Ending the End-of-Life Communication Impasse: A Dialogic Intervention

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ABSTRACT

Providers and their dying patients are stuck in a dysfunctional interpersonal logic that has emerged within the hospital context. Their impasse delays the palliative care that can relieve physical and emotional suffering, dramatically impacting their quality of life. We propose a dialogic intervention: An ongoing conversation in which patients and their families bring life to their personal meanings for post diagnosis caregiving decisions and caregiving tasks. Based upon multiple theoretical models as well as therapeutic and organizational experience, we offer several suggestions for breaking the end of life communication impasse. We believe that giving patients and their families the opportunity to self organize around caregiving will end the end of life impasse. We suggest that family centered post diagnosis care planning conversations with patients and their loved ones will better prepare them to accept hospice earlier than they do today. We propose that patients and their significant others who engage in repeated family centered care planning scenarios will overcome the impasse that exists in the current decision making process.

INTRODUCTION

Gregory Bateson, famed anthropologist and communication scholar, died of
cancer at his own funeral. Here is a portion of his daughter’s, Mary Catherine Bateson, account of their extraordinary “Six Days of Dying”:

“During those six days we were at San Francisco Zen Center, with most of the family and a few close friends sharing in the nursing and the Zen community providing practical help and a context of coherent tranquility….Roger, a friend from Esalen, saw the pupils of his eyes dilate as his mind encountered the dark. So we gathered around the bed, some six of us who had been caring for him most closely, hardly breathing ourselves as we waited from breath to breath, the time stretching, the time stretching beyond the possible, and yet again and again followed by a gasping reflexive inhalation, and then again the lengthening pause. I kept praying that he would be free from each next compulsive effort, let go, rest, and when after a time no further breath followed, we still stood, slowly relaxing with the faintest sighs, barely able to return to a flow of time not shaped by that breathing. Lois reached forward, after her office, and gently closed his eyes.”

“We did not at that time pause to mourn but slowly found our way into the expression of continuing care…in my turn, I reached out and began to straighten his arms, then folding his hands…we all worked together, removing soiled pads, cleaning away the final traces of excrement, lifting and turning and washing each limb…Downstairs we drank sherry and ate the stilton cheese that Gregory loved…”

Like many funerals, Gregory Bateson’s was highly ritualized. Unlike most contemporary funerals, his was a continuation of the caregiving ritual, “so that the shadows of guilt and anger, which so often complicate grief…may be lightened by the experience of tending someone we love with our own hands, so that much that seems externally repellent and painful is transmuted by tenderness.” What is striking about this description of the final days of Gregory Bateson’s life is that the coherent tranquility afforded by his caregivers appears to have allowed him and those around him to preserve some of the qualities that had made his life meaningful. A persistent theme in Bateson’s writing is that meaning, quality, and beauty are possible only in the context of a pattern of connections. In that sense, the meaning and quality of his end of life experience was a continuation of his pattern of living.

As life expectancies increase and the final effects of terminal illnesses are delayed, questions about the quality and meaning of the end of life become increasingly
important. The medical advances that make new options possible for the terminally ill also present new burdens on the social support systems of patients and their families. In this chapter, we explore the communication implications of living longer with a terminal illness. Specifically, we explore what appears to be the paradox of end of life communication: early family led discussions regarding end of life decisions improve the quality of life for patients and their social support network, yet these discussions are often postponed until after many if not all of the options are closed off by death. We offer a therapeutic intervention of family centered care planning dialogues; a metaphor for interpersonal interactions in which patients and their significant others create their own communal meanings for what counts as post diagnosis care and in doing so, construct their own caring rituals, much like the Batesons did.

CONTEXT AND CONVERSATIONS MATTER

Context Matters

Context provides the social permissions and constraints for the kinds of things we can comfortably say and do together. And, in reciprocal fashion, the conversations that occur within these contexts help define their character as well (Pearce & Cronen, 1980). Hospitals, for example, to a large extent define and are defined by the conversations that are held and relationships that are sustained within them (Finnegan & Viswanath, 1990; Harris et al., 2004). It should be expected, therefore, that certain kinds of hospital conversations are more easily held than others. Specifically, as we shall see in our overview of the evolution of hospital and hospice contexts, communication having to do with cure is quite a good fit within hospitals. Conversations about death and the end of life are permissible and even encouraged within a hospice context. However, the evidence of an impasse between patients and their providers regarding end of life communication, reviewed below, suggests there is no reliable way of initiating end of life conversations within the curative hospital context. Our review of recommendations for end of life conversations suggests they are helpful once the patient has shifted into a hospice context conducive of end of life communication but offer no reliable way to initiate the taboo subject of death within a curative hospital context. This chapter offers one way to manage this dilemma.

Rapid changes in U.S. medical care and technology have altered the communicative contexts in which patients and families make their decisions.
concerning end of life care. These contextual shifts have eroded traditional support systems that once guided patients and their families through the unfamiliar territories of death and dying. Although modern medical care has the potential to delay death, and in some cases even seems to offer some hope for avoiding it, ultimately death prevails.

We will ask: In what context can timely death preparations reliably occur?

**Evolution of the Hospital Context in the U.S.** The success stories of modern medical care in the last fifty years make it difficult to recall a time when the hospital was not seen as a place to be healed but rather as a place signifying death. Our ancestors would find it surprising that the modern hospital is now a place where patients sometimes plead to extend their stays, contesting the limitations mandated by cost conscious insurance programs. Yet, this is just part of an ongoing evolutionary drift involving hospitals and the larger culture context. In his history of hospitals, Risse (1999) traces the evolution of the cultural meanings of hospitalization. He observes that hospitals were originally thought of as houses of “mercy, refuge, and dying” (p. 676). But, as a rudimentary understanding of contagion emerged, hospitals became houses of segregation used to isolate contagious patients from the rest of society. During the Enlightenment, the hospital increasingly became a house of science and research. The contemporary hospital has now become a “house of high technology” (p. 677).

With the secularization of hospitals and the shift away from providing a place of mercy and refuge, the patient as a biological entity has benefited in many ways, but patient as a social being has also lost access to some of the community resources that once provided comfort when facing death. Risse writes:

> Historically, hospitals have dealt openly with death and dying, with patients assembled in large wards routinely witnessing such events with a mixture of fear and comfort.... Before the Enlightenment, dying in hospitals was considered a blessing for believers expecting salvation. Surrounded by prayerful care givers and provided with the last sacraments, their redemption was complete. (p. 678.)

As hospitals became secularized, they were forced to compete for funding and this, Risse argues, meant that hospitals began “shunning the fatally ill, viewing their management as a waste of their limited resources and their ultimate death as
detrimental to an image built on low mortality statistics” (p. 679). Risse suggests that a slightly more benevolent version of this attitude is still with us. He writes that “dying is frequently equated with treatment failure, and heroic efforts are made to prolong life at all costs” (p. 679).

**Cancer as Case in Point.** Today families facing a cancer diagnosis typically do so within the hospital’s curative context. It is estimated that 570,280 cancer related deaths are expected to occur in 2005 (Jemal et al., 2005). A majority of terminally ill cancer patients suffer with unrelieved pain, unwanted intrusive life sustaining measures and delayed hospice referrals (SUPPORT, 1995; Field & Cassel, 1997; Fins et al., 1999). This too often becomes a “chronic crisis for cancer patients and their families who find no relief for months or years. Caplan (1971) describes a crisis situation as existing “when a person faces an obstacle which is, for a time, insurmountable through the utilization of customary methods of problem solving. A period of disorganization ensures, a period of upset, during which many different abortive attempts to a solution are made” (cited in Woolley, 1990, p. 1403). Unfortunately, many health care providers are constrained by their training and the curative model of care leave them unprepared to help patients and their families reorganize themselves around the management of a life threatening condition. Misunderstandings, missed opportunities and unnecessary suffering result, as the evidence below, suggests.

**Conversations Matter**

Larson and Tobin write that “For patients and families facing advanced illness, the medical interventions and quality of life that lie ahead are largely determined through a series of conversations they have with their physicians and other health care providers” (2000, p. 1573). This, we believe, is particularly the case for end of life conversations in which quality of life can be enhanced. However, problematic conversations can have a significant impact on the quality of life as well as the evidence reviewed below reveals. There is little research documenting the actual provider – patient dynamics regarding end of life. But we do have access to findings that support Kelly’s multi-site ethnography (1997) demonstrating that families and health care providers hold competing interpretations and concerns related to end-of-life decisions. Our review of this literature takes each perspective in turn, followed by an analysis of the communication impasse these juxtaposed perspectives create.
From the Provider’s Perspective. Ninety-seven percent of doctors told their cancer patients about their diagnosis, according to a survey in 1979, compared to 10% thirty years earlier (Freedman, 1993; Okum, 1961). Physicians are not as forthcoming regarding prognosis. Miyaji found vagueness among physicians when it comes to informing patients about their prognosis. He found that 84% of physicians thought their dying patients were aware of their prognosis. Only half of physicians actually told their patients of their prognosis (1993). In a national survey of internists 90% believed that doctors should try to avoid prognostication. Seventy-five percent replied that they “sometimes find it helpful to shade prognoses to the positive”. Ninety two percent of these internists were “reluctant to make predictions about a patient’s illness when the clinical situation is uncertain” and believe that patients expect “too much certainty”. Eighty-eight percent reported that their patients “might lose confidence in them” if they are mistaken (Christakis & Iwashyna, 1998). A study by Johnston, Pfeifer, and McNutt revealed several reasons, according to physicians, that they do not discuss advance directives, including their fear of depressing or upsetting the patient (1995). Some physicians reported that advance directives were “perceived as the beginning, not the end of the discussion” (Pfeifer et al., 1994).

Providers may block end-of-life conversations to avoid their awkwardness (Morrison, 1998). Schneiderman et al. found that physicians’ projections of what they believed to be their patient’s preferences correlated more closely to their own preferences for less CPR and more artificial nutrition and hydration than their patients (1993). Missed opportunities for communication were identified in 29% of the family conferences that took place surrounding end of life decision making in the intensive care unit. Missed opportunities were defined as opportunities to listen and respond to family members, opportunities to acknowledge and address emotions, and opportunities to pursue key principles of medical ethics and palliative care (Curtis et al., 2005).

Professional training in communication skills has not yet met the perceived need of nurses and physicians (Samaroo, 1996). The SUPPORT project found that even when providing a nurse to facilitate end-of-life discussions most patients had not discussed advance directives with their physicians (Teno et al, 1997).

Our assessment of the providers’ perspective is that their options for managing end of life conversations are limited by the curative and technological context the
medical setting has become. This context offers them multiple justifications to focus on and even intensify the curative tools that have currency in the hospital context. Introducing the topic of death in this curative context places them at perceived risk of awkwardness, for creating anxiety or depression in the patient, or undermining their own credibility.

From the Patient’s Perspective. Passage of the Patient Determination Act (PSDA) in 1990 required health care institutions to inform patients regarding their rights about decision-making and advance directives (1990). However, survey research reveals that although many patients want to talk about end-of-life issues (Miles, Koepp, & Weber, 1996; Reilly et al., 1994; Smucker et al., 1993; Lo, McLeod, & Saika, 1986; Tulsky, Fischer, Rose, & Arnold, 1998), it rarely happens. Happ et al. (1999) found that end-of-life discussions with frail older adults and their families were delayed until the death was imminent if conducted at all. This delay is often accompanied by: a knowledge deficit on the part of both caregivers and patients, denial by the patient, the caretaker’s reluctance to disclose bad news, and an over reliance on high technology (Johnson & Slanika, 1999; Morris & Branon Christie, 1995).

Most patients believed that it is their doctor’s responsibility to initiate a conversation about advance directives, according to a study of primary care patients by Johnston et al. (1995). The great majority believed that doctors should discuss advance directives before their patients are seriously ill (91%), and most patients (61%) thought that discussion should include others, including spouse or significant others.

In a study of older, chronically ill patients, 66% expressed an interest in discussing end-of-life decision but less than 10% had actually spoken to their doctor in this regard (Lo et al., 1986). Gamble, McDonald, and Lichstein found similar results in a survey of older patients who had discussed terminal care with their doctors one year after the passage of the PSDA. Sixty three percent of these patients initiated end-of-life discussions themselves (1991). In a study of the impact of the PSDA upon doctor-patient communication Bradley found of the 40% of alert residents, less than one third had had a discussion with their doctor related to these rights. (Bradley, 1998). The landmark Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), involved over 9000 patients in 5 hospitals (1995). In their subset of seriously ill patients only 23% had talked with their doctors regarding CPR (Hofmann et al., 1997). A study of cancer patients in
London found that 95 of 101 patients wanted “as much information as possible, good or bad” (Fallowfield, Ford, & Lewis, 1994). End-of-life conversations may occur more often among older, more educated patients (Walker, Schonwetter, Kramer, & Robinson, 1995).

Pfeifer et al. found that of the 30% of patients with a life expectancy of less than 18 months, most wanted end-of-life information “in an honest and straightforward manner” (1994). Patients’ conversations are not always in alignment with their medical condition. They may steer conversations away from their “pain, self-blame, anger, loss, fear and other difficult experiences that could be the content of end-of-life discussions” (Larson & Tobin, 2000, p. 1573). Weeks et al. (1998) found that patients often overestimated their chances of survival. Family members may avoid conversations that could move the patient from a curative to comfort form of care (Lynn et al., 2000). Butow et al. (1996) studied cancer patients’ psychological adjustment. Fifty seven percent wanted to discuss life expectancy with their providers but it only occurred in 27% of the cases.

Often patients are frustrated by the lack of end of life conversations but reluctant to initiate them. The physician usually initiates and sets the tone for end of life communication which often relegates the patient to a passive role thereby impacting the flow of communication. Here it makes more sense to not ask difficult questions, placing the responsibility for initiating discussions about death to the professionals in charge of their care.

**Evolution of the Hospice Context**

The increasing emphasis on the curative and the technical aspects of medical cure has created an opening for alternative contexts that offer palliative care. Hospice is one such alternative. Consistent with its roots in medieval times, hospice is primarily concerned with providing comfort rather than cure. Historically, hospices were located along routes popular with travellers, crusaders, and pilgrims. These early refuges were primarily a place of care (Lundgren & Chen, 1986). Stoddard (1978) tells us that the ancient hospice provided “hospitality in its original sense of protection, refreshment, “cherysshing,” and fellowship, rather than the demand of a patient for a cure. (p. 7,cited in Lundgren & Chen, 1986, p. 137).
As modern medical advances made patient cure a realistic option and as the science of pain management developed in the controlled setting of the hospital, the societal appeal of the hospice declined for all but those for whom medical cures were no longer possible. As Morris and Branon Christie (1995, p. 21) observe, “the hospice often is seen as the place one goes to die, the place that says to the patient ‘your end is near.’” This is one of the reasons that, even among the terminally ill, less than 50% receive hospice care (Emanuel & Emanuel, 1998). Approximately one in five Medicare beneficiaries used hospice care in 1998 but the average period of hospice use has declined over the years with half of Medicare hospice users receiving care for 19 days or less and average length of hospice care at one week or less (Government Accountability Office, 2000).

The “hospice as place to die” metaphor obscures the original sense of hospice as a place of refreshment, fellowship, and care. It is the recognition of these important elements of support that has contributed to the recent growth in hospice care, particularly among cancer patients. It is precisely those characteristics along with the possibility of home based palliative care that many find lacking in the more curative oriented based medical context hospitals have become.

**End of Life Communication and the Hospice Context**

Several researchers and practitioners have offered approaches to end of life communication which, we believe, are more reliably conducted in the palliative setting of hospice, given its nurturing context, than in the hospital context:

A recent Institute of Medicine (1997) report recommends that end of life communication should involve:

“not only the preparation of legal documents but also discussions with family members and physicians about what the future may hold for people with serious illnesses, how patients and families want their beliefs and preferences to guide decisions (including decisions should sudden and unexpected critical medical problems arise), and what steps could alleviate concerns related to finances, family matters, spiritual questions, and other issues that trouble seriously ill or dying patients and their families”
Lo et al. (1999, p. 744) remind us that “as patients struggle to find closure in their lives, active listening and empathy have therapeutic value in and of themselves. This is consistent with recent calls for treating elderly patients as “active interpreters, managers, and creators of the meaning of their health and illness” (Vanderford, Jenks, & Sharf, 1997, p. 14; Ragan, Wittenberg, & Hall, 2003). Curtis et al. (2001, p.30) recommends a “family conference” as a way to help patients and families hold on while letting go. Specifically they suggest “moving from hoping for recovery to hoping for some quality time together or for a comfortable death without pain or dyspnea and with as much dignity and meaning as possible.” Von Guten, Ferris, and Emanuel (2000) in their 7 step approach for structuring end of life communication, recommends a family meeting, joined by their physician during which unresolved intrafamily issues can be addressed. Bowman’s (2000) family systems approach to end of life communication offers a similar acknowledgment of the importance of exploring families’ interpretations and unresolved conflicts. Fins and Soloman (2001), Quill (2000), and Choppra (2001) call attention to the value of fostering continual healing relationships, as does the IOM’s recent report on quality of care, *Crossing the Quality Chasm* (2001).

Ragan et al. (2003, p. 221) observe that “all patients, terminal or otherwise, want pain and other noxious symptom management, but patients and their families and caretakers also realize that there are other, equally important concerns at the end of life and that PC [palliative care], ideally, should address these meaning of life issues as well as pain control.” Ragan et al. suggest that palliative care must engage “existential issues of meaning, relationships, autonomy, guilt, dignity, and communication.”

Balaban (2000), in discussing the essential communication elements of palliative care, describes it as “fearless healing”. Fearless healing means listening to and talking about the things that are painful, ‘including patients’ and family members’ suffering and loss. Fearless healing can also mean helping patients and family members “hold on and let go”. As Bowman claims, the “tension between holding onto and letting go of a dying loved one is enormous for any family but can be overwhelming for a family with unreconciled conflict” (2000, p. S19).

Ironically, hospice is the one context in the health care system that offers permission and the expertise to implement the kinds of end of life conversations recommended above. Hospice care can be an important resource offering precisely
the sort of “cherysshing” that may make it possible to experience a high quality of life all the days, even the final days, of our lives. Sadly, few patients with diagnoses of terminal conditions go through these doors.

In summary, hospitals and hospices are not the bricks and mortar that make up their structure. They are the conversations and relational contexts that reinforce each other in shaping what can and cannot be discussed without awkwardness or sanction. The hospital and hospice contexts have created a modern dichotomy between cure and death, and in the kinds of conversations that can comfortably be held about these topics.

There is significant ambivalence and avoidance on both sides, creating an impasse: Patients say they want to talk about issues related to the dying process and many indicate they want the bad news with the good, but when faced with the crisis, avoid the subject in practice. Physicians also want to engage in these conversations but have several motivations to avoid them as well. As a result, in the aggregate, many patients and providers are stuck in patterns of communication in which patients are likely to be both overly dependent upon professionals for defining their fate and overly optimistic regarding their prognosis. Providers often act as though their patients already know they are dying. Discussions about palliative care and hospice options are functionally blocked. As Bowman notes, there is no consensus on the ethical and/or legal approach to communicating about end of life (2000). In fact, providers and patients are more likely than not to define the end of life period in radically different ways (Kelly, 1997). This communication gap “often causes an impasse that is perceived as an either/or choice, and the opportunity to find creative solutions is diminished” (Bowman, 2000 p. S19).

More of the Same is Not the Answer. Some have suggested that more accurate prognosis (Lamont & Christakis, 2001) can move beyond denial and avoidance. Gochman & Bonham (1990) point out that if information about hospice is not provided around the time of the terminal diagnosis, the probability that the patient will make use of hospice care is very small. But this moment is more profound than that. More information is not a reliable solution when patients and providers are determined to interpret each other in ways that avoid the topic of death.

There are times when the provider centric knowledge transfer model of communication is extremely useful. It is efficient in its linear simplicity. It justifiably thrives in the curative medical context where providers’ certainty regarding medical interventions are evidence based. However, a terminal
diagnosis, which is a medically defined interpretation, is unique in all of medicine in that it offers nothing to cure in a curative context. At this point and beyond no one has definitive knowledge regarding the best plan of care. The provider and the dying patient who continue in a dance of avoidance are unintentionally perpetuating a pattern of over dependence on the one hand and sub-standard palliative care on the other. The patient is over dependent on a provider-defined plan loaded with potentially unnecessary curative services. The result is that attention and resources are shifted away from palliative care. Below, we explain how this is so.

UNDERSTANDING THE INTERPERSONAL DYNAMICS OF END OF LIFE COMMUNICATION

As the research reviewed above demonstrates, doctors often assume or hope that their patients are aware of their prognosis and so do not dwell on potentially discouraging news. But patients assume that the doctor knows, and take silence on the topic to mean that there is still hope for a medical cure. This creates an impasse in spite of the good intentions of providers and patients. Here, a focus on the intentions and interpretations of the individual provider or patient will do little to break the impasse because the problem is not with either party—it is between them in their jointly produced interaction.

Interpersonal Logics.

One way out of the impasse is to shift the focus from an individual unit of analysis to an interactional unit of analysis. We find it useful to understand end of life communication by looking to the interpersonal dynamics as the source of the impasse. Specifically we view the impasse as a problem in coordinating competing meanings that frame doctor/patient talk about death (Pearce & Cronen, 1980). This assessment requires an interactional unit of analysis in order to understand the way two or more participants are making sense of a conversation. Based on the Coordinated Management of Meaning (Pearce & Cronen, 1980), the concept of “interpersonal logics” fulfills this requirement.

Interpersonal logics are simply a way to account for the juxtaposition of participants’ moment to moment answers to the question “What should I do next?” Each act in a conversation is contingent on the emergent context and on the sorts of outcomes that each speaker hopes to create as a result of the conversation. The
resulting actions have an interesting kind of logic in that they are always slightly out of control. No individual controls the way the other will interpret a given action and respond to it. But the resulting conversation is not a random collection of spontaneous acts either. The conversation is a function of the rhetorical obligations each speaker feels in response to the acts of the other.

For example, the initial greeting between two strangers has an interpersonal logic that is shared within our culture. It is made up of obligatory reciprocal salutes that guide the joint performance of this ritual. The obligations are so strong for greeting encounters that even the slightest variation (e.g., a greeting between friends, is not returned) can lead to awkwardness and even insults if not repaired with a justification accepted by one’s greeting partner. Yet, it is misleading to suggest that the meaning of the failed greeting was determined unilaterally by the actions of the single individual. For example, using an individual unit of analysis to understand this interaction, either greeting partner who breaks a normative greeting rule may be viewed as socially incompetent or uncooperative. But, clearly many friendly greeting patterns involve an unexpected and even superficially insulting response. In contrast, when we use an interpersonal unit of analysis, we can assess the responses as they fit into the larger pattern of conversation, perhaps even including the relationship or cultural pattern. In this case, it is the greeting ritual itself and its fit within the interpersonal system that determines the level of competence and willingness (Harris, 1979) of the participants.

A similar observation can be made about the end of life communication impasse. Although the research suggests that patients and providers as individuals are willing to discuss end of life options, these conversations are delayed and are often unsatisfying as a result of the interpersonal logic produced when each responds to the other based on competing interpretations and goals.

Because interpersonal logics often produce interactional knots that generate repetitive action, they have also been described in terms of loops. One type of loop is what Cronen, Pearce, and Snively (1979) describe as an “undesirable repetitive pattern” or “URP.” Their research suggests that people can become locked in undesired patterns of interaction when they feel a strong obligation to respond to a particular communicative act. The response is primarily motivated by the existing situation and what was just said or done. An interesting feature of the undesirable repetitive pattern (URP) is that even as people feel compelled to react, they simultaneously disassociate their own responses from the emerging episode of
communication. They feel compelled to respond in a particular way, but they do not experience their voluntary action as either a choice or as an intentional act that was selected to provoke the enactment of the undesirable episode.

Communication impasses concerning end of life decisions may exhibit this looped form of interpersonal logic. Doctors and patients may feel a strong obligation to say or do something, yet they may not be aware that in giving what seem to be appropriate responses, they play into a larger interpersonal pattern that neither individual would choose. For example, a doctor trained in medical interventions may feel a strong sense of obligation to offer options consistent with that training. Yet, even after a terminal diagnosis, merely mentioning a possibility for a cure, no matter how remote, can be heard by the patient and family members as an option that must be explored. For their part, the patient and family feel that they cannot walk away from what they interpret as a potential cure. Even when the provider does not provoke this chain of events with the mention of experimental medical interventions, the patient or family may initiate the pattern by asserting that some sort of treatment must be out there. The urge, or what Pearce and Cronen (1980) would call the “logical force” to look for a miraculous medical intervention is an understandable response when patients frame the context of their care as “healing requires curing.” In this context, nearly all statements by the provider have the potential to trigger a sequence of increasingly intrusive medical interventions with little or no attention paid to palliative care and meaningful discussions about the social, psychological and spiritual needs of the dying person.

A second type of looped interpersonal logic involves reflexivity between levels of meaning (Cronen, Johnson, & Lannamann, 1982). Unlike the undesirable repetitive patterns described above that subvert the good intentions of communicators, reflexive loops sometimes swallow the whole context in which actions are made meaningful. Cronen et al. (1982) use the term “strange loops” to refer to this form of reflexive loops. Strange loops confound the levels of context communicators use to make sense of their actions. A simple example of a strange loop is the command “be spontaneous.” Here, the logic is looped because the relational context necessary to command another’s action is contradicted by the content of the command. To be spontaneous requires that we not follow another’s directions, yet the other has commanded we do precisely that. A strange loop puts people in a double bind where every action seems to change meaning and none of the options allow an escape from the loop. Trying harder within this logic only roots its participants more firmly in their competing justifications for repeating
them as anyone who has told or been told, “You never bring me flowers” can attest.

Not all reflexive loops are strange. We rely on contextual clues to understand the meaning of what is said. But, as the examples above illustrate, what is said and done is not just shaped by context—communicative action also shapes that context. When an action confirms or strengthens the expected context, it implies future actions that are consistent with that frame. In this situation, the loop is a self-confirming one and is referred to by Cronen et al. as “charmed.”

An example of a charmed loop in the curative context concerns the reflexivity between three levels: the context of cure, the relational context in which the doctor is seen as an expert, and the communicative episode of diagnosis. In this case, the curative context legitimates the doctor as having an expert opinion. The act of diagnosing a patient confirms this expertise and strengthens the contextual frame that gives shape to the entire enterprise as being about finding a cure. We can diagram this charmed loop as follows. The direction of the arrows can be read as a short hand for “means that…”

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Curative Context
↓  ↑
Doctor is the expert
↓  ↑
Give diagnosis
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Each element in this charmed loop reinforces the other. In contrast, in a strange loop, one level paradoxically refutes the meaning of the other levels, producing shifts in meaning that can result in confusion, a sense of paralysis, or repetitive attempts to escape the paradox that ultimately continue the vicious cycle.

The end of life communication impasse offers one such example of a strange loop. One half of this strange loop looks like the charmed loop described above. In a context of seeking a cure, the doctor is considered an expert who is able to offer medical opinions to diagnose patients. However, offering a terminal diagnosis is a form of medical evaluation that then changes the context. The terminal diagnosis moves the patient from the frame of “seeking cure” to “facing death.” This shifts the relational frame. Stripped of the possibility of offering a medical cure, the doctor is no longer the expert on how to proceed. Authority shifts to the patient
who now must decide what to do. But here the loop continues. As we saw in the discussion of the undesirable pattern, the patient and family often feel compelled to seek options and their search for options can re-assert the “seek cure” context that then re-establishes the medical sequence. A temporary charmed loop may follow in which patients endure increasingly intrusive medical interventions, each of which confirms the expertise of the doctor in the medical context until, eventually, the terminal diagnosis is given. The loop becomes strange again until time or money runs out.

Editor... an upward diagonal arrow should extend from “Terminal Diagnosis” to “Face Death” and another diagonal arrow should extend from “Patient searches for help” to “Seek cure.”

Strange Loop of Terminal Diagnosis:

Seek cure ≠ Face Death

Dr. is the expert Dr. is not the expert

Terminal Diagnosis Patient searches for help

The result of this strangely looped interpersonal logic can be a desperate pattern of over-dependence on medical technology with too little discussion of palliative care options.

A DIALOGIC INTERVENTION

Like many paradoxes, the end of life strange loop is held together by a cultural assumption that serves as the over-arching context for the various intertwined levels of meaning. The organizing assumption of this loop is the common sense premise that healing requires curing. Consistent with the historical evolution of hospitals and medical technology, the assumption that healing requires curing
locates the physician at the center of decision making discussions and marginalizes the voices of the patient and support givers. When a physician provides a terminal diagnosis, the patient is suddenly thrown into a new context with few signposts for guidance. The bleak choice of seeking a cure or facing death leaves little room for discussing new ways to construct the meaning of care at the end of life. A first step toward ending the end of life communication impasse would be to loosen the grip of the cure or death frame, not by doing more of the same, but by questioning the orienting assumption that healing requires curing. This necessitates a dialogue to open space for new voices and potentially, a new context of healing that is not limited to curing.

We propose an intervention in which dying patients and their significant others assume the lead in care planning conversations. This intervention has a broad interdisciplinary theoretical heritage spanning family systems theory, social construction, and complexity sciences which we review briefly below. These approaches feature an interpersonal unit of analysis and highlight dialogue as a central feature of knowledge creation and change. We then discuss the dialogical underpinnings of these approaches to set the stage for a family centered care planning scenario.

**Theoretical Support**

Watzlawick, Beavin, and Jackson (1967) and others (Watzlawick, Weakland, & Fisch, 1974; Selvini, Boscolo, & Cecchin, 1980) involved in family systems therapy and organizational change management would argue that to the extent that practitioners and patients are locked into a dysfunctional communication pattern there is little room for change. In fact, therapists often find that they are inducted into the dysfunctional pattern of the family by the compelling interpersonal logic that quickly incorporates attempts to change into a pattern of more of the same. Focussing on trying to change individual behaviours and meanings tends only to perpetuate the problem because the pattern is an interpersonal one. Therapists working in the systems tradition have long used an interpersonal unit of analysis for their understanding of communication, knowledge creation, and change. Social constructionists (Chumbler et al., in press; Harris et al., 2004; McNamee & Gergen, 1999; Shotter, 1993; Potter & Wetherell, 1987) also call attention to the importance of relational processes as the source of meaning and action. Similarly, those working in the tradition of complexity sciences highlight the processual, interdependent nature of knowledge. Stacey (2001, 2003), in describing how
people self organize, argues that knowledge “is always a process, and a relational one at that... Knowledge is the act of conversing, and learning occurs when ways of talking and therefore patterns of relationship change.” (p.98). To change the patterns of relationship that characterize the end of life communication impasse, it is necessary to begin new conversations.

In the following sections we review a dialogic model used in family therapy and organizational consulting. We then explore the implications of extending this model of communication to the end-of-life setting.

A dialogic approach to communication emphasizes the relational quality of understanding and the importance of joint action. It shifts attention away from the idea of knowledge as a commodity that is exchanged between two parties. A dialogic approach does not discount medical expertise and the value of specialized training. Rather, a dialogic approach suggests that to be useful, knowledge must be situated in a relational context. Knowledge becomes useful when it is addressed to someone who makes it relevant through a process of conversational give and take. This is consistent with recent calls by Vanderford et al. (1997) and Ragan et al. (2003) to tap into the meaning making capabilities of patients.

The Russian literary critic Bakhtin, one of the pioneers of dialogic thinking, helps us to understand why dialogue is so important at times of crisis. He points out that “understanding is actively responsive” (1986, p. 69). Verbal information is not shared, as a book might be when passed from one friend to another. Rather, spoken words are shaped for the listener who understands them by answering to their call. Speakers, Bakhtin argues, expect “response, agreement, sympathy, objection, execution, and so forth...” (p.69) because these allow a mutual adjustment to and coordination of the emerging flow of conversation.

Dialogic understanding seems particularly important in end-of-life care because it opens a space for patients and their communities of support to actively shape the meaning of their lives together. Compared to models of communication that focus on transmission and information exchange, dialogic approaches are less likely to encounter the various barriers that inhibit initiating palliative care because a responsive dialogue requires that each person experience the multiple voices of the other, including both the hopes and fears of those facing a crisis. The dialogic approach is consistent with Balaban’s notion of “fearless healing” which proposes that health professionals listen to and talk about the things that are painful,
‘including patients’ and family members’ suffering and loss (2000). A relationally situated, responsive encounter fosters a kind of understanding that is improvisational, going beyond the either/or interpretive frames of “cure or death” and “medical intervention or comfort”. We expect that improvisational dialogue can help families reorganize around their crisis in ways that are not likely to be considered within the provider/patient dialogue alone. In addition, a dialogic approach to end of life communication recognizes the multiple voices with which patients, doctors, family, and friends speak. Opening space for these multiple voices is the hallmark of a dialogic approach.

The Open Dialogue Model

Open Dialogue is based upon a dialogic model developed by Finnish psychiatrist, Jaakko Seikkula and his colleagues, (Seikkula, 2002; Seikkula et al, 1995). They have demonstrated the utility of social knowledge construction in their work with patients struggling with psychosis. Drawing on the Bakhtin’s (1986) observations about the dialogic basis of understanding, Seikkula has shifted the traditional focus of medical intervention away from the isolated individual in order to treat the patient as a whole person who is sustained by a larger community. This commitment to understanding the patient as shaped by his or her community requires that Seikkula and his colleagues attempt to bring other voices into the therapeutic dialogue. These “other voices” may include the multiple aspects of the patient whose identity is a composite of many inner voices. The treatment discussion also engages the voices of those other significant people who respond to and define the patient. The result is what Seikkula calls an “Open Dialogue” where the boundaries between the traditional “treatment team” are expanded to include all those who are invested in the patient’s situation.

Seikkula observes that when the treatment team is expanded and open dialogue encouraged, “the joint process itself started to determine the treatment, rather than the team itself or the treatment plan of the team” (1995, p. 64). This observation suggests that a similar approach might interrupt the undesirable repetitive patterns characterizing the doctor/patient communication impasse at the end of life. Specifically, adding new voices to the discussion may provide unique resources for a patient in need of options when faced with a terminal diagnosis. Instead of continuing to search for new options only in the curative context of medical care, the patient can begin to explore healing options that are palliative, not just curative. This is an important shift because it diffuses the assumption that healing is limited
to curing. When that context is changed, the interpersonal logic of the strange loop of cure or death losses some of its force.

**Resource Inquiry.** Resource inquiry (McNamee, 2004) aims to tap the potential creativity generated in open dialogue processes, particularly when the process involves envisioning possibilities that embrace the strengths of the dialogue participants. It involves asking questions that evoke participants’ creative interpretations. Based upon therapeutic and organizational change experiences we suspect that resource inquiry brings a comforting quality to the creative process. That is, people are comforted when their own meanings are given social life.

Resource inquiry is based upon appreciative inquiry which was originally developed for organizational consulting by Cooperrider (1990). This inquiry, based on a reframing of organizational problems, involves asking members of the organization to give voice to times when their commitment to the group was at its greatest, when they felt the organization was at its best. By engaging members in this discussion, Cooperrider is inviting the members to narrate what is possible and to imagine the specific steps that could be taken to construct that future. Though this approach has not yet been widely used to handle the organizational crises families face during end of life care, it is not unreasonable to assume that the same creative energies unleashed when organizations develop positive metaphors to imagine the future can also benefit families searching for ways to make sense of post diagnosis decisions.

Through resource inquiry, end of life dialogues can become a context for exploring and appreciating the narrative and interpretive resources that members of the family and friends bring to the situation. It should lead to the collective constructing of future possibilities, some of which will diffuse the logic of the cure or death frame that fuels the patterns of avoidance and delay when it comes to planning for early palliative care.

**Family Centered Care Planning Scenario**

We have characterized the end of life communication impasse as caused by a paradoxical interpersonal logic which is both guiding and justifying unintentional avoidance of talk about the implications of a terminal diagnosis. Our synthesis of this patterned discourse suggests a conflicting set of rhetorical obligations (Don’t
tell/Don’t ask) constrain providers and patients to talk about curative care, while avoiding talk about palliative care.

**Breaking Through.** We envision an intervention scenario that would be triggered by a life threatening diagnosis. This is in line with the recommendations of the World Health Organization which has re-conceptualized and re-defined palliative care to begin at the time a diagnosis of illness is made. Likewise, Wenrich et al. (2001) suggests that the most appropriate time to consider all care options is at the time a terminal condition is diagnosed. Following Seikkula et al. (1995), we propose the doctor organize a family care planning open dialogue in which the patient is asked to choose those family members, friends and providers he or she would like to have included in the discussion. We expect that this will subtly shift the logic of the undesirable repetitive pattern that constrains doctor patient communication. The prescription by the doctor for an open dialogue plays into the “doctor is the expert” relational context, but the very structure of the open dialogue diffuses this authority and opens the possibility for creating novel responses to the crisis. Used this way, the Open Dialogue model is consistent with evidence that patients want to include others in their conversations at this time (Johnston et al., 2003).

All dialogue participants would be invited to offer possibilities for diagnosis, prognosis and future care options, and to respond to the possibilities offered by others. The knowledge regarding how to proceed reflects a dialogic understanding of the crisis; that is, a way of knowing what to do that is unique to each patient’s support community.

This would differ from the current format of the conventional family conference in that we expect process, not the doctor to determine the agenda. In a fully responsive and open dialogue, no one leads the conversation. Instead, each participant responds to the emerging conversation in a way the gives voice to his or her concerns. This means that values will emerge as a function of the dialogue rather than being “discovered”.

As Bateson and his family illustrated, family dialogue and palliative care can become one in the same when care becomes a ritual, even at the time of death.
A persistent theme in Bateson’s writing is that meaning, quality, and beauty are possible only in the context of a pattern of connections. In that sense, the meaning and quality of his end of life experience was a continuation of his pattern of living.

For families who already have an open, dialogic form of patterned communication, the practice of planning care options will simply provide a platform for them to continue co-creating futures. For families who have not learned to perform meaning creation rituals, the Open Dialogue at the time of diagnosis could usher in their first forms of therapeutic communication and may allow them to create comforting rituals before and after the end of a loved one’s life. To the extent that the open dialogue model allows the construction of narratives that continue long after the initial meeting, there is, we believe, even a place for family conversational rituals among the survivors after a death because a life “carries on in a narrative sense, long after the physical body is dead” (Hedtke & Winslade, 2004, p. 199).

The barriers that inhibit an early discussion of the patient’s prognosis and other end of life concerns are powerful in the context of cure or death, but when healing is expanded to include both the biomedical subject and the social subject, healing is no longer limited to cures. This suggests that dialogic interventions offer a way out of the paradox of end of life communication consistent with Cicely Saunders’ declaration that “We don’t have to cure to heal.”

Based upon the theoretical models above we propose that the dialogic intervention will have the following impact:

- By expanding the relational context to include significant others, each with their own perspective on how to manage a crisis, the group is expected to self organize around a future that is not constrained by the “Seek Cure or Face Death” dichotomy in which the doctor patient dyad interaction had been stuck;
- By introducing new narratives through resource inquiry, members of the open dialogue sessions will generate alternatives to the “Healing = Curing” frame thereby dismantling the context of the strange loop impasse at end of life.
- The self organizing process will have its own therapeutic value for families that have become disorganized by this crisis, particularly as members see their own meaning come to life;
• By turning over the care planning to patients and their significant others, the overdependence upon the doctor at a time when the doctor has limited solutions is diminished.
• Making family centered care planning dialogues a part of the standard of care at diagnosis normalizes a family framed plan of care, thereby granting it and its care options legitimacy.
• A family context will be a more reliable context for considering palliative and hospice care than the current medicalized context.
• Patients, as a result of continued care planning dialogues, will participate in hospice care earlier than those locked in the end of life communication impasse.
• Patients who engage in continued care planning dialogues will experience a higher quality of life than those who receive standard post diagnosis care.

CONCLUSION

We opened this chapter by asking: “In what context can timely death preparations reliably occur?” We have argued that within the curative context, doctor led conversations about death are very difficult to come about. We have also tried to make the case that in the unique instance in which the doctor believes the patient has a terminal condition, post diagnosis planning conversations are best led by the patients and their self selected support communities. We do not attempt to predict specific words that will be spoken to break through the end of life communication in this newly formed family context. We do expect that new ways of relating will yield new ways of knowing and doing that will become more precious to the participants than curative technologies.

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