

Decision making with a complex ethical dilemma: Palliative Care - Case based Discussion

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Introduction: Morality and Ethics

In recent years, there has been an increasing awareness of 'moral challenges' among the health care professionals and public they serve. The complexity of these issues is caused in part by the growing consciousness of the public and by professionals who care for others and believe that they have special claims to deciding what is right and wrong in health and illness. (Randall and Downie 2001)

Morality refers to norms about right and wrong human conduct and it encompasses many standards of conduct, including principles, rules, rights and virtues. Ethics is a generic term for several ways of examining the moral life. Biomedical ethics is a form of applied ethics wherein general moral action guides are applied to answer the question 'which action-guides are worthy of moral acceptance and for what reasons.' (Beauchamp and Childress 2001)

In day-to-day clinical practice, the ethical aspects of patient care fall into two general categories:

- Everyday ethics, which comprise the general approach to patient care and professional practice.
- Ethical dilemmas, in which there is a true complexity to a patient problem and the 'right' course of action may be difficult to determine.

In this assignment, the author will demonstrate an understanding of different approaches to healthcare ethics relating to a scenario at the work place that has raised ethical concerns.

Scenario

Mrs. RT, a 51-year-old Asian woman with advanced intra-abdominal cancer was admitted to a hospice in southeast England for symptom management. After admission, the patient asked to speak to her brother who lived in Liverpool. The hospice team assisted with this. After talking to him, she expressed her wish to go to Liverpool and remain there for end of life care.

Subsequently, Mrs. RT's brother and a family friend who

was an oncology nurse called the hospice and expressed their concern about the domestic abuse of Mrs. RT by her husband. They were very keen that she goes to Liverpool. Because Mrs. RT spoke English as a second language, there were concerns that the hospice team had not ensured that there were no misunderstandings in these conversations. With Mrs. RT's agreement, an independent interpreter was brought in to make sure that all aspects of her decision making and understanding were clear and unambiguous.

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This also enabled a detailed discussion of treatment, prognosis and specific end of life wishes.

The conversation then turned to the team's concerns about domestic abuse. Initially she refused to engage with this, but after mention of her brother's allegation, she disclosed events that were instances of emotional abuse by her husband. She stated that she did not want her husband to know about this part of the conversation, nor did she wish to be referred to any support services. She reiterated that she wanted to go to Liverpool and stay with her brother and his family for good. She admitted that that she felt isolated socially and culturally at the hospice, and as all her relations were residing in Liverpool she could receive better support there. Then the team informed the husband about Mrs. RT's wish. He was shocked and stated that she could not go. The team explained to him that she had 'full capacity' at that time to make her wishes known and, therefore, the hospice was making arrangements for her transfer to Liverpool. Unfortunately, over the weekend prior to transfer the patient deteriorated rapidly. Her relatives arrived from Liverpool and she died the next day.

Ethical Dilemma

There was a conflict within the family about the place of care. The husband, who was the next of kin and the main carer for years, wanted to keep her near him whereas the brother wanted to take over her care and transfer her to his region. There may be hidden family issues within the family about the place of care but in this scenario Mrs. RT's autonomy was taken into account and the transfer was planned to Liverpool.

There was a conflict between truth telling and confidentiality. The husband is still not sure why she made the decision to go to Liverpool and the team kept their promise by not telling the truth to the husband.

Development of the ethical Principles and Overview

From Hippocrates' era to recent decades, medical ethics were seen in terms of a doctor's duties towards his patients. Traditionally these duties have been described as helping the patients to improve their illness (beneficence) and not harming them (non-maleficence). The emergence of the patients' rights movement, 'the patient's advocate', the democratisation of society in the post-war period and the exposure of abuses in medical research contributed to the formation of ethics committees and the other two principles such as 'equal distribution of health care resources or justice' and 'respect of autonomy'(Randall & Downie 2001).

Beneficence

Beneficence is to produce benefit, to do good, and to act in the best interest of the patient. Beauchamp & Childress (2001) define the principle as 'a moral obligation to act for the benefit of others'. Beneficence implies positive acts and includes all of the strategies that health care professionals employ to support patients and their families during the times of suffering. It includes effective symptom control, sensitive interpersonal support, acknowledging their views and acting upon them.

However, beneficence may have such a strong influence that it can lead to coercive behaviour, which limits the patient's autonomy. Coercion can come from the motive of 'I know better', otherwise known as paternalism, which in itself can lead to patient non-compliance (Jones 1996). In *Re C (Adult: refusal of treatment)* the health care professionals tried to act in the best interest of the patient, but the court refused their request as the patient was judged to be competent to make the decision of amputation.

Beneficence can be a positive attribute when, for example, the medical staff act as advocates for the patients whose autonomy is limited. In the case of Re T (1992) the patient's father and the health professionals acted on behalf of the patient, however her mother influenced the patient and tried to limit her autonomy.

In Mrs. RT's scenario, the hospice team acted in the best interest of the patient throughout her stay in the hospice. The initial transfer plan to Liverpool as well as keeping her comfortable at the hospice during her deterioration was in the best interest of the patient.

Non-maleficence

Non-maleficence is closely associated with the Latin phrase 'maxim Primum non nocere' and it means 'Above all [or first] do no harm'. This is the fundamental principle in the Hippocratic tradition of medical ethics. For every medical intervention, the potential benefits must be weighed against possible adverse effects and the treatment should not be prescribed unless there is a strong chance that it will help the patient. Causing unnecessary physical or psychological pain to a patient, insensitive truth telling and denigration of the individual are some examples of violations of this principle.

It is possible omitting that information may harm the patient if he/she is unable to make a voluntary choice. In the UK, however, a patient is not legally harmed if she/he is not given all the information.

Bolam v Friern Hospital Management Committee (1957) established that a doctor is not guilty of negligence if he/she has acted in accordance with a practice accepted as proper by a responsible body of medical professionals skilled in that particular art. In considering Mrs RT's situation, 'the allegation of emotional abuse' was considered seriously, clarified and handled with the view to preventing or minimising further harm.

Justice

Justice deals with the 'concept of fairness'. Beauchamp & Childress present justice in the form of distributive justice and it refers to fair, equitable and appropriate distribution determined by justified norms that structure the terms of social co-operation.

Unfortunately, observations from around the world shows much lack of justice in health care resources allocation and many treatment options are only available to the rich, or those who have power and influence. Collective social protection and fair opportunity are the two arguments supporting the moral right to health care resources. (Beauchamp and Childress 2001)

For Mrs. RT, health care resources were used in the form of hospice care, interpreter service and the referral systems as per her need and to which she is entitled.

Respect for autonomy

Respect for autonomy recognises an individual's right and ability to decide for him or herself according to beliefs and values. The word autonomy originated from the Greek and referred to the self-rule or self-governance of independent city-states. Later it was extended to individuals to describe them as 'self-determining' or 'self-governing beings'. Therefore, personal autonomy is the capacity to think, decide and act independently without any external influence.

The increasing emphasis on 'the sovereign status of the individual' in the health care system has had an effect on the doctor-patient relationship in recent years (Madder H.1997). In relation to legal frame work, Re St. George Healthcare NHS Trust v S [1998], S's detention, treatment and transfer were all found to be unlawful and stated the right of an individual to autonomy and self-determination regarding their treatment.

In *Re R v Collins*, the court of appeal has re-established the principle that; 'even when his or her own life depends on receiving medical treatment an adult of sound mind is entitled to refuse it'.

In the USA, a legal precedent for autonomy was established in *Schloendorff v Society of New York Hospital* (1914) 1. The summary of the judgment was 'every human being of adult years and sound mind has the right to determine what shall be done with his body'. The judgment of these cases reflects the autonomy of each individual and their right of self-determination'. Although various ethical principles are involved in this scenario, 'the principle of autonomy' is discussed in detail in this essay.

Analysis

Beauchamp & Childress outline the various influences that may affect a patient's autonomous decision-making. These include the patient's physical, psychological (dependent) condition, religious and spiritual beliefs, cultural beliefs, close friendships or relationships, available information, others' conflicting decisions and liberty (independence from external influences) and the medical professional's authoritative position.

McParland (and et al 2000) considered that 'the concept of autonomy is fragile, inconsistent, and dependent on individual circumstances'. Jones H (1996) argued that full autonomy can be compromised when the patient is ill, weakened and dependent on others for his/her wellbeing or his/her social status: the higher up the social strata, the greater chance that the patient is treated as an autonomous participant.

However, the hospice team appropriately and effectively overcame the patient's language barrier and assessed Mrs. RT's needs and wishes without her family influence. The patient explained to the hospice team that she was (socially and culturally) isolated at the hospice and wanted to go to Liverpool to enjoy the rest of her life with her relatives. It was a very reasonable and understandable request from a human being from a different social, cultural background.

Beauchamp and Childress outline three moral requirements of respect for autonomy. They analyse the autonomous action in terms of a patient's intention, understanding, and outside controlling influences determining the action. Mrs. RT's intention was clear and her understanding and wishes were taken into account, but was her decision made without any influences? One may argue that she expressed her wish after the phone call to her brother. Therefore, the intimate relationship with the brother and the husband's recent abuse may have influenced her decision. It was an independent decision made by her with a sound mind.

During the meeting with the interpreter, Mrs. RT was initially reluctant to mention the abuse, but after pointing out her brother's allegation (by phone) she opened up about it. This may surprise the reader but when you examine an old Asian community, its culture is built upon a male dominant society. In Asian culture it is commonly accepted that a female in her childhood is protected by her father, during her young age by brothers and later by her husband and then in late life, supported by children within their extended family system. Abuse and torture of females is common and it won't come to light routinely because of poor education, financial and physical dependence.

Fan R (2000) argues that the western principle of autonomy is an individual-oriented principle. A patient with sound mind has the final authority to make the clinical decisions for him/her self; whereas the East Asian principle of autonomy is a family-centred principle and it implies that the family, rather than the individual patient, should have the final authority over clinical affairs. A sick family member should be taken care of by the rest of the family.

Instead of asking for justice, she requested that her statement be kept confidential from her husband. In this scenario her confidentiality was protected until and after her death. Again, one may question whether she was an autonomous person prior to hospice admission? Obviously, it was not in our discussion but her pre-morbid personality,

cultural beliefs and relationships would influence her autonomy a great deal.

From the scenario, no one expected her rapid deterioration and death within a few days, but the team should have considered that possibility. They knew about the patient's current disease status, but made arrangements for the transfer to her brother's place in Liverpool to fulfil her wish. Having said that, the team should have considered alternative places of care. For example, they could have contacted the local Marie Curie hospice (Liverpool), explained the situation to them and transferred her to their hospice or explored with the family friend (cancer nurse), the possibility of managing the patient at her brother's home in Liverpool over the weekend with the help of the local rapid response team. To some extent, it would appear that the hospice team had 'special claims to deciding what is right for the patient'.

Utilitarian Vs Kantian View

Although there are several moral theories and approaches to examine the principle of autonomy, consequence based theory (Utilitarianism) and obligation based theory (Kantianism) are being employed for the discussion/analysis.

Consequence based theory (Utilitarianism) was proposed by John Stuart Mill (1806-1873) and Mill said that actions which are right and wrong are keeping with the balance of their good and bad consequences. Their proposed outcome is calculated by balancing goals, resources and considering the needs of every affected person. Utilitarian theory is founded on the principle of utility. According to this, they always have to produce the maximum balance of positive value over disvalue.

Obligation based theory (Kantianism) was proposed by Immanuel Kant (1724-1804) and according to him individuals, as rational beings, exercise their autonomy by originating universal laws. Kant proposed a test called 'Categorical Imperative' to make a subjective moral

principle into universal law. A Kantian who passes a moral judgment would expect it to apply to everyone.

The Utilitarian would evaluate this case in terms of consequences of different courses of action from the hospice team regarding place of care. The aim is to achieve the best positive value by balancing the interests of the patient and other affected family members. The patient's physical, emotional, social and cultural wellbeing, the brother's allegation against the husband and her brother's request were valued against the husband's wish. Interestingly, due to their cultural influence, the husband or her brother may have considered that they had the 'right' over the patient. In this scenario, a Utilitarian may justify that Mrs. RT's place of care will be in Liverpool.

On the other hand, a Kantian, 'the rational individual being', may consider that the right place of care would be the current hospice because of her advanced disease status. Let us consider that the hospice team managed to organise the urgent transport and appropriate nursing care at Liverpool prior to the weekend. There was a significant probability of Mrs. RT dying or becoming more poorly during the long journey (usually 6 to 8 hours) to Liverpool. The patient may have suffered much more in her terminal stage.

It may have caused more psychological distress to the rest of the family, including her husband. The Kantian might approach the above situation on moral judgements on reasons. Her brother's moral obligation was towards his sister and his autonomous decision to take her to Liverpool was based on his relationship with and loyalty towards his sister and his (cultural) responsibility in relation to her allegations about the husband and his limited knowledge about her current disease status.

The strict Kantian may argue that Mrs. RT's brother might reconsider his decision (of transferring her to Liverpool) if he was fully aware of the risks of her dying while transferring. Therefore, the brother and the rest of his family may have given their psychological support by staying with her in the hospice.

Kant expresses that the principle of autonomy is applicable to all rational beings and, while exercising one's autonomy, one must recognise that other individuals have autonomy as well. The concept of 'respect of autonomy' usually causes issues and confusions when applied to the relatives. In the given scenario, the patient's husband's autonomy was not considered after the allegation. Confidentiality would prohibit the hospice team from telling the truth to the husband and he never knew the truth about her transfer.

The problem of conflicting obligations (truthfulness in conflict with confidentiality) is one of the setbacks in deontological theory because they consider moral rules are categorical, therefore, according to Kant, the team is obligated to do both! Kantian theory fails to provide a solution here!

Resolution

According to Beauchamp and Childress, a prima facie obligation must be fulfilled unless it conflicts on the particular occasion with an equal or stronger obligation. The particular obligation is always binding unless a competing moral obligation overrides or outweighs in the conflicting scenario.

Although the moral theories speak about recognising other individuals' autonomy (Kantian) or 'equal weight to the interests of each affected party' (Utilitarian), the patient's autonomy was overridden by all other principles of morality in Mrs. RT's scenario. Some readers may argue that once the hospice team heard about the 'abuse allegation' from the patient, they became partial in decision making!

The husband, who was her carer for years, has been kept in the dark after the patient's allegation and from his cultural

point of view, his autonomy which is extended to his wife, was not considered or respected. The 'emotional abuse' may be quite normal to him from his cultural background. Confidentiality of Mrs. RT was found to be beyond obligation and therefore, the moral obligation of truth telling to the husband became impossible!

The decision of place of care at different disease stages with Mrs. RT and the conflict of confidentiality and truthfulness were difficult to handle. The author has been unable to reach a resolution in relation to this case study. Some writers may argue that respect of autonomy has priority over all other moral principles and easily overrides other principles. But one should remember that respect for autonomy is being applied appropriately and the impact of the principles is given equal consideration.

If a similar scenario arose again, the author should consider all four principles in the particular 'situation' to determine what weight each of them may bring to bear on the problem.

Conclusion

This is an example of a cultural diversity and family-centred autonomy. Although most of the 2nd and 3rd generation of Asians in the West, are adopting individual-oriented autonomy, one shouldn't ignore family influence in decision-making and expect changes overnight.

The author tried different approaches in biomedical ethics and referencing the legal framework, where ever appropriate. Although unable to reach a resolution, the author has attempted to identify the ways that could be solved if a similar situation occurs again.

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