Study of autonomy or beneficence

An ethics committee was asked to consider the case of Mr. K, a fifty-year-old, morbidly obese Hmong man who lived at a skilled nursing facility. Mr. K had a history of diabetes, hypotension, and heart disease. He recently developed pneumonia and large skin ulcerations that caused him severe pain. Because of his size and impaired mobility, five people were required to safely turn him, clean him, and care for his wounds. To adequately treat the pneumonia and ulcerations, he was moved from the skilled nursing facility to the hospital.

During his hospital stay, Mr. K experienced extreme pain when he was moved for any reason. Multiple strategies were used in an attempt to avoid as much movement as possible but none were completely effective. Additionally, he was provided with a patient-controlled analgesic pump to allow self-management of the pain. The pump provided some relief, but Mr. K still felt general pain and discomfort. Even though the hospital was unable to effectively manage the pain, the pneumonia responded to antibiotics and the doctor felt that Mr. K could return to a skilled nursing facility. However, no skilled nursing facility was willing to accept Mr. K because of the high staffing needs associated with his care.

Mr. K decided that he no longer wanted to live this way and requested a meeting with a Hmong shaman in order to return his soul to his body prior to his death. Additionally, he refused treatments such as being turned or wound care.

Mr. K’s refusal for care caused distress among the nursing staff and prompted an ethics committee consultation. Some of the staff supported Mr.

K in his desire to refuse treatment. They felt that his requests should be honored just as any refusal of medical therapy would be honored. Others felt that a lack of care by the staff would be equivalent to abandoning the patient. All agreed that Mr. K's choice impacted other patients, visitors and staff and created the potential for an unpleasant atmosphere.

Those that supported honoring the request to refuse treatment based their argument on patient autonomy. Those that opposed the request to refuse treatment based their argument on beneficence. Other theories and concepts such as informed consent, virtue ethics, particularism, and universalism were considered. The ethics committee concluded that it was appropriate for the nursing staff to honor Mr. K's refusal of care based on the ethical principle of patient autonomy.

Autonomy or Beneficence

Autonomy

Edge & Groves (2006, p. 385) defined autonomy as " personal self-determination; the right of patients to participate in and decide questions involving their care." Autonomy is a form of personal liberty. Within the realm of health care, autonomy is based on three elements: the ability to decide, the power to act on the decisions, and the respect for the autonomy of other individuals (2006). Individuals are free to use their autonomy and make decisions based on informed consent.

To have informed consent requires that an individual have sufficient information with which to make an autonomous decision (Edge & Groves, 2006). Several core elements of informed consent include: 1) the individual

understands his/her options and potential risks, 2) the individual is not being coerced into a decision, and 3) the individual has the maturity and experience to make a decision (2006).

A foremost theorist in value development, Lawrence Kohlberg, addressed the maturity element of informed consent. In his proposed value development model, individuals go through three levels of maturation: preconventional morality, conventional morality, and post-conventional morality (Edge & Groves, 2006). He suggested that individuals reach the post-conventional level when they are 12-years of age and older. Upon reaching this level, Kohlberg believed that individuals were able to reason and make autonomous decisions.

Once an individual has freely made a decision, Childress & Fletcher (1994) argued that health care professionals are obligated to respect the patient's decision as part of the patient's autonomy. They further argued that limits may be placed on the patient's autonomy when a patient requests treatment but fewer limits should be imposed on the patient's autonomy when a patient refuses treatment. When listening to a patient's request for treatment or their request for refusal of treatment, a patient's values must also be considered.

A patient's values are, in part, influenced by their culture. Ethical dilemmas become more pronounced when the practitioner and patient are from different cultures. As the difference between the cultures increases, so does the risk of inappropriate care. According to Callahan (2000), when the values of a patient's cultural group differ from the normative group, the patient

should be allowed to follow their traditions, particularly if the patient perceives they are burdening those around them in some way. Additionally, Callahan asserted that in the absence of serious harm, there is no reason for the practitioner to interfere with the patient's cultural values. There should be respect for cultural particularism.

Donnelly (2000) emphasized that in order to provide culturally congruent care, practitioners must match the care of the patient to the patient's cultural beliefs and way of life. Practitioners must be willing to include the cultural and spiritual values and requests of the patient in the treatment program. In situations where the nurse and patient are from different cultures, the nurse must remember that they are the patient's advocate.

As patient advocate, the nurse must take the time to understand the patient's fears, needs, concerns and values (American Nurses Association, 1994). This understanding assists the nurse in providing appropriate patient care. In cases where a patient refuses care, the staff must determine if the care is considered ordinary care or extraordinary care. Edge & Groves (2006) considered ordinary care to include treatment that offered a hope of benefit and that did not cause excessive pain. On the other hand, extraordinary care was considered to include treatment that did not offer a hope of benefit and that caused excessive pain.

Should the patient be allowed to refuse extraordinary care? According to Edge & Groves (2006) the courts have upheld a patient's right to refuse treatment. One such court case was that of Elizabeth Bouvia. Ms. Bouvia was a young adult quadriplegic who also suffered from cerebral palsy. She

endured numerous hospitalizations and experienced uncontrollable pain. Because of her intense suffering, she requested that she be allowed to withhold nutrition and starve herself to death. The hospital refused. She took her plea to the court and eventually received a ruling that allowed her to choose informed non-consent of treatment. Ms. Bouvia followed through on her desire to withhold nutrition and eventually died because of her action.

Beneficence

Edge & Groves (2006, p. 385) defined beneficence as " the principle that imposes on the practitioner a duty to seek the good for patients under all circumstances." The practitioner must be promoting the patient's health and welfare above all other considerations (2006). Garrett, Baillie & Garrett (2001), summarized this idea by stating that there was an obligation to avoid evil. Practitioners take an oath that obligates them to help the patient. The responsibility accepted by taking this oath is not taken lightly. As a result, people generally recognize nurses and health practitioners as virtuous people and have high expectations of these practitioners' roles. The willingness of a practitioner to follow their oath, results in patient confidence that the practitioner will work diligently on their behalf.

In practice, the lines between beneficence and virtue ethics may become blurred. Virtue ethics puts the emphasis on the " courage, temperance, wisdom, and justice" (Edge & Groves, 2006, p. 43) of the nurse. By considering what a good nurse would do, the nurse characteristically avoids evil as beneficence requires. Because the nurse intrinsically possesses virtuous qualities, he/she will naturally make decisions that benefit the patient.

Additionally, the nurse has received formal education and accumulated practical experience. This gives them a strong understanding of the medical problem and the potential impact for the patient. This knowledge and understanding makes the nurse more capable of making appropriate decisions for the patient (Edge & Groves, 2006). This approach to medicine is known as paternalism.

While paternalism does limit the autonomy of the patient, it is supported by the fiduciary relationship practitioners have with patients (Edge & Groves, 2006). The fiduciary relationship gives the patient confidence in knowing that the practitioner will do everything they can to benefit the patient.

When considering permissible treatments, deontological theory states that the “ action is perceived as right or wrong and follows certain prescribed guidelines” (Donnelly, 2000, p120). The practitioner’s education and training emphasize the right actions to take and provide guidelines to be followed. The importance of human life coupled with the practitioner’s oath help support the rightness or wrongness of their actions. In other words, as long the practitioner does their duty, they are acting ethically (2000).

In the process of doing their duty, practitioners may encounter opposition from people who argue that the patient’s autonomy has been diminished. Childress & Fletcher (1994) noted that, in addition to the patient’s autonomy, the autonomy of the health practitioner must also be considered and respected. The patient always maintains their personal autonomy, but the practitioner must also be allowed to follow the autonomy of the profession.

Practitioner autonomy is supported by Callahan (2000). If following a cultural tradition puts the patient in a situation of direct harm, the practitioner must follow a treatment program that supports the position of the profession and that maintains the practitioner's professional integrity. This is true even if the program contradicts the cultural values of the patient. The practitioner should respect the universality of his actions.

The conflicting autonomy of the patient and practitioner is best described by the contractarian theory. Thomas Hobbes explained that in contraction theory, the correct choice is made by bargaining between individuals (Edge & Groves, 2006, p. 85). In order to receive services, a person must be willing to surrender some of their autonomy (2006).

Conclusion

Opponents of Mr. K's refusal of care based their decision on beneficence. It was noted that because of their profession, practitioners were recognized as being beneficent and virtuous people. By itself, beneficence is a good principle to follow, but when coupled with virtue ethics it leads to paternalism. In the case of Mr. K, the practitioner's use of paternalism limited the autonomy of Mr. K, as well as, subjugated Mr. K's desires to those of the practitioner.

Additionally, it was noted that the paternalism led to a strong fiduciary relationship. In most circumstances a fiduciary relationship benefits the patient. However, in this case, it lost sight of the practitioner's role as patient advocate. The practitioner focused solely on a desired positive outcome and discounted the pain and suffering experienced by Mr. K.

In regard to Mr. K’s cultural values, they were dismissed completely in favor of universality. Mr. K’s cultural desires became subordinate to the professional standards and integrity of the practitioner.

Supporters of Mr. K’s request to withhold treatment based their decision on his autonomy. Mr. K presented the maturity level and experience required to provide informed consent. Mr. K was well aware that the level of care necessary to tend to his needs was extraordinary as evidenced by the unintentional pain that was experienced each time his wounds and physical needs were addressed. Previous court decisions upheld the right of a patient to choose informed non-consent especially when faced with unmanageable pain.

Additionally, Mr. K held strong beliefs in his cultural values. Even though his cultural values differed from the normative group, his actions were consistent with his culture as was evidenced in his request to have a shaman visit him and prepare his body and soul for death.

Finally, by taking the time to listen and understand Mr. K’s needs, concerns, and values, the supporters of Mr. K understood that to be his patient advocate, they must support his refusal of treatment request.

While the intent of the both supporting and opposing groups was to benefit Mr. K, only Mr. K knew fully what was best for him. Thus, it was concluded that patient autonomy must be respected and Mr. K’s request for refusal of treatment must be honored.