Palliative care in a multicultural society: a challenge for western ethics

AUTHORS

Keri Chater
PhD, Master of Nursing, BA (Sociology), RN
Division of Nursing and Midwifery, School of Health Sciences, Science, Engineering, Technology (SET) Portfolio, RMIT University, Victoria, Australia.
keri.chater@rmit.edu.au

Chun-Ting Tsai
RN, BN, Grad.Dip Nursing, Master of Nursing
Operating Suite Nurse, Peter McCallum Cancer Institute, East Melbourne, Victoria, Australia.
chun6309@yahoo.com.tw

KEY WORDS

palliative care, ethics, autonomy, truth telling, culture

ABSTRACT

Objective
This paper examines the notion of truth telling and its place in palliative care nursing with a particular focus on nursing people from minority cultures.

Setting
The setting is palliative care nursing.

Subjects
The subjects are patients receiving palliative nursing care particularly those from minority cultures.

Primary argument
Australia is a multicultural society yet its dominant ethical paradigm is firmly placed in the western philosophical tradition. The fundamental concept that western ethics is based on is that of autonomy which implies that the individual is a free agent able to make their own decisions including accepting or rejecting medical treatments. These decisions are based on the individual's right to be informed about all treatment options. From this position of the autonomous subject other ethical principles have their genesis. Nurses' ethical behaviour is guided to some extent by ethical principals including beneficence, non-maleficence and truth telling. The major contention, drawn from literature is that truth telling may be an inadequate ethical principle when working with people from minority cultures.

Conclusion
This paper argues that the western ethical concepts of autonomy and truth telling in the practice domain of palliative care nursing may not be appropriate for different cultural groups and that this may become a source of ethical dilemmas and a challenge for western ethics. The paper concludes with an option for nurses working in multicultural societies that accommodates differing cultural perspectives while not compromising the ethical principle of truth telling.

WHAT IS PALLIATIVE CARE?

Palliative care is known for its provision of a comfortable environment for dying or terminally ill people. The focus is on providing care options for symptomatic patients to improve quality of life with the focus on care rather than cure (Davis and Kuebler 2007). Patients can be palliated in the comfort of their own home, a hospice setting, aged care facility or the acute hospital sector (Maddox 2003). Palliative care also provides patients who are able to continue with their medical treatment, relief from the suffering they may experience. Moreover, palliative care also respects a persons' dignity as death approaches. Palliative care is central to cancer care and more increasingly, to end-of-life chronic care (Portenoy 1998).

Also central to palliative care is the patient and their family in relation to their cultural and spiritual needs. In principle, the individual, their family and palliative care nurses work collaboratively to clarify treatment preferences, values and goals which should be included in advanced care planning. The key to successful advanced care planning is effective communication based on the development of trust and respect (Moore 2007).

Bowman (2000) stated that in end-of-life care, medical decision making is the first step. Palliative care nurses need to understand the beliefs of the patient and their family about the treatment of the disease and the outcome of that treatment. The treatment plan should be accepted by the patient, their family and the health care team. Consideration regarding the burden of care between caregiver, family and patient also needs to be addressed. When a person has a diagnosis of cancer, their family faces an unknown future with the possibility of the patient living for ten weeks or ten years. The patient may feel anger, depression and shock; emotions can add anxiety into everyday issues and be a burden for family members or caregivers, both emotionally and financially. In the palliative care system, family members are the most important support for the patient's spiritual and emotional needs as they go through a series of treatment processes. End-of-life

decision making is a complicated process for the patient, the family and palliative care nurses because of a range of complex factors. For example, what are the patient and family beliefs about end of life care; what are the cultural difference between the nurses, physicians, family and the patient? The patient within the context of their family is central to palliative care nursing and the patient's wishes are primary regardless of the demands of the medical treatment. Therefore palliative care nurses have a particular role in advocating on behalf or their patients.

Many ethical dilemmas occur when working in palliative care and the confusion or conflict around advanced care planning is one issue where ethical dilemmas occur. Coveney (2007) argues that with effective communication, clear explanations and respect for the rights for the individual, ethical dilemmas can be reduced. Ethical dilemmas (Chiu et al 2000) can and do happen between the patient, family and medical team relating to issues such as: telling the truth; disclosure; use of medication; decision making; nutrition; and other treatment practices.

The underlying principle is that patients have the ability to understand their prognosis, treatment options and possible outcomes; they want to know their prognosis and treatment and finally they want to participate in advanced care planning. However this assumption is based on the western ethical notion of autonomy which is a concept not all cultural groups subscribe to, even though it is dominant in the bioethical model valued by mainstream health care in Australia.

WESTERN ETHICS

The notion of autonomy has evolved from the ancient Greek concept of 'self-government.' The modern endeavour has been to try and identify the 'self' located in a complex set of contexts and "...closely tied to concepts of liberty and freedom, identity and individualism" (Woods 2005 p.243). This is premised on Kant's (1786) view that liberty or freedom was necessary for moral decision making. An individual must be free to be able to make the right moral choices

and must also have the capacity to reflect on those choices. People have the ability to understand and know what is right and wrong but they can only do what is right for themselves (Tai and Lin 2001).

Autonomy has become the most important principle in western bioethics. A person has the right to their own decision making and to exercise independent action and individual choice (Johnstone 2004; Beauchamp and Childress 1994) after having been fully informed of the treatment options available. It is important to respect what a person thinks and the decisions and actions they take; family and health care professionals listen to their voice and respect their self-determination (Tsai 1999). Applying this to the relationship between health care professional and the patient means the patient is the centre of decision making and their choice of treatment, after being informed of their diagnosis, prognosis and treatment options, is their own decision, even if the decision seems counter to the recommendations of health care providers.

At the end of life it would appear that exercising autonomy, being informed and being capable of making decisions are fundamental. The individual should be in a position to be able to make treatment decisions about how he or she wishes to live out the remainder of his or her days. The ability to choose treatment or reject treatment should be the right of any individual undergoing palliative care. The ability to make informed decisions about treatment options is not only based on the notion of autonomy but also on other western bioethical notions such as truth telling or veracity. Underpinning this is that physicians and nurses speak honestly about diagnosis and treatment options in order for the individual to be able to make an informed decision.

However there is evidence to suggest that other cultural groups, specifically minority ethnic groups (Payne et al 2005) do not access palliative care or underutilise the services and it cannot be assumed that these services are needed less in these communities that in Anglo-Saxon communities. Although Payne et al (2005) undertook their study in Britain; their literature review was international and included an Australian study. It is fair to assume that in Australia, which has a dominant Anglo-Saxon tradition, it would be the same.

A LITERATURE REVIEW OF CULTURE AND PALLIATIVE CARE

There are many different definitions of 'culture', but generally they include notions that allow groups to function smoothly and self perpetuate. Definitions include: shared values and beliefs; common communication; rules of behaviour; and laws. Culture is seen as a dynamic and a socially constructed reality which simultaneously includes and excludes (Huddelson 2004; Chater 2002). Witt Sherman (2006) suggested that "Spirituality and culture are among the most important factors that structure human experience, values, behaviours and illness patterns... As a system of shared symbols and beliefs, culture supports a person's sense of security, integrity and belonging and provides a prescription for how to conduct life and approach death" (p.3).

Hermsen and ten Have (2004) in their literature review of English language journals on ethics found that "(w)hat was particularly emphasized in the articles about truth telling was the need for disclosure of diagnosis and prognosis" (p.392). However Tuckett (2004), in a similar literature review found that truth telling can be seen as a cultural artefact. While it can be argued that all cultural groups hold the truth in esteem, the manifestation and practice of truth telling varies and is tempered by different cultural practices.

Bowman et al (2004) argue that: "... western health care is grounded in patient autonomy. It promotes individual determination, informed consent and disclosure of illness as ideal. Yet in many cultures family duties and obligations take precedence over patient autonomy" (p.406). Their study of 40 Chinese seniors living in Toronto, Canada in relation to 'truth telling' found that the respondents' attitudes toward this topic were deeply rooted in their religious beliefs, namely Confucian, Buddhist and Taoist practices.

In a letter to the editor titled 'A Chinese perspective on autonomy', Xu (2004) drew on her personal

experience of her father's long and debilitating illness. She argued that the notion of 'autonomy' had little relevance to Chinese culture and that disclosure and veracity could actually cause harm if the news was negative. She argues that this was against the western principle of non-maleficence. Tzeng and Yin (2006) conducted a study examining the demands for religious care in the Taiwanese health system. They argued that seeing Taiwan's major religion is Confucianism, palliative care, dying, and death should follow Confucian rites.

In a discussion on Asian-American patient's beliefs and attitudes toward the western concept of veracity in relation to death and dying, Loseth et al (2005) found that willingness to discuss depended on a variety of issues such as acculturation and length of time away from country of origin. They argued that Chinese prefer non-verbal cues and suggested that the concept 'Zhih Yi' - "just knowing what the other thinks and feels" (p.316) and the Japanese term 'Inshin Denshin' of "knowing without being told" (p.316) are the cultural concepts that take precedence over the western notion of 'fidelity'.

Izumi (2006) writing about Japanese nurses, argued that everyday nursing did not include ethical decision making in broad abstract western ethical models. She argued that while Japanese society respected western thought and technology, the ethical concepts were superimposed on a culture with a long and rich tradition of values.

Again focussing on Japanese nurses, Konishi and Davis (2006) argued that in this era of globalisation, the western influence can dominate as countries borrow advanced technologies relating to science, engineering and medicine. Along with this come western concepts of ethics. This overlay of one set of values onto another may not work. They argue that the eastern belief in the Taoism concept of 'non-action' may not sit well with western ethics. They also argue that non-action means reaching an enlightened state. The notion of the autonomous self is not central to eastern ethics and this they argue brings eastern ethics closer in line with feminist ethics "... although for very different reasons ... we are from

the beginning in relation and only secondarily and dependently, individuals" (p.225).

What is evident from this brief literature review is that minority ethnic groups living in dominant Anglo-Saxon societies appear not to uphold the western ethical concepts such as autonomy, veracity and fidelity as their Anglo-Saxon counterparts. What is upheld above western ethics are deeply ingrained philosophical and spiritual values that are perpetuated through cultural practices.

EASTERN ETHICS

In Chinese traditional culture, the family members are seen as a unit rather than individuals within that unit. The individual is seen as part of the whole and because of this, family members are always involved in important personal decisions such as job selection, marriage arrangements and medical decision-making; family members have a major say in anything involving the patient. This is because the moral philosophy and ideology of Chinese culture usually follows Confucian ethics. Thus the notion of autonomy or individual right and choice is subsumed by the family unit. Autonomy is not a traditional part of Chinese culture (Tse et al 2003) and all the implications relating to decision making are replaced by concepts and actions such as benevolence, compassion, filial piety, Jing (virtue) and Cheng (sincerity) (Tai and Lin 2001; Pang 1999).

In Chinese traditional culture, it is important not to disclose the truth of the illness especially to a terminally ill patient. There is a fear that the patient will worry and be sad if his or her health condition worsens. Although physicians have an obligation to inform patients of their diagnosis and the range of treatment available to them, family members will request this information be kept from the patient if they know that the patient has a serious health condition such as cancer. In this situation, truth telling or veracity will not generally be discussed in the hospital setting because family members believe that it will be harmful to the patient's feelings and thus affect the medical treatment. The family members usually try to hide the truth from the patient in order to

avoid any fear or anxiety when the patient's diagnosis is negative. This is in keeping with the Confucian practice of benevolence and compassion.

IS THERE AN ETHICAL DILEMMA

In Australia, nurses undergo a three year degree at university level in order to be able to be registered as nurse. Part of the curriculum is generally a compulsory unit in bioethics and nursing practice. Also, because Australia is a multicultural society, nurses may undertake a unit in cross-cultural studies which has a focus on differing cultural values and beliefs.

However the dominant paradigm through which ethics is taught is the western bioethical framework. Added to this there is a federal privacy legislation which enshrines and protects an individual's right to privacy. Even though nurses in Australia reflect the cultural diversity of this country, they are educated to uphold the concept of autonomy and consequently the notion of truth telling. The privacy legislation compounds this because nurses are obliged to keep diagnoses confidential for the patient. The dilemma of course is trying to uphold one set of ethical principles while caring for people from a wide variety of cultural backgrounds.

There are several ways to deal with this dilemma. It is considered that a palliative care goal is to provide a respect and a good quality of life for the person who is dying. McKinlay (2001) argued that health care teams should understand and care for the patient's feelings as well as their wellbeing. The focus is not always on the clinical condition but may turn to the spiritual or cultural need of the person who is dying; the most important concerns being family issues and spiritual support rather than the physical needs of patient. Therefore health care staff should recognise and identify the patients' values as the key aspect of care and listen to them.

As well, if we shift the focus from the right to know a diagnosis to the need to know a diagnosis, then the argument does not have to appear as a juxtaposition of cultural philosophical and ethical values. An individual may choose not to be told his or her diagnosis. Witt Sherman (2006) suggests that the best way to do this is to "...ask the patient whom the information should be given to and who should make decisions" (p.26). This way the patient can choose to receive the information or not. If nurses proceeded in this way then an ethical conflict could be averted as the issue of truth telling becomes irrelevant. In this way diverse cultural ethics can be integrated into nursing practice but this may require the construction of new methodologies and languages (Tschudin 2006) as well as modifying how nursing ethics is taught.

As well as this, the concept of autonomy does not need to be as narrowly defined as it appears to be. Bowman et al (2004) found that although there is scepticism towards truth telling for some cultural groups, this could be accommodated into the western tradition of autonomy. They argue that: "(t)ruth telling in the West presupposes that a patient values his or her 'right to know' and to make decisions" (p.411). However "true autonomy does not presuppose the right to know, but rather the right to choose whether to know" (p.411). This is a powerful distinction when coupled with the idea of asking the patient who should be told of the diagnosis as well as the difference between the right to know and the need to know.

If nurses working in a multicultural society were to give people a choice about the information they receive in relation to their prognosis then there would be no conflict with truth telling and may also be caring for their patients according to the Jing and Cheng in the Chinese philosophy and medical ethics. A patient's culture always informs their values and beliefs and there needs to be agreement between the patient, their family and health care providers in order to treat patients with the dignity they deserve.

CONCLUSION

This paper examines the ethical concepts of autonomy and truth telling from the practice domain of palliative care nursing and minority ethnic groups and has argued that these concepts may not be appropriate for different cultural groups and that this may become a source of ethical dilemmas and a challenge for western ethics.

A way to resolve this possible dilemma is to broadly define the notion of autonomy and rights. If nurses' move from a position of the patient's right to know based on autonomy to a stand that encompasses a patient's need or choice to know then we open a space for the patient to choose not to know their prognosis and to defer that knowledge to the family. This being the case then palliative care nurses will not be compromising the ethical principle of truth telling while respecting the wishes of their patients.

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