

Cultural Competence in Ethical Decision Making

● Dula F. Pacquiao



Key Terms

Advance directives
Advocacy
Affordable Care Act
Allostatic load
Autonomy
Beneficence
Communitarian ethic of care
Community partnership
Multisectoral collaboration

● Culturally competent care
● Culturally congruent action modes
● Compassion
● Ethical relativism
● Ethic of care
● Fidelity
● Health disparity/inequity
● Health Insurance Portability and Accountability Act
● Human rights

● Informed consent
● Nonmaleficence
● Patient Self-Determination Act
● Principle-based ethics
● Social determinants
● Social justice
● Status syndrome
● Veracity/truth telling
● Vulnerable population

Learning Objectives

1. Analyze the moral dilemma underlying health and health care inequities.
2. Describe how moral philosophies are socially and culturally constituted.
3. Analyze ethical principles and theories supporting human rights.
4. Differentiate social justice from distributive justice.
5. Describe the Model of Culturally Competent Ethical Decision Making.
6. Use research findings relevant to ethical decision making.

Nurses are often confronted by ethical dilemmas in their work. Nurses decide on care priorities and allocate human and material resources for their clients. Ethical decisions are complicated by culturally diverse clients with different socioeconomic capacities within health care organizations emphasizing common standards of care. Nurses need to negotiate with varying values not only

of their clients but also of other care providers and the organization where they work. There is increasing realization of health disparities associated with social inequities in local, national, and global societies. Nurses need to be informed of how social inequalities create differences in health outcomes in populations and develop innovations to prevent vulnerability in individuals

and groups. While culturally competent care addresses diversity, ethical practice grounded in social justice and human rights prevents **health inequity**. This chapter aims to give an overview of differing moral assumptions and the need for ethical relativism. It presents a model of linking cultural competence and ethics to promote the health of individuals and populations.

Contrasting Social Constructions of Morality

A moral philosophy consists of beliefs and assumptions about what is right and wrong. This is the basis of ethics, which prescribes the proper action to take in a given situation. Morals and philosophic beliefs are constituted within the social, historical, and cultural experiences of a society. These beliefs evolve as normative patterns of assumptions that serve as an implicit framework guiding the actions and thoughts of group members, which may or may not be shared by persons outside of the cultural group. Contrasting conceptualization of human beings exist in Western and non-Western cultures.

In Western cultures, there is a pervasive belief that human beings are endowed with the capacity for reason and action. Reason is assumed to be a universal capacity for all humans, and it is through reason that humans can be expected to make valid and truthful judgments in any situation. Since the era of Enlightenment, the philosophic traditions of universalism and rationalism have shaped the Western concept of the person as the focus of moral reasoning. The person is the basic unit imbued with a universal capacity for reason and action (Lloyd, 2002). Individual differences are attributed to deficits in cognitive skills, motivation, information, and/or linguistic capacity. Approaches to ethical dilemmas, therefore, are based on the belief that by compensating for these deficits, a person can be expected to make a rational decision that is universally regarded as logical and morally acceptable. However, not all human behaviors can be classified as simply

rational or irrational. Culture can be arbitrary, and human beings create their own distinctive, symbolic realities. Many of our ideas and practices are beyond logic and experience.

In some groups, religious and spiritual dimensions highly influence behaviors. Among such ethnoreligious groups as devout Muslims, Hindus, and Jews, religion is embedded in everyday life. Among Pakistani immigrant women, Islamic religious beliefs are observed during childbirth (see Evidence-Based Practice 14-1). Orthodox Jews may not accept euthanasia because of their belief in the sanctity of life. Jews generally consult their rabbi regarding matters pertaining to life and death decisions. Religion increases the awareness of the power and benevolence of God over humans; hence, earthly decisions are left to God, and the attitude is one of acceptance of fate rather than control over one's destiny. Members of Jehovah's Witness oppose blood transfusion as a lifesaving measure, and Christian Scientists may prefer their own religious and spiritually based practices of healing to those of traditional medicine.

Organ donation may be considered heroic in the biomedical profession and mainstream American culture. Religious, historical, and cultural influences, however, may prevent individuals from becoming organ donors. African Americans may be hesitant to become organ donors because of past and present experiences that built a collective sense of mistrust of the health care system and health professionals (Benkert, Hollie, Nordstrom, Wickson, & Bins-Emerick, 2009). Cultural practices such as female circumcision, body piercing and tattooing, and taking home a newborn's afterbirth may appear illogical and without any scientific basis. Yet, these practices are supported by value-belief systems that are deeply entrenched in religious, philosophical, and social structure of certain groups. To professional practitioners, resistance to scientifically proven measures belies common sense, but cultural traditions of some groups transcend rationality and logic. Indeed, common sense is not common after all; it is uniquely constructed within the social and cultural life contexts of human groups.

Birthing Practices of Pakistani Immigrant Women in the United States

This ethnographic study used a purposive sample of 26 immigrant women who originated from Pakistan. Participant observations over 3 years occurred in their homes located in urban and suburban areas in the northeast. Audiotaped individual interviews lasting 60 minutes and telephone follow-up were used. The study found women experiencing difficulty in observing cultural traditions because of loss of extended family support consisting mostly of women. Pregnancy, birthing, and child care are traditions reserved for women, and young mothers depend on this support for guidance and performance of activities to promote successful outcomes for both mother and baby. Motherhood is highly regarded and expected soon after marriage and becomes an extended family commitment. Mothers depend on female kin to prepare dietary supplements and provide massage and emotional support. Extended kin also take care of navigating the health care system from pregnancy to delivery. Study participants had difficulty navigating the US health care system and relied on a social network of other women in the neighborhood and Pakistani community. While they maintained their transnational gendered support by frequent telephone contact, they were unable to practice those traditions at home, such as preparation of nourishing diet as “panjeeri,” because they lack time, energy, ingredients, and know-how. They were especially concerned with their inability to observe the Islamic rituals after the birth of the newborn—whispering

the “Azan” (call to prayer) to the newborn’s ear and feeding of “ghutti” (honey or herbal product) to the newborn—because of absence of kin or a religious leader in the hospital. Sometimes, these rituals had to be postponed until they reached home. Cultural accommodation of the absence of gender-congruent support was evident in the couple’s decision to postpone pregnancy until a female kin can come to assist the woman, scheduling delivery back in Pakistan, and/or sending young children to be cared for by kin back home. Increased participation of husbands in traditional female roles such as care of the baby and household chores was an adaptive strategy.

Clinical Implications

- Identify potential ethical dilemmas that can be presented by cultural practices of Pakistani immigrant women during childbirth in the hospital.
- Identify approaches to preserve valued traditions, negotiate with the hospital policies, and repattern professional caregivers in your organization.
- Identify ways by which you can promote community involvement in your organization to create changes in policy and promote culturally congruent care.

Reference: Qureshi, R. I., & Pacquiao, D. F. (2013). Ethnographic study of experiences of Pakistani women immigrants with pregnancy, birthing and postpartum care in the United States and Pakistan. *Journal of Transcultural Nursing*, 24(4), 355–362.

In the West, the person is viewed as a self-contained entity, fully integrated and self-motivating, independent of social roles and relationships, and distinct from all others (Lloyd, 2002). In contrast, among collectivistic cultures, there is greater continuity and mutuality among group members. Collective decisions by the extended family represented by the clan, tribe, or

village make major decisions about the distribution of human and material resources to provide care for their members. Members of collective cultures expect to be physically present for family members who are dying or seriously ill. Numbers of family members present generally exceed the norm for visitation in most hospitals. Negotiating with the religious leader and/or group leader can

effectively arrange numbers of visitors in one room at the same time with the client.

In the West, the concept of the individual being imbued with rational capacity translates to an expectation that one can make the decision and be responsible for himself/herself. Respect for autonomy has become the focal context for health care decisions in the United States and Canada. Ethical principles are applied to ensure and maximize individual autonomy. The autonomy paradigm, which has been institutionalized in health care, underlines interactions with and expectations of clients and families by practitioners. The **Patient Self-Determination Act** passed by the US Congress in 1991 mandates health care practitioners to provide clients with information about advance directives intended to assure their autonomy in situations when they can no longer make a decision. Individuals' choices are presumably carried out on their behalf in the event that they cannot consciously and competently represent their own will. Although the intent of advance directives is consistent with the Western ethos of self-determination, other cultures subscribe to the belief that the fate of human beings is beyond their control. Some believe that executing advance directives will tempt fate and result in unexpected death.

In addition to the **Patient Self-Determination Act**, the US Congress also passed the **Health Insurance Portability and Accountability Act** (HIPAA) in 1996 that sets national standards for protecting the privacy, confidentiality, and security of individually identifiable health information by covered entities and business associates. HIPAA ensures confidentiality of an individual's health information. Health care practitioners are required to seek the client's informed consent before any information is shared with others, including family members. This poses difficulty for collectivistic groups where family members decide which information is shared with the client and other family members. The concept of individual autonomy brings an associated expectation of individual responsibility and accountability. This creates a predilection to reward

self-care and label those individuals as noncompliant when they do not adhere to prescribed biomedical regimen. Health professionals often ignore social factors that hinder an individual client's ability to act on health teaching and prescribed regimen. Because the focus of care is on individual responsibility and accountability, vulnerable groups tend to avoid seeking medical help unless they are desperately ill or selectively act on parts of the regimen that they have the capacity and resources to implement.

A consequent expectation of self-reliance associated with individualism demands the use of oneself as an instrument to achieve self-determined goals. The ethical principle of autonomy is closely linked with respect for an individual's free will and includes the right to make choices about issues affecting one's well-being. **Truth telling** or **veracity** demands avoidance of lying, deception, misrepresentation, and nondisclosure in interactions with clients by health care providers. The ethical principle of **fidelity** requires health care providers to maintain therapeutic, trusting, and honest relationships with their clients. Veracity and fidelity uphold the concept of individualism and the fundamental right of individuals to be treated with respect and dignity.

By contrast, collective cultures favor group decisions and role assumptions by individuals based on their status in the established group hierarchy. Family and kinship patterns assign different roles, status, and power among group members. The social hierarchy governs decision making, interactions, roles, and obligations of members. Whereas Western health care providers value the individual's autonomy in decision making, filial piety and respect for the authority of one's elders are the guiding principles among traditional Asian cultures in making decisions about care. Influenced by the Confucian ethic, the Korean culture accepts inherent social inequality among family members as a condition for achieving collective harmony. By contrast, the Western value of instrumental individualism prizes the ability of individuals to make choices and rely upon themselves to achieve their purpose in

life. Although a traditional Chinese adult relies upon family members and the physician to make decisions, a typical American or Canadian adult expects to be given information so he or she can make a decision.

In some cultures, such as African and Islamic groups, elder males occupy higher status and greater influence in decision making. They may decide to withhold the truth about hopeless prognosis from the client in order to protect the vulnerable member from the burden of truth and despair. Advance planning to identify potential ethical conflicts should be done so that cultural brokers such as a community or religious leader respected by the family can identify an acceptable resolution. A durable power of attorney or health care proxy may be an acceptable accommodation of their group decision making using a group-designated decision-maker and spokesperson.

In the United States, the mandate to use a trained interpreter who is not related to the client is another source of potential conflict. Group-oriented cultures tend to trust members of their in-group more than do others. In fact, some clients insist that their next of kin is present during their encounter with health professionals and expect their kin to speak on their behalf. Knowing the norms of the groups that the organization serves and working with community members to negotiate between these norms and the legal mandate in health care could prevent potential problems. Some hospitals have developed an interpreter program using community volunteers and bilingual staff members.

Ethical Diversity

Ethical relativism holds that morality is relative to the norms of a particular culture; hence, there are no universal truths in ethics. It emphasizes the need to examine the context of the decision because sociocultural differences influence whether an act is moral. Ethical relativism is unlike universalistic moral philosophies such as deontology, which upholds the existence of universal truths and unbreakable moral rules

applicable to all situations (Butts & Rich, 2008), and teleology, which judges the morality of an act based on its consequence or outcome. Ethical relativism states that what is right for one group may not be right for another (Wong, 2006).

Feminist theory supports ethical relativism in that it does not support universal truths and requires examination of the context of the situation before making a decision. Drawn from feminist theories, the **ethic of care** emphasizes the need for health care practitioners to develop empathy, compassion, and relationships that promote trust, growth, and the well-being of others (Edwards, 2011). This relationship is significant in caring for the frail and vulnerable individuals who are unable to advocate for themselves, such as disabled, mentally ill, abused, and elderly persons. Decisions about withdrawal of life support should take into consideration the individual's particular life context (e.g., previous life, current situation, and relationships with significant others). **Communitarian ethic of care** upholds collective decision making over individual autonomy. In collectivistic groups such as Nigerians, Haitians, and Filipinos (Figure 14-1), decisions about care of an individual family member are made by the group and may supersede the individual client's decision, regardless of his/her age or mental capacity to decide.

Principle-based ethics, or principlism, attempts to reconcile the divergence between teleological and deontological models. Ethical principles are derived from ethical theories and commonly used to resolve ethical dilemmas because they link moral decision making to scientific findings rather than universal rules. Principlism is based on the philosophical pragmatism of William James (Beauchamp & Childress, 2009). The principle of **fidelity** is the obligation to remain faithful to one's commitments. Nurses have an obligation to maintain standards of professional practice as a condition of continuing licensure. The principle of **veracity** upholds the virtues of being honest and telling the truth. **Truth telling** is recognized as a prerequisite to a trusting relationship. **Informed consent** requires



Figure 14-1. Three generations of a Filipino family. In collectivistic groups, decisions about the care of an individual family member are made by the group (Monkey Business Images/Shutterstock.com).

veracity of information presented to clients and fidelity of practitioners to professional standards. The principle of **autonomy** upholds the capacity of individuals to act intentionally without controlling influences by others and from personal limitations that prevent meaningful choice. Autonomous persons are allowed to determine their own actions or delegate decision making to others when they become incapable of making such decisions. **Advance directives** provide specific directions about the course of treatment to be followed by health care providers and caregivers if a client is unable to give informed consent or refuse care because of incapacity.

The principles of **nonmaleficence** and **beneficence** require that care providers act in ways that cause no harm and benefit consumers of their care, respectively. Focusing on client safety emphasizes prevention of harm. The goal of using evidence-based practice is to promote the most effective and safe interventions for clients. Beneficence is a much higher-level principle as it does not only address prevention of harm but also acting to benefit the client. A nurse working with a poor Vietnamese immigrant family

affected by tuberculosis (TB) applies the principle of nonmaleficence by using the services of a culturally appropriate interpreter to explain the care regimen to the client and family. The principle of beneficence is applied when, understanding the high incidence of TB among Vietnamese immigrants, the nurse forms a community collaborative consisting of families, vendors, church leaders, and the local schools to work with the Mayor's Office, Department of Health, and the Visiting Nurses to develop policies and programs for prevention and to control the spread of TB in the community.

Ethics and Health Disparities

Globalization has heightened the awareness of health inequities across population groups in local, national, and global contexts (Population Reference Bureau, 2010; Labonté, 2012). The terms used to refer to these differential health statuses, health outcomes, and access to quality health services in population groups vary across the globe. European countries and the World

Health Organization (WHO) have adopted the notion of social inequality and injustice as the explanation for differences in morbidity and mortality in populations. WHO (2013) defines **social determinants** as:

the conditions in which people are born, grow, live, work and age that are shaped by the distribution of money, power and resources at global, national and local levels which are mostly responsible for health inequities. Health inequities refer to the unfair and avoidable differences in health status seen within and between countries.

In the United States, the term health disparity is used by government agencies such as the Department of Health and Human Services (USDHHS), the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH). **Health disparity** is defined as:

A type of difference in health that is closely linked with social or economic disadvantage. Health disparities negatively affect groups of people who have systematically experienced greater social or economic obstacles to health. These obstacles stem from characteristics historically linked to discrimination or exclusion such as race or ethnicity, religion, socioeconomic status, gender, mental health, sexual orientation, or geographic location. Other characteristics include cognitive, sensory, or physical disability. (U. S. Department of Health and Human Services, 2009)

The USDHHS established the national goal of eliminating health disparities through its *Healthy People* initiative by setting goals and objectives for national health promotion and disease prevention and identifying targeted health indicators to be achieved over a 10-year period. In 2011, the Health Disparities and Inequalities Report by CDC noted health disparities as differences in health outcomes between groups that reflect social inequalities.

Social Determinants of Health

Carter-Pokras and Baquet (2002) define health disparity as a “chain of events signified by a difference in: (1) environment, (2) access to, utilization

of and quality of care, and (3) health status or a particular health outcome” (p. 427). Environment incorporates both physical and social aspects that impact health status. Exposure to pollutants, overcrowded residential areas, and neighborhoods with absent or marginal resources are associated with poor health. The seminal study of British civil servants by Marmot, Rose, Shipley, and Hamilton (1978) found a social gradient in health among Caucasians who are not poor and have equal access to health services. The higher their social position, the better their health. The social gradient was evident in mortality from coronary heart diseases and other causes of death. Marmot labeled this phenomenon the **status syndrome**. Conventional explanations such as lack of access to medical care and unhealthy lifestyles only partially explained the status syndrome. The lower individuals are in the social hierarchy, the less likely they are able to meet their needs for autonomy, social integration, and participation (Marmot, 2006). In the United States, income, education, and occupation have all been shown to predict morbidity and mortality (Miranda, Messer, & Kroeger, 2012; Seith & Kalof, 2011; Williams, John, Oyserman, Sonnega, Mohammed, & Jackson, 2012). According to the Centers for Disease Control and Prevention (2011), despite progress over the past 20 years, racial/ethnic, economic, and other social disparities in health persist.

Krieger (2012) has suggested that societal patterns of disease are the biologic consequences of life conditions produced by a society’s economic and political structure. People incorporate in their bodies the social and economic conditions of their lives from utero to death. Studies of racial residential isolation concentrating poor blacks in neighborhoods with overcrowded housing, low-quality health services and schools, violent and polluted environments, and limited availability of affordable healthy foods create cumulative health risks and limited opportunities for economic mobility that perpetuate social and environmental injustices resulting in poor health (Kwate, 2008). Class and racial inequality differentially affect the

living standards, working conditions, and environmental exposures of the dominant and subordinated classes, creating class and racial/ethnic health differences (Reardon & Bischoff, 2011; Dennis, Webb, Lorch, Mathew, Bloch, & Culhane, 2012). A society's economic, political, and social relationships affect both how the people live and their environment and shape different distribution of diseases. Patterns of morbidity and mortality are linked with social inequalities.

Studies of chronic stress associated with experiences of discrimination, marginalization, and lack of control over one's life circumstances create a "wear and tear" effect on the body, or **allostatic load**, which is linked with sustained high levels of cortisol and other stress hormones that increase one's susceptibility to chronic diseases such as hypertension, cardiac disease, diabetes, cancer, and increased incidence of preterm births (Barker, 2007; McEwen, 2009; Sheridan, Sarsour, Jutte, D'Esposito, & Boyce, 2012; Shuey & Wilson, 2008; Williams et al., 2012). Poor intrauterine conditions such as increased levels of maternal stress hormones and malnutrition have been correlated with coronary disease in adulthood (Burton, Barker, Moffett, & Thornburg, 2011). The effects of chronic stress on the brain are linked with high-risk behaviors and impaired decision making (see Evidence-Based Practice 14-2). Williams et al. stressed the importance of addressing social determinants as more significant in improving health than physical pathologies alone. Understanding the fundamental causes of poor health facilitates accurate assignment of responsibility and identification of measures to rectify the problem (Krieger, 2008).

The association between social inequality and health disparity is observed worldwide (Babones, 2010). Greater social inequality is directly related to increased disparity in health outcomes between the privileged and disadvantaged groups. In contrast to most developed countries, the United States does not provide universal health access for all its citizens (Schroeder, 2007). Although the United States spends the most for health care in the world, it lags behind other developed

countries and some less developed countries in health outcomes (OECD, 2014).

The Patient Protection and Affordable Care Act or the **Affordable Care Act (ACA)** was signed into law by President Obama on March 23, 2010, to provide access to health coverage to more than 40 million Americans. The ACA expands health care coverage to most US citizens and permanent residents by requiring most people to have or purchase health insurance (HealthCare.gov, 2012). Citizens have a choice of private insurance, employer-paid insurance, Medicaid, Medicare, or state-based insurance exchanges. The ACA produces a new kind of nonprofit health insurer, Consumer Operated and Oriented Plan (CO-OP), which offers consumer-friendly, affordable health insurance options to individuals and small businesses through the Affordable Insurance Exchanges. In 2014, all covered benefits were made available to individuals, and insurance companies can no longer deny individuals coverage based on their health status. The ACA provides free access to most preventive services and drug coverage for eligible seniors. Individuals can add or keep their children on their health insurance policy until they reach age 26. An individual mandate requires all individuals to obtain health coverage if they are not covered by an employer-sponsored health plan, Medicaid, Medicare, or other public insurance programs to secure an approved private insurance policy or pay a penalty, unless the applicable individual has a financial hardship or is a member of a recognized religious sect exempted by the Internal Revenue Service. The law includes subsidies to help people with low incomes comply with the mandate. An employer mandate requires businesses that employ 50 or more people but do not offer health insurance to their full-time employees to pay a tax penalty if the government has subsidized a full-time employee's health care through tax deductions or other means.

While ACA's intent is aligned with ensuring greater access to health insurance and care services by Americans, it is not equivalent to a single-payer, tax-supported, universal access to

Hispanic Men Who Have Sex with Other Men

Using the snowball recruitment technique, 20 foreign-born Hispanic bisexual or homosexual men between 26 to 54 years of age who were residing in South Florida participated in three focus groups to gather their perceptions and concerns regarding how risky sexual behaviors, substance abuse, and violence affected the Hispanic men who have sex with other men (MSM) community. Data were analyzed using grounded theory. Participants identified the “roots of risks” for risky sexual behavior, substance abuse, and violence in the following factors: (a) stressors from immigration, acculturation, discrimination, and economic situation, (b) peer pressure, (c) Hispanic value of machismo, (d) inability to maintain stable intimate relationships, and (e) lack of psychosocial support. Participants identified risky sexual behaviors as a result of negation of risks and substance abuse to buffer negative

events and emotions. Lack of psychosocial support and acceptance breeds the threat of violence from individual partners and the community.

Clinical Implications

- Analyze the ethical implications of the social determinants of vulnerability of Hispanic MSM.
- Describe ways of cultural repatterning of social attitudes toward Hispanic MSM.
- Identify approaches that promote beneficence for Hispanic MSM at the individual practitioner, organizational, and community levels.

Reference: DeSantis, J. P., Gonzalez-Garda, R., Provencio-Vasquez, E., & Deleon, D. A. (2013). The tangled branches (*Las ramas enredadas*): Sexual risk, substance abuse, and intimate partner violence among Hispanic men who have sex with men. *Journal of Transcultural Nursing*, 25(1), 23–32.

health care. The prevailing ethos of individualism in the United States is associated with the expectation of self-responsibility for one’s own well-being. However, catastrophic illness can destroy gainful employment and place clients and their families in poverty. The ACA attempts to ameliorate some of these problems but there are other considerations beyond access to health care services. Poverty, racism, residential segregation, and environmental injustices need to be addressed squarely in order to prevent and remedy their consequences for health and quality of life (Johnstone & Kanisaki, 2008).

Culturally Competent Ethical Decision Making

Globalization has heightened the need for health professionals to have a worldwide perspective and assume an ethical–moral obligation to enter and

function in a worldwide community (Leininger & McFarland, 2006). World citizenship skills require one to critically examine one’s self and one’s own cultural traditions (Pacquiao, 2008) to determine reasonable support for personal beliefs rather than accept them as absolute truths. World citizenship involves a genuine concern and commitment to the welfare of all persons and to see the world from the lens of others. Understanding and feeling the distress of another provides the impetus for the desire to help.

Figure 14-2 presents the model for culturally competent ethical decisions. Culturally competent ethical decision making is proposed as the pathway to promote health equity. It is built on **compassion** as the critical motivation that compels people to act on behalf of others, which emerges from an affective and cognitive understanding and identification with others’ experiences. It is the fire that ignites the energy to take action on problems involving enormous risks, complexities, and resources. Compassion

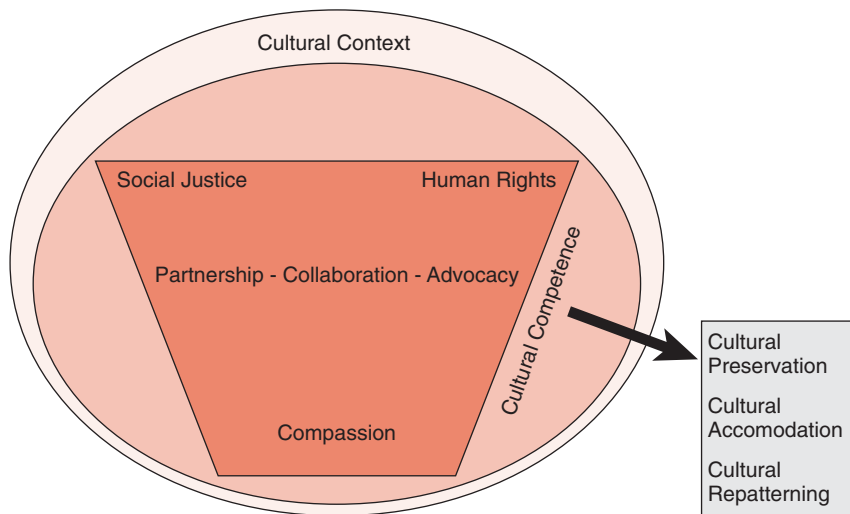


Figure 14-2. Model for culturally competent ethical decision making.

requires the ability to distinguish the oppressed from the oppressor, victims from perpetrators, and the disadvantaged from the powerful. Compassion is the commitment to go beyond the purview of one's own perspectives and affiliations. Compassionate actions are effective and realistic when culturally informed. Culturally competent compassion is immersed in balancing the rights of the vulnerable with those of others within particular contexts.

The goal in this model is the achievement of social justice and protection of human rights through culturally competent collaboration, partnership, and advocacy particularly with vulnerable individuals and communities. **Vulnerable populations** are people who experience a higher risk of poverty and social exclusion than does the general population (EQUAVET/EU Quality Assurance in Vocational Education and Training, 2014). Vulnerable groups have the greatest risks to health because of greater social or economic obstacles to health that are historically linked to discrimination or exclusion such as race or ethnicity, religion, socioeconomic status, gender, mental health, sexual orientation, or geographic location (U.S. Department of Health and Human Services, 2009). Health programs and policies

that fail to address the needs of vulnerable groups tend to widen health inequities when these initiatives focus only on a specific risk rather than the multiple risks in these groups (see Evidence-Based Practice 14-3).

Culturally competent care promotes health equity for vulnerable and disadvantaged individuals and populations through social justice and protection of human rights. Culturally competent care is not merely at the level of *doing no harm* (nonmaleficence), but more importantly, it creates a *positive* difference in people's lives (beneficence). Cultural competence has a moral agenda to understand the impact of culture on people's lives, respect these cultural differences, and minimize the negative consequences of cultural differences (Pacquiao, 2008). Elimination of health disparities could not occur without culturally competent practitioners, but cultural competence alone is not enough to eliminate health inequalities. It requires practice within the framework of social justice and human rights. To minimize population health disparities, cultural competence should occur at the level of individual practitioners, health care organizations, governmental agencies, and empowered communities.

Traditional Birth Attendants in Sierra Leone

Sierra Leone, a country in sub-Saharan West Africa, has suffered more than a decade of civil war that destroyed its health infrastructure and impoverished its people. The country is plagued with high illiteracy and has the highest maternal mortality rate (MMR) in the world. In West Africa, 80% of births are attended by unskilled birth attendants. In Sierra Leone, traditional birth attendants (TBAs) are mostly untrained, illiterate women who perform deliveries as their main occupation. In 2010, the government introduced free health care for all pregnant women, lactating mothers, and children less than 5 years of age. It banned TBAs from delivering babies and mandated that they refer expectant mothers to health care facilities for birthing. This qualitative study used focus groups to describe practices of TBAs in urban and rural settings in Sierra Leone. The purposive sample included 20 TBAs and 20 mothers and 10 health professionals familiar with their work. The study found that TBAs are valued by mothers, health professionals, and their communities because they provide accessible and affordable care to mothers who are poor and live in distant places far from health care services. Since TBAs are embedded in these communities, they are trusted by the people and maintain long-term relationships with mothers and their families. Their services may be paid for before or after they are rendered; they accept any form of payment (cash, goods, services, etc.) depending on the capacity of the family. Participants, including TBAs themselves, identified that TBAs need training, supervision,

and resources. Despite the government mandate, mothers continue to use their services because of lack of transportation to birthing facilities, inability to meet expenses for their stay in the hospital and provide for their families back home, and inability to negotiate with hospital norms and communicate with health professionals. TBAs have also lost their means of livelihood. Some health professionals believe that TBAs have been scapegoated by the government as the cause of high MMR instead of improving its health infrastructure and addressing rampant corruption in the system.

Clinical Implications

- Define the ethical dilemma precipitated by the government mandate.
- Identify population groups who are disadvantaged by the mandate.
- What recommendations do you propose to promote beneficence to disadvantaged groups? To promote social justice and protect their right to access maternal and child health services?
- Identify actions using the three modes of decisions of cultural preservation, negotiation, and repatterning at the individual practitioner, organizational, and community levels.

Reference: Dorwei, F. M., & Pacquiao, D. F. (2013). Practices of Traditional Birth Attendants (TBAs) in Sierra Leone and perceptions by mothers and health professionals familiar with their care. *Journal of Transcultural Nursing, 25*(1), 33–41.

The Universal Declaration of Human Rights (Universal Declaration of Human Rights, 1948) was based on Immanuel Kant's work, which emphasized treating every human being with dignity as an end by itself. **Human rights** aim to protect the inherent dignity and equal and inalienable rights of all people. The UDHR is especially focused on the poor, vulnerable, and marginalized populations who are routinely

excluded from the benefits and opportunities of the political, economic, and social mainstream. Every individual has a right to a standard of living adequate for health and well-being that includes medical care and other basic necessities like food, clothing, and housing. The right to health is a free-standing human right that is closely linked to many other human rights protections contained in international treaties and domestic

constitutions, including right to life, nondiscrimination, privacy, and freedoms of associations, assembly, and movement. Thus, human rights are universal and indivisible. While the rights of speech and religion protect individuals from interference in their exercise of personal activities or liberties (Loewy, 2007), the right to health is dependent on a society's willingness and ability to provide.

Justice is a concept of moral rightness, equity, and fairness. According to John Rawls (1999), justice, and especially distributive justice, is a form of fairness or an impartial distribution of goods. Rawls proposes two principles of justice: (1) each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all, and (2) social and economic inequalities are to be arranged so that they are both to the greatest benefit of the least advantaged. **Social justice** is the ability of people to realize their potential in the society where they live. It implies fairness and mutual obligation in society or the mutual responsibility for one another, to ensure that all have equal chances to succeed in life. Social justice generally refers to institutions that enable human development or the people to lead a fulfilling life and be active contributors to their community (Rawls, 1999). The United Nations' (2006) document *Social Justice in an Open World: The Role of the United Nations* states that "Social justice may be broadly understood as the fair and compassionate distribution of the fruits of economic growth..." (p.16).

In health, social injustices occur when there is a preventable difference in health states among a population of people or health inequities that tend to be more prevalent among impoverished nations or groups (Farmer, Nizeye, Stulac, & Keshavjee, 2006). These negative health states can often be prevented by providing social and economic structures such as primary health care, which ensures the general population has equal access to health care services regardless of income level, gender, education, or any other

stratifying factor. Integrating social justice to health inherently reflects the social determinants of health model without discounting the role of the biomedical model (Cueto, 2004). In nursing, justice is often related to the delivery of services. In countries without universal access to health services, care may be differentially patterned by the type of health insurance coverage of clients or their capacity to pay.

Social justice relates to the fair, equitable, and appropriate treatment or use of resources in light of what a person needs, weighed against the needs of others. Rawls (1999) stipulates two requirements for fair and equitable distribution of goods. First, people have maximal liberty compatible with same degree of liberty for everyone—there are limits to individual liberty. Second, deliberate inequalities are unjust unless they work to the advantage of the least well-off. Social justice focuses on the social consequences and responsibility for actions by the society or the government. According to Shanley and Asch (2009), distributive justice is not social justice; there is a difference between giving all persons equal rights and opportunity within a system of inequity (i.e., distributive justice) and altering the conditions under which inequality or oppression arises (social justice). Social justice, according to Hofrichter (2003), is:

an opposition to inequality and demands an equitable distribution of collective goods, institutional resources and life opportunities. Achieving equality requires not merely redressing or ameliorating inequitable outcomes but creating a society that does not produce material inequality.
(p. 12)

Social justice and human rights principles are necessary conditions to achieve health equity for vulnerable groups. They are fundamentally complementary. Social justice shifts accountability and responsibility solely from individuals to institutions and society. Right to health is a right of citizenship and is a shared responsibility of society and the individual. Ensuring the right to health becomes a moral obligation of

society and not just the individual and/or his/her family alone.

The United States, however, is a market-driven economy emphasizing the culture of individualism, entrepreneurial capitalism, and individual responsibility. Kirch and Vernon (2009) assert that there is a neglect of justice and a lack of a unified theory of justice in the US health care. Although the traditional ethos of medicine has focused on the fundamentals of beneficence, nonmaleficence, individual autonomy, and justice, the principles of nonmaleficence and autonomy are front and center. Nonmaleficence emphasizes patient safety, and autonomy has taken for granted respect for individual patient and physician autonomy. Physician autonomy has been aligned with fiscal independence. The American concept of autonomy is based on John Stuart Mill's work on liberty, which is construed as freedom from restraint, to do what everyone wants as long as it does not harm others. By contrast, autonomy according to Kant is based on the integration of freedom and responsibility. Autonomous individuals can adopt moral constraints and willingly submit to norms to which they have given their consent.

Culturally competent care for vulnerable populations is achieved by commitment to both principles of social justice and human rights. Social justice is doing what is best for a person or group based on their needs and the fundamental tenet that human beings have inalienable rights. Social justice implies that because of certain conditions that increase risks to a person or group compromising their capacity to self-advocate and access to life with quality, actions of health care professionals, organizations, and government should not only be nonmalevolent (doing no harm) but most significantly do what benefits the people (beneficent). Social justice is central to advocating for elimination of health disparities by ensuring the basic human right to health.

Advocacy for social justice and human rights requires collaborative partnerships with individuals, families, and communities. It involves partnership between the national and local

government and among health care workers, local communities, and nongovernmental organizations. It requires **multisectoral collaboration** that attends to the whole spectrum of keeping people healthy by improving their life and work conditions, going beyond access to health care services and disease-based care. It promotes individual and community empowerment and control of their health. It involves people locally, empowering them to advocate for themselves by influencing policies and programs and monitoring that social justice is applied. The community becomes a real partner in health achievement by building community solidarity, social cohesion, and effective social networks (Gargioni & Raviglione, 2009). Health enables and empowers human capacity to achieve life conditions supportive of one's well-being (Health Canada, 1986).

Community partnership for social justice and human rights protection can be achieved at so many levels. Entry-level nurses can develop a comprehensive knowledge of the communities in which they live and work. Assessing the strengths and challenges of these communities is important in focusing effective partnerships between the health care organizations in which they work and their communities. Participation in organizational committees targeted toward community development and partnership building is a pathway of individual and organizational involvement in local communities for health. Nurses can also participate in influencing health and social policies impacting the community through their professional organizations, churches, parent-teacher organizations, and municipal boards. Communicating with legislators and political leaders is another venue for advocacy.

Culturally congruent action modes, according to Leininger (2002), include cultural preservation, accommodation, and repatterning. One or all three modes of action may be used simultaneously or in a continuum of actions. *Cultural preservation* means maintaining the core values, beliefs, and practices significant to the individual



Figure 14-3. Gawad Kalinga housing for the poor in the Philippines.

or group. *Cultural accommodation* involves negotiating with existing cultural differences in order to find a meaningful existence of one's cultural life-ways with those of others. *Cultural repatterning* means attempting to help individuals and groups change their way of life to achieve a healthy, safe, and meaningful existence. Cultural repatterning enables health practitioners and organizations to promote preservation and accommodate cultural differences. Leininger's culturally congruent decision modes promote bridging of differences applicable with individuals, organizations, and communities. These are significant approaches in bridging cultural differences and finding a common ground among different groups, which are critical in building multisectoral collaboration and partnerships. The force that moves individuals and groups to engage in culturally competent advocacy for empowerment of vulnerable individuals and communities is compassion.

The Gawad Kalinga (GK) project has established homes for the poor in 2,000 communities in the Philippines through global and local partnerships among individuals, governmental and private organizations, and local communities to eradicate poverty (Figure 14-3). Motivated

by compassion for the vulnerable groups in the Philippines affected by socioeconomic and health disparities, several Filipino organizations overseas, such as the Philippine Nurses Association of America, provided funding and technical assistance for these communities. GK has built sustainable communities with access to healthy food, health care services, and livelihood for the residents. GK was initiated in 1995 by a local religious movement, *Couples for Christ*, became a national partnership between the government and the private sector, and now has become a foundation worldwide.

Model Application

Two case studies are presented to illustrate application of the culturally competent model for ethical decision making. Case Study 14-1 looks at childhood immunization and the sometimes competing interests of the parents and health care providers. Case Study 14-2 highlights the planned takeover of a local hospital by a religious organization and the impact of that change on the mostly low-income ethnic minority population served by the hospital.



CASE STUDY 14-1

Several children in a nursery school were diagnosed with measles. Investigation by the local health department revealed that majority of those affected were not immunized—some parents were concerned that the vaccine would cause more harm to their children; others objected to vaccination on religious grounds. Scientific evidence has established that childhood immunization is effective in controlling epidemic of infectious diseases such as measles, diphtheria, pertussis, and polio. Vaccinated individuals are rendered safe and prevent infection of others.

The vaccination mandate is based on the principle of beneficence, which may conflict with parental belief of nonmaleficence toward their children. Almost all states mandate childhood vaccination but may grant exemptions based on religious and philosophical reasons. State-mandated vaccination presents an ethical conflict between individual rights and public health protection. Conditions when a public health mandate may supersede an individual right to autonomy include (a) effectiveness of the vaccine, (b) proportionality of the

mandate in terms of public good versus individual right, (c) presence of immediate threat of epidemic or deaths, (d) availability and accessibility of services to the individual if he/she gets sick from the vaccine, and (e) strength of public justification for the mandate such as threat of an epidemic and lack of more effective treatment available for the disease (Schwartz & Caplan, 2011).

Cultural maintenance and preservation of individual rights can be fostered by building consensus (Buchanan, 2008). Meetings with parents by listening to their concerns and clarifying the facts about vaccination can help build mutual trust. Religious and community leaders can help facilitate cultural negotiation with conflicting values and beliefs to facilitate consensus building. Cultural negotiation and repatterning can be applied by using media, health experts, community leaders, and former patients to disseminate scientific information and facts about vaccination. Collaboration and partnerships between public health workers, community cultural brokers, schools, and church leaders can help clarify misperceptions, build trust, and facilitate consensus. Health care organizations and professionals can benefit by repatterning their mind-sets by listening to the local people, addressing their concerns, and building mutual trust and reciprocity.



CASE STUDY 14-2

Because of financial losses, the publicly funded hospital serving a mostly low-income ethnic minority population is scheduled to be taken over by a local Catholic hospital. The merger will leave this one integrated health system under the auspices of the Catholic archdiocese as the only hospital serving the whole city. The takeover will minimize access to health care services by low-income, Latino population and eliminate access of poor childbearing women to contraception and abortion services. Local community leaders and health advocates raised their concerns with local political and community leaders. They were successful in gaining support from the local community and

politicians as well as state legislators and obtained an injunction to stop the merger.

The merger between these two hospitals presented an ethical dilemma between a hospital's assertion of its religious right and loss of access to services by a particular sector of the population. Local community advocates objected to the merger on grounds of social injustice or unfairness for vulnerable populations in the city. They gained greater support for social justice for childbearing women, especially low-income minority women. The struggling hospital was their only access to family planning services, which would no longer be provided upon becoming an entity of a Catholic organization. The merger was approved after proof of accommodation of access to these services was provided to the state legislators. The Catholic hospital had to make arrangements with local community facilities and other hospitals in neighboring towns.

(continued)

This case demonstrates how multisectoral collaboration and partnerships between local community advocates and political leaders can make a difference (beneficence) for a population that is considered disadvantaged (low-income, ethnic minority women). Advocacy for their right to family planning services is an example of a social justice issue that confronts vulnerable population groups who have less economic and social power. Advocacy grew out of local women leaders who are trusted in the community and well connected with local and state politicians. Although advocacy did not save the

fledgling hospital serving a primarily low-income Latino community, it successfully negotiated with business and religious entities in recognizing the right of women to access family planning services.

Cultural repatterning was achieved by effective partnerships between community advocates, community members, and local and state politicians. The media provided sufficient coverage of the problem sustaining public debate on the issue. It is important to point out that this city has traditionally elected Democrats who espouse support for social and health programs.

Summary

Strategies in facilitating the transformation of an individual's compassion to culturally competent actions to promote social justice and human rights protection are centered on partnership, collaboration, and advocacy. Collaborative partnership with individuals, families, and communities is built on mutual understanding, trust, and reciprocity. Listening to the stories of clients, families, and communities within their social and environmental contexts can sensitize caregivers to the subjective and highly personal construction of their health experiences. Immersion in the client's life conditions develops empathy for his or her suffering and facilitates a full understanding of the person as a human being and vulnerable communities.

Repeated cultural encounters enhance the health care professional's ability in demonstrating attentiveness, genuine concern, presence, warmth, and empathy. Clinical encounters with diversity are found to be significant in developing cultural proficiency and effectiveness (Pacquiao, 2007). Community involvement and immersion in diverse communities create the appropriate context for partnership, collaboration, and compassionate understanding.

Health care providers need experience in caring especially for vulnerable populations locally or abroad. Experience with organizations and advocacy groups such as local churches, the

Red Cross, homeless shelters, Doctors Without Borders, and other opportunities can build the skills for culturally competent ethical thinking. Awareness of resources locally, nationally, and globally promotes access to and development of more comprehensive services. Building collaborative partnerships with organizations and communities is important as vulnerable populations have complex, multiple needs that are both simultaneous and evolving.

Partnerships allow sharing of resources, services, and best practices across local, national, and global contexts. Service learning is an excellent opportunity for nursing students to learn about organizations and the communities they serve. Strengthening the community health nursing experience in the curriculum sensitizes students to public health issues and social inequities affecting population health.

REVIEW QUESTIONS

1. Describe ethical dilemmas associated with the current state of population health and health disparities.
2. Discuss the cultural underpinnings supporting pros and cons of health care reform and the Affordable Care Act in the United States.
3. Explain how the principles of social justice and human rights protection reduce health disparities.

CRITICAL THINKING ACTIVITIES

Identify an example of an ethical dilemma that you have encountered at work or in your community. Identify the particulars of the situation:

1. Who are the people involved?
2. What is the setting?
3. How do different individuals or groups perceive the problem?
4. Identify conflicting values and beliefs at the individual, organizational, and societal levels that influence perceptions.

5. What assessment data about the situation are missing?
6. How can additional information be obtained?
7. Using the Model of Culturally Competent Ethical Decision Making, how would you redefine the problem?
8. What culturally congruent strategies do you recommend?

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