

TOWARDS A "GOOD" DEATH: END-OF-LIFE NARRATIVES
CONSTRUCTED IN AN INTENSIVE CARE UNIT

ABSTRACT. End-of-life decisions regarding the withdrawal and withholding of life supporting technology have become commonplace within intensive care units (ICUs). In this paper, we examine the dialogue between ICU team members and families regarding limitation of treatment as a therapeutic narrative – that is, as a story which frames therapeutic events as well as the critically ill patient's experience in a meaningful and psychologically comforting way for families and health care providers alike. The key themes of these end-of-life narratives are discussed, as well as the qualities that the stories share with other narratives of the same genre.

End-of-life decisions regarding the withdrawal or withholding of life supporting treatment have become commonplace within intensive care units (ICUs). Several studies indicate that the majority of adult ICU patients die following the intentional limitation of some form of basic or advanced life support (Smedira, Evans, Grais et al. 1990; Best, McLean and Mazer 1994; Wood and Martin 1995). A recent study (Prendergast and Luce 1997) found that 90% of patients who died in the two study ICUs did so following a recommendation to withhold or withdraw life support.

Life support recommendations usually occur within the context of an on-going, emotionally intense dialogue amongst intensivists, family members, ICU residents, specialist consultants (such as respirologists, nephrologists, and surgeons), nursing staff, and pastoral care and social workers. Respiratory therapists and the unit pharmacist and nutritionist may also be involved to a lesser extent. The ability of many ICU patients themselves to participate in end-of-life discussions is often impeded by unconsciousness, pre- or co-morbid cognitive impairment, mechanical ventilation, and sedation or analgesics. Thus, it is family members, along with physicians and other ICU team members, who typically engage in such discussions.

In this paper, we examine the discourse between ICU team members and families regarding withdrawal and withholding of life support as a therapeutic narrative – that is, as a story which frames therapeutic events as well as the patient's illness experience in a meaningful and psychologically



comforting way for families and health care providers alike. We begin with a brief overview of the concept of therapeutic narratives, followed by a description of the study from which the data in this paper emerged. Next, we describe the key themes of the stories and discuss the story elements of indeterminacy, metaphor and narrative tension in relation to the literature on illness narratives.

THERAPEUTIC NARRATIVES

The use of narrative, or story-telling, among health professionals, in the form of case history presentations, has a long and well-recognized history (Brody 1987). In recent years, attention has been drawn to other uses of narrative in the clinical setting. Among these is the elicitation of patients' stories of their illness experience as a means of understanding the meaning that symptoms and disorders have in the lives of sufferers (Eisenberg 1981; Kleinman 1988). In a similar manner, Hirst and McKiel (1997) have proposed that nurses encourage their elderly patients to tell stories about their lives, thereby creating a narrational relationship between the nurse and patient. Within this relationship, patient story-telling is supported as a vehicle not only for arriving at shared understanding between the health professional and patient, but for achieving therapeutic goals such as grief resolution. Emphasis is given to the patient's voice and the need for the health professional to act as listener or audience. In contrast, Mattingly (1991, 1994) has advocated for a much more active role for health professionals in narrational relationships with their patients, acting as co-authors of narratives which themselves serve as therapeutic interventions.

"Therapeutic emplotment," the term used by Mattingly (1991, 1994) to describe the focus of the narrational relationship between health professionals and patients, involves clinicians structuring therapy or the course of treatment as an unfolding story. The health professional, together with the patient, envisions a "possible and desirable" ending to the treatment story. Therapeutic events are then "emplotted" within an emergent story, gaining meaning in view of the projected ending. In this way, health professionals "actively try to create certain types of clinical plots, to make certain kinds of therapeutic stories come true and to persuade patients to become partners in this therapeutic story making" (Mattingly and Garro 1994: 771).

This clinical use of narrative is, in many ways, akin to the use of narrative in certain streams of psychoanalysis, which view the therapist's task as that of retelling the patient's past such that it finds a new sense of meaning (Hillman 1983). The therapist, thus, constructs with the patient a

new story because his old story "no longer makes his life events cohere" (Brody 1987: 10).

In using the term "therapeutic narrative" to describe the end-of-life stories ICU team members strive to construct in their dialogue with families around withdrawal and withholding of life support, we refer to an emerging genre of illness narratives, constructed within the clinical or therapeutic context by health professionals and patients. We also refer to the healing or therapeutic intent of such stories. It is the stories themselves, however, that are the primary focus of this paper rather than the dialogical process through which they are constructed.

We favour Byron Good's (1994: 80) function-oriented definition of narrative as "one means of organizing and interpreting experience, of projecting idealized and anticipated experiences, a distinctive way of formulating reality and idealized ways of interacting with it" (cf. M. Good et al. 1994). Such a definition accords with our finding that the construction of an overarching story within which details and events are organized neatly to form a coherent and meaningful structure is seldom realized in the context of end-of-life narratives. The narratives we describe, in contrast, are perhaps better understood as narratives-in-the-making or narrative fragments. They are often incomplete and rarely "neat." The notion of constructing an "overarching story" is itself an idealized experience that narrators strive for because of its promise to bring desperately desired coherence, meaning, and a confident basis for action. Viewing narratives from the stand point of the role they play in the lives of their authors and audience permits an analysis of stories beyond the singular element of plot structure, to devices such as metaphor, imagery and narrative tension. We are particularly intrigued by the themes or, to paraphrase Bryon Good (1994: 165), "the grand ideas" embodied in the narratives.

What, then, are some of the key themes of the end-of-life narratives-in-the-making we encountered in the ICU? How are they communicated through plot structure, metaphor, imagery and narrative tension? What qualities do the narratives share with other stories of this genre and with narratives constructed by patients within the context of their everyday lives about their illness experience? How are they different? How is it that they are healing?

METHODS

The data presented in this paper are drawn from interview and fieldnote data collected during an ethnographic study, the purpose of which was to describe the decision-making process around withdrawal and with-

holding of life support in an ICU. The study was conducted between November 1996 and October 1997 at a large university-affiliated urban teaching hospital. Seven intensivists attend in the 15-bed closed ICU in one-week blocks. There are 52 full-time and 25 part-time nurses. Four junior residents rotate through the ICU every two months.

In total, we observed 25 ICU rounds and 11 family meetings in which withdrawal or withholding of life support was discussed. Participant observation during family meetings was strictly observational and consent for the researcher to be present was obtained from individual families by the attending ICU consultant prior to the meeting. Because of the highly emotional nature of the family meetings, the researchers did not audiotape them. Observations conducted during rounds also included informal interviews with the attending intensivist, residents, nurses, and other housestaff. Extensive fieldnotes were recorded immediately following each observation period. In-depth interviews were conducted with each of the seven intensivists and four residents. Five specialist consultants who care for patients in the ICU and frequently engage in life support discussions were also interviewed. Semi-structured and unstructured interviews related to specific topics or patients were conducted with eight nurses. In addition, we interviewed the ICU nurse manager, the ICU nutritionist, three pastoral service workers, the hospital ethicist, and the families of two patients who died during the study period. On average, the interviews were about 45 minutes in duration. Each was audio-taped and transcribed verbatim.

Transcripts were reviewed for accuracy and, along with fieldnotes, were entered into a qualitative data management software program which facilitated manipulation of the over 20,000 lines of text comprising the project data base. Using a grounded theory approach, data were independently analyzed by members of the research team for emergent themes and areas of further exploration. Data collection and analysis thus proceeded iteratively until interviews and observations were found to produce no new information or analytic insights. The protocol for this study was approved by the ethics review committees of both the hospital and the university. Fieldnote excerpts use fictitious names and identifying information to protect the confidentiality of study participants.

END-OF-LIFE NARRATIVES AND "THE DYING PATH"

In charting any patient's clinical course, ICU team members find themselves functioning simultaneously as actors, authors, and readers in the midst of a therapeutic story, trying to make sense of how it will unfold. Will the patient get better? Will she die? Often there is uncertainty about

prognosis. Many times there are surprising plot twists. A patient who is expected to recover may, for example, suddenly become septic and fair poorly. In contrast, a patient teetering near death may begin slowly to improve. What the stories constructed about illness episodes in the ICU share is a focus on "endings" or "how it will all turn out."

While death as a possible ending has tremendous immediacy at the point of many patients' admission to the ICU, intensive therapeutic efforts are directed at "doing everything" to bring about the desired ending of recovery. The dialogue between ICU team members and family is initially characterized by a sense of indeterminacy. Indeterminacy, which Byron Good defines as "an openness to possibility and the potential for change and healing in the lives of the sufferers" (1994: 146), is created through the maintenance of competing plot lines, each with a different ending. Hope lies in the possibility of a desired ending.

The notion of competing plot lines finds metaphorical expression in the discourse among ICU team members about illness "paths." Like the metaphor of "clinical course" described by Layne (1996), that of illness paths comprises both the concept of the natural history of disease and the patient's response to clinical intervention. In a similar way, its usage "combines both the observed regularity of diseases and their normal response to certain interventions *with* their unique manifestations in a particular individual" (ibid.: 638). Both metaphors convey the idea of a journey (the patient's) from one place and time to a future place and time. Directionality, however, is more strongly implied in the path metaphor. Paths, while they may be described, like clinical courses, as "rocky," "smooth" or "uneventful," are ultimately about destinations or "endings."

Over time with some patients, there is an increasing sense among the ICU team members of the inevitability of death as an ending. They begin to speak, among themselves, about the patient being "on the dying path" and consideration may be given to withdrawal or withholding of life support which would hasten the story's foreseen ending. In the next sections, we examine the themes embedded in the end-of-life narratives ICU members construct with the families of these patients.

Hope Dispelled

Once there is a narrative commitment to the inevitability of a particular patient's death, end-of-life narratives begin to work to dispel hope. Many families, we learned, feel the need to hear that there is "no hope" before considering to withdraw or withhold life support. This part of the narrative that is so crucial to families can be emotionally difficult for ICU team members to communicate. Nonetheless, many times intensivist consultants

and residents will state outright that they feel there is “no hope” or “no reasonable hope.” Other times, “no hope” may be communicated indirectly through the recitation of a litany of medical problems experienced by the patient.

In broaching the subject of withdrawing or withholding life support, for example, many intensivists begin by reviewing “where things are at.” This serves several functions. The family is updated on the current status of the patient. The ICU team is ensured that family members share the same information. They obtain feedback on the family’s perception of the patient’s prognosis. The enumerating of medical problems at the outset of the discussion affirms the family’s building sense that the patient’s prognosis is grim. This experience of “things falling apart” is recounted in the following fieldnote:

On January 31st, Mr. Hunter underwent surgery to “excise the lump.” “On the weekend,” his daughter-in-law recalled, “he was doing well.” Several days later, he began “to sour” and developed “post-surgical complications.” Mr. Hunter had become confused and agitated. The nurses explained to the family that this was not uncommon . . . It was at this point, the daughter-in-law stated, that she had become concerned. In the first few days following the surgery, her father-in-law had been “calm” and was “joking with the nurses.” The following day, he was “fighting the nurses,” “thrashing about in the bed,” “tubes were coming out” and he was “very agitated.” . . . Shortly thereafter, things “started falling apart.” The family learned that the intensivist on call had “spent most of that day and the night before with Dad.” “Dad’s sutures had started separating,” the daughter-in-law explained “and an infection had set in spreading everywhere.” His lung had also collapsed . . . The family was told that Mr. Hunter’s condition was “very, very worrisome.” In addition, a second pathology report revealed that the excised mass was malignant and the cancer had “spread around the local site.” . . . It was at this point that the daughter-in-law knew “the outcome was not good, but for my mother-in-law and the other family members it had not sunk in.” . . . On Saturday morning, the family, along with their minister, met with the attending resident. The daughter-in-law wanted to know “is this hopeless?” She did not feel that her mother-in-law nor her husband were at the point yet where they could ask this question. The resident responded by explaining that Mr. Hunter had developed sepsis and his “lung had burst.” Because of this perforation in his lung, he had “ballooned from 150 pounds to about 300 pounds.” “The air was escaping from his lungs into his body.” As a result, Mr. Hunter had become “unrecognizable.” [Fieldnotes]

The answer to the daughter-in-law’s question “Is this hopeless?” was implied in the blunt listing of further problems.

Communicating the patient’s prognosis (as well as diagnosis) is the responsibility of the attending physicians. Other team members are, therefore, prevented by professional boundaries from making direct statements about prognosis. Yet, they often reinforce the message of “no hope” by participating, along with physicians, in the use of several narrative strategies. One such strategy involves the evocation of images of the body “shutting itself down.” In cases of multiple organ failure, in particular,

images of the body "turning itself off," organ by organ, may be invoked in discussions with family or patients:

Dr. Taylor explained to Mr. Jamieson's wife and daughter that he agreed with the cardiologist's "best guess" that what is happening in Mr. Jamieson's case is that his heart is becoming so progressively weak that various organs are "shutting down." . . . The nurse described how "the heart is working so hard to pump that what the body does is to begin shutting down the other organs to preserve the heart and that is why other organs start to fail." [Fieldnotes]

While these images of the body gradually shutting itself off are grounded in the physiology of the dying process, they gain potency from their insistence that it is the patient's body, as a result of the disease process, that is bringing about the death of the patient – in essence that the disease process is "authoring" the story. Implied is that this "natural" and mysterious process is unfurling toward an inevitable end in a manner that defies intervention.

Another narrative strategy used in dispelling hope concerns the notion of competing plot lines. Typically, narratives maintain the possibility of different story endings. Mary-Jo Good and her co-authors (1994), by way of example, have demonstrated how American oncologists construct therapeutic narratives with their patients, which instill hope by keeping endings ambiguous in terms of time and chronology of events. These oncologists "deliberately blur the horizon of the future" and create for patients an experience of immediacy or living "for the moment."

In contrast, the ICU team members often portray for families explicit "endings" in which death occurs. The ending formulated may be one of days or weeks more of suffering on life support. In the end, death will occur as the result of "a small thing" – a mild infection – which the greatly weakened patient will not be able to rally against. The picture is one of the battle lost before it is waged – and one that is not worth fighting. It is a battle waged not against a formidable foe such as heart disease but a paltry one:

Mr. Jamieson's daughter asked, "Given how very, very weak his heart is, is it possible for it to recover? How is it possible for him to build himself up?" Dr. Taylor explained that "it is very, very difficult and it would take perhaps months and months for that to happen. In that time, there will likely be complications – a pneumonia or some other kind of infection – a pressure sore that becomes infected – which he just doesn't have the strength to rally against." [Fieldnotes]

Dr. Lebreque emphasized that they all hoped that Mr. Ballantyne would pull through this episode even though the odds were heavily against him. "But," Dr. Lebreque cautioned, "even if Mr. Ballantyne pulls through, he will fall ill to another infection because his bone marrow is not functioning to protect him from infections. This could happen in two weeks time, two months time or six months time." "Nobody knows for sure," he added. [Fieldnotes]

An alternative formulation is that of the patient with an underlying terminal illness – a cancer – that they have bravely fought. Days or weeks of protracted suffering lie ahead and in the end death will come in which there is little valour. In both “endings” death is portrayed as inevitable, without dignity, and is likely to be preceded by extensive suffering.

Lastly, the setting in which discussions occur are as important as the more narrative elements of the stories in dispelling hope. Nearly always, discussions regarding withdrawal or withholding of treatment take place in the context of a “family meeting.” These meetings tend to be experienced as events, and as such gain a certain import. Requested usually by the ICU attending physician or resident, they gather family members together as a group and are generally held in a “quiet room” or small conference room outside of the unit. Family members are invited to sit. More importantly, perhaps, in terms of their solemnity is that physicians and other members of the ICU team also sit. These meetings contrast sharply with the informal bedside or corridor conversations held, usually while standing, with family members. The request itself for a family meeting may initially signal the family to the gravity of the patient’s condition. The lowered eyes and quiet tones of the physicians, nurses, pastoral care and social workers, as well as the pauses filled with silence may say more to dispel hope than their words.

At the same time as the narratives work to dispel hope and convey the inevitability of the patient’s death, they also begin to hold out the possibility of an unavoidably sad yet satisfactory ending to the patient’s story. Having formulated less desirable endings in which there is prolonged suffering and loss of dignity, limitation of treatment or life support is proffered as a means to a “good” and timely death.

Withdrawal and Withholding of Life Support as a Therapeutic Act

The act of withdrawing or withholding treatment gains significance within the context of the illness episode. The phrase “withdrawal [or withholding] of life support” has gained a particular set of connotations which may equate it popularly with euthanasia. Most patients, however, leave the ICU one way or another having had life support technology withdrawn, but what varies is the expectation behind the act of limiting treatment. For instance, slow withdrawal of mechanical ventilation with the expectation that the patient will regain self-sufficiency is commonly referred to as a “wean.” Discussions about the withdrawal or withholding of treatment with the expectation that the patient will die, often appropriate the language of treatment, referring, for instance, to the cessation of treatment as a “terminal wean.” Similarly, ICU team members frequently refer to

"D/Cing [discontinuing]" life support in the same terms as they refer to the discontinuation of drugs such as antibiotics.

Some ICU consultants actively attempt to frame withdrawal and withholding of treatment as a therapeutic act.

I think this [withdrawal of life support] is a misnomer and I don't like it one bit. . . . If you phrase it as withdrawal of life support, it leaves you only one part of the story. You present yourself as a person interested in withdrawing life support rather than establishing what is best for the patient. That's really what we're interested in. So, rather than talking about withdrawal of life support, I try to rephrase the topic as establishing optimum level of care for a given patient, and on some occasions it may involve withdrawal of life support. [Interview with Dr. Lebreque (ICU consultant)]

Conceptualizing the act of withdrawing life support as a "therapeutic act" – as doing good for the patient – affirms the decision as a medical rather than moral one (Zussman 1992). It also affirms the decision as the practice of "good medicine," by providing "optimal care" and relieving pain and suffering. It is no doubt psychologically comforting for ICU team members as well as families to think of the act as producing good (optimal care), rather than harm (death).

It is at this point in the construction of the narrative, that a "teleological shift" (Mattingly 1994) occurs. The narrative viewpoint shifts between the present and the future such that current and previous "events" are given new meaning in light of the story's envisioned ending. In particular, new meaning is ascribed to life supporting technology. Technology which previously prolonged life becomes technology which prolongs death. Treatment endured becomes treatment suffered, as the following fieldnote excerpts reveal. Both relate to the same patient, but illustrate the similar narrative tact taken by two different ICU attending physicians.

Dr. Donnars began, "As you know, Mr. Velez is very sick and there is nothing left that we can do for him other than keep him comfortable. It is now time to think about withdrawing some treatments." He explained that Mr. Velez was currently breathing 100% oxygen and that doing so further damages the lungs. He suggested that "we turn down the amount of oxygen closer to normal levels." [Fieldnotes]

Dr. Taylor related on rounds how he had explained to the family that the ICU staff wanted to now think about changing the way in which they cared for Mr. Velez by providing palliative care only. According to Dr. Taylor, Mrs. Velez perceives her husband to be struggling to stay alive. Dr. Taylor replied that perhaps the struggling they were witnessing is fighting to stop what is being done to him or to stop the pain. [Fieldnotes]

Technology and treatment become the villain. They are obstacles that stand in the way of reaching the desired object (Mattingly 1994) – the desired object being a "good death." Like their literary counterparts, technology and treatment reveal malefic qualities. These qualities lie in their "unnaturalness."

A “Natural Death”

Much has been written in the literature on death and dying about the notion of a “good death” (Justice 1997). Within the context of end-of-life narratives, a “natural death” is formulated as the ideal. As Dr. Barfoot describes, it is envisioned as the desired ending towards which ICU team members, family members, and patients strive:

I was uncomfortable bringing up the question of whether or not to remove the ventilator because [the family] clearly gave me the message in a passive way that they did not want to be responsible for ‘letting mother go.’ I, therefore, did not raise this again with them. Clearly, her body died several days ago and we were now trying to be as compassionate as possible, treating the family more than, or as much as, the patient. So I did not bring up the idea of removing the endotracheal tube and the ventilator. What the machine removal would have done is sped up her death by several hours. In the last two hours of this patient’s life, the family asked me what my recommendations were and they said that they would go along with whatever I suggested. Knowing that they didn’t want to take this responsibility, I explained to them that we were prolonging her death and that one approach would be to die naturally without the technology or machinery around her. I suggested to them that she may have wanted to die this way rather than with pipes and tubes and electrical lines throughout her body. After about half an hour of debate [among themselves] they agreed with this. [Interview with Dr. Barfoot (ICU Consultant)]

The notion of a “natural death” has many connotations, even within mainstream North American culture. A natural death may be one that comes at the end of the life cycle as opposed to “premature death” at a young age (Justice 1997; Marshall 1995). In a similar vein, it may be one that occurs when “one’s life work had been accomplished” and “one’s moral obligations to those for whom one has had responsibility have been discharged” (Callahan 1977). A natural death may be one that occurs at home with family, rather than alone in a hospital (Sudnow 1967). Within the context of end-of-life discussions in the intensive care unit, however, a natural death is foremost one unhampered and unprolonged by technology.

A death without “machines,” “tubes,” and “lines” is considered both more dignified and aesthetically pleasing. The body, encumbered by “ugly,” noisy, and invasive equipment transfigures the patient into a cyborg of sorts, making his or her humanity and biological self less recognizable. The presence of this equipment also heightens the sense of the patients’ dependency and vulnerability, robbing them of their personal dignity (Moller 1990). Withdrawal or withholding of treatment – in particular, treatment of the highly invasive, technological sort – is conceptualized as restoring patient dignity and, to a small degree, personhood.

A “natural death” is also romanticized as one that happens in its own time, according to “nature’s course” (Pabst Battin 1983). As a pastoral services worker explained:

I would say [to families] "Well, as long as he's on the respirator we're interfering with his process of living and his process of dying. I think in this case if you take him off the respirator really all it's going to do is let nature take its course."

The same pastoral service worker explained how, in talking with families and patients, she would harken back to a golden age prior to today's era of technology intensive medicine:

I've often said to the patients "You know, what did your mothers and fathers do?" "Well, they died at home." And I'd say "Well, that's nature taking its course without any interference." And they can accept that.

Technology that in other sorts of therapeutic narratives may be storied as "intervening" to preserve life, in the context of end-of-life narratives, "interferes" with and disfigures what is "natural."

Similarly, interventions which are performed routinely and the everyday therapeutic efforts of ICU team members are recast as "heroic measures" (Zussman 1992). In their discussions with families, ICU physicians and residents often tag the phrase to the end of their summary of the patient plan: "no CPR, no defibrillation, no surgeries – nothing heroic." It seems to serve as a highly abbreviated statement of the terms of a contract between the ICU team and families, in which the moral boundaries of what is demanded of the team are loosely defined as not exceeding what is "humanly" possible.

A second and less explicit connotation of a "natural death" is that of a death which is juridically and ethically neutral (Hopkins 1997). Deaths from "natural causes," as Hopkins notes, are "not killing and thus are neither illegal nor immoral, and they do not confer responsibility" (ibid.: 31). In this way, the notion of natural death may offer "protection, exoneration, and comfort" (ibid.: 31) to those engaged in making end-of-life decisions.

"Stepping Back"

The distinctions between nature and technology and the human and the heroic are played out in the central theme of the narratives. This theme concerns the conflict or tension between, on the one hand, the limits of technology and the fallibility of ICU team members as health care professionals and, on the other hand, the tremendous potency of medicine and individual practitioners who are able to intervene in the disease process to the extent that they can orchestrate the manner and time of death. A similar tension exists between families' reluctance to "play God" and their desire to participate in the decision-making process. Both tensions are resolved through the powerful metaphor of "stepping back" and letting

nature take its course. It embodies the ethical distinction between passive (letting die) and active (bringing about death) euthanasia. Also bound up in the metaphor is a sense of mystery that hints at a source of potency – translated variously as “Nature,” “Fate,” or “God” – as the “true” author of lived stories. The metaphor may gain particular satisfaction with ICU team members in that “stepping” or “standing back” does not convey a sense of defeat or giving up. Rather, a certain grace is portrayed in the actions of both the ICU team and families.

A particularly interesting twist on the use of the metaphor came to light in a teaching session conducted by the hospital ethicist with several ICU residents. The residents complained that they had become frustrated in their interactions with Mr. Pollock’s sister who would not agree to withdraw mechanical ventilation. In expressing her reluctance to withdraw life support, Mr. Pollock’s sister had noted that her brother had survived a previous ICU admission in which withdrawal of life support had also been raised. The ethicist pointed out that “if it has been said to the sister three times before that her brother won’t pull through and he has, her hesitance to not give him another chance is understandable.” Continuing, he suggested, that the residents put to her that “if your brother is meant to get well, he will do so even if we [ICU team] back off.” The disease process is again seen as authoring the story and there is a sense that the ending is fixed or “meant to be.” Technology, however, takes on a somewhat different characterization. In this particular narrative, a potentially positive ending (“do well”) is permitted, but technology is neutral – neither life preserving nor life impeding. It is merely in the way. “Backing off” lets the story unfold as writ by Nature, Fate, or God’s Will.

What the Patient Would Have Wanted

As noted earlier, seriously ill patients seldom participate directly in the creation of end-of-life narratives within the ICU. Stories are created primarily by ICU team members and families. Consequently, patients are continually in danger of disappearing as protagonists in their own stories. As the patient’s real voice disappears, so too does any sort of access to the patient’s immediate experience of the illness – in particular, pain or suffering. As one specialist consultant explained:

The fact that the patient is sedated on a ventilator (pause) I think again buffers the emotional trauma that people feel from looking at this but you don’t know what the patient is going through and it almost certainly is not pleasant. We like to think that they’re not aware, maybe in some – maybe in many cases – they aren’t. I think the point is we don’t know. [Interview with Dr. Neeson (Specialist Consultant)]

Ironically, it is the perception that "[t]here's something that is undignified – cruel – in providing ongoing care to these people" that is communicated to families when withdrawal of life support is contemplated. The patient vacillates between sensate and insensate, as required by the story narrators to construct a tale of compassionate action.

Equally inaccessible may be the patient's wishes in regards to aggressiveness of care. A fictional voice is, therefore, often created for the patient, fulfilling a legal and cultural mandate that the patient authors decisions to limit treatment. End-of-life discussions are framed within the context of "what the patient would want." In prefacing the discussions, ICU team members outline the task at hand as determining what the patient would wish for him or herself:

Family was brought into the x-ray room. Present were Mr. Tomchuk's wife, daughter, son-in-law and young granddaughter as well as Dr. Leetham, a resident, the charge nurse, and myself. The resident and I stood just inside the doorway leaving the chairs for Mrs. Tomchuk, her daughter, and Dr. Leetham. The son-in-law stood at the back towards the counter trying to keep a restless 3-year-old in check. Frowning at the young girl's presence, Dr. Leetham began by stating that Mr. Tomchuk is "very, very sick." He went on to explain that Mr. Tomchuk was "extending his heart attack as we speak" and that his condition was very tenuous. He noted that the ventilator was doing the work of breathing for Mr. Tomchuk. He asked Mrs. Tomchuk if she and Mr. Tomchuk had ever spoken about what he would want for himself if he became as sick as he was now, adding that, "Some patients would not want to be hooked up to machines. Others would want us to go to all lengths." Mrs. Tomchuk replied that they had not discussed the matter: "We've never thought anything like this would happen so soon." Mrs. Tomchuk volunteered that she believed her husband would not want to be "hooked up to machines like he is" stating that, "I wouldn't want for him to be in an institution. He wouldn't want that either. If he can't come home . . ." She left the sentence unfinished. [Fieldnotes]

Discussions about what the patient would have wanted, however, appear to be less about patient desires, goals, and motivations in the context of the dying experience – as proponents of advance directives and adherents of the dying with dignity movement would have it – and more about assigning moral agency for the decision to limit treatment to the patient.

Another powerful metaphor used in the construction of end-of-life narratives is that of the patient "declaring" himself. Used widely within the context of the ICU and not just end-of-life discussions, it is rooted in a larger medical discourse around "declaring." For example, "declaring the patient dead," "declaring the cause of death," "declaring the patient ventilator dependent," and "declaring the patient brain dead" are commonly heard expressions. "Declaring" involves formally and openly announcing an assessment of the patient's status that then dictates the health care professionals' plans and further actions in regards to treatment (or non-treatment). In the ICU, it is physicians, in particular, who voice

declarations. It is they who assume responsibility for them. When there is uncertainty about the illness course or trepidation on the part of any of the actors about a decision to withdraw or withhold life support, a “wait and see” strategy may be adopted, allowing *the patient to declare himself*. The act of declaring – an act typically reserved for physicians – is ascribed to the patient. Moral responsibility for the consequences of the declaration is also transferred to the patient. Below are two examples of the use of the metaphor. The first occurs within the context of a discussion involving dialysis, and the other is employed with respect to withdrawal of life support:

A 76-year-old man was in Bed 5. He was undergoing dialysis. The patient was reportedly groggy. A primary concern was whether his grogginess was the result of his sedation or not getting enough dialysis. Dr. Barfoot stated that they [ICU team] hoped he would “wake up and get with the program” – that is, “lose his grogginess and declare himself with respect to the dialysis.” [Fieldnotes]

The physician [may spend] a lot of time talking to this family member, trying to get them to understand that this patient is not going to make it. Pastoral Care is wonderful. They really help us out quite a bit. And a lot of times, or sometimes, the family member never does give in but then the patient declares himself and just starts to deteriorate anyway, and the physician tells the family member “there’s nothing else we can do, your mother or your father is dying, there’s nothing else we can do” and then that family member just has to accept it. [Interview with Renata (ICU nurse)]

In both cases, the decision is, in a sense, taken out of the hands of ICU team members and family.

Sandelowski and Corson-Jones (1996) note that a similar metaphor which they describe as “nature’s choice” was employed by couples who had terminated their pregnancy following fetal demise or detection of ultimately lethal anomalies. “Given that their baby was dead or would die anyway,” the authors observe, “they perceived their choice to terminate as having been made for them” (ibid.: 357). Like the couples studied by Sandelowski and Corson-Jones, it seems that ICU team members and families seek to transfer moral agency for the “ending” or outcome to the patient.

Disappearing the Patient as Person

As suggested by the “declaring” metaphor, the patient becomes an oracle of sorts to both family and ICU team members. Like the Solomon Islanders studied by W.H.R Rivers (1926), ICU patients who are considered to be “on the dying path” are counted among “the near dead.” The near dead hover in a liminal state (van Gennep 1960; Turner 1967) between life and death and where the boundaries between technology and biology are

blurred as machines take over the biological functions of the lungs or liver. In this transitional state, there is a sense of strangeness or mystery about the patient. "Questions" may be posed to this being in the bed much as they might be to an oracle: "Are you really dying?" "Can you hear me?" "Are you in pain?" "Is this what you would want?" In this way, the smallest shifts in vital signs and lab values or movements, facial expressions, and utterances are awaited, searched for, and imparted significance:

Mr. Felice was described as "awake" but having difficulty making "purposeful movement." Dr. Taylor said that he had heard from a family member that Mr. Felice had lifted his forearm slightly and "waved" to family. The bedside nurse interrupted to say, "Well, this is always a problem we have with family. They see purposeful movement when it isn't purposeful." There was then a brief discussion about whether Mr. Felice was able to respond to a command to squeeze with his right hand during a neurological exam. Dr. Taylor concluded by saying, "Well, Dr. Vance (Neurology Consultant) thinks it [squeezing] is real." The group moved on to the next patient. [Fieldnotes]

The "answers," like those yielded by an oracle, are ambiguous. The meaning of such signs are interpreted and re-interpreted over the course of the patient's illness.

Many families struggle for a sign that the patient knows of their presence or that the patient as person is "still in the bed." An underlying narrative tension between asserting and denying the patient's personhood surfaces in the search for meaning in signs:

The family commented that during their visits with him, Mr. Chan was "trying to tell them something." This was particularly a concern to his sister and brother who related that Mr. Chan had been moving his mouth as if to form words and trying to move his hands as if to gesticulate. Dr. Barfoot explained how the ventilator prevents Mr. Chan from making sounds (speaking). The nurse gently added that the tube in Mr. Chan's mouth is uncomfortable and some of his mouth movements may be "chewing" on the tube. In the hallway after the meeting, the nurse insisted that Mr. Chan was "chewing" on the tube and that his family may be reading things into his mouth movements. [Fieldnotes]

The resident explained that Mr. Fredricks had a cardiac arrest and had been resuscitated after being hypoxic for roughly 10 minutes. Mr. Fredricks is presently breathing spontaneously but displays no reaction to pain or "even to suctioning." The resident described Mr. Fredricks as being "in a vegetative state." The nurse emerged from Mr. Fredrick's room at this point and reported that the family had thought his blood pressure had gone up while they were speaking with him. They wondered whether Mr. Fredricks was "responding" to their presence – whether he was "aware" that his family was with him. The nurse said that she had not seen anything to substantiate this observation. [Fieldnotes]

As there is an increasing sense among ICU team members that the patient is one of the near dead, the narratives they construct both among themselves and with families work to "disappear" the patient as person. That is, the narratives convey the death of the patient's social self, which, as noted by Justice (1997), may precede the death of the biological self. They

do so, in large part, by deeming the searched-for “signs” as meaningless rather than meaningful. Such was the case, in a discussion that took place between Dr. Edwards and Mr. Fredrick’s family:

Dr. Edwards explained to the family, that over the next few days as they waited out the results of the EEG that they may begin to see Mr. Fredricks move his body. “He may twitch or move his arm.” “He could even open his eyes, I’ve read?” Mr Fredrick’s sister asked. “Yes,” Dr. Edwards replied. “That could happen.” Dr. Edwards explained that “right now his spine is in shock and there is no body movement, but in the next few days, Mr. Fredricks could begin making involuntary movements. It is like burning your finger. You pull it back before your brain even registers the pain. This is an automatic response and those responses are still there but any of the brain activity that makes Mr. Fredricks a person – the person you knew is no longer there.” [Fieldnotes]

It appears that when a social death of sorts can be perceived as having occurred, it may be psychologically easier for both family and ICU team members to broach a decision to withdraw or withhold life support.

In fact, tremendous distress around end-of-life decisions can occur when the patient is “wakeful” or conscious and communicative. As one of the residents remarked, “If [the patient] wasn’t so damn awake this would be much easier. He’s really awake and responsive now. It would be much easier if he were comatose.” His statement echoes that of a number of residents, nurses, intensivists and other consultants interviewed:

I think when you have someone who’s awake and able to write you sentences, you know, even crack a joke with you, sort of thing, that’s tough. It’s *always* tough when there’s enough response from the patient that they can still be thought of as the person they were, even through the pain. [Interview with Dr. Edwards (ICU Consultant)].

The implication is that a person who is communicative, awake, or appears awake is difficult to consider socially dead, or sometimes even among the near dead.

DISCUSSION

To summarize, the end-of-life narratives constructed by ICU team members in our study work both to disappear patients as persons and to dispel hope. The latter is accomplished by making endings explicit. Alternative endings such as a protracted and painful death may be envisioned. But these are endings to be dreaded rather than desired. Withdrawal or withholding of life support is held out as a means to a good and timely death. The act of withdrawing or withholding is conceptualized as a therapeutic act by which the ICU team members strive to provide optimal care, including relief of pain and suffering. Life prolonging technology is recast

as technology that prolongs death. Treatment endured is viewed as treatment suffered. A "natural death," unhampered by technology, is formulated as the desired ending towards which ICU team members, families and patients strive. While few patients actively participate in end-of-life discussions, these are framed in terms of "what the patient would have wanted." The task of families and the ICU team then becomes one captured by the metaphor of "standing back and letting nature take its course."

These particular narratives share several of the characteristics Byron Good (1994) attributes to patients' narratives of their illness experience and which Mattingly (1994) ascribes to therapeutic emplotments. They are told from the patient's point of view and change as events unfold. Events or actions are emplotted in view of the envisioned ending. Tension and conflict are evident and there are obstacles to be overcome in the quest to bring about a desirable ending to the story.

Of particular note is the central place of metaphor in the narrative process. Metaphors draw upon deeply cultural associations or sets of meanings that can suggest resolutions to narrative tensions. For example, in ascribing a voice to the patient muted by his or her incapacity, the metaphor of the patient declaring himself evokes biomedical understandings of the natural history of disease (Kirmayer 1988) and the more popular notions of self-determination and self-efficacy that underlie the advance directive movement and patient-centered models of decision-making. In this manner, the narrative tension between the necessity to exercise a decision to intervene in the dying process and a reluctance to "play God" is resolved or at least suspended.

The end-of-life narratives constructed by the ICU team members and families in our study are also similar to other narratives in their heteroglossia – that is, in the multiplicity of voices involved in their construction (Good 1994). Other "voices" indirectly involved in their construction may include those of the institutional setting, professional associations, the legal system, lobby groups, or health policy-makers.

As noted at the outset of the paper, end-of-life narratives are socially and dialogically constructed by various members of the ICU team with the patient's family. They are, thus, vulnerable to asymmetrical power relationships among those involved in their construction. Slomka (1992: 252) notes that society confers on medicine "a scientific, economic, political, linguistic and symbolic power and authority." This authority oftentimes privileges the physicians' or ICU team members' voices over those of families in the construction of end-of-life narratives. It would be naïve to claim that the potential for physicians to abuse their authority, wittingly or not, is not present in their interactions with families. We did find, however,

the dialogical process between ICU team members and families to be one characterized not by negotiation between competing professional and lay narratives (Slomka 1992) or the outright imposition of a professional narrative (Kayser-Jones 1995), but by tentative yet creative movement toward a shared narrative in which neither physicians nor families seem to relish power or control over either the narrative or the clinical actions taken at the end of life. We acknowledge that this particular finding may be unique to the study setting, in which a consensus-building model of end-of-life decision-making is worked towards by the ICU team.

There are also important and obvious dissimilarities between the end-of-life narratives examined and other narratives. First and foremost, end-of-life narratives about withdrawal and withholding of life support are stories about dying, not about “the potential for change and healing in the lives of sufferers” (B. Good 1994: 146). They function to dispel rather than create hope. The indeterminacy that marks other sorts of illness and therapeutic narratives gives way to a building sense of the inevitability of the patient’s death. The mysterious, which Good (1994) notes is represented in illness narratives as a source of potency which holds out possibilities of cure or healing, instead propels the end-of-life story to its conclusion. Nature, Fate, or God may be portrayed as authoring the stories.

Suspense or drama inherent in other narratives (Mattingly 1994) is replaced by *denouement* in end-of-life narratives. In particular, tensions such as that between the potency of the mysterious and the potency of medicine or individual health care professionals are resolved. Much of this resolution, as we have noted, comes through the use of powerful metaphors such as “stepping back.” There is also a sense of closure, in that obstacles have been overcome and the goal of a “good” death is within reach.

Lastly, although patients are the protagonists in the narratives, it is families and ICU team members for whom the stories are constructed. As Dr. Barfoot observed in a passage cited earlier in the paper, when their therapeutic efforts with patients become futile, ICU team members often begin “treating families.” By treating families, ICU team members mean that they stage their conversations with families over days or sometimes even weeks, allowing families time to reconcile the inevitability of the patient’s death and come to a decision in regards to limiting treatment. Less obvious to the ICU team members, perhaps, is that the narratives which they construct are themselves a therapeutic intervention.

Like the therapeutic emplotments described by Mattingly (1991, 1994) or M. Good et al. (1994), the end-of-life narratives in question give meaning to the illness experience. Yet, their healing intent lies not in the creation of hope (B. Good 1994; M. Good et al. 1994) or the imaging of

treatment goals and pathways (Mattingly 1991), but in the provision of psychological comfort, which may vary along cultural lines, to families and ICU team members. It seems crucial that neither party feels they have failed the patient. Also important is that there is a shared understanding that the best therapeutic efforts have been exhausted, that the patient will die "a good death," that the burden of the decision-making responsibility has been shared between the participants in the discussion, that the patient's wishes have been fulfilled, and that no moral or ethical wrongs have been committed.

As human beings we need to make sense of our lives; we need to make sense of illness and death. Narrative is a principal means by which we do so. In engaging in a dialogue about limitation of treatment, ICU team members and families attempt to construct narratives of a particular sort. These narratives are about endings. They are about death and about human authorship in death. As such, they are very much moral stories, embodying both the personal values of those involved in their construction and larger lay and biomedical cultural values. Consequently, end-of-life narratives provide a framework for *what it all means* within which the participants in the decision-making process carry out the more ostensible task of negotiating *what to do* when considering withholding or withdrawing life support.

ACKNOWLEDGEMENTS

We wish to thank the physicians, nurses, and other members of the ICU team who shared their experiences with us and allowed us to observe them at their work of caring for critically ill patients. We also would like to thank the people who told us the stories of their family member's stay in the ICU or who permitted the researchers to intrude on the intensely private emotions that arose during meetings with ICU team members in which end-of-life decisions were discussed. Finally, we wish to acknowledge the insightful comments and advice of Ellen McDonald (RN) throughout the course of the study and Barbara Hill's careful transcriptions of the interview data. This work was funded by the Medical Research Council of Canada and the Father Sean O'Sullivan Research Centre. Dr. Cook is a Career Scientist of the Ontario Ministry of Health. Dr. Giacomini is a National Health Research Scholar of Health Canada.

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