
Assessing the ethical weight of cultural, religious and spiritual claims in the clinical context

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Abstract

The aim of this paper is to expand upon the conclusions reached by Orr and Genesen in their 1997 article (published in this journal), Requests for 'inappropriate' treatment based on religious beliefs.¹ Assuming, with Orr and Genesen, that claims made in the name of religion are not absolute, I will propose some principles for determining when claims based on religious beliefs or cultural sensibilities "trump" other considerations and when they do not.

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A case

Mr D W, age 75, is admitted to the hospital following an outpatient appointment where it is learned that he has a large cerebral aneurysm, which is dangerously close to bursting. He is transferred to the hospital by ambulance, and the aneurysm ruptures as he is being brought to the operating room. Surgery is performed immediately, but the patient does not recover consciousness.

The patient has a wife and two sons. One son is unmarried and works as a laboratory technician in a nearby hospital; the other is an evangelist with a local Pentecostal church, is married and has four young children. Upon the patient's admission to the hospital the patient's wife and married son, along with the son's family, remain constantly in the family room: sleeping, snacking, playing the guitar and singing around the clock. This is reported to the nurse manager, as their activities in the family room are sufficiently disruptive to make the room unavailable to the family members of other patients. Hospital administration is called, and when attempts are made to discuss the matter, the son states their religious freedom is not being respected, and threatens legal action.

From the beginning the minister son, along with the patient's wife, state they are expecting a miracle for the patient. At the same time they are demanding every possible medical treatment for him. The patient's wife takes the stance that her son is in charge, and often he is the one who communicates with the physicians.

After three weeks the medical team discusses with the patient's wife the possibility of removing

life-support systems, as the patient remains unconscious and is not recovering from his surgery. His kidneys and liver are failing; in fact his entire body is deteriorating.

However, at the insistence of the wife and one son, he remains at full code status. The doctors believe the current level of treatment is futile, and the patient will not recover. The wife and son refuse to permit withdrawal of any medical treatment. The staff is concerned about not allowing the patient to die with some sense of peace, dignity and serenity; they foresee the possibility of having to make all efforts to resuscitate the patient as he dies.

The wife's pastor has spoken to her and to her son about removing life-support systems. They state that there is a time to die, but still expect a miracle. They describe how the doctors have medically mistreated the patient, and talk about possible litigation. The son has received ongoing pastoral visits from the hospital's chaplaincy staff, but remains unwilling to change his position about expecting a miracle, or to consider withdrawal of life support. As the patient's hospital stay approaches sixty days, there is some concern among hospital staff about the limits of Medicare funding, since the family has no insurance or other financial resources.

After nearly seven weeks in the intensive care unit (ICU) the patient dies in the course of a 90-minute full code, which causes much distress to the staff.

Commentary and reflections

It is not uncommon in clinical practice for issues pertaining to spiritual beliefs, religious practices or cultural sensibilities of the patient and/or loved ones, to arise in ways that require some consideration or action on the part of health care providers.

In most cases this presents no problem. However, the aim of this essay is to consider instances like the above case, in which what the patient wants (or does not want) under the rubric of belief, culture or religion, causes conflict for those providing care, or for the health care system in general. Addressing this topic in a 1997 journal article, Orr and Genesen conclude in part:

"We . . . believe that persistent requests based on deeply held religious beliefs should most often be honoured. However, we do not believe that such claims are absolute. We agree with others that

professional integrity requires physicians occasionally to refuse to provide an intervention based on professional conscience or medical standards. We are unable to give clear guidance on when such a stance is professionally or theologically justifiable.”²

The intention of this essay is to expand on Orr and Genesen’s conclusions, and to offer some suggestions for determining “when such a stance is professionally or theologically justifiable”.

Throughout this paper “the patient” will be used to designate not only the identified patient, but also family members, loved ones and others who speak on the patient’s behalf and often in the patient’s stead. Health care providers who are usually, but not exclusively, doctors will be broadly referred to as “the physician”. Patient requests based on cultural, spiritual or religious considerations will be called “the claim”. Finally, the terms “spirituality”, “culture” and “religion” are often used together in this paper. This is not because they should be considered interchangeable, but because they share an important characteristic: their intangible dimensions often make them difficult to assess in the same breath with other realities more clearly rooted in the empirical sciences, which currently dominate the practice of medicine.

Common humanity

In fact there are many who hold that spiritual beliefs, religious practices and cultural values are by definition so subjective, unique and “irrational” that it is pointless to make any attempt at orderly scrutiny and reasoned dialogue. From this belief it follows that all claims made in the name of culture, religion or spirituality are regarded as equally incredible³ or equally credible, depending upon the observer’s sympathies in that regard. In the clinical context, this results in any personally held conviction of value or faith being considered either unsalvageable or irrelevant. Even in those instances when our common humanity and good sense tell us this is not true, we have few tools to address issues or resolve conflicts.

The position taken in this essay is that these issues **are** grist for reasonable dialogue. Further, our propensity for relegating beliefs and values based on life realities such as culture and religion to the realm of the individual and subjective, itself constitutes a significant cultural bias—one that follows from three widely held assumptions:

- the near-absolute value we place on individual identity and personal autonomy;
- the extent to which empirical methodology dictates that only that which can be measured is clinically meaningful, and
- the tendency to privatise (and thus banish from the public dialogue) any convictions claiming a foundation in faith or religion.⁴

This essay proceeds on the following assumptions:

intangible realities such as “culture,” “spirituality” and “religion” do not reside exclusively in the domain of the individual and subjective; convictions, decisions and actions that purport to be based upon these realities are subject to reasonable examination, dialogue and evaluation, just as are other convictions, decisions and actions, and in such examination some outcomes will be found to be more defensible than others.

The word “defensible” is used advisedly; for what we are considering is not the sincerity or vehemence with which a belief is held, nor the authority or influence of the person holding it, nor even its internal coherence (though these may, and often do, affect our efforts at dialogue). We are examining the **relative weight** that claims made in the name of cultural, spiritual or religious convictions may have when they conflict with other claims that also have their proper ethical weight: claims based on the skill, authority and judgment of the physician; on the rights or sensibilities of others; on legal considerations; on economic realities, and on issues of distributive justice.

An error to which we are societally inclined is to identify the value of personally held convictions with the value of the personal self; we believe that to challenge one is to challenge the other. This is an error in logic, the converse of the *ad hominem* argument. Let us be clear in distinguishing critique of a claim based upon personal conviction, from criticism of a person. For our purposes the rule is: **respect the person; critique the claim**. All the more reason why respectful dialogue is vital to resolving these issues. What follows is a series of questions intended to stimulate reflection in preparation for that dialogue.

1. Does the claim conflict with clinical, legal or other indications? That is, does the patient want something that is illegal, clinically harmful or otherwise contraindicated in the judgment of those providing care? The principles that are in conflict here are straightforward: the patient’s autonomous wishes are set against the caregivers’ view of what is in the patient’s best interest: beneficence or non-maleficence. In the case of legality, we can further say that the law purports to articulate the societal consensus of what is best for the patient within the broader context of the society, ie, protecting the rights of both the individual and others. In our cultural milieu where personal freedom is prized as it is, considerations of patient autonomy usually override those of physician beneficence except when the law clearly dictates otherwise. This is generally true with one important exception, which leads to the next question.

2. Does the claim pose a conflict of conscience for those providing care? That is, does the patient want the caregiver to do or omit to do something to which the caregiver is opposed **in conscience**? Abortion and physician-assisted suicide present prototypical cases. We might describe this as an instance of competing autonomies; and

professional ethics and law both make provisions for the caregiver who is conscientiously opposed to participating or cooperating in specific actions.

3. Is it a positive or a negative right that is being claimed? This is not so much a discrete question as it is an overlay to other questions, but it may help clarify why some situations seem more urgently problematic than others. Generally a patient's declining a particular treatment (even though the physician disagrees) is perceived as a less thorny issue than the patient's demanding a kind or degree of treatment that is inappropriate or futile in the judgment of the physician. In fact, the patient's exercise of the (negative) right to decline treatment that s/he considers excessively burdensome has, in the United States, been legally established in the Patient Self-determination Act of 1990,⁵ and has become an accustomed part of the clinical scene. The ethical principles that must be balanced are respect for autonomy (the wishes of the patient) and beneficence (the physician's judgment of what is best for the patient); and in our prevailing Western culture respect for autonomy tends to be the weightier consideration—particularly when the patient is asking **not** to be treated.

On the other hand (as the case cited at the beginning illustrates) the patient's demanding the positive right to an action or treatment considered by the clinician to be futile or inappropriate, presents a somewhat different set of conflicts. The patient's autonomous wishes stand in opposition to the judgment and professional integrity (autonomy) of the physician; and when the demand involves the use of costly resources, as it often does, it likewise stands in opposition to the principle of justice, since no society can sustain every individual's (theoretically) unlimited demands upon its resources. It is this that has fuelled in recent years the debate about "medical futility", unresolved at the time of writing.

The above questions are applicable to cases generally. Those that follow apply more clearly in cases where patient preferences based specifically on cultural values or religious beliefs are central.

4. Is the culture or religiosity that supports the claim rooted in a community? Or is it idiosyncratic? Many believe any individual appropriation of culture or spirituality is by definition idiosyncratic; as the reader will have guessed by now, I do not hold this view. Even in these eclectic times, ("eclectic," a patient I was visiting said once—wonderful malapropism!) there remain identifiable constructs of religion and culture which present concepts, names and communities we can recognise and distinguish. For example, "Muslim" is different from "Hindu"; "Lakotah" is distinct from "Serbian"; "Catholic" is clearly not "Baptist," even though both are "Christian". Since these conceptual packages and the cultural or religious communities that stand behind them are often invoked as the basis for claims (for example, "As an observant Jew, I must keep *kashrut*," or "The way we Westerners expect people to make decisions is not

meaningful in a tribal culture such as that of the Hmong," or "As a Jehovah's Witness I cannot accept blood transfusion,") it seems reasonable to ask if the beliefs and values purported to justify the claim are in fact those of the religious or cultural community with which the patient is identifying. Predictably, some values and beliefs will be found to be firmly congruent with such a community and others will be found to be partly or entirely the construction of the person who holds them: idiosyncratic, as has been said.

It might be protested that any attempt to make such a determination is an intrusion into the chambers of personal faith and insight. My response is that each is free to believe and practise as s/he sees fit, irrespective of fitting into the orthodoxy of a particular community. However, if one makes a claim that purports to be grounded in the sensibilities, values or teachings of a given community, the question of whether it is in fact so grounded is not simply a matter of the claimant's assertion. It should be capable of rational examination. To propose an extreme example: if I as a Roman Catholic were to claim my church's teachings about compassion as warrant for demanding that my physician assist me in ending my life, anyone remotely familiar with the teachings of Roman Catholicism might understandably find such a claim lacking in integrity precisely because it is not congruent with Catholic teaching about physician-assisted suicide, but rather the opposite.

A more subtle (and more frequently encountered) application of the same principle occurs when a patient asserts that her or his religious or cultural community mandates or forbids a particular course of action, and it is discovered upon examination that the identified cultural or religious group neither forbids nor demands, but benignly allows or gently discourages, the action in question. Here the discrepancy between claim and fact is one of degree rather than kind; but discrepancy it is.

Granted, others will say: so what? Why is a connection between claim and community important, or even relevant? It is relevant for two reasons:

- a community provides a supportive structure of psychic and physical resources that makes realistically possible the implementation of a difficult decision or action which might otherwise be beyond the capacities of the lone individual or nuclear family; issues of distributive justice may thus be dealt with in a modest and elegant way, placing fewer demands upon the resources of the broader society;
- a community likewise provides a consensus environment within which the validity of individual insight and personal conviction is tested by time and challenge.

Of all people, physicians and scientific researchers should be in a position to appreciate both these dimensions of community: the collective efforts of many contributors over time make possible achievements beyond the reach of any single

individual; and the ordinary scientific process whereby ideas are challenged and hypotheses tested, provides a solid intellectual and empirical foundation for the progress of medicine and other orderly endeavours.

This is not to minimise the importance of individual insight (Archimedes' "Eureka!" and Galileo's "Eppur, si muove!" come to mind), nor to assert that the community is always right, particularly in the short run: Galileo once again serves as an example; and Alfred Wegener's theory of plate tectonics was derided in his lifetime as being "quantitatively insufficient and qualitatively inapplicable".⁶ Only after his death was the validity of Wegener's theory recognised by the same scientific community that had rejected it earlier. On the whole, however, it is accurate to say that both scientific and other sorts of communities have established and orderly processes whereby ideas are tested and validated by experiment and experience. This feature of community is generally a strength rather than a weakness, for ideas and values that have been so tested and validated—even though they may not be universally held—usually constitute a stronger foundation for progress than those found to be novel or idiosyncratic. Without such a foundation in community there is nothing to distinguish a claim motivated by cultural values or religious beliefs from one based on unilateral imposition of the individual's will upon others. This is heteronomy, not autonomy.

5. Is the person making the claim willing to suffer for it? Or expecting that others suffer for it? The use of "suffer" may be problematic as it takes us into metaphorical language. Certainly "pay" is more helpful in conveying the reality that we are often dealing with issues of distributive justice and use of communal resources. Nevertheless I deliberately use "suffer" to embrace not only instances involving the just use of resources—an urgent and familiar concern—but also those situations whose currency is not limited to money or its surrogates.

Granting this is a difficult idea, let us nevertheless observe that we do tend to regard differently a person who makes a decision and accepts its consequences, than we do someone who makes the same decision and demands that others pay for the consequences. Generally speaking, we are inclined to respect those who accept the consequences of their own decisions and actions, even when we disagree with them; the same respect is not accorded those who would require others to shoulder the consequences of what they decide or do. Social mores and legal manoeuvres to the contrary notwithstanding, our sense of justice is offended by those who would, without permission or consultation, shift to others the burden of paying for their preferences.

I suggest that this intuitive distinction is not irrelevant to the task of assessing the defensibility of a claim. Nor is it without precedent. Gandhi, for instance, made it a clear principle that those practising civil disobedience—breaking the law for

the sake of a higher law—must be willing to suffer the consequences of breaking the very law whose validity they are challenging, thus giving witness to the integrity of their beliefs by their personal willingness to lay their lives on the line. And history has acknowledged the moral resonance of that principle by the respect we show to those who have practised it. Likewise our courts have upheld the right of competent Jehovah's Witness patients to place their lives at risk by refusing blood products; the same courts have denied Jehovah's Witness parents the right to refuse blood on behalf of their minor children.⁷

It may appear that applying this question becomes a judgment upon the integrity or sincerity of individuals who make a claim that shows their values, standards or actions to be different from those of the broader community. Not so. What is being assessed here is neither sincerity nor integrity, but the claimant's recognition of a basic existential reality: that none of us can please others all the time; that there is often a price to be paid for being visibly different, for "going one's own way," for—in current ethics language—behaving autonomously. Sometimes that price is the good opinion and support of at least part of one's communities. I suggest that recognising that reality and coming to terms with it is reasonable, mentally healthy, and a basis for ethically sound decisions.⁸

However we may frame the issue in ethical terms, it does appear in the end to be a matter of justice and accountability, and it plays out in different ways: use of resources ("What does it cost and who's paying for it?"); long term consequences ("What are the likely outcomes, and who will be affected by them?" "Is this course of action sustainable?"); decision making ("Are those most affected by this decision involved in making it, to the extent that that is possible?"). When there is a congruence of accountability our sense of justice is satisfied, and when such congruence is absent we are troubled and sometimes outraged.

Conclusion

In summary the following general principles are suggested for assessing the ethical defensibility of a claim made in the name of cultural, spiritual or religious considerations:

- A claim made on the basis of these considerations is prima facie worthy of, and subject to, public, reasoned and respectful discourse. It does not follow that such a claim is absolute.
- A claim is defensible when it balances patient autonomy against physician beneficence; less so when the physician's conscience (autonomy) is involved, or when societal beneficence in the form of law dictates otherwise.
- A claim based on exercise of negative rights only, is easier to defend than one in which positive rights are invoked, since exercise of positive rights often is found in conflict either with a reciprocal autonomy (cooperation in a decision or action) or with principles of justice.

A spiritual or cultural claim is generally more defensible when the teachings or values that motivate it are grounded in an identifiable and established community, than when they are peculiar to the one who holds them. This places upon all those participating in such discernment the obligation to be accurately informed concerning the teachings, values and practices of the relevant communities.

A claim is more defensible when the one making the decision is willing to be responsible ("pay") for the consequences; less so when it is proposed that others bear the burden of responsibility.

As we apply these principles to the above case study, the following observations might be made:

The physicians, staff and hospital administration are ethically obliged to engage the patient's family in respectful, informed and candid dialogue. Avoiding the issue simply because the family is not easy to deal with, constitutes a form of abandonment.

The family members' action in appropriating a waiting room for their own use to the practical exclusion of others, has no ethical basis even though freedom of religious practice is invoked in support of it. It is a violation of the principle of justice, and should be dealt with decisively by the hospital's administration. Some accommodation might be reached by the hospital's providing space for the family's use that does not compromise others' rights.

The family's claim insisting on maximum treatment for the patient lacks ethical strength because it refuses to recognise any limits to the obligations that society has to this patient, particularly in view of his pessimistic clinical prognosis (distributive justice).

The teachings of the family's identified religious community do not require a "belief in miracles" such as the family presents. Pentecostalism accommodates, but does not mandate such beliefs. Religious beliefs peculiar to the family appear to be a weak ethical basis for a claim to unlimited treatment "while waiting for a miracle".

Considering all these factors together, we conclude that the family's demand for maximum treatment for the patient rests on an ethically weak foundation. However, this does not absolve the institution or the caregivers of responsibility for providing support to the family and compassionate care for the patient. As the case demonstrates, this issue is not a matter of absolutes. Nevertheless, the above observations will perhaps contribute to respectful and orderly dialogue in cases that are often perplexing precisely because they involve considerations which, though not easily quantifiable, are among life's most precious realities.

Author's note

The views expressed in the article are those of the author, and do not necessarily reflect the opinions of the Chaplain Services Department or the Mayo Foundation.

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