Refusal of treatment and decision-making capacity

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Abstract

This article explores refusal of medical treatment by adult patients from ethical and legal perspectives. Initially, consequentialist and deontological ethical theory are outlined. The concepts of autonomy, paternalism and competence are described and an overview of Beauchamp and Childress's principle-based approach to moral reasoning is given. Relevant common law is discussed and the provisions of the Mental Capacity Act 2005 in assessing competence is evaluated. In order to demonstrate the consideration of moral issues in clinical practice, ethical theory is applied to two well-known incidents: the case of Re MB, where doubt over decision-making capacity led to a paternalistic act to override a patient's choice; and the death of Emma Gough, a situation where respect for autonomy prevailed when healthcare staff acted lawfully in following a patient's refusal of life-saving treatment. Finally, guidance from regulatory bodies on the roles and responsibilities of health professionals in relation to this topic are considered.

Keywords

capacity, competence, consent, refusal of treatment

Introduction

A competent adult has an indisputable and absolute right to refuse medical treatment under UK law.[1] This reflects the importance the law places on respecting people's right to determine what happens to their own body.[2] However, complex situations arise in clinical practice when it may be difficult for nurses to respect a patient's decision to refuse treatment; for example, where their decision could cause them serious harm; or if there is doubt over their 'competence' or ability to make autonomous choices. An understanding of ethics and law is therefore important in order to guide decision making. Ultimately this can help to uphold patients' rights and protect vulnerable people from harm. Furthermore, in this age of litigation, acting in accordance with legal and ethical principles can help to protect accountable health professionals from legal action. This report will explore ethical and legal aspects of refusal of medical treatment by adult patients.

Ethical aspects

Normative ethics address the question of what kind of acts are right or wrong through examining the norms by which people make moral choices.[3] Consequentialism and deontology are two key theories which can be used to apply normative ethics to making decisions in healthcare. Consequentialism considers the consequences of actions in order to identify which choice is likely to yield the most 'good' and least 'bad',

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or most 'net benefit'.[4] Deontology emphasizes that certain acts are inherently right or wrong, independent of the outcome[4] and asks what one 'ought' to do in relation to duty or obligation.[3] Consequentialist theory could be used to justify overriding a patient's decision to refuse treatment if it is believed that this will result in the best overall outcome. This contradicts the deontological assertion that it is fundamentally wrong not to respect a patient's right to determine what happens to their own body.[4] Thus, the two theories appear to conflict if a patient refuses treatment and this decision could result in serious harm. Edwards[5] argues that both approaches are necessary in ethical decision making by considering the consequences of action and the rights and duties of the people involved in order to reach a morally acceptable solution. Indeed, elements of both theories can be seen in everyday healthcare practice; with benefiting patients being the ultimate goal of care and the duty of nurses to promote well-being and not to harm patients while respecting their autonomy.

The concept of autonomy is central in refusal of consent to treatment. It encompasses the right to decide how we wish to live our lives, which – it could be argued – is a fundamental aspect of an individual's humanity.[6] This is echoed in the Human Rights Act 1998, Article 8,[7] which asserts that everyone has a right to private and family life with no interference from a public authority. In a medical context, this could be seen as the right to 'bodily integrity',[8] or the right not to have treatment without consent. The concept of paternalism involves overriding autonomous choices or actions to provide benefit or prevent harm to the individual.[4] Mental and physical capacity or 'competence' to make choices and act on them are involved in exercising the right to determine what happens to our body.[3] If a person significantly lacks this capacity, a decision made in their best interests is considered to be a paternalistic act.[5]

Beauchamp and Childress[9] developed a framework for moral reasoning based on moral judgements, rules, principles and theories at different 'levels' of moral thinking. At the principle level, four core moral principles can be applied to an ethical dilemma in order to identify and weigh up ethical issues. This approach does not offer prescriptive solutions to ethical problems but aims to aid decision making in healthcare practice.[6] The principles are: respect for a patient's autonomy; beneficence, or ensuring actions are for the benefit of patients; non-maleficence, or doing no harm; and justice, or acting fairly and equitably.[8] In applying this approach to refusal of treatment, respect for a patient's autonomy, beneficence and non-maleficence would be key considerations and may conflict in situations when the refusal could lead to serious harm for the patient, or if there is doubt over a patient's capacity to make autonomous choices regarding their treatment.

Legal aspects

The principle of respect for autonomy underpins the law on consent and refusal of treatment. Touching a patient without consent is recognized in common law as the tort of battery or even the crime of assault.[12] For consent to be legally valid it must be given freely by someone with decision-making capacity or 'competence', who has been reasonably informed.[2] It follows that when a competent adult refuses treatment, under law their decision must be respected; even if it appears irrational or could place their life at risk.[13]

Decision-making capacity is a key condition of legally valid consent. The Mental Capacity Act (MCA) 2005[10] states that a patient must be presumed to have capacity unless there is evidence otherwise. This statute provides guidance on assessing capacity and acting in the 'best interests' of those who lack capacity, with the fundamental aim of balancing the rights of potentially vulnerable people with their protection.[14] The act states that if a patient is considered to lack capacity following assessment, they should still be involved in decision making as far as possible; thus enhancing their ability to exercise autonomy.[5] Under the MCA[10] there may be doubt over a patient's capacity if functioning of their mind or brain is impaired or disturbed in some way. To conclude that a patient lacks capacity to consent or refuse the treatment, it must then be shown that the patient is unable to understand the information relevant to the particular decision, unable to retain the information, unable to weigh up the information as part of the decision-making process,

or unable to communicate the decision in any way. It does not matter that a decision may appear irrational or unwise. Furthermore, assessment of capacity must be decision-specific. The MCA 2005[10] also acknowledges that capacity can fluctuate and emphasizes that assessment of capacity should be carried out at the time a decision needs to be made. This could be relevant in the care of patients in the early stages of Alzheimer's disease. If a person is only able to retain information for a short period this does not mean that they necessarily lack capacity; although the decision must be made during the period when they have the requisite capacity.[15]

The provisions of the MCA 2005[10] could be said to represent a triumph of the right to self determination over the 'doctor knows best' approach to medical decision making which had prevailed in the past.[6] However, Walters[14] argues that the requirement for a patient to understand the information given regarding the nature, purpose and effects of treatment is subjective and could be manipulated by the practitioner carrying out the assessment; thus giving them control over decision making rather than the patient. Equally, it could be argued that the test for capacity is not rigorous enough in order to protect vulnerable people from harming themselves.[6] Walters[14] uses the example of people suffering from *anorexia* to illustrate this point. Although commonly accepted that treatment should be imposed because capability to decide on treatment is compromised by an irrational belief that they are fat, people with this illness could potentially pass the test for competence. However, DoH[2] reference guidelines include such an example, stating that where the decision which appears irrational is based on a misperception of reality, it can be concluded that the patient is unable to comprehend and make use of the relevant information, and therefore lacks capacity. Yet the irrationality of decisions and even 'misperceptions of reality' are subjective; some personal and religious beliefs may seem unreasonable but make sense to the patient.[6]

Application to practice

In order to apply the theory discussed above to clinical practice, the ethical basis of decisions made in two cases involving refusal of medical treatment will be analysed. In the first case; Re MB (Adult, medical treatment)[11] a woman withdrew her consent to a caesarean section necessary to save her baby's life due to her phobia of needles. The hospital providing treatment to MB obtained a court declaration in order to lawfully carry out the procedure, overriding her decision. The second case did not involve a court decision but received much media coverage and some public disapproval of what could be seen as an unnecessary and preventable death.[1] It involved a young Jehovah's Witness, Emma Gough, who died hours after giving birth as doctors respected her decision to refuse blood transfusions due to her religious beliefs.[16]

In Re MB,[11] the patient contested the legality of overriding her refusal of treatment after the birth of her baby. The Court of Appeal concluded that MB suffered temporary impairment of the mind due to fear and panic, preventing her from taking in and weighing up the information regarding the decision to have a caesarean in a rational manner. Therefore, the hospital had acted lawfully in overriding MB's refusal, illustrating paternalism being justified in practice. In the death of Emma Gough, doctors also acted lawfully in respecting her competent decision to refuse life-saving treatment. If they had overridden her decision, this would have been viewed as treating her without consent; constituting an actionable battery.[17] The difference in the outcomes of the two refusals was due to the 'competence' of the two patients, although both decisions could be viewed as irrational.

Applying ethical theory to these two cases, consequentialist and deontological reasoning can be demonstrated; and the principles of respect for autonomy can be shown to conflict with the principles of beneficence or non-maleficence. A nurse's obligation to respect the patient's autonomy could mean accepting the patient's decisions and allowing serious harm to occur. However, in Re MB the health professionals carried out the operation against the patient's expressed wishes, in order to result in the 'net benefit' of helping her baby to be born alive and prevent harm to MB's health. Reinforcing this decision was the health

professionals' duty to help and protect those who cannot help themselves.[18] The UK Clinical Ethics Network[19] assert that the course of action chosen on the behalf of a patient lacking capacity should be in line with the individual's values and beliefs or sense of identity as far as possible, in order to promote their autonomy while acting in their best interests. It was established that MB did wish her baby to be born alive more than she wished to avoid the injection.[6] Thus, although she refused the caesarean section, carrying out the procedure can be justified as it was in her best interests at a time when she temporarily lacked capacity.

In the case of Emma Gough, health professionals acted on their duty to respect her autonomy by abiding by her decision. Conversely, it could be argued that the resulting consequences of her refusal were so harmful that it would have been morally right to override her decision, as implied by some of the media coverage of the events surrounding her death.[1] However, Banja[20] argues that it is not ethically acceptable for health professionals to override a competent patient's refusal based on their own personal values and beliefs. Moreover, Beauchamp and Childress[9] state that acknowledging the right of patients to act based on their personal values and beliefs is part of respecting autonomy. In analysing the conflict between ethical principles, the patient's perspective should be considered.[6] Emma may have believed that more harm would result had her wishes not being respected, as this would violate her fundamental right to decide how to live her own life. Furthermore, Emma may have believed that suffering eternal damnation by receiving a blood transfusion, as believed by many Jehovah's Witnesses, would have been worse than death.[21] Analysed in this way, the conflict between the principles is somewhat reduced.

Regulatory bodies provide guidance for health professionals on the application of law in clinical practice. The Nursing and Midwifery Council (NMC)[22] and General Medical Council (GMC)[23] guidelines of professional conduct specify the duties and roles of nurses and doctors in keeping abreast of and abiding by the law. They also provide specific guidance on consent, refusal of treatment and capacity. Assessment of mental capacity is the responsibility of the clinician providing the treatment.[24] This implies that in situations such as Re MB, doctors would make the ultimate decision about whether to respect a refusal of treatment when there is doubt over capacity. However, the NMC[24] also emphasizes that nurses are expected to take part in discussions regarding this assessment. A fundamental aspect of a nurse's role is in advocating for patients, making sure they are fully informed, respecting and supporting their rights to accept or decline treatment and involving them in decisions about their care.[22] Formal guidance should be obtained from the courts where there is a dispute as to a person's capacity or best interests which cannot be resolved in practice.[24,25] In cases where refusal would lead to serious harm to the patient, professional guidance is clear that refusals of treatment by competent adults should be respected.[2,24–26]They also emphasize the importance of being non-judgmental and communicating effectively with patients when discussing treatment decisions.[26,27] According to the NMC, it is not acceptable for a nurse to refuse to treat a patient based on their own personal beliefs, with the exception of refusing to take part in abortion or artificial conception procedures.[27] In contrast, the GMC states that doctors can withdraw from providing care if they disagree with a patient's decision to refuse life-prolonging treatment on moral grounds; provided they first make arrangements for another clinician to take over care.[28] This could potentially put the rest of the healthcare team in a difficult position. Further guidance on nurses' obligations should such situations arise would therefore be beneficial.

Conclusion

In conclusion, it has been demonstrated that a knowledge and understanding of ethical frameworks as well as law governing refusal of treatment and capacity is highly important. This will help nurses to take part in decision making in practice and uphold patients' rights to self-determination while protecting the interests of vulnerable patients. Ethical theories and concepts can be used to help identify moral issues and conflicts between ethical principles. Common law and the Mental Capacity Act 2005 aim to safeguard patients'

rights and autonomy. They can be referred to for definitive guidance on the acceptability of respecting or overriding a patient's decision. However, decision making may not always be clear-cut in practice. Professional guidelines highlight the requirement to keep patients at the centre of decision making, keep them fully informed and respect their personal beliefs. Recommendations for future practice include that healthcare organizations and the NHS should facilitate the continued acquisition of knowledge of ethical and legal issues by nurses and other healthcare professionals in practice, and open discussion in decision making between patients and clients and all professionals involved in care delivery.

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Conflict of interest statement

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