Institutional policies, professional practices, and the discourse of end-of-life discussions in American medicine

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Abstract

The discourse analysis of end-of-life discussions presented here describes the interplay between the institutional order and interactional order in American medicine, following Sarangi and Roberts (1999). In American hospitals, the institutional order of end-of-life discussions is accountable to a bioethics model of patient/surrogate autonomy for making medical decisions. In end-of-life care, medical futility is the basis for the decision to withdraw life support from a terminal patient; under autonomy in a bioethics model, this decision should be made primarily by the patient’s surrogate in consultation with the attending physician. The interactional order of discussions with patients’ families, however, is largely without accountability to institutional policies mandating autonomy, instead following the clinical and ethical standards of the profession of medicine, which preserve the determination of medical futility as a professional judgment and limit the scope of surrogate autonomy to an account of the patient’s wishes. In these discussions, physicians and families can be seen as constructing an ethics of emerging consensus as the basis for end-of-life decision-making.

Keywords: medical communication; end-of-life care; autonomy; medical futility; end-of-life discussion; medical discourse

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Introduction: theoretical and methodological frameworks

This discourse analysis of end-of-life discussions draws its theoretical and methodological frameworks from Sarangi and Roberts’ (1999: 14) conceptualization of the institutional order and the interactional order. The relationships between a given institutional order and an interactional order within it are typically dense and complex, and sometimes involve power struggles between the institution and its goal to regulate the practices of professionals in order to achieve accountability to its policies, and the competing goal of professionals to define accountability primarily with respect to the profession rather than the institution. In American medicine, this is exactly the tension between hospitals as institutions and physicians as practitioners who seek to control their professional practices, including their practices of medical communication. This situation is exemplified by the relationship between federal and state laws, hospitals, and medical practitioners: it is hospitals that are heavily regulated, not individual physicians or the profession of medicine, and hospitals are largely powerless to enforce their own policies with respect to the practices of physicians. For example, in end-of-life care, hospitals are regulated by the federal Patient Self-Determination Act of 1990, which mandates patient autonomy; more specifically, hospitals are required to provide every patient with information about their rights to (1) accept or refuse medical and surgical treatment, (2) prepare an advance directive, and (3) have that information documented in their medical record (42 USC 1395cc 1992). But in an example of the ineffectiveness of the institutional order when it comes to the professional practices of medicine, advance directives have been shown to be largely irrelevant with respect to the actual end-of-life care that patients receive under the care of individual physicians in American hospitals, especially when they die in intensive care units [ICUs] (Curtis & Rubenfeld, 2001; SUPPORT Principal Investigators, 1995). In fact, a recent study found that 65% of physicians would follow their own professional judgment over the instructions of an advance directive (Tulsky, Fischer, Rose & Arnold, 1998). In this article, I argue that the medical profession’s control over its own practices extends to end-of-life communication as well, specifically to the end-of-life discussion physicians have with families of patients whose status is terminal.

The study reported here describes the interplay between the institutional order and interactional order of end-of-life discussions. The work is part of a larger team project.¹ It draws its wider thick description of the institutional order primarily from an ethnography of life and death in a surgical intensive care unit [SICU] at a large, urban teaching hospital, here called Midwestern Hospital (Cassell, 2005). It develops its discourse analysis of the interactional
order of end-of-life discussions from a corpus of 20 recorded and transcribed discussions in the SICU at Midwestern Hospital. The end-of-life discussion is a recognized communicative event in medicine, one that is convened with the purpose of achieving consensus with the family on end-of-life decision-making (Curtis & Patrick, 2001; Curtis, Engelberg, Wenrich, Niels et al., 2002; Shannon, 2001). In this corpus, 14 discussions ended in a decision to withdraw life support and 6 did not (see Appendix A for transcription conventions; the specific methods of analysis will be described below in the section on the interactional order).

In this article, I consider the interplay of the institutional and interactional order with respect to the ethics of the end-of-life discussions. I first describe this interplay contextually, focusing on the ethical concepts of patient autonomy and medical futility in the institutional order. I then describe the emergence of these concepts in the interactional order of end-of-life discussions, showing how physicians directly and indirectly construct autonomy and medical futility in a professional discourse that is largely without accountability to institutional policies. I conclude by suggesting that research in applied linguistics on the interplay of the institutional and interactional order has the potential to make a significant contribution to current discussions of the ethics of end-of-life care and communication since discourse analysis focuses not primarily on abstract principles but specifically on the ways that the ethical concerns of both physicians and families actually emerge in end-of-life discussions.

The institutional order: end-of-life care in the SICU

In American medicine, the end of life is the center of a complicated nexus of personal, sociocultural, professional, economic, legal, and ethical dimensions, all of which play significant roles in the institutional order of end-of-life care.² There are two certainties within this context: first, that end-of-life care in American hospitals will continue to grow as the population ages and the technology of medicine continues to advance; and second, that the ethics of end-of-life care will continue to be a hotly contested issue not only in medicine but also in American society. America has been called a death-averse culture, as has American medicine (Kagawa-Singer & Blackhall, 2001; Levy, 2001). Recently, there seems to be a growing consensus in some sociocultural groups (mainly white and middle-class) that a good death is one that is meaningful and dignified, without suffering from prolonged and excessive technological intervention, and the growth of palliative care and hospice in American medicine is one response of the profession to this notion of death (Kaufman, 2005). However, the deep ambivalence about medical care at the end of life is reflected in the contrast between the number of Americans who claim that
they wish to die at home without excessive measures (70%) and the number who actually die in hospitals or nursing homes (75%) (Last Acts, 2002). Similar ambivalence within the profession of medicine is illustrated by the low status of palliative care as a medical specialty (Cassell, 2005) as well as the minimal utilization of hospice: hospice care is utilized in less than 20% of deaths, and the majority of patients are referred to hospice fewer than two days before death (Approaching Death, 1997). Of those patients who die in American hospitals, one of every five dies in an intensive care unit, and this number is expected to increase (Angus, Bonata, Linde-Zwirble et al., 2004). Of these deaths in intensive care, the majority involve the withdrawal or withholding of life support (Curtis, Patrick, Shannon, Treece et al., 2001; Prendergast & Luce, 1997; Keenan et al., 1997).

The withdrawal of life supporting treatment(s) is a central dimension of the ethics of end-of-life care (Mularski & Osborne, 2001; Beauchamp & Childress, 2001). Within the current framework of bioethics in American medicine, two concepts are particularly relevant to end-of-life care: the general concept of autonomy, which has come to govern the relationship between physicians and patients, particularly with respect to decision-making; and the specific concept of medical futility, which has become the basis for the decision to end treatment for a terminal patient (Schneiderman, Jecker & Jonsen, 1990; 1996). Medical futility is defined as a treatment (or set of treatments) that does not have a ‘reasonable chance of achieving a therapeutic benefit’ (Schneiderman, Jecker & Jonsen, 1996: 669); in other words, as Kaufman (2005: 29) describes it, futility is ‘no more physiologic response to therapy’. A determination of medical futility is the basis for the decision to move from therapeutic treatment aimed at cure to palliative treatment aimed at comfort for a patient who is dying. In an intensive care setting, the decision to move to palliative care typically involves withdrawing or withholding life support, particularly the use of a ventilator to support a patient in respiratory failure and/or the use of pressor medication to support blood pressure in a patient in cardiac failure, shock, or other end-stage conditions. Often other life supporting treatments are withdrawn or withheld from patients as well, including dialysis for kidney failure and antibiotics for infection.

In the doctor-patient relationship in American medicine, one of the most significant changes in the past 40 years has been the emergence of the field of bioethics and its central principle of autonomy (Beauchamp & Childress, 2001; for an important critique of autonomy, see Schneider, 1998). In contrast to paternalism, which characterized a hierarchical doctor-patient relationship in which the physician made all medical decisions, autonomy is generally defined as the right of patients to self-determination in medical care, in particular by making their own medical decisions and treatment choices based upon
their personal values and beliefs. With respect to the institutional order of end-of-life care, the Patient Self-Determination Act mandates that hospitals offer all patients the chance to exercise autonomy by executing an advance directive. Preparing a living will and/or designating a durable power of health care attorney are examples of advance directives that delegate an incapacitated patient’s autonomy to a surrogate decision-maker.

One of the areas of American medicine most affected by the rise of autonomy is medical communication. In a paternalistic model, communication is at the discretion of the physician, so the physician decides whether and what to reveal about a diagnosis or prognosis. In an autonomy model, however, communication is essential since patients (or their surrogates) are to be active participants in medical decision-making. With respect to end-of-life care, ethnographies of hospital deaths in the 1960s reported that physicians rarely told families that a patient was terminal or that death was imminent (Glaser & Strauss, 1965; Sudnow, 1967). However, current ethnographies of deaths in hospital intensive care units note that physicians now routinely talk to families and sometimes patients about terminal status and treatment decisions (Cassell, 2005; Kaufman, 2005). Autonomy, then, may be the driving force behind current norms of end-of-life communication, in which families become involved in discussions about withholding or withdrawing life support for a terminal patient.

The institutional order of end-of-life care thus incorporates both patient autonomy and medical futility. A discourse analysis of the interactional order in end-of-life discussions, however, shows that futility is typically presented strictly as a medical decision, and autonomy is often simplified to an account of the patient’s wishes without asking the surrogate for an explicit decision about withdrawing life support. The authority of the medical profession is thereby systematically preserved over the policies of the hospital in the discourse of end-of-life discussions and, thus, in end-of-life decision-making.

The interactional order: end-of-life discussions in the SICU

It has been argued in the literature that the end-of-life discussion is not necessarily a decision-making discussion, particularly for the family. Anspach (1993) reported in her ethnography of a neo-natal unit that physicians did not initiate an end-of-life discussion with parents until they had decided to withdraw life support. Similarly, Cassell (2005) noted that end-of-life discussions were not initiated in the SICU at Midwestern Hospital unless the attending physician had determined that it was medically appropriate to discuss the withdrawal of life support and other futile treatments. Kaufman (2005) also argued that end-of-life discussions take place only when the patient no longer responds to
treatment, noting that this point is fraught with conflict in American medicine with its extreme commitment to a treatment imperative. Cassell (2005) and Kaufman (2005) further note that end-of-life discussions blur the nature of and authority for decision-making, and Iedema, Sorensen, Braithwaite, and Turnbull (2004: 1) also describe how blurred decision-making can lead to ‘wicked problems and tragic choices’. The specific conventions that construct blurred decision-making will be described in this discourse analysis of the interactional order of end-of-life discussions.

To describe this particular interactional order, the methods of discourse analysis were qualitative and inductive, following Johnston (2000); Schiffrin, Tannen and Hamilton (2001); and Sarangi and Roberts (1999). The analysis focused specifically upon identifying conventions within the interactional order of the end-of-life discussion. Following Morgan (1978) and Schiffrin (1994), conventions are defined in terms of a relationship between structure and function: in discourse, a structure is a patterned stretch of language that is in a typified, and therefore conventionalized, relationship with its functional use for a particular purpose. Sarangi and Roberts (1999: 16, 25) note that conventions play a particularly important role in decision-making, in part by being one of the ways in which interpretation within an institutional context is ‘both brought along and brought about in a situated encounter’ (authors’ emphasis). In the analysis here, conventions were identified primarily by repetition across the corpus: to be identified as a convention, a particular discourse practice had to be present in at least four discussions. The data was coded multiple times in an open and consensual process between the author and a colleague acting as second coder (Strauss & Corbin, 1998); drafts of the analysis also were sent to the anthropologist and SICU physician on the larger team for participant verification of the interpretation, as suggested by Roberts and Sarangi (2005).

The argument of the analysis is that physicians interactionally aim at consensus rather than decision-making in end-of-life discussions, which has the effect of preserving futility as a medical decision and minimizing autonomy to a personal account, thereby privileging the perspective of the profession of medicine rather than the institutional policies of the hospital, which call for patient/surrogate autonomy. The analysis will consider the establishment of medical futility first and the framing of decision-making second, since this is the order of phases in the end-of-life discussion. The analysis will be presented primarily with examples from the corpus; unfortunately, space limits allow the presentation of just one example to illustrate each convention, but the frequency distribution of each convention across the corpus of 20 discussions is noted.
Medical futility

In previous work on the corpus of end-of-life discussions from the Midwestern Hospital SICU, Barton, Aldridge, Trimble, and Vidovic (2005) identified four structural phases of the end-of-life discussion, each with a particular set of functions: the Opening (Phase 1), which functions to establish the traditional authority of a medical encounter with the physician in the interactional and decision-making lead; the Description of Current Status (Phase 2), which functions to establish the terminal status of the patient and imply the futility of continued treatment; the Decision-Making (Phase 3), which functions to effect a holistic decision to withdraw life support; and the Logistics of Dying (Phase 4), which functions to describe the specifics of dying in the ICU and to revisit issues arising in the previous phases. In that work, we argued that establishing terminal status and medical futility in Phase 2 is crucial to the progression of an end-of-life discussion to the decision to withdraw life support; in other words, if Phase 2 of the discussion does not interactionally establish terminal status among physician(s) and family members, the decision to withdraw life support does not take place. This claim was supported in a more detailed study of the corpus (Aldridge & Barton 2007): in a comparative analysis of decision-making and non-decision-making discussions (14 and 6, respectively), we found that in the six non-decision-making discussions, terminal status and medical futility were not definitively established interactionally in Phase 2 or in recursive reiterations of Phase 2: families could block decision-making by not aligning with the statement or inference that the patient’s status was terminal, for example, by remaining silent, but more often physicians equivocated about medical futility by mentioning the possibilities of positive outcomes and further treatment options. Barton (2006) describes three trajectories of alignment in end-of-life discussions: overt, negotiated, and blocked.

The analysis in this section will describe a number of conventions by which physicians establish futility as a medical decision in the end-of-life discussion: medical description is the main convention, but there are additional direct and indirect conventions aimed at establishing futility, including the indirect means of presenting the consensus of medicine and the more direct means of presenting medical decisions solely as the province of the physician. Futility is also established as a medical decision by describing end-of-life care primarily in terms of the standards of the profession.
Medical descriptions

Not surprisingly, Phase 2 of the end-of-life discussion is primarily a description of the patient's medical status, organized as a problem list with each problem typically described in terms of negative outcomes. In the corpus, 19 of 20 discussions included a Phase 2 with medical descriptions of the patient's problems (for a fuller description of the medical description in Phase 2, see Barton, 2006; see Aldridge & Barton 2007, for an analysis that compares the presentation of problems in terms of negative vs. positive outcomes, which correlates with decision-making). The following example is a medical problem described in terms of negative outcomes:

(1) Dr: She's had two strokes on one side of her brain. These are very serious strokes.

The problem list in Phase 2 presents an accumulation of medical evidence based on the negative outcomes of the patient's specific problems.

In terms of the patient's overall condition, Phase 2 culminates in a summary section that directly or indirectly establishes the patient's status as terminal. The following examples are direct [(2a)] and indirect [(2b)] summary statements of terminal status:

(2a) Dr: His changes of recovering from this are zero. He will not get better . . . If things were left to progress he'll die from this in and of itself.

(b) Dr: It is unlikely that she does become the same sister you knew two months ago. That's the best case scenario.

In the corpus, 19 discussions included summary statements; physicians were more often indirect in their summaries than direct (17 indirect summaries compared to 2 direct summaries).

In terms of medical futility, what is important about summary statements like those in (2) is that terminal status—dying—is a lay concept. To a medical professional, however, these statements establish medical futility inferentially within the expertise of the profession of medicine: in Kaufman's (2005) terms, the inference of futility means that the patient is no longer responding to treatment. In the corpus, however, the medical term futility was used only rarely: in just one discussion did a physician overtly mention futile care. The use of the concept of terminal status in lay language may be aimed at family members without much knowledge of medicine, but this arguably has the effect of preserving the determination of futility within the professional domain of medicine alone. When families agree to terminal status, then, they may not necessarily realize that the determination of medical futility is its basis. For
families, the decision-making that follows in an end-of-life discussion is thus based on a lay understanding of the patient's status as terminal (i.e., the patient is dying), while for medical professionals, the decision-making is primarily based on medical futility (i.e., the patient is no longer responding to treatment). In consequence, professional decision-making remains a domain separate from family understanding.

Consensus of Medicine

Physicians also use a number of subtle discourse conventions to reinforce the lay understanding of terminal status of the patient and to reserve the determination of futility to the professional judgment of medicine: two of these are references to the consensus of physicians and references to the consensus of their medical experience.

One of the conventions by which the terminal status of the patient is reinforced is to incorporate references to the agreement of all physicians involved in the patient’s care. This reference can be a direct reference to medical consensus, as in the summary statement in (3a); or it can be a more indirect reference implying consensus, as in the description of team-based care in (3b):

(3a) Dr: So from two different standpoints– And again I want you to know I just spoke to Dr H this morning and he [would] be here himself but he’s in the operating room right now and asked me to speak for him. So from two different standpoints we don’t think that it looks very good for her.

(b) Dr: Dr G actually has been involved with Mrs. [Quorn] from the beginning when we were consulted by the medical service yesterday and he was with us last night in the operating room as we were doing this long procedure and Dr B as I have mentioned is the director of the ICU up here and has been my partner for eight years now.

In (3a), the physician interrupts his first articulation of the summary statement in order to directly establish the agreement between him and the patient's surgeon, thereby allowing him to position the summary statement within their consensus. The shift to the pronoun *we* strengthens the summary statement with its pragmatic antecedent of the medical professionals and the authority of their consensus. More indirectly, in (3b) the physician implies consensus by describing all of the members of the team who are, presumably, working together. With the medical authority of multiple physicians from different specialties in agreement, the culmination of Phase 2 in the establishment of terminal status is presented as a collaborative consensus within the medical team. Interactionally, physicians can and do use medical consensus as a power-
ful resource in the end-of-life discussion: in 20 discussions, 14 referred to or implied consensus. Any disagreement from the family would thus be with the entire medical team and its already established consensus.

Physicians sometimes establish a consensus of medical expertise by incorporating references to general medical experience. In the following example, the physicians cite the experience of the medical teams in the SICU with respect to a specific medical problem as a terminal condition:

(4) Dr: Balanced against that is some of our experience here with people who have this type of massive wound. . . . We have also had a long experience here over the time I have been working with Dr Y and I am going to ask him to speak to this in a moment—of older patients, especially older women, who have these types of massive tissue ulcers and what our experience has been—has frankly been not good.

Dr: Both of us have had the experience . . . of working very hard over sometimes extended periods of time trying to get patients like Mrs. [Quorn] better and have not had any success.

Here, both the consensus of physicians and the similarity of their experience are combined in a double set of summary statements establishing terminal status. References to general medical experience occurred in 4 of the discussions in the corpus.

Medical decisions

Another direct convention for strengthening the establishment of terminal status based on the professional determination of futility is when physicians directly say that they alone are responsible for medical decisions in the patient’s care, including end-of-life care, as in the following example:

(5) Dr: When I have this conversation with families it is always difficult for both the family and the doctor, but what I want to mention to you first is that I never ask families to make medical decisions.

In 5 of 20 discussions, medical authority was directly established in terms of decision-making based on the standards of the profession alone.

Medical resources

One final convention related to medical futility is the mention of resources being brought to bear upon the care of a patient. Cassell (2005), Kaufman (2005), and many others have noted that the economic resources devoted to end-of-life care in American hospitals are excessive, given that much end-of-life
care is futile (Financial Implications, 2002). In end-of-life discussions, however, resources are never discussed either in economic terms, such as reimbursement policies, or in institutional terms, such as crowded ICU units or utilization review. Both Zussman (1992) and Kaufman (2005) argue that the course of ICU care is in significant part an economic one, driven by bed availability and reimbursement in the rush to discharge patients from high cost ICU beds.

But in end-of-life discussions, resources are described in terms of the profession of medicine only, and families are routinely assured that every medical resource possible was expended in the care of their patient:

(6) Dr: If I thought there was a ten percent chance that she would wake up and be your mom again, we wouldn’t be having this conversation. I would tell you that we’re doing everything as aggressively as we can possibly go, and if we take days or weeks- We have patients who are in here for months and as long as we believe that there’s a reasonable chance that they’re going to get better, we’re willing to go on for months. We want everybody to get better and it doesn’t matter whether it takes one day or five months.

The pronoun we in this example has the pragmatic antecedent of the medical we, specifically the aggressive medical we that fights death with all the resources it can bring to bear, regardless of cost or any other institutional policies. In 9 of 20 discussions, medical resources were discussed in this way. The care of the patient, including the determination of terminal status based on the judgment of medical futility, is thus presented as aligned with the professional standards of medicine.

In sum, physicians regularly use discursive conventions in the end-of-life discussion in order to establish and strengthen their description of the status of the patient as terminal, not only by describing the medical problems of the patient in negative terms but also by presenting the consensus of the profession of medicine to family members. These conventions provide physicians with a powerful resource in moving toward consensus in the end-of-life discussion; in effect, the family is positioned to simply join the medical consensus.

**Autonomy**

By focusing on the lay understanding of terminal status rather than the professional judgment of futility in the end-of-life discussion, physicians could be seen as hierarchically curtailing the principle of autonomy by situating the determination of futility solely within their professional judgment and not providing or explaining key pieces of medical information. Autonomy could seem to be further curtailed by its conventional construction as a framing
device rather than an actual surrogate decision in Phase 3 of the end-of-life discussion. Again, physicians use a variety of conventions in order to establish consensus concerning the withdrawal of life support from a terminal patient, including the description of the patient as a person, the framing of decision-making as an account of the patient's wishes, and the absence of physician references to advance directives.

**Patient as person**

In Phase 2 of the end-of-life discussion, the focus is on the patient as a patient, one with serious medical problems leading to terminal status, and physicians use the we of the profession of medicine to establish consensus on terminal status based on medical futility. In Phase 3, however, physicians shift to a focus on the patient as a person. The we invoked in the decision-making phase of the discussion is not the exclusive team of medical professionals but the larger group of medical professionals and families working toward a consensus about the patient as a person, a consensus that allows a decision to withdraw life support to be effected without being specifically made. This inclusive group and its function to work toward a holistic consensus based on the patient as a person is sometimes foregrounded in Phase 1, as in (7a), or in Phase 3, as in (7b):

(7a) Dr: What I wanted to do was chat with you a little bit as I try to do with all family members when I come up to the ICU because the patients are all new to me but they are very special to each family in particular . . . [W]hen patients are having long and difficult courses I like to chat . . . . because it’s pretty important that we speak the same language.

(7b) Dr: But what we can do is you can help us understand what his life was about up until the time he came in here- how were things going a month ago or two months ago? . . . What would be a good life for him and what would be a miserable life for him?

The family is thus positioned to talk about the patient primarily as a person in Phase 1 and Phase 3 in the end-of-life discussion: in the corpus, this focus on the patient as a person occurred 4 times in Phase 1 and 10 times in Phase 3.

**The patient’s wishes frame**

Even more specifically than describing the patient as a person, the decision-making in Phase 3 of the end-of-life discussion has a particular frame (Ainsworth-Vaughn, 2001; Tannen, 1993). The beginning of Phase 3 was strikingly uniform across the corpus of EOL discussions: in 16 of 20 discussions
physicians deployed the frame of establishing the patient’s personal wishes as the basis for decision-making:

(8) Dr:  And when we’re faced with a situation like this we rely a lot on you all because you obviously know her better than we do and know what her wishes are and in many cases have had conversations with her about what to do in this type of circumstance where she obviously can’t speak for herself.

Through this frame, the family’s knowledge of the patient as a person is foregrounded as the relevant basis for decision-making.

It is important to note that the patient’s wishes frame does not ask for a decision. It asks only for information, which the families typically provide, as in the response to (8) by the patient’s son and daughter:

(9) Son:  I thought– I don’t know about the others, I know she does– She wouldn’t want to be on a life support machine, we’re thinking in our heads that we’re having it done to her right now.
         Dtr: I don’t think she’d like all the tubes in her because she’s too active. She does not want to be confined to the bed.
         Son: We asked her at [another hospital] before she had the surgery, do they want to put it on her and she said she didn’t want none of that.

In the sequence of (8) – (9), the family is not asked to and does not make a specific decision to withdraw life support. Given that the patient’s status has already been established as terminal in Phase 2, the family’s account of his/her wishes in Phase 3 licenses an implicit decision to withdraw life support.

In contrast to the abstract principle of autonomy, which calls for patients or surrogates to make medical decisions, Phase 3 of end-of-life discussions typically does not include overt decision-making sequences. Families are not presented with a direct interactional sequence asking them to decide explicitly whether life support should be withdrawn. Rather, the discourse of Phase 3 is constructed more as a trajectory of alignment between the person’s wishes and the physician’s previous account of the terminal status of the patient, which, in combination, lead to a holistic consensus that allows life support to be withdrawn. Again, the basis for decision-making is split: families provide information in lay terms that licenses the unspoken medical decision to withdraw life support based on futility.

Once this consensus seems established, physicians typically move directly into Phase 4 of the discussion, which describes the logistics of dying in terms of the withdrawal of life support, as in the following example:
In effect, the decision to withdraw life support is not made as a decision; instead it is a consensus that is assumed in the progression of the discussion toward the logistics of death for the patient.

With the use of the patient’s wishes frame, the agency for the decision to withdraw life support is assigned to the patient him/herself rather than the physician or the family:

(11) Dr: So the one thing that should make everybody feel comfortable, we’re doing what she wants to do. We didn’t do something that she didn’t want. We’re not going to keep her in here for months or weeks against her wishes.

With the patient him/herself constructed as the agent of decision-making, it thus makes sense that the family is not asked for an explicit decision or assigned the responsibility for decision-making in Phase 3 of the end-of-life discussion.

**Advance directives**

In the corpus of end-of-life discussions, physicians routinely used the expression of the patient’s wishes as the licensing factor for the decision to withdraw life support. Physicians did not use the institutional policies of the hospital, including the existence of an advance directive, as a resource in end-of-life discussions at all. A patient’s advance directive was mentioned by a physician only one time in the corpus, and that was after the decision-making framework of the patient’s wishes had been established.

However, in 6 of 20 discussions families used references to advance directives, living wills, and durable powers of attorney as a resource in the end-of-life discussion. When asked to express the patient’s wishes, families often mentioned advance directives as evidence for the patient’s wishes not to be prolonged with life support:

(12) Wife: I can tell you what he wanted. He has signed language.  
Dtr: He’s told us all.  
Wife: He has got a living will and he said he did not want to live that way and that is-  
Dtr: And we do not want him to live that way.
For families, then, advance directives are relevant in their account of the patient’s wishes, which licenses the decision to withdraw life support.

For physicians, however, advance directives seem almost irrelevant, at least as judged by their absence as a physician-initiated topic in the end-of-life discussion. This is, perhaps, the clearest evidence that physicians construct the discourse of end-of-life discussions without accountability to the institutional order. The resources physicians use interactionally are the professional medical judgment of futility and the patient’s wishes as the frame for licensing implicit decision-making.

**Conclusion – an ethics of consensus**

The end-of-life discussion in American medicine is a communicative event that exists within a significant tension between the institutional order of hospitals and the professional practices of physicians. The policies in the institutional order of American hospitals are oriented toward current models of bioethics, with ethical decision-making presumed to be operating under the principle of autonomy, which gives primary responsibility to patients and surrogates in consultation with medical professionals. The interactional order of end-of-life discussions, however, has been shown to be primarily a professional encounter, with physicians in the interactional and decision-making lead. The discourse analysis of the interactional order described a number of conventions used in end-of-life discussions. Taken as a whole, the description of these conventions suggests that physicians organize the end-of-life discussion with a distinct separation between medical decision-making and family contributions. More specifically, a set of conventions, including the description of medical problems in terms of the standards of the profession, situates the determination of medical futility as a professional decision; another set of conventions, including the description of the patient as a person and the frame of the patient’s wishes for end-of-life care, limits the family’s contributions to providing the basis for an implicit decision to withdraw life support, a decision that is thus more a medical decision than a family one.

One perspective on this analysis would be to argue that it provides evidence that the principle of autonomy is systematically violated in the discourse of end-of-life discussions in American medicine. More specifically, physicians do not follow the institutional order that mandates autonomy in end-of-life care and communication, instead interactionally establishing and reinforcing a separation between the expertise of the profession of medicine and the lay understanding of the family. Another perspective, however, suggests that
physicians are holding themselves primarily accountable to their profession in end-of-life care and communication. More specifically, physicians follow the standards of the profession not only to provide treatment but also to decide when that treatment is futile. The relevant consensus with respect to medical futility is thus the consensus of the profession, clinically and therefore ethically. When the professional determination of futility has been made, physicians hold an end-of-life discussion with the family, interactionally working toward a larger consensus that incorporates both a professional and lay consensus that supports the decision to withdraw life support.

The implications of this discourse analysis point to an ethics of emerging consensus in end-of-life discussions. Throughout the discussion, both physicians and families can be seen to be negotiating the ethical issues within this consensus, including medical futility (for physicians) and the patient’s wishes (for families). The research is preliminary, in that it was based on a small corpus of 20 discussions. But the research has the potential to provide another view of ethical decision-making, an inductive view of how ethical concerns emerge in interaction rather than a deductive view of how ethical decisions should be made in the abstract. By investigating ethical decision-making in particular encounters, applied linguistics and discourse analysis can make an important contribution to work on the ethical dimensions of medical communication precisely because this approach foregrounds the interaction among the principals actually involved in important decisions and the ethical concerns that they themselves raise and negotiate.

About the author

Ellen Barton received her PhD in Linguistics from Northwestern University. She is now a Professor of Linguistics in the Department of English at Wayne State University. Her research interests in medical communication include end-of-life discussions, recruitment to clinical research, the discourse of specialty medical encounters, and, most recently, the emergence of ethical principles and deliberation in the interaction of medical encounters. A chapter on Ethics in Interaction will appear in the forthcoming Handbook of Applied Linguistics (Mouton de Gruyter).

Notes

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2 The medical and popular literature on end-of-life is enormous, and it cannot be covered systematically here. For this article, I relied most heavily on the ethnographies of Cassell (2005), Kaufman (2005) and the accounts of physician-writers (Christakis 1999; Murray, 2000), as well as the Curtis and Rubenfeld (2001) volume on death and dying in the ICU.

3 The technical and popular literature on bioethics is similarly enormous, and also cannot be covered systematically here. For this article, I relied on a chapter in Curtis and Rubenfeld (2001) entitled ‘The changing ethics of death in the ICU’ (Mularski & Osborne, 2001). I also refer the reader to Beauchamp and Childress (2001), widely cited as the seminal text in bioethics, as well as Schneider’s (1998) critique of autonomy.

References


