Special Section:
Difference and the Delivery of Healthcare

Approximation and Negotiation: Clinical Pragmatism and Difference

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Introduction

When addressing cultural and religious differences in the clinical setting we need to be realists. Despite our public homage to pluralism and good intentions, it is just not possible to overcome all the differences that might exist and achieve perfect understanding of others. Try as we may, we will never be able to see perfectly the world through another's eyes. Instead of reaching for such perfection, we should instead reach for an approximation of shared understanding that will promote discourse and civility when peoples of different races, genders, cultures, religions, and sexual preferences interact in the clinic.

As disappointing as it may be, we never really achieve perfect understanding of another's culture or religious beliefs. Even the expatriate who moves into another land and lives there for years remains an outsider curiously peering in. This is even more true in the healthcare setting, when we encounter strangers in an antiseptic environment not of their own choosing.

As a second generation, white, American, physician who has spent the better part of his adult life working in a hospital and living in Manhattan, I cannot truly appreciate how my recently immigrated Dominican, Russian, or Chinese patients perceive me, the hospital where I work, or the city they now call home. The best I can hope to do is to approximate what they know and feel to promote collaboration and minimize hostility or antagonism.

Although my hopes for an approximation may seem modest, the preparation needed for such an encounter is not. Even achieving this minimal level of engagement takes time, strategic planning, and patience. In this paper, I will suggest how this approximation might be achieved in clinical practice by using a method of moral problem solving that we have called clinical pragmatism.[1,2] This approach is one directed to physicians, nurses, and other clinicians to help them address ethical questions in a clinical practice, including—but not limited to—the challenges posed by difference. I will illustrate this method of moral problem solving through two case narratives involving objections to the determination of brain death.

Clinical Pragmatism

Inspired by the work of the American philosopher and pragmatist John Dewey,[3] clinical pragmatism seeks to overcome the divide between ethical theory and medical practice. This method seeks to resolve ethical dilemmas in clinical practice by approaching conflicts systematically and with a special focus on the

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interpersonal dimensions of moral problem solving. Clinical pragmatism combines techniques of clinical and ethical assessment in a way that is congruent with the process of clinical problem solving through its cultivation of details, hypothesis formation, experimental trials, and formulation of plausible but contingent conclusions. Clinical pragmatism uses an inductive method of problem solving that is analogous to differential diagnosis. In the process of differential diagnosis clinicians translate the details of a specific patient's history and physical examination into a range of plausible and generalizable diagnoses that will allow therapeutic interventions. Analogously, clinical pragmatism operates through a shared process of investigation, planning, decisionmaking, and action in which all the stakeholders concerned with the moral problem collaborate to create an ethically appropriate consensus.

Although this method might be critiqued as an attempt to medicalize moral problem solving, this would be a mistake. Our intention, by specifically drawing a parallel to differential diagnosis, is to exploit a powerful analytical tool that physicians already possess and to broaden its application to humanistic dimensions of clinical practice.

The method of clinical pragmatism directs practitioners to engage in moral problem solving according to a series of interconnected steps.[4] Practitioners faced with a case that poses a moral problem first engage in this process when they review the medical facts and clarify the clinical diagnosis. Concurrently, they can assess the patient's medical condition, decisionmaking capacity, beliefs, values, preferences, and needs. Taking a broader view of the patient's situation, clinicians should also consider family dynamics and the impact of care on family members and others intimately concerned with the patient's well-being. Putting the patient's illness into an institutional and societal context also requires an appreciation of institutional structures of care and broader social norms that may influence patient care.

Once this initial data-collecting phase is completed, the clinician can begin to identify the range of moral considerations relevant to the case in a manner analogous to the clinical process of differential diagnosis. Provisional goals of care may emerge from this process and these goals may be suggested to the patient and/or family as a plausible plan of action. An acceptable treatment and care plan can then be negotiated and the agreed-upon plan can be implemented. These interventions can then be evaluated through periodic review by all the stakeholders so that modifications can be made as the case evolves.[5]

In this process of moral problem solving there is a genuine attempt at *individuation*, in which our generalizable knowledge is tested against the particulars of a given patient narrative. Using the experimental method, these generalizations are framed as hypotheses to be assessed in practice against the details of a case. Through an inductive process of reasoning we can either confirm or refute our general knowledge by focusing on the specific narrative details of a given case. Approaching narrative details in this way is analogous to how clinicians reason when they approach physical complaints and symptoms in formulating a diagnosis. If a clinician, for example, is considering a diagnosis of a heart attack, she will draw upon her textbook knowledge of heart disease in order to extract additional clinical details to determine if what she has observed in a particular case approximates what she generally knows about heart disease. In this way a clinician can reach a contingent diagnosis that can point the way to a therapeutic intervention.

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Testing one's general knowledge against the particulars of an individual case is not only crucial for the assessment of physical complaints, it is also crucial for the assessment of ethical dilemmas that arise in clinical practice. This is true for encounters with all patients, but may be especially useful to remember when working with patients and families from diverse religious or cultural traditions. For example, a clinician caring for a patient might have a general sense of how the patient's religious tradition addresses death and dying. The clinician can then use this knowledge as a starting point to explore further the patient's beliefs and to confirm whether what he generally knows about the patient's religion applies in a particular case. In this way, the clinician avoids trivializing religious or cultural differences, which are important to a patient, by grossly labeling him as a member of a group or practice with which he does not identify. In testing general knowledge of a cultural or religious tradition against the particulars of a case the clinician can avoid such a misattribution and being *indifferent to difference*.[6]

Clinical pragmatism is especially well-suited to dealing with the challenges posed by difference because it treats moral rules and principles not as absolutes that trump decisionmaking but as hypothetical guides that identify a range of reasonable moral choices when patients, families, and clinicians find themselves in morally complex circumstances. This view of principles as hypothetical guides is especially critical when patients of diverse cultural and religious backgrounds bring cultural norms or guiding principles to the clinic that differ from those of the dominant culture.

Viewing these "alien" principles as hypotheticals that require respect is particularly helpful. It avoids the sort of moral absolutism that could undermine dialogue at precisely the moment it is needed most: the beginning of a brewing conflict. Although we might eventually come to reject the principles embraced by others, there is something therapeutic, and indeed diplomatic, in listening and considering them without rigid preconceptions about their moral standing.

Using this approach and suspending our own moral certitude, we might even surprise ourselves and learn something that we had not known. This might allow us to integrate some aspects of a cultural belief system while rejecting other elements. Perhaps most critically, this consideration illustrates to those with whom we are engaged that we are open to discourse, and that their deeply held beliefs—which are important to them—are also taken seriously by us. This is the first step toward approximation, compromise, and conflict resolution.

First Case Presentation

To illustrate clinical pragmatism as a method of moral problem solving, I present a case involving a religious objection to brain death. I begin by reviewing the prevailing social and legal context which sets the stage for this case.

I work in a state that has acknowledged the importance of difference when it comes to brain death. Because of the religious diversity of our population, most notably, the presence of Orthodox Jews and some fundamentalist Christians, who vote with great discipline as a bloc, the New York State Department of Health developed a compromise policy on brain death determinations. It requires that hospitals establish "a procedure for the reasonable accommodation of the

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individual's religious or moral objection to the determination as expressed by the individual, or by the next of kin or other person closest to the individual."[7]

Although New York law deviates from the Uniform Determination of Death Act accepted in 48 states,[8] the law in New Jersey is even more expansive with respect to the accommodation of religious objections to brain death determinations. New Jersey law states that:

> The death of an individual shall not be declared upon the basis of neurological criteria . . . when the licensed physician authorized to declare death, has reason to believe . . . that such a declaration would violate the personal religious beliefs of the individual. In these cases, death shall be declared, and the time of death fixed, solely upon the basis of cardio-pulmonary criteria . . .[9]

This accommodation of religious beliefs, in our region, provides the backdrop for the case of Jacob,[10] a 2-year-old child with a glioblastoma multiforme brain tumor. He was transferred to the pediatric intensive care unit from a neighboring institution after he developed herniation after one of multiple courses of chemotherapy for his brain tumor.

The child was the son of Hassidic Jews whose first language was Yiddish. He was one of several children. At least half of his short life has been spent in and out of a number of different hospitals. Most recently he had been admitted elsewhere for an experimental chemotherapy protocol after more conventional therapy did not elicit a response. After a brief stay at that institution, he developed incipient herniation and was transferred on an emergency basis to our pediatric ICU. Upon admission, Jacob was described as having "failed" chemotherapy, even though a more accurate description might have been that the medication had failed him.

I first heard about the case when an ethics consult was requested. The herniation had progressed and there was a suspicion that the child had become brain dead. A first apnea test was performed and the patient did not breathe spontaneously. This suggested that the child was brain dead but did not confirm the diagnosis because New York State law mandates a second apnea test before a declaration of brain death is allowed. The second apnea test was scheduled for 12 hours later. We were called because the mother, after learning of the first apnea test, refused a second study and refused to leave the child's bedside. Interposing herself between the doctors and the child, she would have had to have been physically removed in order to perform the "confirmatory" study. On the eve of the Jewish High Holidays, we were asked what should be done.

Removed from the tension of that moment and the difficulties I anticipated, I can now look at this dilemma and abstractly contemplate difference in all its scholarly nuances and richness. But back then, I must confess, I initially became angry. Anger, which so often accompanies cases involving difference, is often unexplored to the detriment of all parties concerned. Too frequently, emotions take hold and prevent constructive dialogue and negotiation.

A first step, then, in addressing this dilemma was to recognize that my initial response betrayed unarticulated assumptions that needed further exploration. Why did I become angry? What did my response imply about my views of life and death and my goals of care for this patient?

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It is hard to know in retrospect what exactly led me to engage in this analysis, but fortunately I was able to appreciate that a moral problem lay buried beneath my initial anger. My feelings signaled a moral stance that needed further cultivation and alerted me to what John Dewey called the "problematic situation"—the perception or anticipation of a moral dilemma.

I recognized that my response was in fact a reflection of my own countertransference and as such a diagnostic clue.[11] Difference was challenging my expertise in clinical ethics, my scientific world view internalized as an acceptance of the brain death definition, and my identification as a secularist. Incompatible world views were being brought together by tragic circumstances and conflict seemed inevitable.

It could have stopped here and we could have had a confrontation. I have seen it happen since. It is not a pretty sight. The neurologist in white. The Hassid in black. Both in different worlds, one secular, the other theocentric, disagreeing on the definition of *life* itself. The careful reader will observe that I did not say death itself, because to the Orthodox Jew, the patient whom the scientist describes as dead is still very much alive. This is an important distinction because differences are defined in two directions: in this case how the parents defined themselves and how the clinicians viewed *them*. "We" could see their views as deviant. "They" saw them as expressive of a long and rich religious tradition. We could see them as choosing to be different. They see their practices as quite the same as they have been for millennia.

Appreciating the competition between these two world views, I recognized that I needed time to build trust and engage in a negotiation. To do this, I took refuge in the ambiguity of the medical facts—which is the first thing we need to consider when addressing an ethical dilemma in clinical practice. Although there was a strong suspicion the patient was brain dead, the lack of a second apnea test did not make Jacob *legally* brain dead. This provided us some time to gather more facts and begin the narrative journey that often can turn apparently principled differences into resolvable disputes.

The ambiguity of the diagnosis allowed me to consider the ambiguity of the classification of brain death itself. Like all human constructs, this definition is contingent. Acknowledging this contingency—which incidentally has become more apparent with the emerging debate over brain death[12,13] since it was introduced in the Harvard criteria in 1968[14]—allowed us to appreciate that there is often a range of reasonable moral choices and that none of us has moral or scientific certitude. One might ultimately continue to equate brain death with the cessation of cardiopulmonary function. But when prompted by a dispute such as this, the clinician should at least entertain the perspective of the other in a serious manner.

Part of that task is to explore that patient's cultural or religious tradition, to familiarize oneself with the general norms that might be relevant to the particulars of a case. This can be done in two complementary ways. The first is by self-study. The second is by expanding the dyad and bringing in cultural intermediaries from the same group or tradition who can assist in guiding the deliberations and in the negotiation process. These individuals might be coreligionists or members of the same ethnic group who work in the healthcare setting and have a foot in both worlds. They can help translate the views of those involved in a dispute either literally or figuratively and provide the trust needed for the discussion of delicate issues.

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In this case, self-study was critical because it might have prevented an error that we characterized earlier as an indifference to difference. As this case began, we assumed that the family's objection to brain death was religiously motivated because we believed that Orthodox Judaism rejects brain death. Study, however, proved this to be incorrect. Some Orthodox Jews accept brain death as if it were a physiologic decapitation[15] akin to a story in Talmud when an individual was decapitated by a tree. Although his heart was still beating, he was considered dead because the heart and the body could not be sustained without the head.

Although the parents of the child in this case were not of the sect that accepted brain death, it would have been grossly inattentive to neglect this possibility. Again, it is critical to stress that when encountering difference it is important to recognize that traditions are not monolithic but may encompass a diversity of interpretations and views. Here it was not enough to assume that there was a difference because the patient and family were Orthodox Jews. It was necessary to know about differences within their community. If we had stereotyped their beliefs, we would have done them a disservice and constructed a difference that might not have existed.

Furthermore, it was possible that the invocation of a specific religious difference cloaked a more universal phenomenon, that of parents grieving for a lost child and not wanting to let go. If we knew more of the religious beliefs—and referred the family to religious sources who could help them recognize the parts of their own tradition that consider brain death to be death—then we could help them legitimately begin the grieving process.

On the other hand, if we learned that the family did not accept brain death, then we could respectfully continue the discussion with their knowing that we had sought to study their texts and respect their tradition. As it turned out, their sect did not accept brain death. But in the process of learning of this, we had begun to build a relationship of trust that allowed us better to approximate their views and beliefs.

With the stage set in this way, we had a number of fruitful meetings with rabbinic representatives of the family. In those meetings we sought to identify the range of moral considerations that might be common to our secular approach and their religiously informed view of the child's situation. Assisted by cultural intermediaries we mutually agreed to abandon the divisive question of whether the child was dead. This was not a resolvable question. Though it started as the most important of considerations, it had in fact become a distraction. Instead we sought to reframe the problem pragmatically, drawing upon Jewish sources.

In this approach, we sought to move beyond a dispute over the moral meaning of brain death. We asked how Jewish law would interpret the conflicting mandates to preserve life and not prolong the dying process. Instead of struggling over a definition of brain death, we engaged the observant family, on their own terms, in the moral dilemma posed by a patient's illness.[16]

Our interventions helped to de-escalate a potentially volatile situation and fostered a dialogue across a religious and cultural divide. We negotiated a plan acceptable to both caregivers and the family and withdrew some elements of ICU care. The child ultimately suffered a cardiopulmonary arrest and succumbed.

I noted previously the importance of the cultivation of the narrative, contingency, and periodic review in describing the method of clinical pragmatism. We engaged in a self-critique of this case. Although we did better than we might

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otherwise have in approximation and negotiation, we were not entirely successful. Our efforts to reach consensus prolonged the process and took a toll on the staff, many of whom felt they were obliged to provide medical care to a corpse. Nearly three years after this case occurred I am still asked by staff about what happened during that High Holiday season. Nonetheless, I remain a realist. I think we did the best we could under difficult circumstances to achieve a tenable, if not perfect, consensus. In retrospect, although I still reflect on the decisions that were made, I am consoled by the comprehensiveness and democratic nature of our process of moral reasoning as we tried better to understand and accommodate difference.

Second Case Presentation

In addressing ethical conflicts in clinical practice that have their roots in a question of difference, it is important to consider what counts as an adequate resolution and whether 'agreement' among the parties is the ideal that always should be sought. To illustrate what might be termed an 'agreement' that may have accentuated rather than attenuated difference, I would like to introduce briefly another case involving an objection to a brain death determination.

This case also involved a child. The patient was an 11-year-old African-American girl of Caribbean descent. Keisha had a medulloblastoma. She too had spent half of her life in treatment. But unlike Jacob, she had enjoyed a brief respite several years earlier when she had been able to go to school.

Like our first case, she was transferred from a neighboring institution when complications set in from chemotherapy. She had a long hospital course in the ICU, during which time the goal had become to take the patient home so she could die there in familiar surroundings with her family. After extraordinary efforts to make this modest goal become a reality, the patient was taken home by her parents. She was home for less than a week when she herniated and was brought back to the hospital. That was when we became involved.

This was an especially difficult circumstance. When first confronted by the staff about the possibility that the child was brain dead her father became agitated and violent, even saying that if the child, "went home in a body bag, someone else would too." Both the father and mother were under enormous stress. The staff complained that this family's playing of loud reggae music disturbed other families and that the child's parents were often insulting.

The situation required a cooling off period, which was again provided by the creative and appropriate use of some medical facts. In this case the antiseizure drug levels were marginally too high to do the apnea testing. This reprise allowed everyone to cool off and the father did eventually agree to the brain death testing. By explaining that we were not forcing the testing upon them—but "playing by the rules" and testing according to protocol—the staff gained a modicum of trust that allowed for the determination. The child was found to be brain dead.

Although this might be viewed as a successful outcome, in contrast to the first case when the determination was not done, the second case was far more disappointing. Unlike the first, where relationships had been built and some healing and closure was possible, nothing of the sort occurred in this case. Despite the family's agreement to the brain death determination, overt tension and hostility persisted to the end and cast a cloud over the task of bereavement.

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What is unfortunate about this case is that this family might have been helped to deal with their loss if we had been better able to overcome cultural differences and if there had been more of an opportunity for dialogue and approximation. Unfortunately, several factors in this case precluded a more fruitful intervention at the late stage when we were consulted. Echoing what Annette Dula has noted about perceptions about race and racism,[17] a hermeneutic of suspicion in this case made it very difficult for this family to trust their doctors or the hospitals they were in. Although clinicians or bioethicists might "objectively" see the lack of continuity of care from one hospital and team of doctors to another as the tragic consequence of a futile attempt to seek an elusive cancer cure, this family might have interpreted the same facts to be a symptom of racism.

Indeed, for this family, trust was a problem from the beginning. At the outset they had delayed seeking treatment because of their suspicions about the therapeutic options they had already received. To speculate for a moment, the bad news doctors shared with them may have been emotionally easier to interpret as a racist gesture by a society "which gave up on black folks" than as a frank appraisal about their own daughter's chance for survival. Here the issue of race, justified or not, might have been nothing more than a cover for sadness. This concern about racism led to a delay in treatment, which may have led the parents to question whether their initial caution had ultimately undermined their child's care.

What saddens me about this case is that if clinical staff had appreciated this initial problem of trust, care might have been more timely and the outcome different. At worst, Keisha's death might have been more peaceful and her care more prudential and palliative when cure was no longer possible.

All of this could have been prevented by a physician—any physician—who recognized the power of difference to affect perceptions about care and who sought to overcome the suspicions of the family by demonstrating competence, regard, and fidelity. That would have been essential at the outset. At the end of this child's tragic course, negotiation and approximation would have been more difficult. It would have been remedial and not preventative.

A first step might have been to recognize that the reggae music, which was perceived as annoying and intrusive by staff, was actually an expression of a shared cultural identity that the family wanted to declare and have acknowledged. This family needed attention and regard. One could assert that the music, played loudly, defiantly, and proudly was a call for help and healing. Yet, in this context, it was perceived more as a threat than as an entreaty to help grieving parents untangle suspicions that had malignantly allied themselves with denial.

Conclusion

Because discussions of difference often begin and end with a chorus of despair and the challenges that confront us, I would like to end with an optimistic note. Although difference can present formidable challenges in the clinic, we should not forget that there is something to be said for fully engaging the mystery and challenge that attends new encounters with peoples and cultures different from one's own. Hard-won knowledge and understanding can be especially rewarding. Anthropologists know well the challenge and rewards of such understanding.

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Physicians too can begin to attend to difference by paying closer attention to the particularities of the very different lives of their patients.

Notes

1. Fins JJ, Bacchetta MD. Framing the physician-assisted suicide and voluntary active euthanasia debate: the role of deontology, consequentialism, and clinical pragmatism. *Journal of the American Geriatrics Society* 1995;43:563–8.
2. Fins JJ. From indifference to goodness. *Journal of Religion and Health* 1996;35(3):245–54.
3. Miller FG, Fins JJ, Bacchetta MD. Clinical pragmatism: John Dewey and clinical ethics. *Journal of Contemporary Health Law*. In press 1997.
4. Although this methodology is presented as a linear sequence, this presentation is a schematic illustration of a process in which many of the steps occur simultaneously.
5. For a more detailed account of this methodology see: Fins JJ, Bacchetta MD, Miller FG. Clinical pragmatism: A method of moral problem solving. *Kennedy Institute of Ethics Journal* 1997:7(2):129–45.
6. I am grateful to Erika Blacksher for this phrase.
7. Adopted Regulation 10 N.Y.C.R.R. 400.16. Determination of Death.
8. 12 Uniform Laws Annotated 320 (1990 Supp.). Uniform Determination of Death Act.
9. The New Jersey Declaration of Death Act. P.L. 1991, Chapter 90 (To be codified as Chapter 6A of Title 26 of the Revised Statutes). Section 5: Exemption to Accommodate Personal Religious Beliefs. *Kennedy Institute of Ethics Journal* 1991;1(4):289–92.
10. Aspects of these cases have been changed, although key narrative elements remain.
11. Fins JJ. *Breaking the silence: futility, fear and anger.* In: Solomon ME, ed. *Decisions Near the End of Life*, vol. 7: *Futility*. Newton MA: Education Development Center, Inc., 1997:26–7.
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14. Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death. A definition of irreversible coma. *JAMA* 1968;205:337–40.
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