

DISCURSIVE ARTICLE

Treatment withdrawal of the patient on end of life: An analysis of values, ethics and guidelines in palliative care

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Abstract

Aim: Family surrogate decision-making during the later stage of a patient's life may sometimes result in conflict and emotional distress among the parties involved. The present article aims to promote ethical end-of-life decision-making among health-care professionals in a view to eliminating any misunderstanding that may arise while meeting the care needs of the patient.

Design: A case study involving a request for treatment withdrawal by the family of a patient on end of life.

Methods: This paper draws upon a scenario encountered during practice to analyse the moral commitments in delivering high-quality end-of-life care with much emphasis on pre-existing palliative care guidelines for adults.

Results: Healthcare professionals are bound by the principle of beneficence, non-maleficence, autonomy and justice. Although the use of guidelines may be tenable, decisions often take into consideration the patient's choice and then weighed against the moral values of healthcare specialists and those required in the profession.

KEYWORDS

dilemma, end-of-life care, ethics, nursing, palliative care, values

1 | INTRODUCTION

Ethical decision-making in health care has become one of the most sort professional standards which underpin nursing practice (Cody, 2013; Mooi, 2017; Seedhouse, 2017). Lesley and Sharon (2015) further proposed that a person's values, culture and beliefs are major factors that shape one's attitude and behaviours which further impacts on the quality of care delivered. These principles are also embedded in the essential skills clusters for nursing education and code of conduct and proficiency for Registered Nurses (Nursing & Midwifery Council [NMC], 2018a, 2018b). While values and beliefs influence our decisions, it is also important to recognize how organizational policies and professional codes affect our relationship with patients and families. Ellis (2017) also stressed that ethical congruence with organizational and personal values is required in

delivering holistic patient-centred care. Therefore, ethical sensitivity with regard to healthcare delivery entails demonstrating high moral standards by health professionals to meet the patient's needs in a holistic, thoughtful, non-judgemental way, and with respect for patients' autonomy and dignity.

The rise of patient's autonomy has brought about significant changes in health care, a positive movement which according to Johnstone (2016) has eliminated the impression of being privileged as a patient. The International Council of Nurses [ICN] (2012) recognizes patients' rights as a person's fundamental right to health care. These include, but are not limited to confidentiality, right to decline treatment, the right to be treated with respect, right to informed consent, right to be free from degrading treatment and right to dignity. While this gave rise to increased moral values among health professionals, equity and person-centred healthcare delivery,

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conflicts do sometimes arise due to opposing values of patients and healthcare professionals in relation to the code of ethics of the profession, thereby leading to the patient's autonomy being impeded (McCormack & McCance, 2017; Ringdal et al., 2017). As healthcare professionals, patients' wishes and interests are meant to come first (Ong et al., 2012). However, from a utilitarian perspective, a voluntary request to end one's own life with unbearable suffering may be considered obligatory in order to distribute more resources for the welfare of a greater number of people (Beauchamp & Childress, 2019). Such unbiased approach is based on the quality-adjusted life years (QALYs), a more neutral system of healthcare resource allocation which takes into consideration the remaining number of lived years following treatment (Salomon, 2017; World Health Organization 2019a). Nevertheless, many authors disagree with this system as it gives less value to human life and encourages healthcare discrimination during decision-making (Harris, 1987; Mckie & Richardson, 2018; Neumann et al., 2016). While prioritizing healthcare resources to individuals with the best chance of survival seem morally acceptable when considering scarce healthcare resources, from a different viewpoint, it demands that the individual gives up their right to life for others.

There have been controversies over commencing, withholding or withdrawal of treatment during the care of patients in their end of life. Ong et al. (2012) advised that ethical dilemmas emanate from having to choose between undesirable alternatives, and the vast majority encountered during end-of-life care involve those pertaining to disagreements over either withdrawing life-sustaining treatment or imposing futile medical intervention on patients. Tong (1995) and Johnstone (2016) also suggested that the conduct of healthcare professionals in such a situation is often out of the fear of litigation or compliance with established guidelines. Although the practice of assisted death has been legalized in countries like Netherland, Belgium and Switzerland, it is illegal to aid suicide in the United Kingdom (UK) and therefore considered a crime (Rehmann-Sutter et al., 2015; Suicide Act, 1961). Nevertheless, Ellis and Engward (2017) asserted that a person's stance on this disputable issue depends on their philosophical and spiritual beliefs. This suggests that as humans, our way of thinking tends to determine our moral conduct.

In the UK, the Liverpool Care Pathway for the dying (LCP) was established to guide healthcare practitioners in decision-making for patients in their end of life (Ellershaw & Murphy, 2005; Marie Curie Palliative Care Institute Liverpool, 2013; Seymour & Clark, 2018). Several authors maintained that the LCP was an exceptional model because it eliminated medical futility and prolonged suffering for patients (Jack et al., 2003; Marie Curie Palliative Care Institute Liverpool, 2009; Wrigley, 2014). However, Braganza et al. (2017) advised that such decision depended on the views and values of the medical specialist. It can thus be suggested that the LCP framework required the development of strong virtues within one's character to take a moral decision in the best interest of patients. In the Neuberger review (NR) which led to its phase-out, it was highlighted that lack of awareness of ethical decision-making and poor communication with patients and relatives contributed to its failure in

What does this paper contribute to the wider global clinical community?

- Current palliative guidelines promote the timely identification of individual needs, and any form of advanced directives needed to be put in place towards the end of life.
- Surrogate decision-making comes into play where a patient lacks the capacity to express their preferences. However, it does not supersede the patient's right to self-determination where an advance decision is already in place.
- It is almost certain that the demise of the Liverpool Care Pathway paved way for the application of individual virtues in ethical decision which in turn enhances one's competence and commitment to delivering quality and compassionate care.
- The courage to make moral decisions in end-of-life care where there may be conflicting interests between the patient and their relevant others requires an avenue for health professionals to exercise their beliefs, virtues and moral values which further impacts on their subsequent actions.

meeting the spiritual, physical and psychosocial aspect of care delivery (Neuberger et al., 2013). A probable explanation for these lapses is almost certainly due to the unceasing conflict resulting from the inability to create a balance between delivering compassionate care, respecting the wishes of families or adherence to guidelines within the healthcare profession. This will be further elucidated in subsequent sections of the article.

2 | DESIGN

This position paper uses a scenario encountered during practice to analyse the moral commitments in delivering high-quality end-of-life care with much emphasis on pre-existing palliative care guidelines for adults. The next section reflects on the dilemma encountered by healthcare professionals during communication with the family of a patient on end of life.

3 | METHOD

3.1 | Case presentation

The scenario presented was encountered in a geriatric care environment. Strict measures have been adopted to maintain confidentiality in line with the code (Nursing & Midwifery Council [NMC], 2018b). James, 71 years old, lives with his wife and has a past medical history

of cerebrovascular disease, dysphagia, osteoarthritis and osteoporosis. James was admitted with late-onset epilepsy from the previous haemorrhagic stroke. Computed tomography scan reveals no new infarct. James was also referred to the speech and language therapist for his swallowing difficulty. While on treatment, the patient presents to have late-onset hospital-acquired pneumonia and was started on intravenous antibiotics. Owing to his underlying health condition, a further assessment of James' mental status showed that he seemed to lack capacity to express his preferences for care and a suggestion was to be made on transferring him to a hospice for end-of-life care. Although there was no formal advance statement about his future care needs, it was made known to the charge nurse by a relative that James wished not to spend his last days in a hospice but in his home. In such a situation, relatives who are not legally appointed as the patient's welfare guardian may give relevant information about the patient's previously expressed wishes, beliefs, values and preferences (Gov.Uk,n.d.; Scottish Government, 2018). But during a consultation with the clinical team, the family nullifies James' desire and further requests the withdrawal of treatment and nutrition (food and fluids) to ease his suffering. Considering that withdrawing James' treatment might just be too soon, the healthcare professionals were caught in a dilemma of either to respect the wishes of the family or "allow a natural death" for James in his end-of-life journey.

3.2 | Exploration of the ethical issues raised by the family's request

In the view of understanding the ethical issues raised from the above scenario, a conceptual clarity on palliative and end-of-life care must be established. According to the World Health Organization (2019b), palliative care is aimed at improving the quality of life, reducing rapid progression through symptoms control; relieving pain and distress associated with the prognosis of a terminal illness in patients and likewise family members. While palliative care can commence at any a stage of chronic illness, end-of-life care involves the care of patients nearing the end of their life (Krau, 2016). From the above definition, it can be considered that early patient engagement enhances quality care and encourages ethical decision-making during the end stage of life.

Owing to the need to promote patient involvement, anticipatory care planning has been recommended to enhance communication and care during the disease progression (Dixon et al., 2015; Worldwide Palliative Care Alliance, 2014). Coulter and Collins (2011) have previously advised that this form of shared decision-making enhances concordance with treatment and nurse-patient relationship which is also in line with the Department of Health (2010) policy on person-centred care. Much emphasis on the development of anticipatory care plans has also been placed on patients having complex palliative care needs, impaired mental capacity and those on polypharmacy and opioids (Tapsfield et al., 2019). Anticipatory care planning in palliative care may be considered as a patient-led document

which takes into consideration patients' priorities of care towards their end of life and serves as a guide to healthcare professionals.

With regard to the scenario, where there is a perceived deterioration in James' health condition, he may be consulted on making advance directive regarding his care such as a "do not attempt cardiopulmonary resuscitation" (DNACPR) decision (Resuscitation Council United Kingdom [UK], 2016). It was further emphasized that such directives must be respected as long as the decisions are informed, current and made without coercion from others (Scottish Government, 2010). While the law on advanced directives or living wills differs with various health bodies, the Human Rights Act (1998) and Adults with Incapacity (Scotland) Act, 2000 recommends that where no legal proxy has been appointed for the patient, the clinical team should enquire about the patient's previously expressed wishes from the relevant others. Considering the information revealed about James' preferred place of death, the clinical team is responsible for making a verdict based on whether such decision will be to the benefit of the patient or not.

Nurses have the responsibility to act as patients advocate and support autonomy and participation in decision-making regarding their care (Choi, 2015; Nursing & Midwifery Council [NMC], 2018b). Hornigold (2015) also advised that respecting a patient's self-determination to die at their preferred place of death is regarded as a quality indicator of palliative and end-of-life care. While the patient's residence is often their preferred option, the place of death is, however, determined by their level of independence, disease prognosis and available social support (Abel et al., 2013). Oftentimes, a patient's wish to be cared for at home against other available services could be due to their culture and spiritual beliefs, which may not be fulfilled elsewhere, and thus places many responsibilities on the family (Abel et al., 2013). The tension raised by the conflicting standpoint of patients and relatives remains a challenge in palliative care.

The philosophy of end-of-life care could be viewed as respect for life until its natural end; however, patients may not often get such privilege in the face of death (Hurst & Mauron, 2006). The major ethical issues raised was James' right to self-determination, right to be free from degrading treatment and right to be treated with dignity and respect, while a "dignified death" could mean embracing death sooner (without long suffering) and to die in a particular way and place. Kennedy (2016) stressed that dignity encompasses autonomy, respect, consent and communication. Therefore, it may perhaps be considered that James' right could be breached where there is an omission of any of these significant attributes. However, clinical judgement in individual patient's care may vary which further determines whether the benefits of a decision outweigh the likely burdens.

Furthermore, considering James' health conditions, another ethical concern raised was the capacity to make an informed decision. The distress from the impression of being a burden on others is often expressed by patients at some point with the diagnosis of a life-threatening ailment (Kübler-Ross, 2009; Rehmann-Sutter et al., 2015). However, from the time of the diagnosis of a terminal illness, denial of the reality and then the acceptance of the

inevitable, Rehmann-Sutter et al. (2015) further argue that this feeling is likely to come at the final stage. Since this phenomenon is normal for a terminally ill patient, then one may contemplate on when it should be considered as depression, a coping mechanism or actual suffering. Apparently, even with an advanced directive in place, a patient's wishes may change in the dying phase. To ensure that the most recent instruction is observed, it is recommended that advanced directive should only apply to the current clinical situation or care setting and constantly reviewed with changes in the patient's condition (Gov.Uk, n.d.; Scottish Government, 2018). Thus, where the information regarding James' future care needs was presented, it is recommended that the period when such decision was made is taken into consideration and further weighed if it creates additional burden for the patient.

The place of family members in making an informed decision in the best interest of the patient is vital in palliative care. Braganza et al. (2017) advised that owing to potential cognitive impairment or further health deterioration, less than one-tenth of patients are unable to communicate their wishes in the last days of life. While it becomes the responsibility of relatives to make decisions in conjunction with the palliative care team, effective communication is certainly required to clarify the end-of-life care plan to family members. Manalo (2013) also laid emphasis on a perceived tendency of the palliative care team to take the lead role in order to avoid any form of futile care or possible litigation by regulatory bodies. However, conflicts often arise due to opposing values and the family's poor understanding of the ethical principles in such a context. Therefore, the inclination of decision-making towards healthcare professionals may lead to patients and relatives being disadvantaged. Hence, a high level of emotional intelligence and altruism from nurses and physicians, respectively, have been established as a requirement for reaching an ethical decision with relatives (Francis, 2013; Harris, 2018; Holman, 2014; Rankin, 2013; Zomorodi & Foley, 2009). It can be therefore considered that maintaining a good relationship with families fosters good quality care that takes account of patients' dignity which is agreeable by both parties.

4 | DISCUSSION

4.1 | An in-depth analysis of ethics and guidelines for end-of-life care

According to Ellis and Engward (2017), there is no moral justification for prolonging a patients' suffering where it can be reduced, nor hasten death to end their pain. Yet, the palliative care team has to make a good ethical decision about the care of terminally ill patients. The LCP served as a support for clinical judgement in end-of-life care prior to its discontinuation. According to Wrigley (2014), its main aim was to provide a range of options for patients and their relatives. However, Neuberger et al. (2013) stressed that it was regarded as a series of process which must be adhered for each patient. A possible explanation for the poor clinical judgement by healthcare

professionals may be due to the adoption of a one-size-fits-all model which eliminates the need for ethical decision-making.

Although the LCP has been recognized as a model of good practice if decisions are justifiable by good virtues and morals (Bunn, 2014; Dobson, 2017), the major concern raised in the NR was its use as an excuse for poor care delivery. The dilemma around the benefit and harm of administering food and fluid to a dying patient has long been debated (Royal College of Physicians, 2010). The General Medical Council (2012) places much emphasis on the withdrawal of nutrition during the terminal stage, as it possibly results in increased secretions as well as pulmonary and peripheral oedema. While it can be argued that neither nutrition nor hydration is life-supporting at the end of life, the Leadership Alliance for the Care of Dying People [LACDP] (2014) advises that patients should be offered oral nutrition and hydration as part of their basic care if safe to do so.

Healthcare professionals are somehow faced with the lack of evidence or guideline underpinning quality healthcare delivery for patients in their end of life (Wrigley, 2014). There has been a call for further research into guidelines on palliative and end-of-life care owing to the withdrawal of the LCP (Leadership Alliance for The Care of Dying People [LACDP], 2014; National Institute For Health And Care Excellence (NICE), 2015; Scottish Government, 2014; National Institute For Health And Care Excellence (NICE), 2019a; National Institute For Health And Care Excellence (NICE), 2019b; Health Improvement Scotland, 2019). However, Seymour and Clark (2018) advised that the lack of value-based evidence supporting end-of-life care exposes patients to more risks with the rollout of a new framework. As previously highlighted in seminal literature, the application of virtues in ethical decision gives chance for morality to manifest in the form of compassion and care (Anscombe, 1958; MacIntyre, 2007). Hence, it could conceivably be hypothesized that a person's beliefs, virtues and moral values have an impact in their way of thinking which in turn affects their behaviour and actions.

4.2 | Case follow-up

There was a need to reach a consensus on whether the family's request reflected person-centred care, and if it goes against the values of the healthcare professionals. Allen (2009) and Fox (2011) had earlier suggested that reaching an ethical decision entails considering different viewpoints and its possibly ethical connotations across the multidisciplinary team members. Considering the concerns highlighted by Neuberger et al. (2013), the issues deemed applicable to the scenario in relation to developing good practice on ethical decision-making were as follows: recognizing dying and individualized care plan; needs of relatives and patient's choice; and nutrition and hydration.

While there is an uncertainty in diagnosing dying based on varied disease prognosis and epidemiology, it has become necessary for proper communication among nurses and doctors on any perceived deterioration in the patient's health condition in order to determine whether further treatment would be futile (Carline et al., 2003;

Dobson, 2017; Scottish Government, 2015). Sleeman and Collis (2013) and Kennedy et al. (2014) suggested that, where such an assessment has been made, any further intervention should be directed towards easing pain and discomfort. Braganza et al. (2017) further advised on the use of opiates, benzodiazepine and anticholinergic drugs to relieve pain and distress. With regard to James' care, the intravenous antibiotics therapy was reviewed and treatment withheld in line with the National Institute For Health And Care Excellence (NICE) (2019a); National Institute For Health And Care Excellence (NICE) (2019b) guidelines for antimicrobial prescribing. A decision was reached regarding James, and the option of hospice care was then ruled out and his home would not be ideal either due to the perceived high dependency care.

Although it may be common for patients to leave decisions regarding their care to family members, Carter (2020) advised that there could be a possibility of family persuasion, where the patient's views oppose those of their family. To confront the issue regarding nutrition and hydration, families resort to forced feeding or acceptance or may be undecided (Del Rio et al., 2012). These modes of family coping are often based on individual belief and may not be evidence-based, thus resulting in conflict. The Leadership Alliance for The Care of Dying People [LACDP] (2014) further emphasized the need to enlighten family members and continuous staff training in delivering high-quality end-of-life care.

From a cultural and religious perspective, withholding food and fluid may have a different connotation depending on their belief. For instance, in Buddhism, it is perceived that the patient's soul will be restless if they die hungry; however, in Catholicism, administration of food and water should not be seen as a medical act to prolong life and its withdrawal could be regarded as euthanasia—"death by omission" (Carter, 2020). Hence, staff members must become aware and respectful of the patient's or families' culture and religion, furthermore, ensure that their own beliefs do not prejudice the decision-making process.

The palliative care team also deemed it unethical to totally refuse fluid to the patient. Due to James's dysphagia, minimal oral hydration and switching to subcutaneous fluid was suggested to reduce further distress from neuromuscular complications while providing a path for a natural death (Del Rio et al., 2012). Like medication, the initiation, termination or withholding of nutrition and hydration needs to be ethically justified (Beauchamp & Childress, 2019; Carter, 2020). Nevertheless, towards the last days or hours of life, food and drink may seem to be less enjoyable for patients. In view of the National Health Service (2019) long-term plan, any intervention delivered during the last days of life should be in the goodwill of the patient and directed towards maintaining comfort, relieving distress and reducing treatment burden.

5 | CONCLUSION

This article explains how ethical issues emanate in end-of-life care due to differences in values between healthcare professionals,

patients and relatives. The analysis of the dilemma presented in this article reveals that establishing an evidence-based guide for end-of-life care may not be feasible as it takes account of personal values and beliefs of patients and individuals involved in care delivery. This value-laden process is likely to cause conflict where individual needs are not met. In addition, disease prognosis and family involvement may also influence ethical decisions in end-of-life care. In order to strengthen the trust placed in healthcare professionals, anticipatory care planning with the active involvement of patients and effective communication with relatives is required to aid healthcare decision-making.

The scenario in which this article is centred may be often encountered during practice in palliative care settings. The moral implication and definitive outcome to follow-upon such request is not backed by a specific ethical framework. Furthermore, the decision on whether medical intervention such as food and fluid is to be considered futile or life-sustaining is often based on individual patient condition. However, the application of personal virtues in ethical decision enhances one's competence and commitment to delivering quality and compassionate care where there may be conflicting interests between the patient and their relevant others.

CONFLICT OF INTEREST

The author declares no conflict of interest.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no data sets were generated or analysed during the current study.

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