

Taming death and the consequences of discourse

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Abstract

Healthcare environments have become increasingly complex, especially around the end of life. As they become more complex, organizational members are often pulled in competing directions as they manage to bring order to what otherwise would be a disorderly world. This extensive ethnographic study of a hospice and an emergency department (ED) critically analyzes the nature of discourse and its resulting accomplishments. I use the notion of ‘taming’ to describe the way providers talk about and make sense of their work and work environment, and the consequences it has for their own personal well-being, as well as for care around the end of life. The goal is to elucidate how reclaiming struggle and choice over meaning production is needed for healthcare challenges of the 21st century.

Keywords

burnout, discourse, end of life, healthcare organizations, organizational culture

If you ever – he said – see 4 dead children from the same house fire, you will have had enough. You will understand why you can't do this forever. And the fear is real when they come in younger than you – as young as your children – or a year or two less, but something awful. And you ask 'I assume she smoked,' which is not, in fact a question, because you don't truly want an answer; because no one wants to know it could be you. And you will start to realize about blame, and who wears helmets and who doesn't watch their children run in traffic, and whose fault it is. You will start to realize how fortune favors the brave except when it doesn't. And they will pile up behind you – dozens at first, and then hundreds. You run until it hurts, and you keep running until it feels good again. This is what the marathoners say. At some point the fear becomes gratitude – you have more than most already, even if it will never be enough. Once you find your stride you could run forever. – Rebecca Jeanmonod, MD (2012: 327)

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The aging of the US population is one of the major public health challenges of the 21st century (Centers for Disease Control and Prevention, 2012). Aging baby boomers and longer life spans will combine to double the population for Americans aged 65 and older during the next 25 years. Currently, about 80 percent of older Americans are living with at least one chronic condition and the prevalence of mental illness among elderly is high (Dartmouth Center for Aging Research, 2012; Loeb et al., 2012). Additionally, the cost of providing care for an older American is three to five times greater than the cost for someone under 65. This confirms a 25 percent increase in healthcare spending by 2030. Consequently, the demands for healthcare services for an aging population are exploding.

As the population ages, the demand for emergency and hospice services will continue to be an integral feature of modern healthcare in the USA and other countries. Service industries, like the emergency department (ED) and hospice that care for people who are ill and dying, have long struggled with their own tensions and problems. The famous SUPPORT study (1995), for example, that measured patients' treatment preferences and outcomes concluded that clinicians often did not follow patient preferences at the end of life. The demand for these services is also increasing alongside astonishing rates of medical error. The well-known 1999 study from the Institute of Medicine reported that roughly between 44,000–98,000 people die in hospitals each year because of medical errors that could have been otherwise prevented (Eisenberg et al., 2005; Institute of Medicine, 1999). Outside the hospital, this statistic is equivalent to four completely full commercial airplanes crashing every single week and killing everyone on board (Nance, 2008).

In addition to understanding preferences at the end of life, a dramatic increase in medical error, and an increasing aging and chronically ill population, the ED and hospice struggle with another problem yet: burnout (Kuhn et al., 2008; Zink, 2006). As many as one-third of emergency physicians report burnout that includes dissatisfaction with career, increased number of shifts per month, and even intention to leave the practice. Similarly, a review of international literature reported widespread stress, burnout, and compassion fatigue among hospice nurses because of their work with the terminally ill (Keidel, 2002). Caregiving professions struggle to manage the contradiction of providing care that is simultaneously meaningful yet exhausting. Learning how to sustain, or find your stride, is part and parcel of doing this type of work, but it is not without consequences as patients and families turn to these organizations to make choices surrounding health and treatment.

Understanding the way providers talk about and make sense of their work and work environments in light of contemporary struggles surrounding healthcare is key to the quality of care. Based on data from a two-year ethnography, this article critically analyzes the on-site discourse of how health providers at hospice and the ED talk to and about individuals who are dying and the consequences of talking in this way. Specifically, this article is interested in understating the way providers handle the complexity of these settings discursively, and essentially bring order to what otherwise would be a disorderly environment. Activity at both the ED and hospice is different from care delivered elsewhere. Although both settings have death in common, their practices for handling death are different.

Studies of communication around end of life

To date, research about EDs has been influential in directing attention to how interaction processes construct and maintain culture, including which patterns of interaction are likely to lead to medical errors (Murphy et al., 2008). In doing so, research has started to expose relations between power, knowledge, and the politics surrounding care (Murphy et al., 2008). Additional literature has continued to expose the role of narrative rationality over technical rationality for making decisions and creating a supportive environment wherein patients feel comfortable to tell their story (Browning, 1992; Charon, 2006; Eisenberg et al., 2005). However, observation hours for these studies do not generate rich and extensive understandings of how, for example, narrative rationality gets chosen over technical rationality; how providers manage competing dialectics; how some discourses become privileged over others, and what happens when they do (Murphy et al., 2008).

Similarly, recent literature surrounding hospice care underscores how communication issues are central to discussions about how to improve care for the dying. For example, a recent ethnographic study moved beyond previous understandings of hospice care to illustrate the emotional and affective elements that can be found in mundane interactions (Foster, 2007). From the perspective of a volunteer, this study underscored how relationships can be discovered in dialogue with others during a time that consists mostly of loss (Foster, 2007). Moreover, studies have attempted to explain the complexities of communication during the end of life and even propose a more patient-centered approach to care in contrast to the dominant bio-medical model (Ragan et al., 2008).

This article, however, takes an organizational approach to end-of-life care, meaning it details how communication organizes meaning in particular ways and how these meanings make certain relationships possible over others. Furthermore, rather than focusing on one site or one illness around end of life, this article details the way language shapes decisions around end-of-life care in two diverse settings. I do not argue that these sites are similar; rather, they are profoundly different. However, their juxtaposition illustrates common themes around language use and serves as an exemplar of the larger healthcare system. Both sites have different cultures, climates, rhythms, and purposes for providing care. Nevertheless, they are part of the same system, and the way language is used is more similar than different.

My research responds to the need to explain how providers use discourse and its resulting accomplishments for making sense of end-of-life care. My specific research questions are as follows. First, how do providers' own work practices shape talk and how does talk shape these same practices? Second, how does talk in both environments enable and constrain providers' ability to make choices around the end of life?

Research methods

To assure rich data I ventured through the glass doors of both sites hidden mostly from public view, to the workers, providers, families, and patients who bear witness to the pain and suffering of death, as well as the joy and hope of life.

As a participant observer, I followed medical professionals at the ED through patient intake interviews, diagnostic consultations, and bed rounds for 22 months, being there

two or three times per week for two to four hours. Further, I observed and interacted with both patients and staff at hospice and attended interdisciplinary team meetings to gather a wide range of viewpoints. I worked as a volunteer at hospice and still do, pushing the hospitality cart (a beverage and snack cart) into all 40 patient bedrooms.

As an ethnographer, I developed data collection with a general plan, but have been sensitive to ongoing opportunities and restraints within the field. I have gathered data over a 22-month period, logging close to a total of 200 research hours and yielding more than 1000 single-spaced typed and handwritten pages of raw data consisting of field notes, interview transcripts, and other related documents (i.e. training manuals, documents, and handouts). I also have handwritten notes, scratch notes, and audio-recorded field notes that I wrote every time after leaving the field. When I could not write immediately after, or had too much to write, I tape-recorded myself on my way home (40 minutes from either hospice or the ED), and these recordings were later transcribed.

I carried a notepad with me at both sites to log phrases, questions, and language used. I often did this after immediate interactions, or after such things as the interdisciplinary team meeting where so much happened and the exact words and flow of events made a difference. However, because I did not want to disturb the providers, patients, or families, I mostly wrote my notes after leaving the scene. In total, I completed 15 in-depth interviews of clinic and professional participants, and a number of informal conversations about these issues during my observations. Together, these empirical data provided significant substance for the project.

Critical analysis of discourse

All empirical data were critically analyzed in order to understand discursive struggles and to ultimately 'open-up' discourse. To achieve this I followed an approach used by Deetz and McClellan (2009). The goal of this approach is to discover and promote differences in meanings, often disguised within organizational discourse. Importantly, and one way this differs from Critical Discourse Analysis (CDA), is that it focuses on the way people talk in organizations at a local level, as well as the accomplishments of talk in an effort to transform discourse. For this reason, I critically assessed language in light of the situated discourses that exist over time and within the socio-historical and cultural contexts of both settings, rather than in light of larger formations like the Discourse of dying or the Discourse of medicine, for example.

I do not distinguish between the d/D split (see Alvesson and Kärreman, 2000, 2011; Bargiela, 2011; Hardy and Grant, 2011; Iedema, 2011; Mumby, 2011) for this article because I am interested in the usage, rather than the origin of discourse. Specifically, my critical analysis of discourse allowed me to identify struggles surrounding the normalization of experience and identities to expose how certain values are chosen over others at the ED and hospice.

This approach provided a close examination on the processes that constrain communication in order to uncover alternative choices, values, and meanings suppressed in everyday talk. Consequently, the analysis centers on the systematic and institutional constraints of meaning production.

Critically analyzing discourse can come across as sounding elitist, if not superior, insofar as it is only understood as showing where power and privilege exists. The goal is not superior insight, however. In essence, critically analyzing discourse is about reclaiming and re-opening conflicts that are treated as invisible, natural and normal.

Because discourse has a variety of meanings, including recent controversy over an 'all-encompassing' role trying to account for everything and consequently losing its analytic value and social relevance (Mumby, 2011), let me outline my conception of discourse for this article.

I understand discourse to be a set of interconnected concepts, expressions, and statements that constitute a way of talking and writing about an aspect of the world, thereby framing and influencing how people understand and act with regard to that aspect of the world (Watson, 2002).

Like many who are interested in language use, I turned to Foucault (1972, 1973), whose work crystalizes the relationship between discourse and end-of-life care. For Foucault (1972), discourse makes possible the appearance of certain objects and meanings by forming divisions that produce conformity and commonsense observations. Discourses carry values, beliefs, and ideas that encourage us to think in some ways and not others. Additionally, discourses organize and naturalize the world in particular ways. Therefore, the significance of discourse is the way it achieves normalization through hidden and masked rules of formation (Foucault, 1973).

By rules, I mean internal rules where discourse exercises its own control by classifying, ordering, and distributing meaning, as well as the conditions under which discourse can be used. For instance, how is it that one particular statement appears rather than another? Rules make meaning possible and set the necessary conditions for various statements to appear over others. For this reason, understanding how discourse is constrained becomes central for regaining choice. It is helpful to think of choice as values, because it underscores that something is always chosen over something else (Deetz, 1992).

Moreover, values are not beliefs or attitudes that someone holds and possesses. Rather, 'to value is to differentiate – to act, choose, or desire. To differentiate is to stratify, not by holding the one differentiated thing over the other but by differentiating along this line rather than another' (Deetz, 1992: 61). Differentiating matters because it produces a way of thinking based on a dominant definition of reality. What becomes problematic is that definitions, norms, vocabulary, and practices appear as normal and commonsensical, rather than as value-laden, political, and contestable. Choice becomes a preference of the system and certain meanings and values become visible at the expense of others. For this article, the privileging of values comes in making the separation or the production of struggle.

Before something becomes separated, a degree of struggle exists over what to value. Discourses do not simply represent meaning and culture; they are the very elements that produce meaning and culture surrounding the end of life by becoming routine, naturalized, institutionalized, and accepted (Foucault, 1973). Further, discourses produce approved conflicts, approved responses, identities, decisions, treatments, practices, vocabularies, feelings, resources, and so on. Once identities and feelings become normalized or decisions become common sense, the opportunity for learning is missed as the only thing someone can do is discover where decisions and practices fit into an already existing system.

As organizational dynamics, especially around power and discourse, become increasingly intertwined, many earlier concepts are not equipped to make sense of the incredible nuances of organizational life. Therefore, I use the idea of discursive struggle (Fleming and Spicer, 2008) to help make sense of the relationship between discourse, power, and choice around the end of life. Such a focus already shapes organizational and clinical life as not always filled with order, consensus, and stability, but filled with noise, chaos, cynicism, irony, and fragmentation (Fleming and Spicer, 2008). Moreover, understanding organizational and clinical life as a struggle moves beyond rather limiting vocabularies and understandings to a more generative vocabulary.

Developing a more generative vocabulary helps capture the fears and hopes of struggle rather than its mere causes and effects (Fleming and Spicer, 2008). Struggle can be used to 'get by' or it can be used as a type of engagement that entails change, communication, reflection, and creativity (Fleming and Spicer, 2008). The ED and hospice are extremely rich sites for understanding the affective components of discursive struggle as patients, families, and providers negotiate treatment and care options from diverse fears, hopes, and cultures.

While not drawing on the familiar D/d conceptions in order to understand discursive struggle, I did separate two levels of discourse in light of my research questions. I use the word 'level' cautiously, knowing the constraints and boundaries I put into play in using the term (Hardy and Grant, 2012). However, I believe it is useful for identifying different degrees of language use, or the nature of discourse at these sites (micro level), and its organizing and situated characteristics (meso level). These two levels allow me to focus on the interrelationship between language, meaning, and material practice at the end of life.

Focusing on the way communication constrains meaning is difficult around end-of-life issues because not only am I trying to understand what is happening, but I am also critiquing what is happening. Without a doubt, focusing on processes of discursive closure required the strongest of ethical commitments in places that cut to the core of who I was as a person, friend, sister, daughter, engaged scholar, and lone researcher. In order to handle these competing roles I developed coping strategies to overcome the tension and discomfort of being present at these sites, just as providers, patients, and family members did.

Consequences of providers' discourse

The following section is two-fold. First, I will describe how everyday understandings of death and dying are being shaped in these environments through the accounts and stories of providers. Second, I will detail how providers' talk is simultaneously enabling them to bring order and sense to the complexities of working, but at the same time concealing them and their work practices from critical engagement. I have chosen the word, *taming*, as a way to describe the consequences of providers' discourse. Specifically, I explore how meaning surrounding death becomes tamed, which allows providers to bring order to what otherwise would be a disorderly environment.

Because I am interested in the resulting accomplishment of talk and the process by which providers manage contradictions and tensions around end-of-life care, I have

decided to turn to a narrative-based analysis. I have countless interviews, observations, and conversations that I could include, but I choose two specific narratives. Both narratives are comprehensive exemplars of my larger data set and allow me to achieve the goals of a critical analysis of discourse by detailing the processes and discursive rules that condition their everyday talk. I also made this decision because I want to give the reader a better feeling for what providers' worlds are like, how they think, and how they make sense of their experience in process. The two narratives I have chosen come from two providers, Gerry and Susan, who describe their work. Interwoven into the narratives is my own critical reflection of what is being said in order to understand, critique and ultimately transform discourse.

The language at hospice

The first narrative comes from Gerry, a nurse practitioner at hospice. I have taken these passages from an interview with her; my questions are in regular font and her words in italics:

What's a bad day here? *Well a bad day is when I can't help somebody in the sense that they don't seem to understand what I am saying or maybe the team isn't able to communicate effectively – I mean that is really one of the key challenges with our role, is what we say and what people hear.*

This passage details the way hospice begins to shape a particular meaning and experience about death. Defining a bad day as when patients do not understand providers, positions us to accept that their understanding must be prioritized. I want you to imagine for a moment being a new patient at hospice. You just arrive to hospice after receiving a terminal diagnosis with very few days left to live. The place you have been admitted to is quickly defined as your new home. The moment you begin to take in some of your surroundings, gaze out the window to the empty bird feeder, and re-adjust your legs under the white sheet of an uncomfortable bed, an incoming volunteer walks in and before asking you whether you would like a soda or a bag of pretzels, she asks, 'how are you?' You respond, 'not very good actually.' The volunteer comes closer and says, 'don't worry, this is a place different from any other hospital experience you have had.' Would you feel understood? For both the patient and provider, not feeling understood and not wanting their experience and role to be defined so quickly for them produces a misalignment between what providers say and what patients hear, and vice versa:

And if we are speaking different languages, which can often happen at the end of life, then poor communication is going to make for a really bad day. And it happens in all different shapes and sizes. Each situation is going to be different but if you have a day where you are just not able to communicate openly with another person, it's going to make for a really bad day. What do you mean by different language? Could be a cultural difference. Could be just a knowledge deficit about their disease process. It could be in the form of – maybe they are just in a different place of their illness, their journey – they might have an expectation that is not aligned with hospice necessarily. Not everyone comes to hospice knowing what hospice is or understanding what hospice is, or being ready for hospice. So we're not here, I'm not here to

make them ready, but to meet them where they're at and to see how I can help them best. And that may be staying here on hospice or it may be finding what's in line with their particular goals and values.

This paragraph illustrates how Gerry's everyday language describing what hospice does is accomplished by describing what hospice does not do. Further, hospice here comes across as having choices or meeting them (patients) where they are, but the options of 'staying here on hospice' or 'finding what's in line with their particular goals' suppresses other options from ever being discussed or implemented. In essence, her language conceals the purpose of the organization by promoting that hospice is indeed a different place. Claiming that hospice is different, which is a common move by many organizations, immediately helps Gerry, as well as other providers, patients, and families make sense of this unusual and complex environment:

What's important for this kind of work? First and foremost, you are a human being so don't forget you are a human being! You have to be genuine. I would say listen to other people as much as you can and when you find that you are not able to interact with people anymore whether it is on that given day or that you have to take care of yourself because you're never going to be able to take care of other people. So care for yourself, be genuine.

You have to be really empathetic. You have to be very compassionate. You absolutely have to have a good heart, which probably encompasses all of the above. I would say the primary characteristic that you really need is to be an empathetic person. But at the same time you have to realize that this is the patient's and family's experience and not your experience. So that they – the patient and the family – are essentially the ones that are going through this and you are trying to guide them.

Are there any barriers that get in the way trying to guide patients and families? Yes, in fact, the day-to-day nonsense I like to call it, just the interruptions, the flow of events and the work environment. Essentially, when I talk or meet with a patient and the family, I try to immerse myself in that experience and really close everything else out and not be thinking about what else I could be doing, whether it's with another patient or whether it is something personal, to really give 100% when I am with that patient.

This moment during Gerry's interview was the moment that began to clarify what my data were saying. Hearing her describe 'nonsense' as 'interruptions' and listening to how she tried to 'close everything else out' became the very moment I went back to my data set and re-read it over and over. Reading through it again and listening to how Gerry brought order to her daily life, I began to realize how providers' linguistic practices were taming the disorderly nature of these settings, as well as death. For me, taming means the suppression of something in order to bring it under control. In many ways, interruptions serve as disruptions to routine ways of working that make everyday life a little less tamed and more disorderly. Defining the dying experience as unique and personal immediately suppresses the uncertainty, wildness, and complexity of the experience that so many people struggle with. Further, defining the dying experience as unique and personal helps providers to make sense of the process and therefore allows them to find more meaning in this type of work:

Hospice care is different and people often don't have a good sense of what it is. How come? Well, there is a real interest coupled with fear. It's a real conversation stopper at times. There are a lot of people that just say, 'ooooohhhh'. My family and friends will still ask me, but there is still kind of a veil that comes over them when they talk with me about how are things at hospice, their voice changes and it's serious stuff and I realize in conversation with them how open I have become to talking about dying and the end of life, and how comfortable I am on a professional level with discussing dying and end-of-life issues.

Because the word 'hospice' can stop a conversation, understanding what this place is like is difficult if not impossible. Having a 'veil' come down when people talk about hospice is common. This is not unlike other organizations that determine what can be discussed and even thinkable, thereby producing a particular way of how work should be done. Moreover, it shapes a particular understanding of the organization that becomes fixed and naturalized, thereby precluding any need for a discussion.

Further, Gerry mentions how 'comfortable' she has become talking about death on a professional level, which again helps her make sense of her role and experience at hospice and allows her to talk about something like death more comfortably. In saying there is a professional way of talking about death tames the more affective elements, including the fatigue and stress associated with this type of work. Ultimately, this discourse makes it possible for providers to feel enough compassion to come to work every day and go home with a little bit less of a heavy heart. Although it helps, embodying and acting out a professional vocabulary with professional roles precludes other ways of interacting, talking, and making decisions that do not fall into categories or values deemed 'professional':

Why do you think this problem exists? I think a lot of it is very emotionally charged. You know each and every one of us has known someone who has died and for most people it kind of elicits a painful emotion, probably a mixture of feelings. And so when people talk about dying, especially if they don't have the professional perspective, it becomes a very personal event and it's kind of, they may be respectful, they may feel a lot of gratitude towards hospice professionals either in the past, but for a lot of people it really isn't a pleasant experience so it is something that makes them very emotional and not necessarily in a good way.

Gerry's language simultaneously sets up the contradiction around the difficulty of working here (staying detached) and the satisfaction of working here (providing nurturing and meaningful care). More, her language begins to humanize work practices and experiences as she keeps returning to the purpose of hospice, while suppressing some of the challenges providers face when delivering care around end of life. Again, this process of taming the affective struggles of this type of work is what ultimately lets providers find their stride to keep doing this type of work, even if it hurts.

Throughout Gerry's narrative are subtle calls to whether providers are still sacred in an environment that is remarkably routine, yet through the stories they tell, try to make it unique and special. Providers like Gerry seek to transform routine work practices through a professional vocabulary that for the most part is sealed off to others who have not seen, felt, and heard what their world is like. For those without access to this professional discourse, talking about death becomes un-tamed and therefore scary and uncomfortable. When events like death occur, providers, patients, and families seek out and

take on stories of hope and beauty that allows them to make sense of the situation. In doing so, the less beautiful stories remain invisible, thereby taming alternative meanings and experiences surrounding this type of work.

The language at the Emergency Department

Interestingly, taming is not unique to hospice; it is also a characteristic of the ED. A second clear version of how providers make sense of their work comes from Susan, an ED physician:

It's like a job like everyone else's job. You know, you pack your lunch, hoping you get a few minutes to eat in peace. I mean, it's just weird, you know sometimes a patient will die and a minute later we are ordering pizza and it's not that we have disregard for that person's life, it's that – that's our job and it's no different from the guy who is a car mechanic where it is tragic for the car owner whose transmission fell out, who can't afford to replace it and that car is dead. Yeah, you say, but we're talking about a life. I get that, but everything is still a job and you don't want us – I mean what are you going to do, someone dies in the ER and everyone has to go home because they are so emotionally distraught so we have to bring in a whole new crew? That is a hard thing for people to get. It's not that we are not compassionate – we've been doing it for 20 years and our job goes on. As soon as you finish with this one person who died and console their family, now you are 15 people behind and they are all mad as hell at you.

Susan describes her way of sustaining this type of work for over 20 years. Comparing her job to a car mechanic can sound surprising, but it is her way of coping. Making this comparison transforms the meaning of the ED into something normative and instrumental: this is a job with routines to follow. In doing so, it calls forth a particular set of assumptions and expectations for how this work should be done. Her approach is not unique to other providers at the ED who also make sense of their job in a similar way in an effort to not get overburdened with fatigue by the complexity of the ED. Again, the affective struggles of this type of work become tamed so that providers can do their job in a more orderly way without bringing in a whole new crew:

What makes for a good day at work? I think the personalities in the ER – different nurses, and other docs you are working with – is definitely one of the bigger variables. If you've got the right mix, everyone has good energy, it's funny, sarcastic, playful and we can diffuse a patient's energy with each other. The patients that wear us down are the patients that are demanding, have ridiculous expectations, like I have had this for 15 years and I have seen 10 specialists and I am here Friday night at 10pm and I expect you to have an answer to why this is going on. That can be absurd and sometimes you can let it roll off you, but sometimes patients are so in your face and make you in your weak moments really defensive and engage that behavior and that makes for a bad shift.

Diffusing a patient's energy through play, fun and sarcasm is another way of taming patients' energy, which allows providers to cope and bring order to the complexity of this setting. Her language describes the difficulty of this work, and the way patients wear her down. Although diffusing a patient's energy helps providers to sustain themselves, diffusing becomes an acceptable and routine response for dealing with patients

that otherwise would wear them down. This, in turn, closes off other ways of managing the complex energy of patients that enter the ED, as well as providers' energy:

And then there are other things in the mix that make for a bad shift – last night it was a bad shift because there were a lot of patients that had a lot of sad diagnoses, like one woman came in, had breast cancer 15 years ago, she had bilateral mastectomies, they didn't recommend chemo and radiation, they said it was not called for because it was such a small tumor, and she comes in with a complaint of a herniated disc kind of symptoms and has enough neurological symptoms that I did an MRI because she had lost her reflex, she had lost some bladder control, and sometimes that means you have to do something surgical. Got an MRI and she had bony metastases throughout . . . and you know it was like taking all the wind out of her sail and I think she thought it was never something she'd ever worry about that came back . . . you know that is hard, it's hard to give somebody that diagnosis, it's hard to feel like in the ER you're doing anything but dumping all this horrible information on them saying, alright, why don't you follow up with your doctor, we need the bed, there's 15 more in the waiting room.

Listening and reading this passage about giving bad news makes you feel as if this work is taking all the wind out of her sail too. You feel her struggle with the difficulty of this work. You also feel her struggle to make a difference within the organizational constraints of the healthcare system. Her language and stories, like other providers, quickly sucked me in and made me sympathize with their difficult work life. I got sucked in listening to devastating stories about telling a patient they have bony metastases, or the father was not going to make it, or the son's HIV has taken a turn for the worse. But the moment I got sucked in my critical reflection stopped: reflection about how they make care choices, how they wind down at the end of the day, and how they continue to do this work. Stories begin to drop a 'veil' over their work environment and care practices, which essentially closes off others who are not part of their world:

You know it's like you can't spend enough time with them – you know it's not like they need you to spend more time with them that minute because they need some time to take it all in and sort it out, but the ER seems like a funny place to be handing out that info. So, bad diagnoses can wear us down because we are people too you know and we have our own illnesses and fears about getting illnesses. Or it might remind you of a friend you had that had something and it just sometimes gets really personal and it's hard to keep your defenses. And it's not to say that you are like a wall and impervious to all that is around you, but I don't know that people get that. At some level we have to have the wall up or we would be consumed by horrific diagnoses and sadness and other stuff we do.

Susan eloquently describes the struggle of remaining a human being in these settings, and how providers must not only care for others, but also care for themselves. They do this by keeping up 'defenses'. In doing so, the responsibility falls on themselves, rather than the system for managing their feelings, actions, and decisions. She also points to an important aspect of this type of work that often gets overlooked and suppressed: why providers keep a wall up in the first place. She discusses how easy it is to brush off ED providers as cold and distant, who do not care. But throughout her narrative, and throughout my time at the ED, it is unbelievably clear how much she and others care about this

work. What is less clear is how much of the extraordinary effort providers make to care for themselves is actually being chosen:

Having to try and save someone's life while family are wailing right next to you, is not an easy task. You have to somehow put it aside and though you know it hurts – you're trying to help somebody and I guess that is the hardest part in medicine, at some point you have to figure out how to manage it and if you don't find a way to let it out later it starts to make you a bitter, cynical, burned-out doctor that takes it out on people. And that is the end result that patients see and say what an ass that doc is. But they might not appreciate all the pain and suffering we've had to bear witness to that has taken its toll on us, even though we signed up for it. It still is hard and they don't teach us how to manage that. And there are conferences and lectures on how to handle the difficult patient, or whatever, but it is not really something we embrace. You know, it's not like, hey look what I am going to. It's more you take it on because somewhere down the line you learn you've got to do these things to save yourself.

The enormous pain and suffering providers have had to bear witness to will not excuse poor practice. Interpreting a provider as an 'ass,' however, who 15 minutes before had to tell a family member their son would not make it is not a reasonable or fair interpretation. This type of work is exhausting. Burnout is common, and often the burden falls on providers to manage the exhaustion on their own in order to 'save' themselves in a culture that does not embrace help from the outside. Saving becomes something instrumental that helps providers adjust to the tensions of their work. Hearing her say, 'we signed up for it' again puts the burden on them and makes it so this is the way things should be, which maintains a particular rhythm.

Providers are very creative as they develop a number of ways to cope and ultimately tame the wildness and difficulty of working in the ED and the hospice. Their stories prevent others from asking meaningful questions and therefore understanding the tensions they face. Throughout both narratives providers struggle to make a difference in a system that tames difference.

Discussion: Taming as a re-occurring theme

I chose these two narratives not only because they are rich examples of discourse and the accomplishments of it, but also because they illustrate the process of taming found in a majority of my interviews, observations, and field notes. Specifically, they illustrate how providers' work practices shape talk and how these same practices enable and constrain their ability to make choices around the end of life in these settings.

Listening to providers' accounts of their work experiences illustrates how their language is shaping a particular experience for the coordination of care around the end of life. Part of understanding this experience is understanding how their worlds are organized around the tension of providing humanistic care in an environment that is uncomfortably routine at times. These settings are complex and difficult to work in. For this reason, providers have created practices to tame the wildness and overwhelming emotional struggles of this type of work through a variety of linguistic practices. As a result, taming ultimately saves providers, while naturalizing a system that precludes change

about how to better handle some of these struggles, and better represent a full range of human interests and values (Thackaberry, 2004).

The discourses surrounding end-of-life care are filled with conflict and ambiguity. When there is conflict and ambiguity, there is struggle over what to value. Out of struggle comes choice about how to handle the complexity of providing humanistic care in light of institutional constraints. Certain meanings become prioritized that help providers manage unclear and contradictory organizational expectations, thereby serving as suggestions or rules for how work should be done.

Furthermore, the 'total institution' atmosphere constrains opportunities to reflect and talk about work as providers at the ED and hospice expressed disconnect between what their work is really like, and what their family and friends think their work is like. Consequently, feelings and experiences become tamed and closed off from examination because total institutions are 'a place of residence and work where a large number of like-situated individuals cut off from the wider society for an appreciable period of time, together lead an enclosed formally administered round of life' (Goffman, 1961: xiii, in Tracy, 2004: 516). Together, discourses surrounding end-of-life care are shaping a particular culture.

Culture is a way of understanding how things work at a particular organization, and also what is expected. Although culture, as Gerry and Susan have described it, allows them to survive at these places, culture is also becoming a form of entrapment. The culture at both the ED and hospice – unique to each setting, even though death is common at both – puts into play a set of actions from which they cannot disengage, and consequently, leads to a process that is never questioned. This cycle produces lines of action that become fixed, justified, and confirmed (Weick and Sutcliffe, 2003). For example, recall Gerry talking about having access to a professional discourse. This way of talking quickly became a fixed way of acting around patients. It was justified because it allowed her to close off everything around her in order to be present with the patient. It was confirmed by her describing how comfortable she feels with the dying experience because of her access to this professional vocabulary. Moreover, this degree of comfort justifies the importance of having access to this line of action, and the need for it because it allows her to do the job.

Another way cultural entrapment worked was when Susan compared her job to a car mechanic. This immediately fixed specific roles, feelings and actions of a mechanic that consequently fixed a particular attitude for working at the ED. She then justified this by saying how a patient will die and 15 minutes later we are ordering pizza and it is not because we don't care, but because we can't be consumed by their emotions and bring in a whole new crew. Therefore, acting like a mechanic becomes justified because it allows her and the rest of the crew to continue working. Lastly, this line of action is confirmed as she describes that after consoling with a family whose relative died, there are 15 more people in the waiting room who are mad as hell, justifying the need to tame emotions in order to quickly move on to the next patient. These sequences happened over and over as the culture at both places condition providers to justify and confirm that their actions make sense. Although these sequences help providers and organizations, they disguise important cues that things are not as they necessarily think they always are, or need to be (Weick and Sutcliffe, 2003).

Commitment to a justifying and disguising culture precludes other types of performance (good or bad), conflict, and ambiguity, as well as the need to learn (Weick and Sutcliffe, 2003). Further, commitment to this culture fixes individuals to their behavior, which becomes an unchangeable aspect of their world. Without these processes and practices, death would be wild and out of control. However, because these types of statements and behaviors are made within a certain discourse, dying becomes explainable insofar as justification and disguise exist, which ultimately constrains the ability to develop other ways of handling and understanding death (Du Gay, 2000).

The ED and the hospice are filled with unexpected events, and 'when an unexpected event occurs, we need to explain it not only to others, but to ourselves. So we imbue it with meaning in order to make sense of it . . . people attempt to rescue order from disorder' (Weick and Sutcliffe, 2003: 80). Rescuing is synonymous with taming, as it brings order to discursive struggle and always involves some degree of concealment and justification (Weick and Sutcliffe, 2003). If discourse continues to work to conceal and justify behavior as a way of making such behavior meaningful, the grounds for transformation often work against a culture of reflection and learning.

A culture of learning and reflection remains invisible because 'through repeated cycles of justification, people enact a sensible world that matches their beliefs, a world that is not clearly in need of change' (Weick and Sutcliffe, 2003: 81). This is the very power of discourse: its ability to hide itself and normalize the world. The point is not to argue that the ED and the hospice are doing something wrong or that end-of-life care is broken, because to do so would suggest there are solutions to it. Rather, through my data, I wanted to show how discourse works at these complex and tension-filled settings and the resulting accomplishments of it. Taming is useful for understanding how choices over how to act, how to think, how to feel, and how to make decisions around death are shaping a larger culture surrounding medicine. Moreover, taming helps illustrate how something is always chosen at the expense of something else, which could potentially disrupt the seemingly orderly culture shaped through discourse.

Conclusion

This study details the way providers talk about and make sense of their work and work environment, and the consequences it has for their own personal well-being, as well as for care around the end of life. 'Taming' is a key feature of discourse and sense making at both sites.

Taming is not exclusive to just the ED and the hospice. Every day individuals attempt to bring control and order to the complexities and uncertainties of life. In many ways, taming provides an escape to some of humanity's basic fears: aging, illness, loneliness, homelessness, hunger, and dying. Like the opening quote of this article, finding your stride allows you to escape the pain, even temporarily, so that you can keep going. But this escape is one of the consequences of taming because it prevents different types of discussions from ever taking place, and different types of questions from ever being asked.

The crisis is not about death, but about the meanings surrounding death. The way language is used at the ED and hospice holds incredible power to produce and reinforce

a particular understanding of death and dying. Taming meaning around death, for instance, standardizes policy rates and reimbursements that determine how death should be handled; when it should be handled; how long it should be handled; where it should be handled; and by whom. Further, taming standardizes our access to resources, care choices, and treatments, including what should be said, and not said, around the end of life. Further yet, even specific smells, sounds, colors, spaces, and feelings around end of life are becoming tamed and standardized. Consequently, this kind of inertia, or constant motion in one direction, is naturalizing certain behaviors, practices, and choices around death without disruption.

Finally, taming helps providers manage the stress, burnout, and compassion fatigue associated with the contradictory nature of the ED and hospice. In doing so, taming disconnects providers from their own work experiences, their support systems outside the healthcare setting, and from their original motivations for considering a career in a health service industry. As the population gets older and the demand for care increases alongside cost, understanding the situated discourses of settings that care for the terminally ill and the dying is essential in order to better respond to the public health challenges of the 21st century.

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