

# Difficult Conversations in Health Care: Cultivating Relational Learning to Address the Hidden Curriculum

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## Abstract

The authors describe the philosophy and pedagogical approach of an innovative educational program, grounded in principles of relational learning and designed to improve the preparedness of health care professionals for engaging in challenging conversations with patients and families. The Program to Enhance Relational and Communication Skills (PERCS) is a project of The Institute for Professionalism and Ethical Practice at Children's Hospital Boston, developed in collaboration with Education Development Center, Inc. The one-day workshop is interdisciplinary in its

structure, includes practitioners with varying levels of professional experience, uses trained actors to portray patients and family members, and involves learners in improvised case scenarios. The program responds to several developments in contemporary health care: medical education reform, changing definitions of professional competence, and calls for greater attention to qualities of compassion, trust, and respect in practitioners' relationships with patients and families. The program's pedagogy responds to these developments by creating a safe

climate for relational learning, by enacting emotionally challenging and ethically salient case scenarios, and by integrating patient and family perspectives in novel and substantive ways. By creating a curriculum and learning environment that explicitly embraces the moral experience of learners, the program's developers aim to exert a countercultural influence on the dehumanizing effects of the hidden curriculum.

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—In this sometimes hierarchical environment, it was a pleasure to leave one's badge at the door and allow ourselves to brainstorm and break down barriers with colleagues across departments and disciplines.

—What I learned is that one doesn't have to be perfect or have all the answers—one has to be genuine and real.

—I have learned that working together as a team means more than just inviting the nurse or social worker into the room, but also inviting them into the conversation. This insight has permanently changed the way I interact with families in the ICU.

—In an environment that places an enormously high premium on advancing surgical and technical standards, it was refreshing to devote collective intellectual energy to cultivating the other half of the medical equation—the emotional standard of care.

**T**hese comments were offered by an interdisciplinary group of health care professionals after their participation in a daylong workshop titled *Difficult Conversations at the End of Life*,

conducted by the Program to Enhance Relational and Communication Skills (PERCS) at The Institute for Professionalism and Ethical Practice, Children's Hospital Boston, developed in collaboration with Education Development Center, Inc. Their remarks are typical of the sentiments of the more than 600 physicians, critical care residents, nurses, social workers, psychologists, and chaplains who have participated in the workshop since its inception in 2002. PERCS is a continuing education effort, organized from the perspective of relational learning.<sup>1</sup> This article aims to unpack these participants' comments, and explore what they reflect about the learning experience that participants describe.

Our reason for launching this educational program was to help practitioners become more competent and prepared to engage in difficult conversations with patients and families. We chose to focus initially on challenging conversations in the pediatric context, such as when clinicians must communicate a very bad prognosis to parents about their child or assist them in making particularly difficult end-of-life decisions. Since the inception of the program, we have adapted and applied

the program's learning principles and pedagogy to other kinds of high-stakes conversations in medicine, such as discussing organ donation, disclosing medical error, and assisting family members during the invasive medical procedures of loved ones. In this article, however, we focus on the method as implemented in the inaugural program, which addresses end-of-life conversations with children and families. We describe the program's rationale, goals, value premises, structure, and format. We then explore *how* the program works, by providing an in-depth account from a typical workshop. We close with our reflections about *why* the program works, by exploring key features of our pedagogical approach.

A separate manuscript provides evaluative data documenting changes in knowledge, attitudes, and skills for program participants. We have completed a pre–post evaluation study including baseline, immediate follow-up, and five-month self-report questionnaires. Participants reported better preparation, improved communication and relational skills, greater confidence, and diminished anxiety when holding difficult conversations with patients and their

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families. Open-ended questions indicated that participants deepened their understanding of patient and family perspectives, learned a range of generalizable communication and relational skills, recognized inherent interpersonal capacities that could be drawn upon, and grew in their understanding of interdisciplinary teamwork (Meyer et al., under review).

## Overview of the Program

### Rationale

Concerned about erosion of altruistic ideals that typically motivate young people to choose health care as a profession, there is a growing chorus of voices expressing alarm about dehumanization and declining professionalism in the U.S. health care system.<sup>2,3</sup> For physicians especially, there is increasing documentation of a wearing away of empathy and other relational capacities that takes place over their years of professional training.<sup>2,4,5</sup> In our experience, this “breeding out” is a problem that is not unique to medical students, but rather one that is shared in large part by all health care professionals during their training and the unfolding of their careers. In response to these worrisome developments, there have been calls for new definitions and standards of professional competence,<sup>6</sup> for reform in the culture of medical education, including new pedagogies that better address the hidden curriculum and moral development of practitioners,<sup>2,7,8</sup> and for increased attention to interdisciplinary collaboration and knowledge sharing in the training of health care professionals.<sup>9</sup>

In an effort to understand this erosion and find workable solutions, many thoughtful commentators have discerned patterns of discrepancy between what is taught in formal educational settings and what is actually learned by practitioners in the informal flow of professional training and everyday practice.<sup>1,8,10,11</sup> This *hidden curriculum* has been defined by one observer as “what we *actually* do in our day-to-day work with patients and one another—not what we say *should* be done when we stand behind podiums in lecture halls.”<sup>2</sup> By creating a curriculum and learning environment that explicitly embraces the moral experience of practitioners as they engage in difficult conversations with colleagues, patients,

and family members, our goal has been to exert a countercultural influence in relation the dehumanizing effects of the hidden curriculum on everyday practice.

### Goals

Our program aims to embody and promote new and expanded definitions of professional competence in the medical world. We concur with Epstein and Hundert’s<sup>6</sup> perspective that competence depends on habits of mind, including attentiveness, critical curiosity, self-awareness, and presence; that it includes the cultivation of emotions, values, and reflection in daily practice; and that it is developmental, impermanent, and context dependent. Working from their premises, we have identified a set of relational capacities and habits of mind (List 1) that, in our view, are tied to becoming competent in these conversations. Accordingly, the pedagogical design of the program is intended to promote the *discovery*, through experiential learning, of these relational capacities and habits of mind.

### Value premises and pedagogical approach

All approaches to professional education are premised on value assumptions about what constitutes learning and how it should occur. Often, educators describe programs and educational approaches without explicitly articulating the underlying values that have informed their pedagogical decisions. Our approach, which we call *relational learning*,<sup>1</sup> is based on the conviction that the learning that matters most in the professional development of health care professionals occurs in the context of relationships established among practitioners, patients, and family members. We wish to be explicit about

our value premises, to make clear why we hold them, and to articulate their pedagogical implications for a curriculum constructed to counteract value premises operating in the hidden curriculum. Haidet and Stein,<sup>8</sup> in their insightful examination of the impact of medical culture on the professional formation of physicians, uncovered several of these value premises, typically unacknowledged in medical culture, that contribute to the hidden curriculum of health care. Table 1 presents these five premises, juxtaposed with the value premises in our program and a description of key features of our pedagogical approach.

### Structure and format

The program is interdisciplinary in its structure, with physicians, nurses, social workers, psychologists, and chaplains in attendance. Participants with varying levels of experience, from beginning students to senior clinicians, take part in the workshop. Actors, specially trained to enact realistic scenarios corresponding to critical junctures in the trajectory of a life-threatening condition, portray patients and family members. Although the scenarios and roles of patients and family members are defined in advance, the unfolding of each conversation is improvised, varying substantially depending on the approach taken by providing the opportunity for direct practice. Interdisciplinary teams of two or more practitioners, and at times individual professionals, engage in improvised case scenarios while their colleagues observe on closed-circuit television. They then rejoin the larger group and are given the opportunity to reflect and receive feedback from colleagues, faculty facilitators, and the actors. Video playback is used to

## List 1

### Program Goals: Relational Capacities and Habits of Mind

- Sense of confidence and self-efficacy to engage in challenging conversations
- Capacity for reflective self-awareness in relation to values, thoughts, and feelings
- Validation of existing relational capacities (both recognized and unrecognized)
- Capacity to empathically “step into the shoes” of patients and family members
- Willingness to share the moral burden of decision making with patients and families
- Tolerance of imperfection, ambiguity, and vulnerability
- Appreciation of the contextual uniqueness of difficult conversations
- Integration of personal authenticity with one’s professional role
- Enhanced experience of professional integrity

Table 1

**Value Premises and Pedagogical Approach of a Daylong Workshop in Difficult Conversations in Health Care**

| <b>Hidden curriculum: <i>The value premises underlying the culture of medicine suggest that . . .</i><sup>8</sup></b> | <b>Difficult conversations: <i>The value premises underlying competency in difficult conversations suggest that . . .</i></b> | <b>Implications for pedagogical design: <i>To counteract the effects of the hidden curriculum, educators must create an atmosphere in which . . .</i></b>                    |
|---|---|--|
| Doctors must be perfect.  | Clinicians must be comfortable with their own imperfection and vulnerability.   | There is sufficient safety and trust for learners to explore matters of personhood and professional integrity.   |
| Outcome is more important than process.   | Attention to process can be critical to the achievement of successful outcomes.   | Exploration of moral and relational dimensions of difficult conversations are emphasized.  |
| Hierarchy is necessary.   | Hierarchy can hinder optimal learning across disciplinary lines and between less and more experienced clinicians.             | Hierarchical structure and rules are suspended so that knowledge can be encountered on its own merits and not unduly influenced by power, authority, or level of experience. |
| Uncertainty and complexity are to be avoided.   | Uncertainty, ambiguity, and complexity are to be expected.  | The learning ethos is one of reflection, self-awareness, and tolerance for situations in which there is no single right answer.  |
| Medicine takes priority over everything else.   | Medicine finds its appropriate niche in interdisciplinary practice and optimal collaboration with patients and families.      | The knowledge and insights of patients, family members, and clinicians from multiple disciplines are afforded appropriate status and authority in the learning process.      |

highlight particular teaching points. Brief didactic presentations, focused on the evidence base for practicing relational and communication skills and on ethical and legal considerations pertinent to the conversations being enacted, are interspersed throughout the day. Short films, developed by the Initiative for Pediatric Palliative Care,<sup>12</sup> portray the experience of children with life-threatening conditions and their families<sup>13,14</sup> and the experience of health care professionals who care for this population.<sup>15</sup> The films are used to highlight patient and family perspectives and to ground the learning process in the everyday relationships of clinical practice.

**How It Works: Teaching Example**

In every daylong workshop, the same two case scenarios, each involving a small cohort of actors who have become increasingly familiar with their roles and the improvisation process, are used as the primary focus for learning. Each scenario unfolds uniquely, because practitioners approach the conversation in their own distinctive ways, eliciting particular responses from the actors, which in turn elicits particular responses from the practitioners, and so on. In this respect, the contribution of the actors differs from programs that use predefined scripts or standardized performances. Predictable themes that are structured into the scenarios emerge consistently in the workshops, but the particular direction of learning is uniquely shaped

by each new group of learners. Characteristically, salient themes that develop early in each workshop reverberate throughout the day, as the learning connected to those themes deepens.

In the teaching example presented here, a female physician and male nurse, after reading the case scenario (Appendix 1) of a five-year old boy involved in a drowning incident, volunteer to meet with the boy's parents shortly after their arrival in the intensive care unit (Conversation 1). Appendix 2 presents a transcript of their conversation. What follows is a description of the debriefing discussion, led by faculty facilitators, after the nurse–physician pair rejoins their fellow learners.

We initiate this dialogue with an open-ended question, such as “What was that like for you?” The question conveys a message to this nurse and physician that the ensuing conversation will be shaped by their particular experiences and learning needs, and encourages them to express “off the cuff” thoughts and emotions. Routinely, participants comment about how *real* and emotionally intense they found the conversation to be, how anxious they felt, and how relieved they are to have the experience behind them. By creating this “breathing space” and validating the emotional world of the practitioners, facilitators send a clear educational message that anxiety and vulnerability in

these conversations is normal, expected, and worthy of reflection.

The debriefing discussion focuses next on the manner in which information about Billy's medical condition has been shared with the parents. This particular physician has been very direct and forthcoming in the way she presents Billy's condition and prognosis to the parents, though clearly she has been compassionate at the same time. Facilitators and participants discuss the potential advantages and disadvantages of this directness. The tension in the conversation between wanting to be truthful, while at the same time supporting the hope of family members, is explored.

After these initial reflections, the actors who portrayed Mr. and Mrs. O'Brien join the discussion and are invited to offer feedback to the practitioners. They describe the directness of the physician's approach as “a bit jarring,” but they also say they appreciated the honesty and compassion shown by both clinicians. They discuss how it might have helped if the physician had “eased into” the communication of bad news by reviewing the sequence of events from the time of the drowning incident up until the present, because they had only recently arrived at the hospital and this was their first contact with the clinical team.

Then, one of the facilitators comments on a juncture in the conversation when

she observed the nurse saying to the parents, “He’s still Billy.” These words were spoken twice, first in response to Mrs. O’Brien’s anguished question, “Can he hear us?” and then a bit later, with rather more conviction, as the nurse prepares the parents for seeing their son enveloped by the machines that are keeping him alive. The nurse responds by sharing that he was uncertain about the appropriateness of this comment and that he “started second guessing” himself. He opens himself to group feedback by revealing, “I didn’t know if that was the right thing to say or not.”

In response to his uncertainty, one of the faculty facilitators observes that, in her view, “you brought Billy right in that room—that was very powerful.” She is followed in her comments by the parent facilitator, who adds, “I thought that was a very effective comment—you gave expertise back to those parents.” Another participant agrees, reminding colleagues that in nursing report or rounds, Billy could easily be referred to as “the comatose patient in bed 12.” The actors explain that they appreciated both practitioners consistently referring to their son by name, and that the nurse’s words, “He’s still your little boy” helped them to remember that, even in this alien and intimidating intensive care setting, they still had a vitally important role to play as parents.

It is important to note that the very words that may have been most important to the parents are the same words that this nurse finds himself doubting and worrying about in terms of their *correctness*. As faculty facilitators, we have observed that when practitioners experience their own words emerging from a place of authenticity in these conversations, when they speak spontaneously without searching cognitively for what they imagine to be the “right words,” they often feel uncertain and wonder whether they have said the wrong thing.

There is an important kind of moral inquiry happening here. This nurse seems to be struggling with the paradox inherent in not knowing what to say, yet needing to say *something*. Perhaps he has decided the only morally credible things he *can* say in the face of unspeakable parental suffering must connect somehow to the affirming of parental

love. So, in response to the anguished parental plea, “Can he hear us?” he encourages the parents to “talk to Billy, just as you would earlier in the day.” Then, in a stronger voice, he reminds them, “He’s still Billy. . . . He’s still your little boy.” If his words are in some way *right*, as the consensus within this group of learners seemed to suggest, perhaps it is because they emerge from an intention to share, to the extent possible, the moral burden these parents must shoulder. By focusing on this practitioner’s effort to be morally and emotionally present in this challenging conversation, we explicitly emphasize the centrality of authenticity and professional integrity over technique or “how-to” skills. In these kinds of conversations, we have observed that it is often not the words themselves, but rather the authenticity and moral courage beneath their uttering, which seems to make the difference.

In this debriefing discussion, the personalization of the parents’ bond with their son leads to a spirited discussion about how patients and family members are, in the context of the hidden curriculum, habitually *depersonalized*. One of the faculty facilitators provides the illustrative example, from the intensive care unit where he is chief, of parents posting photographs of their child (taken outside the hospital, before the child was sick) at the bedside. He describes this as a “subversive strategy to keep clinicians engaged and remembering that this is really not just any child but a special child.” He adds frankly that this parental practice is disconcerting for him, in that “it drags me into a more emotional connection that makes it more draining to deal with.” The parent facilitator, who has been listening intently to the physician’s words, acknowledges that she herself always places a picture at the bedside every time her own daughter (who has had a chronic, life-threatening illness for many years) is admitted to the hospital, stating “I want to drag you in. I want you to know that this cranky, unresponsive person in pain has another life and has a place in the world.” The snapshot at the bedside is, indeed, a subversive strategy aimed at humanizing her child for the clinical team. “It’s not for me,” she tells the physician. “I *know* who she is.” The group laughs and nods in acknowledgement; the relational message in her comment is understood.

In the evolution of *this* debriefing discussion, the terrain of dialogue has expanded beyond an evocative conversation with two anguished parents into the complex moral and emotional geography of the health care setting in which it occurs. This cohort of learners is now engaged in exploring a rarely explored ethical–relational tension in the culture of pediatric intensive care in which, on the one hand, parents want practitioners to relate to them and to their children with compassion and authenticity and, on the other hand, practitioners wonder to what degree it is possible, or even desirable, to remain so humanly connected over the months and years of a demanding career. The tension is not resolved; rather, it is framed in the form of a closing question posed by one of the faculty facilitators: Should practitioners who must routinely engage in these kinds of high-stakes conversations demand from their professional cultures a new ethos, one that cultivates a more robust integration of personhood and moral reflection into the structures of professional education and everyday practice?

### Why It Works: Key Features of Our Pedagogical Approach

We have observed the unfolding of this type of case scenario and debriefing discussion in approximately 60 workshops, involving, as we noted above, nearly 600 health care professionals. As we reflect on our experience, five key features stand out that we believe account for the responsiveness of learners to our approach.

#### Creating safety for learning

Being willing to practice one’s interpersonal skills in a highly charged emotional context and to receive feedback from colleagues and faculty facilitators is a deeply vulnerable act. We have learned that the willingness of health care professionals to honestly explore their own feelings, doubts, and uncertainties as they approach these difficult conversations depends largely on our ability as facilitators to create a learning atmosphere that is welcoming, trustworthy, and respectful. Sadly, we have become accustomed to hearing from participants about previous professional learning experiences in which they were shamed or humiliated. Parker Palmer, a

sociologist and educator recognized by the Accrediting Council for Graduate Medical Education for his contribution to medical education, describes the normative process of academic education as one in which professionals are taught about the world as if it were a world they do not themselves inhabit.<sup>16</sup> This is especially ironic when applied to health care professionals who are committed to helping patients and family members cope with suffering and loss, because these are universal life experiences that all human beings must endure.

Our goal is to reverse this devaluation of relational knowledge and to awaken practitioners' sense of empathy toward—and solidarity with—patients and families. We have found that meeting learners at this personal–professional “learning edge”<sup>17</sup> effectively invites them to remember the motivations and aspirations that led them into their chosen professions in the first place. In this process, we hope to support these professionals in the reclaiming of “tacit knowledge”<sup>18,19</sup> and “practice wisdom,”<sup>20,21</sup> and thereby increase their moral and relational competence in everyday clinical practice.

### Emphasizing moral and relational dimensions of care

When we examine difficult conversations with pediatric patients and their families as events that evolve in real time,<sup>22</sup> the relative focus of learning shifts from content to process and relationship. We share Zoppi and Epstein's<sup>23</sup> concern that “skills-focused training is not always directed toward fostering a genuine, strong, compassionate, caring relationship between physician and patient.” Although we do spend a modest amount of time presenting the evidence base for helpful communication behaviors and providing guidance about key communication skills, the pedagogical emphasis is placed on communication as shaped by the moral terrain of difficult conversations,<sup>24</sup> wherein patients, family members, and practitioners alike are struggling to do their best in existential circumstances that might best be described as impossible.<sup>25</sup> Accordingly, the emphasis shifts from how to deliver news to the larger ethical challenge of how to support this particular patient or family in these often overwhelming life circumstances.

This connects to another salient facet of the hidden curriculum that we address directly in our program, described here by a physician-in-training:

It all goes back to that old adage, “monkey see, monkey do. . . .” The way you treat me as a student will set the tone for how I treat patients. So if you want me to take a personal interest in my patients and to treat patients as partners, the most powerful thing you can do is to treat me the same way.<sup>26</sup>

We accept as axiomatic that how practitioners relate to patients and families is directly influenced by how their teachers, supervisors, and mentors have related to them. Therefore, we take seriously the obligation to treat our “trainees” with the same compassion and respect we want them to extend to patients and families.

### Suspending hierarchy

The learning environment created in our workshops is shaped by the ground rules for relational learning established at the beginning of the day. We explain that we are coming together to learn as equals, and that hierarchical roles and relationships are “suspended” for the duration of the workshop. Our objective is to create a space for learning in which the knowledge of a social work intern in her first week of training will be valued on its merits equally alongside the knowledge of an attending physician with decades of experience. The inclusion of both novice and experienced practitioners is a particularly important pedagogical feature, because we are promoting the growth of relational capacities that the academic literature<sup>2,4</sup> suggests have been lost by many in the course of professional training. Indeed, our experience has been that beginners often offer compelling insights that may elude more senior clinicians, including the faculty facilitators. The participation of novice clinicians alongside seasoned practitioners has persuaded us to adopt a more nuanced understanding of expertise as it applies to these challenging conversations, and to appreciate the Buddhist insight that in the mind of the beginner, there are many possibilities, but in the mind of the expert, there are few.<sup>27</sup>

The suspension of hierarchical rules enables participants to explore the important question of whose knowledge matters, or should matter, in any

particular conversation. One salutary effect of this leveling process is that the burden and opportunity inherent in these challenging conversations becomes more of a shared interdisciplinary undertaking for practitioners, and the respective contributions of the various disciplines are better understood and appreciated. When the learning environment is fashioned in a manner that factors deleterious aspects of power and hierarchy out of the interactional equation, it becomes more likely that the group will benefit from whoever's knowledge—patient, family member, physician, nurse, social worker, or chaplain—is most relevant to the situation at hand. Our efforts to attend to issues of power, rank, and authority are congruent with other major change efforts in health care, including the patient safety movement<sup>28</sup> as well as calls for more sophisticated interdisciplinary collaboration<sup>9</sup> and greater transparency and democratization in health care organizations.<sup>29–32</sup>

### Valuing reflection and self-awareness

The practice of difficult conversations with patients and families is a potent reminder of the need to embrace uncertainty and complexity in the relational practice of clinical medicine. Because no two encounters are alike, and there is no single right answer in these situations, the ability to practice in contexts of uncertainty and complexity is critical. By focusing our pedagogical approach on direct practice in difficult conversations and on reflection immediately afterwards about the extent to which the encounter was meaningful or helpful, practitioners are required to examine what they are doing, to hold themselves accountable for the impact they have on patients, families, and colleagues, and to consider the deeper moral significance of their work. This emphasis on reflection and self-awareness connects to a substantial literature calling for change in these aspects of health care practice,<sup>33–35</sup> as well as ongoing documentation that many medical cultures remain averse to reform in this area.<sup>33</sup>

### Honoring multiple perspectives

In a health care culture where medicine is prioritized over everything else, a thoughtful exploration of difficult conversations offers physicians and their

interdisciplinary colleagues a unique opportunity to discover how and where to position themselves, in a moral and clinical sense, in their relationships with patients, families, and colleagues from other disciplines. Our experience, borne out consistently by the participant evaluations, is that this path of discovery depends on the thoughtful integration of multiple perspectives in the learning process. In this context, the perspective of patients and family members themselves is paramount. Perhaps the most troubling omission in the research on communicating bad news, as well as in many training programs built on this research, is that patients and family members—the persons to whom the bad news is communicated—are rarely included or even consulted.<sup>36</sup> In the patient safety movement, there is an oft-repeated axiom expressed by patients and families: “Nothing about us, without us.”<sup>28</sup> In developing the pedagogy for our program, we have taken seriously the moral challenge implicit in these words, because we believe it addresses a salient contradiction in the hidden curriculum of many medical cultures, wherein an overt endorsement of compassionate and patient-centered care is combined with an implicit culture in which patient and family knowledge is routinely devalued or ignored. When the expertise of patients and families is accorded its appropriate status in professional learning activities, a powerful message is conveyed about whom practitioners-in-training should consider their most important teachers. Such formative learning experiences can serve as a counterweight to the negative influence of the hidden curriculum.

In the design of our program, we have incorporated patient and family perspectives in several ways. First, our pedagogy is responsive to recent research documenting what matters to parents of children living with life-threatening conditions.<sup>22,37–40</sup> Second, scenarios are reviewed for accuracy and authenticity by parent advisors who have experienced the serious illness or death of a child. Third, parent advisors work closely with psychosocial and physician facilitators as core faculty for the program. Lastly, actors are chosen for their capacity to function effectively as “ethical understudies” for the patients and family members they portray. Actors are carefully selected for their roles and

mentored to provide honest, constructive feedback. Their skillful capacity to shed light, when offering feedback to learners, on the moral and relational nuances in these conversations, marks a difference from other programs using simulated or standardized patients.<sup>41</sup>

We have observed that our efforts to honor the life experience of patients and families in the learning process can have a salutary effect on a particular aspect of the hidden curriculum—how patients and families are talked about. Clinical conversations among professionals in health care settings can be prone to a certain moral and intellectual carelessness, leading to insensitive, judgmental, or overmedicalized characterizations such as “incompetent cervix,” “harvesting organs,” “pathological grief,” or “dysfunctional parents.” By encouraging learners to attend to their language, and by ensuring that patients and family members are physically present and involved in the learning itself, we hope to have a positive impact on this “ethic of representation,”<sup>42</sup> thereby increasing the potential for authentic patient-centered and family-centered care.

## Conclusion

Our knowledge as educators has deepened immensely as a result of our immersion in this project for the past several years. Experience has taught us that it is indeed possible, in the busiest of hospital environments, to fashion learning experiences that promote moral reflection and reconnection with one’s humanness, and that participation in this kind of relational learning can be transformative, both personally and professionally. We have learned from workshop participants, as evidenced in the comments that open this article, that becoming morally and relationally competent in these difficult conversations includes such skills and habits as leaving one’s badge at the door, learning to be genuine and real, inviting colleagues from other disciplines into the conversation, and better attending to the emotional side of caring for patients and families. The strength of our educational approach, developed initially to explore end-of-life conversations in the pediatric context, has led to its expanded application to a range of high-stakes conversations in pediatric as well as adult

medicine, including discussion of organ donation, disclosure of medical error, and assisting family members during the invasive medical procedures of loved ones.

William Carlos Williams,<sup>43</sup> the renowned American poet and family physician who found congruence throughout his career in the simultaneous practice of poetry and medicine, wrote:

It is difficult  
to get the news from poems  
yet men die miserably every day  
for lack  
of what is found there.

Dr. Williams’ insight applies to the challenges we have faced in constructing a pedagogy for exploring difficult conversations, and in articulating the substance of this pedagogy to others. In a medical world that places a premium on checklists, algorithms, and standardized interventions, it can be difficult for medical educators to know how to honor and elucidate the moral “news” inherent in the complex, actual conversations that unfold on a daily basis among practitioners, patients, and family members. It can be pedagogically challenging indeed to craft learning experiences aimed at excavating the hidden curriculum and unearthing the unique, irreducible, and poetic nature of these conversations. We are convinced we will miss the mark, however, and surrender a piece of our *own* humanity, every day we fail to do so.

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## Appendix 1

**Case Scenario: Billy O'Brien.** From a daylong workshop in difficult conversations in health care, using relational learning

Billy is a five-year old boy from an Irish American family. He arrives by helicopter from a nearby community hospital. He was playing on the beach with his family when he disappeared. Mr. O'Brien had been in the water with Billy, and went back to his blanket for a flotation device. After a 5- to 10-minute search, Billy was found submerged in shallow water, initially pulseless. CPR was performed at the scene by his mother; he was transported by EMS to the nearest hospital. On arrival he was unresponsive with GCS of 3 but with normal sinus rhythm, hemodynamically stable, on moderate ventilator settings. CT of head was normal, C-spine films normal, cervical collar in place.

Exam on arrival: pupils 4 mm bilaterally and poorly responsive, no spontaneous movements, no response to deep pain. Blood work sent and pending.

### Conversation 1 (Sunday morning)

The parents (Bill Senior and Lisa) have just arrived by car and are in the waiting room. The physician and nurse go to meet them. On the basis of the presentation, the clinicians know that the most likely outcome is death. If the child survives, he will probably be in a persistent vegetative state, or pvs (i.e., permanent unconsciousness). There is a small chance that he may regain some features of consciousness, but almost certainly he will never regain relational capacity.

### Conversation 2 (Monday afternoon, eight days after accident)

Billy's parents have been at his bedside since Sunday. Billy received standard medical management for increased ICP and had remained hemodynamically stable, on moderate ventilatory settings, with no spontaneous respiratory effort. CT showed diffuse cerebral edema. Neuro exam otherwise unchanged, without any detectable neurological function.

An examination for brain death was performed on Wednesday morning after rounds, but during the apnea test Billy started to make some respiratory efforts, so he was placed back on the ventilator.

The results of the test were explained to the family. Billy is not brain dead at this point, but other than this respiratory effort, he has no evidence of neurological function. His prognosis continues to be dismal, most likely either death or pvs. The chances for a better outcome are extremely slim.

Billy still shows no spontaneous motor activity, and he shows posturing in response to deep pain. When attempts are made to wean the ventilator, he makes occasional respiratory efforts, but he is still definitely ventilator dependent. If the ventilator were withdrawn at this time, Billy would likely die within minutes to hours (although one can never be sure). Otherwise, he will require a tracheostomy and g-tube with transfer to a rehabilitation hospital or nursing home. He may eventually wean from the ventilator, but is likely to remain in a vegetative or near-vegetative state.

The physician and nurse meet with the family to discuss options. Legally and ethically acceptable options cover a wide range. At one end of the spectrum, the family could opt to do everything possible to keep Billy alive, including tracheostomy, g-tube, and chronic ventilation. At the other end of the spectrum, the family could opt for comfort care only. This would involve removing the ventilator and providing only those treatments that contribute to patient comfort, including the administration of sedation and analgesia, titrated to any signs of pain or suffering. As noted above, this would probably (but not definitely) lead to Billy's death in a matter of minutes to hours.

Although these decisions do not need to be made emergently, this point represents an important "fork in the road," and the clinicians need to guide the family in choosing the path that is most consistent with their beliefs and values.

The physician and nurse stop by the bedside.

### Conversation 3 (Next day)

This is a continuation and completion of the conversation from the previous day.

## Appendix 2

**Transcript of Conversation 1 between Clinicians and Parents: Billy O'Brien Scenario.** From a daylong workshop in difficult conversations in health care, using relational learning

*Physician:* We've been taking care of Billy since he got here from your community hospital. He's in one of our resuscitation rooms and his condition is stable, but it's quite serious. His heart is beating on its own . . . but he is not responding to us. He is essentially in a coma. He is not responding. So we don't know—right now, I don't have a crystal ball, but this is a very serious situation, and. . .

*Father:* When you say *coma*, that means he could wake up at some point, or are you saying he's never going to wake up?

*Physician:* I don't know the answer to that for certain. Right now the indications are that . . . the near-drowning incident has caused significant damage to his brain, and there is a very, very real possibility that he may not wake up.

*Mother (crying):* Oh, God. . . .

*Physician:* I know this is the worst thing that you can hear right now. We'll talk for a few moments and then we'll take you in to be with him.

*Mother (imploring):* What can you do for him? How can we help him? His heart is beating, he's alive. What can we do? We'll do anything. I don't care. Anything we can do to help or try or—

*Physician:* I think that what we can do for you and for him right now is to have you be with him. We are supporting every part of him we can, but his brain is something that he has to heal or not heal on his own. There is no direct therapy.

*Father:* Is he thinking? Is he breathing, or what?

*Nurse:* Right now, we have him hooked up to a machine that is doing the breathing for him. Whether or not he'll be able to breathe on his own, we'll have to wait some time.

*Mother:* How long do you think it will take before we know a little more about what's going to happen?

*Physician:* I think the first 24 hours are the most critical period. And if there's no significant change, at that point the likelihood of improvement will be very, very small.

(Appendix continues)



## Appendix 2, continued

*Father* (crying): Oh, God, this is my fault. I swear I thought he was only in there for a minute.

*Nurse*: Try not to blame yourself.

*Physician*: Accidents happen. They just happen.

*Mother*: Can we stay with him overnight?

*Nurse*: You can stay with him the whole time.

*Mother*: Can he hear us?

*Nurse*: He might be able to hear you—he will not be able to express to you that he hears you. But I would encourage you to talk to Billy just as you would earlier in the day or as you always have talked to him. He's still Billy . . . he's still your little boy.

*Mother*: I just don't understand what's happened. . . . How could this happen . . . why did this happen?

*Physician*: I don't think any of us can understand that.

*Father*: Is this kind of thing common?

*Physician*: Unfortunately, it is not an uncommon occurrence for us.

*Father*: You're saying he's brain dead. He's just breathing or what. What's wrong with him exactly? His heart isn't working? His brain isn't working?

*Physician*: His heart is working on its own. His brain is not working normally. There is a possibility that he is brain dead. I don't know that now. That's something that will become clear over the next 24 to 48 hours.

*Father*: I assume brain dead means there's no recovery from that.

*Physician*: That is what that means.

*Nurse*: I want to prepare you for what you'll see when you go back to see Billy. We have him on a ventilator machine that's doing the breathing for him. So, he has a tube in his mouth that goes into his lungs, and you'll see that. He also has a couple of IVs in place to give him some medication, some fluid. His skin is probably going to look a little paler to you—he probably won't have the same kind of skin tone that you're used to seeing. But he's still Billy. He's your little boy . . . it might be disconcerting at first.

*Mother*: We can just hope for a miracle. I don't know what else.

*Father*: Doesn't that happen—I've seen things on TV where somebody wakes up out of a coma and they're fine again. Can that happen? Does that ever happen?

*Physician*: Things do happen that we don't expect or predict. That does exist.

*Father*: I came back to the water and I saw him face down and I thought he was playing. He does that at home in the little pool—he sometimes pretends to be drowning.

*Physician*: This is a tragic accident, and tragic accidents happen in the blink of an eye.

*Father*: Could we just have a minute and then go in?

*Physician*: Take as long as you need. . . . We'll be right here when you're ready.