropriate prolongation of dying; to achieve a sense of control; to relieve the burden; and to strengthen relationships with loved ones. Two of these domains require further exploration in the context of this discussion.

Achieving a sense of control

In the above study, participants were adamant that they wanted to retain control of their end-of-life care decisions while they were capable of doing so, and that they wanted the proxy of their choice to retain control of doing so if they became incapable. One of the participants said, ‘That’s my life. Nobody has any right to tell me that’. This essentially captures the true voice of autonomy. This true voice is, however, often not heard or, as in the case of Mr X, is either ignored or silenced from dwindling energy levels secondary to the disease process and the crippling side-effects of aggressive treatment. This silencing of the true voice is
characteristic of the disempowering nature of medical paternity in certain clinical situations.\textsuperscript{14}

Avoiding inappropriate prolongation of dying

The inappropriate prolongation of dying has been described by some as the deliberate medicalization of death\textsuperscript{46,47} and the failure to palliate rather than continue fighting the disease at all costs.\textsuperscript{48} Caring for terminally ill patients in a system by system or organ by organ approach, as is typical in tertiary settings, fragments the process of dying into a series of medical events. By ‘demedicalizing’ death\textsuperscript{49} via the holistic nature of care that renders nursing different from medicine,\textsuperscript{50} such inappropriate prolongation of dying may be successfully challenged.

How can we determine a patient’s quality of life?

Despite efforts to develop measurements for and indicators of quality of life\textsuperscript{51} none of us can claim legitimately to know truly and authoritatively what another’s quality of life is. The quality of one’s life, based on rational decisions, can be measured only by the individual’s own value system.\textsuperscript{52} As nurses we may be in a position to make observations and assumptions about patients’ semblance but, unless we are living in their body and mind, and in their intrinsic world of experience, we cannot claim to know how they perceive or value the quality of their existence. Essentially, a patient’s personhood is that of the patient. Consequently, only patients themselves are in a position to impart reliable and meaningful information about their own quality of life. Moreover, recent studies have documented the outright disqualification of health care providers and family members to know accurately how patients actually assess their own quality of life.\textsuperscript{53–56} Despite the dilemmas inherent in the quality of life debate, the inclination to provide only those treatments that will preserve, restore or ameliorate quality of life reverberates throughout contemporary discussions on medical futility.

Delivery system differences

More than death itself, what seems frightening is the very real prospect of losing control over one’s own dying process.\textsuperscript{57} As Salem\textsuperscript{49} explains, the reaction to this exorbitant sway of medicine from caring to curing has been nourished since the 1970s by virtue of patients’ empowerment or, more generally, the liberal individualism that has extended vigorously into the medical system. In response, advance directives, health care proxies, durable power of attorney for health care and other devices founded on the right to forgo medical treatment aim to protect patients from doctors, medicine and hospital institutional imperatives. This, however, is essentially the US view that emanates from the consequences of what can simply be defined as a ‘capitalized/privatized’ health care delivery system. The situation in other developed countries, especially those that espouse a health care delivery system that is commonly referred to as socialized
medicine and/or universal health care is very different. In the UK and Australia for example, the litigious nature of health care is something that is seen as almost exclusively ‘American’, possibly resulting from the capitalized/privatized nature of health services provision. This model of health care delivery can only raise patient (or more aptly ‘consumer’) awareness, rights, ownership and control. In this case it could be argued that the elusive trait of medicine’s power is so deeply embedded in a socialized system of health care delivery that it goes unnoticed. Essentially, the point here is that medical paternity is alive and well, as is patient ignorance of their rights as recipients of health care to say ‘no’.

Conclusion

By challenging the judgements that doctors can make in order to restrict patient access to desired treatment raises obvious concerns about protecting autonomous patients from unwanted and unnecessary medical paternalism. This is reflected in the opening scenario, where access to palliative management was requested by the patient and the family, yet not granted by the medical team until the last moment. From the position of patient autonomy, we may even ask not which value judgements doctors should be entitled to make or whether they should make them, but when (i.e. under what circumstances) they should be sanctioned to supplant their own values or their sense of appropriateness for those of their patients.

To claim that patients have autonomy is to argue that they have the capacity and right to decide for themselves the values and rules that will govern their existence. This claim works because it provides a justification for limiting the power that doctors can exercise over patients, specifically the power to judge and make decisions without their knowledge, understanding or consent. If doctors exercised such power over patients, they would violate the capacity and right of patients to self-determination. Ultimately, granting doctors unilateral decision-making power on the basis of medical dominance would substitute a system of medical paternity for patient autonomy. Nurses can situate themselves realistically within this ever-present dichotomy and in effect are in a position to challenge such a process. By assuming the role of patient advocate plus embracing their own professional power via professional development within this area of clinical ethics, nurses can make a significant and worthwhile contribution to ensuring that patients’ true wishes are respected, or at least heard.

Respect for patient autonomy should occupy a prominent place in the moral commitments of all health professionals. Understanding the differences between nurses’ and doctors’ views on patient autonomy, the role of the nurse as patient advocate, and the need for doctors to heighten their awareness for more established therapeutic communication in end-of-life situations, can give everyone valuable insight into each other’s strengths and weaknesses as ethical decision makers. This will surely improve the ability of doctors and nurses to complement each other in the decision-making process, ultimately for the benefit and holistic well-being of patients and their families.
References


