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Patient-Centered Care and Cultural Practices:

Process and Criteria for Evaluating Adaptations of Norms and Standards in Health Care Institutions

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It is widely recognized that health care providers and health care organizations need to take into account the cultural frameworks of patients. Such an orientation is consistent with patient-centered care that focuses on the particularity of individual patients (Stewart, 2001). In a patient-centered approach clinicians individualize the care they provide to each patient, and seek to develop and promote partnerships with patients. Eliciting and engaging a patient's cultural values and perspectives is a key component of patient-centered care. An important body of scholarship has developed around the question of how attending to the needs of culturally diverse patient populations should affect the provision of clinical care and other health services (Betancourt, 2004). This discussion has led to many practical changes in how health care providers are trained. Today, educational programs in faculties of medicine, schools of nursing and schools of allied health incorporate cultural competence training in their curricula.

Despite the increased focus in education and clinical practice on providing patient-centered and culturally sensitive care, challenging situations can arise when patients wish to perform practices that do not fit within institutional or clinical norms. In many such situations, health care providers and hospital administrators adapt institutional or clinical norms and structures. In other cases it may be difficult to decide whether particular adaptations should be made or not. Such scenarios may be sources of important concern and stress for patients, families and health care providers. The assessment of a given situation is rendered more complex when the adaptation being considered has the potential to infringe on the rights of others (such as other patients, visitors to the hospital, or health care providers). In this paper, I propose a

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process, including four evaluative criteria, for assessing such scenarios. This discussion is also relevant for considering practices that require adaptation of institutional or clinical norms, but which are not based in a specific cultural or religious framework. Given a commitment to respect autonomy, administrators and clinicians should also carefully consider requests for adaptation which patients associate with their own core beliefs and deeply held commitments.

Cultural Practices and Health Care

A culture is a system of meaning encompassing shared values, symbols, traditions, practices, beliefs and styles of communication that are learned and passed on within a group (Geertz, 1973). Kleinman and Benson describe culture from an anthropological perspective as a dynamic process "through which ordinary activities and conditions take on emotional and moral tone and meaning for participants" (2006, p. 835). Culture plays a central role in how patients and health care providers understand and experience health care; the cultural frameworks of individual health care providers and patients influence every clinical encounter. How individuals experience and understand health, illness, disability and death, as well as expectations regarding health care, treatment choices and clinical outcomes, is influenced by culture (Kleinman, 1988). In addition, biomedicine itself has been described as a cultural system with associated cultural values that shape how health care is provided to patients and influence the ways that clinical settings are organized (Taylor, 2003; Fox, 2005).

Specific practices related to healing, sickness and death are important components of many cultural frameworks. A particular health-related practice may be considered an integral aspect of how an individual should respond to disease or ill-health and associated with particular goals that the patient holds to be of great significance. In this way, patients and families may understand a particular practice to be an important means of preserving one's personal integrity and cultural identity. Such practices include, but are not limited to healing ceremonies, dancing, coining, herbal or dietary remedies, burning of incense, prayers or chanting.

Addressing Cultural and Religious Diversity in Hospitals

Health institutions routinely adapt elements of the services they provide to reflect the culturally, religiously and linguistically diverse populations that they serve. These adaptations include menu options consistent with the dietary restrictions of particular religious communities, access to pastoral

care, availability of space for prayer and other spiritual practices, and banks of interpreters and culture-brokers. Some hospitals have also developed multicultural departments to provide assistance in responding to the cultural concerns of patients. Each of these practices and services represent ways that hospitals address the religious, cultural and linguistic needs of patients.[1] These initiatives contribute to the delivery of relevant and effective care to diverse patient populations.

While some cultural needs are more easily met in the hospital setting, other cultural values and practices present challenges for health care providers and hospital administrators. In some circumstances, differences of values and expectations between perspectives may result in "cultural collisions" that challenge patients, families, clinicians and administrators (Gorlin, Strain and Rhodes, 2001). A number of authors have discussed the difficult and complex situations that arise when a patient, or his family, requests treatment on the basis of religious convictions or cultural values, but which clinicians consider to be futile or inappropriate (Brett and Jersild, 2003; Orr and Genesen, 1997). Efforts have been made to develop approaches to enhance communication and negotiation of conflicting perspectives in end-of-life decision-making (Burns and Tuog, 2007). Questions of accommodating practices and approaches that diverge from Western biomedicine have been considered from a variety of perspectives. Ethical considerations related to the use of complementary and alternative medicine (CAM) have been examined and, in particular, the interface between conventional medicine and CAM (Thorne, Best, Ballon, Kelner and Rickhi, 2002; Ernst, Cohen and Stone, 2004; Adams, Cohen, Eisenberg and Jonsen, 2002). In Quebec, Canada, the provincial government formed the Bouchard-Taylor Commission to explore issues related to "reasonable accommodation" of cultural values, including in health and social services settings (Consultation Commission on Accommodation Practices Related to Cultural Differences, 2008). The intersection of different cultural frameworks in the context of healthcare has been examined in diverse contexts and from a variety of perspectives. The analysis I develop in this article focuses on situations when patients in hospital settings wish to perform practices that do not fit within existing institutional and clinical norms and structures. The process and criteria that I propose to guide the evaluation of such scenarios are intended to support attentiveness to the particular context of a given situation, encourage communication and negotiation, and seek mutually acceptable solutions.

Dilemmas may occur when patients wish to perform cultural practices that require the adaptation of institutional or clinical norms. Health care providers are often alert to the possibility that cultural or religious practices

are important to patients and families, and are receptive to making adaptations that enable such practices to take place. Challenging situations arise in adapting clinical or institutional approaches when doing so may interfere with the rights of others, or with duties and obligations of health care providers or institutions. For example, the adaptations required to enable certain practices in hospital settings may result in risk of harm for other patients or staff. However, the refusal to make adaptations, when there is not compelling rationale for such refusal, is also a potential source of harm for the patient. Thus, there is a need to evaluate individual cases to determine whether clinical and institutional norms and structures should be adapted.

An example of this type of situation comes from a clinical scenario described by Kaufert, Putsch and Lavallée in a paper discussing end-of-life care for aboriginal patients (1999). The family of a terminally ill aboriginal patient requested that sweet-grass be burned in the patient's room in accordance with the cultural traditions of his community. To allow the sweet-grass to be burned, hospital administrators agreed to deactivate smoke alarms in that part of the hospital. This situation continued for several days until it was decided that the safety concern for patients and staff was too serious for the smoke alarms to remain deactivated. After this concern was explained to the family, they agreed to relocate the sweet-grass ceremony to another location.

This scenario is not unique and analogous situations take place in other hospital settings. A patient may wish to participate in a healing ceremony involving chanting and dancing that would take place in a hospital room shared with other patients or to use a traditional remedy during hospitalization. In other situations, the family of a deceased patient may request that the patient's body not be moved from the room for an extended period after death, or that candles be lit at the patient's bedside. When such requests are made the treatment team and, in some cases, hospital administrators evaluate the situation and consider possible adaptations of institutional and clinical practices.

Reasons to Consider Adapting Institutional and Clinical Norms to Enable Cultural Practices

As described above, culture is an important factor in how individuals experience health and illness. In responding to this reality, health care providers should approach cross-cultural encounters with humility and openness to learning (Tervalon and Murray-Garcia, 1998). Attention to the roles that culture plays in health care, particularly differences in cultural perspectives between health care providers and patients, is essential (Jecker,

Carresse and Pearlman, 1995). Health care providers should attempt to identify and address the potential for negative consequences to result for patients as a result of such differences of cultural perspectives (Paasche-Orlow, 2004). A patient-centered approach to care that seeks to address the particular needs of patients should lead healthcare providers and managers to examine opportunities for hospitalized patients and their families to enact practices that are of significance to them. Patient-centeredness suggests that health care providers and organizations adapt the services they provide to reflect the goals, needs and values of individual patients. This approach also supports opportunities for patients to define health related goals that are meaningful for them. Patients should be involved in the process of establishing treatment objectives and developing the care plan. Within this approach, clinicians and institutions should be oriented towards adapting local structures and norms to enable patients to perform practices that they understand to be important, unless there is persuasive rationale for not doing so. The principles of respect for autonomy, beneficence and justice also support an orientation toward carefully examining the possibility of adapting local norms and standards to enable cultural practices to occur in hospital settings.

The principle of respect for autonomy supports efforts to adapt clinical and institutional norms to enable patients to enact cultural practices that they understand to be important. Autonomy encompasses the opportunity and right of persons to make choices for their own lives and to practice self-determination. It also suggests the duty of others to not interfere in the exercise of one's autonomy. Health care providers should seek opportunities to support and promote the autonomy of patients (Bergsma and Thomasma, 2001). Also, patients do not exist separate from family, community and social relationships. These interconnections and interdependencies should be considered. The complex nature of these relationships, and their importance to the patient, should be accounted for in seeking to respect and promote the patient's autonomy (Sherwin, 1998). Attention to community and family relationships may be of particular relevance given the shared nature of cultural frameworks.

The second consideration is the principle of beneficence. If we are to do "good" for individuals we need to reflect on whose account of good we base such determinations. It is problematic to appeal to a set of goods that does not reference the particular concerns of the individual patient. Health care providers need to be deliberate about exploring with their patients what values are important to them. This orientation to consider the patient's conception of his or her own wellbeing and interests is a key aspect of beneficent care. Thus, a health-related practice that is highly valued by the

patient (and seen by the patient as providing an important good) should be given heed by clinicians and administrators with the view of facilitating the practice. A constraint on how the principle of beneficence is to be enacted is the recognition that health care providers are accountable to exercise their professional duties in ways that are consistent with accepted standards of practice and in line with other relevant obligations and duties.

Concerns of justice also suggest that health care providers should attend to the roles of culture in access to health care. Several studies from the United States have shown that minority groups receive fewer health care services and lower quality care than non-minorities (Fiscella, Franks, Doescher and Saver, 2002; Weinick and Krauss, 2000). This pattern is evident even when variables such as insurance status and income are controlled for. This situation is accentuated for migrant newcomers or refugees who have language and cultural barriers that impede access to health resources and contribute to their vulnerability. Social justice concerns should lead health care providers to be vigilant in striving to meet the health needs of individuals who are at risk of being marginalized and under-served in the health care system. Furthermore, certain communities, such as many indigenous peoples, have experienced historical injustices. Arguments based on social justice have been made for taking additional steps within multicultural societies to address the particular needs of minority groups that have experienced historical injustice (Kymlicka, 1996).

In light of patient-centeredness and the principles of respect for autonomy, beneficence and justice, there should be a strong predisposition towards adapting organizational and clinical structures and norms to enable patients to perform health-related practices that are meaningful to them, and that the individual associates with their sense of personal integrity. Health care institutions and their staff should be careful not to force patients into institutional molds that make the hospital more efficient but ignore patients' cultural identities and core beliefs.

Evaluating Possible Adaptations

In hospital settings, health care providers and administrators respond to situations when patients wish to perform cultural or religious practices that do not fit within existing clinical or institutional structures and norms. Determinations of whether to adapt clinical or institutional structures are typically made on an ad hoc basis. There may be limited guidance by which to make such assessments. Health care providers and administrators may espouse the need to evaluate the reasonableness of a potential adaptation. However, short of recourse to the courts, it is difficult to employ this

standard. Appeals to "reasonableness" are open to questioning. How does such a determination get made in practice? What group or individual will decide on the parameters for reasonableness? The ambiguity of appeals to reasonableness when seeking to evaluate a particular practice in a given clinical setting points to the value of establishing a process to guide the evaluation of such scenarios. In the following section I describe criteria that can be employed to evaluate possible adaptations of institutional and clinical structures. I also outline a process by which such decisions can be made.

In situations where a patient or family makes known their wish to perform a specific practice, the treatment team typically makes an initial assessment of the situation. In many circumstances institutional norms and structures are adapted to facilitate the practice. Certain adaptations relate to broader organizational or management practices or policies. Managers and administrators will often participate in discussions regarding the possibility of adapting institutional policies.[2] Negotiation and communication skills are important attributes for health care providers and administrators who participate in such discussions.

Evaluations of requests to adapt local structures and norms should be oriented toward examining the particular contextual features of the situation (not looking at an issue in an abstract form). In situations where the treatment team or hospital administrators question whether to adapt particular structures or organizational practices, they should take sufficient time to discuss in depth the situation with the patient and family. Exchange and dialogue are essential. Health care providers and managers will benefit from seeking to identify how their own values and expectations influence their understanding and assumptions regarding the practice under discussion.

I propose four criteria related to institutional and professional goals and responsibilities that can be used to evaluate potential adaptations: safety of patients and staff, significant disruption of other patients, managing limited resources fairly, and practices in opposition to the medical standard of practice. These criteria relate to the impact of adaptations on other agents, and consistency with the goals and obligations of health care providers and health care institutions.

Safety of others

Some cultural or religious practices have the potential to result in harm to other individuals. Ruth Macklin presents the example of the use of mercury in rituals associated with the Santeria religion (1998). In other situations, it is the adaptations required to accommodate a particular practice that may place others at risk. Hospitals have a moral and legal responsibility to promote the

safety of patients, visitors and staff. Hospitals and health care providers are accountable for taking steps to identify and address situations that place individuals at risk of harm. Adaptations of institutional and clinical norms to facilitate a particular cultural practice should not be implemented when the adaptation could compromise the safety of other patients, visitors to the hospital, or staff. Actions such as the disconnection of fire alarms to allow a sweet-grass ceremony as described earlier in this paper should not be undertaken. Similarly, other potential adaptations of institutional structures that increase the risk of harm for other patients, visitors or staff should not be made.

Disruption of other patients

A second consideration to be examined is the possibility that a proposed adaptation would lead to significant disruption of other patients. A number of cultural practices could impact fellow patients beyond issues of physical safety. For example, chants or loud prayers at a patient's bedside may not only inconvenience other patients but also prevent them sleeping or resting. Also, some may claim cultural reasons for exceeding the number of visitors, or the visiting hours, allowed by an institution. Such claims may indeed be valid. However, health care providers and managers will need to examine the impact of particular situations on other patients. There should be a strong orientation towards allowing such adaptations. However, significant disruption of other patients is sufficient justification for not adapting policies on the ward or unit. In such situations the team should consider whether the patient might be provided a private room or a room at the end of a hall where there is less likelihood of disturbing others. However, this may be impossible in a setting such as the ICU or other critical care ward. In such situations, families may be given access to another space such as a family or conference room where they could perform cultural practices. It is important that critical reflection take place so that this criterion is not employed too broadly and used as a cover for an unwillingness to adapt institutional practices.

Limited resources

A third evaluative criterion is limitations of health care resources. Health care providers and administrators have a responsibility to manage limited health resources fairly. They are accountable for how they apportion resources and need to do so in a just and equitable fashion. Adapting institutional norms will sometimes place burdens on limited resources. Administrators and managers must decide if such adaptations can be

justified. While seeking to respect individual autonomy, they must also balance considerations of equity and fairness in the distribution of limited health care resources. Gorlin, Strain and Rhodes observe: "in order to proximate a just distribution of health care we may have to sacrifice some of our accommodations to minority perspectives" (2001, p. 15). For example, a request for a private room to allow for the performance of cultural practices may not be justifiable when this would limit access to a bed for another patient. In other circumstances, the family of a deceased patient may ask that their family member's body not be moved for an extended period of time. In a setting of bed scarcity this may prevent another patient from accessing this resource. The extent of the resource limitation should be considered in light of the extra burden placed on these resources as a result of adapting institutional practices.

Practices in opposition to medical standard of practice

A fourth category for evaluating requests relates to practices that are in opposition to the medical standard of practice. This category is different from the previous three categories, as the proposed practice may not infringe upon the rights of other patients or visitors to the hospital. Such practices do not increase risks for other actual or potential patients. It is useful to recall that in hospital settings patients make decisions that are associated with important risk and uncertainty. Patients may refuse potentially beneficial interventions or opt for an apparently less effective intervention. Thus, patients routinely make decisions that entail risks that health care providers believe to be unwise or ill advised. Some cultural practices that patients wish to perform while hospitalized may also place them at risk. In such situations, open communication is essential to allow opportunity for health care providers to discuss risks and alternatives relating to a particular practice. Adaptations to the care plan to decrease the potential for harm can also be considered. There may be challenges to informed consent and achieving shared decision-making if there is uncertainty about the risks associated with particular practices (Sugarman, 2003). Such concerns are elevated when the patient is a child or has limited capacity (Wellis and Sheldon, 2001). There can also be circumstances when the exercise of a cultural practice is viewed as being in opposition to relevant standards of professional practice. Particular cases should be evaluated in light of the circumstances of the case and the harms that might result for the patient, as well as possible consequences for the therapeutic relationship between patient and health care providers.

The following process can be followed in situations where the initial

evaluation by the health care team or hospital management identifies concerns regarding a potential adaptation of institutional and clinical norms based on the preceding criteria. In such cases, those involved in the evaluation should clearly communicate the process that they went through to reach this decision. Specifically, they should explain to the patient and family how the decision was arrived at and the rationale upon which the decision was based. If hospital administrators or the treatment team judge that a specific adaptation should not be made due to conflicts with other duties and obligations, the persons involved should work with patients and families to identify alternatives. Seeking alternative arrangements is a key step in the process. In many circumstances, there will be compromises that can be identified and that are acceptable to the patient and family, as well as clinicians and administrators. Depending on the particular issues under consideration, and if acceptable to the patient, input from a chaplain, community representative or culture-broker might provide valuable insight. It is worth noting that in the case involving the sweet grass ceremony discussed earlier, the patient's family agreed to have the ceremony moved to another location where there would not be the safety concern for other patients, visitors and hospital staff.

If a negotiated alternative cannot be identified it is relevant that there is a means by which patients can challenge a decision to not adapt clinical or institutional norms. This possibility should be explained to patients and families by the treatment team or administrators. Consultation with the Clinical Ethics Committee may be an appropriate mechanism to provide further review of such cases.

If institutional or clinical norms are adapted so that a patient or family can enact a particular cultural practice, health care providers and administrators should consider whether there is a need to review the existing policy or standard. Adaptations should prompt reflection and discussion. For instance, if the number of visitors allowed in a patient's room is expanded for a particular patient this might stimulate discussion of whether the unit's visiting policy should be reconsidered. As a matter of justice for all patients, it is important to consider whether the policy is overly restrictive or limiting. In some circumstances this review may lead to changes of policy.

Conclusion

Health care organizations provide services for diverse patient populations. The resulting plurality of values and perspectives may challenge health care providers and health organizations as they seek to provide effective, respectful and compassionate care to their patients. In some circumstances

patients may wish to perform cultural practices that require adaptation of existing policies and norms in a particular clinical setting. Health care providers and administrators are often receptive to making such adaptations. However, in other situations health care providers and administrators may feel conflicted as to the appropriateness of a particular adaptation. This conflict will be most acute when competing obligations and rights are identified. In this paper, I propose a process and four evaluative criteria for assessing such situations. In developing this analysis, I emphasize the importance of seeking negotiated and mutually acceptable solutions, and for carefully examining the particular contextual features of each case. Decisions should be based on a rationale relevant to the duties and obligations of the institution and health care providers. Criteria that can be used to evaluate particular cases are safety of other patients or staff, the significant disruption of other patients, fair distribution of limited resources, and practices in opposition to accepted standards of medical practice. When a particular adaptation is not made, the treatment team and administrators should work with the patient and family to seek to identify an alternate arrangement that is acceptable to all.

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NOTES

[1] Many institutions also develop policies that respond to the cultural or religious frameworks of particular communities. Perhaps the most obvious examples of this are guidelines that relate to the use of blood products for patients who are Jehovah's Witnesses. Such policies usually describe a process by which the institution will respond when the patient requires blood transfusion, blood products or surgery.

[2] It should be noted that administrators and health care providers have different sets of duties and will evaluate individual cases in the light of these obligations and preoccupations. In particular, health care providers have fiduciary duties towards patients in their care. Administrators have

primary duties towards ensuring that the institution runs well and that resources are managed efficiently and used effectively. These differences will influence how particular cases are viewed and may sometimes lead to divergent opinions between health care providers and administrators.

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