

From sense-making to decision-making when living with cancer

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Short title of the Article (for running head): From sense-making to decision-making when
living with cancer Sense-making and decision-making when living with cancer

Word count (all inclusive): 4119 (entire file); 3651 (text only)

Character count (with spaces): 26,993 (entire file); 23,433 (text only)

This is the author's manuscript of the article published in final edited form as:

Goering, E. M., & Krause, A. (2018). From sense making to decision making when living with cancer. *Communication & Medicine*, 14(3), 268–273. <http://dx.doi.org/10.1558/cam.32234>

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Abstract:

The diagnosis of a catastrophic illness, such as cancer, brings with it a whirlwind of decisions to be made. As healthcare systems rely increasingly on shared decision-making (SDM), understanding how patients make sense of health-related information and equip themselves to participate as equal partners in health-related decision-making is essential. Coordinated Management of Meaning's (CMM) LUUUTT (Lived, Unknown, Untold, Unheard, Told, Telling stories) model provides a useful conceptual and methodological framework for better understanding how stories are woven together to create meaning and influence decision-making. This Research Note illustrates the potential of applying the LUUUTT model to autoethnographic vignettes and personal health narratives to reach a deeper understanding of the sense-making and decision-making processes related to living with cancer.

Keywords: LUUUTT model, relational communication, autoethnography, health narratives, Coordinated Management of Meaning, decision-making in healthcare, living with cancer

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From Sense-making to Decision-making When Living with Cancer

1. Introduction

I'm lying here, 5 days after the doctors removed a tumor the size of an American football from/with my uterus and another smaller tumor from/with my ovaries, still waiting for pathology reports. I find myself blaming myself for being in this situation. I should have followed all of the standard medical advice and had regular check-ups, but I didn't. I should have gone to a doctor in Indianapolis at the first sign of trouble instead of flying to Germany. And now it's too late for all those 'should have done's.'

Even knowing that the blame is partly/largely mine, I also know that the decisions we make about health evolve from a system in which meanings are constructed in community, and those decisions that "I" made weren't really made by me alone. My decisions to not get regular physicals were made within the context of my past experiences and conversations related to health. They were made within a context of iatrophobia, of almost always leaving doctors' offices feeling bad about myself. They were made within the context of recent experiences with friends who did everything right and died anyway within six weeks of receiving a cancer diagnosis (Goering, personal diary, June 2014).

As this autoethnographic vignette illustrates, diagnosis of a catastrophic illness immediately throws a patient into a whirlwind of decision-making. Much has been written about decision-making in healthcare (i.e., Vahabi 2008; Joseph-Williams *et al.* 2014; Wigfall and Tanner 2016); however, relatively little is known about the sense-making processes that inform patients' decision-making. As healthcare shifts to models of shared decision-making, with patients playing a much more active role in determining treatment plans, understanding how patients make sense of health-related information and subsequently make health-related

decisions is important. This study is part autoethnography, part personal health narrative, and part qualitative research. The goal of this Research Note is to illustrate how these approaches can be intertwined to provide a useful methodology for offering richer, deeper understanding of sense-making, and ultimately decision-making, related to healthcare. After introducing Coordinated Management of Meaning (CMM), the theoretical framework for the analysis, and providing a brief review of relevant literature, we describe the methodology employed in the study and then illustrate how CMM's LUUUTT model can be used to illuminate the sense-making and decision-making processes associated with living with cancer. The paper concludes with a discussion of the implications of our study.

2. Conceptual Framework

The conceptual framework for the study is Pearce and Cronen's (1980) Coordinated Management of Meaning (CMM). This theory assumes communication is constitutive; in other words, communication episodes are the central processes whereby humans co-create their social worlds. Further, CMM assumes that communication episodes are patterned and that, by analyzing communication patterns, we can see the world we are co-creating. CMM is generally recognized more as a collection of models about how meaning is communicatively constructed and coordinated than as a single "theory."

The CMM model that is particularly relevant for this study is the LUUUTT Model (Pearce Associates 2004: 58). LUUUTT is an acronym for Lived, Unknown, Untold, Unheard, and Told stories as well as the Telling of stories. The model explores how we create our social reality through the interplay between stories lived and stories told. As we live experiences and then tell stories to others about those experiences, we co-create meaning. Complicating this process are the three U's – untold, unheard, and unknown stories – that also affect the reality that is constructed. An analysis of the reality that is being constructed

through the exchange of lived and told stories needs to consider these absent stories as well as the stories that are shared and the process of sharing them. This study seeks to illuminate the meaning-making processes in interpersonal interactions that impact health-related decision-making by exploring in-depth the experiences of one relational unit as they traveled together through one partner's cancer journey.

3. Literature Review

Research shows that interpersonal relationships are an important part of health-related decision-making. Early research on health information-seeking (e.g., Connell and Crawford 1988; Johnson 1990) confirms that informal interpersonal channels are used as much as more formal sources of health information, such as doctors or health organizations. This tendency was confirmed more recently in Eliacin, Salyers, Kukla, and Matthias's (2015) study that reported that many patients prefer to include friends and family members in decision-making.

Clearly interpersonal networks are an important part of health-related decision-making. In their groundbreaking research that challenged the assumption that health communication is situated primarily in health institutions, Tardy and Hale (1998) identify a variety of functions served by conversations individuals have within their interpersonal networks, including "cracking the code" and "bonding." These authors conclude that these interpersonal conversations are not just information exchanges; rather they are a vehicle through which "shared experiences are created and maintained" (Tardy and Hale 1998: 151). In addition, Dohan *et al.* (2016: 270) note that, "when making healthcare decisions, patients and consumers use data but also gather stories from family and friends." While quantitative information can be overwhelming for a patient, stories shared interpersonally can "provide compelling and actionable information." Nonetheless, Dohan *et al.* suggest that how these stories and narratives influence decision-making is "poorly understood." This study utilizes

the LUUUTT model to zero in on the co-construction of meaning within relational networks and its influence on health-related decision-making.

4. Method

The methodology used in this research is a LUUUTT analysis of autoethnographic vignettes, personal health narratives, and meta-analytical conversations produced by the co-authors of this paper as together they faced a cancer diagnosis. In June 2014, while teaching in Germany, Beth was diagnosed with cancer. She was operated on in a German hospital and in August returned to the U.S. for follow-up care, which consisted of chemo and Brachy radiation treatment. Throughout this journey, Beth's primary interpersonal support was her partner, Andrea, the co-author of this paper, who was teaching at a university in Germany at the time. Personal journals and diaries were kept during the 8 months of treatment, and these artifacts served as the narrative texts for the study.

For this particular study, we selected those vignettes from the journals and diaries related specifically to decision-making. We shared those stories with each other, and then "interviewed" one another about our narrative accounts, the sense we had made individually, the meaning we had co-constructed, and the way this had affected health-related decision-making. Finally, we analyzed the narratives and interview transcripts using the LUUUTT model.

5. Coordinating Meaning through LUUUTT

Because of the restrictive nature of a Research Note, we have limited our analysis to a handful of vignettes. Our intention is to illustrate the potential of CMM and LUUUTT for deepening our understanding of the interconnections between relational communication, sense-making, and decision-making in healthcare.

Decision-making is, indeed, a primary activity when confronted with a health crisis. Nearly all of the individual journal entries written by the co-authors included observations about or descriptions of decisions that had to be made. There were decisions about diagnostic procedures, treatments, whom to tell about the diagnosis, how to keep friends and family in the United States informed; the list goes on and on. These decisions ranged from the seemingly inconsequential (e.g., what to do when chemo-induced baldness set in) to much more serious considerations (e.g., do the benefits of Brachy treatments outweigh the risks of radiation). Together the stories stand as a testament to the pervasiveness of decision-making in a health crisis.

As one might expect, a common focus of decision-making in these narratives was related to treatment. In our case, one of the first decisions to be made was where to undergo treatment: in the U.S. or in Germany. That was not the first treatment decision that had to be made, though. Prior to that was the decision about whether to pursue treatment at all:

Today we went to the Krebszentrum for more tests – more poking and prodding to confirm what we all already know. It's cancer. I can't help but think of a similar scenario about 5 years ago when Andrea and I accompanied a friend of ours to a Cancer Center in Indianapolis. We sat there dumbfounded as the doctor shared his diagnosis and prognosis with our friend. Later Andrea said to me, "I've never been in a room when someone was given a death sentence before." Indeed, in less than 2 months, our friend had died. I think we both were thinking of that experience, because when the doctor recommended surgery as the best treatment option and talked about the chemotherapy that would probably follow, Andrea asked, "Is it worth it?"

Without actually saying it, she was asking how much longer I would live with the treatments than without. Even though I couldn't make myself ask that question, I was

glad she asked. I both want to know and don't want to know what my prognosis is. If this is the end of my life, then I would rather spend my last weeks or months at the seaside with Andrea, or traveling around spending time with friends and family. I don't want to spend it going through treatments that might extend the quantity of my life by a few days, weeks, or even months, but where I'd spend that extra time in hospitals, hooked up to machines, and not out living my life. (Goering, personal diary, June 2014)

The LUUUTT model provides a useful framework for analyzing this vignette. In this case, the lived story was, in fact, not a singular story; it was multiple interconnected stories that were being lived by people whose lives and stories overlapped. In this conversation, where patient, caregiver, and oncologist were deciding on the next steps to take, multiple stories – lived, told, and untold – were coming together.

One lived story that clearly influenced both patient and caregiver was the shared experience of being in a similar conversation several years earlier with a friend who died shortly after being told that she had cancer. Although this story was not told in the moment, its influence is evident in the decision-making. Through the living and telling, that story had been incorporated into the mindsets that now informed our efforts to make meaning and decisions in this situation. Of course, to the German oncologist, the story of our friend was an unknown story. Since we did not mention it, the story of our friend was untold and, thus, remained unknown. The oncologist, however, obviously had her own lived stories, untold to us, that shaped her perspective, as evidenced by her response to Andrea's question, "Is it worth it?" "Yes," the oncologist replied, "I've seen many women who have had this surgery for years after the operation."

As we shared and reflected on our treatment-related decision-making stories, we noticed how we were superimposing sequence on them when, in reality, they were not sequential. We were in the process of making many of these treatment decisions all at the same time. We were exploring whether insurance would cover the treatment in Germany while we were discussing prognosis and treatment alternatives with the doctors. In fact, we had checked into the hospital and were planning the implementation of treatment decisions with the surgeon while we were still waiting for approval from the insurance company in the U.S. This observation is reinforced in a comment made in our meta-analytical conversation: “I guess decisions aren’t always logical and sequenced; they don’t always follow those neat little decision trees.” The complexity of decision-making at this point in time, immediately following diagnosis, was exacerbated even more by the fact that patient and caregiver were simultaneously living the stories individually and together; they were both shared and individual experiences. It was only in the telling of the stories after the fact that the stories were placed into a sequential “story line.” The lived reality was much more complicated, a web of interconnected story threads that represented multiple decisions that needed to be made.

Decision-making was a primary activity throughout this healthcare journey, but in the two weeks from the first doctor’s visit to the actual surgery, both patient and caregiver felt caught in a whirlwind of decisions. It is important to recognize that not all of the decisions that had to be made during this time were as major as the ones described up to this point. In some instances, even minor decisions played an important role, as illustrated by the following vignette written by Andrea:

Not all of the decisions that had to be made in this health crisis were of such a serious nature. In fact, now looking with hindsight, some were almost

humorous – such as the decision about what to wear in the hospital. In Germany there is a particular script – a dress code, so to speak – for when you’re in the hospital. I was in charge of figuring this out, and what I had running through my head was what I had learned from home. My mother always said that you had to keep a clean, spare nightgown in your closet “in case you had to go to the hospital.” So with that narrative in my head, I went and bought Beth nightgowns, a bathrobe, and the kind of slippers she needed to wear to sort of “blend in.” And even though that sounds sort of funny that that’s what I needed to spend time making decisions about, I think in the end it helped Beth blend in and cross that cultural divide that she had to cross in addition to having this life-threatening illness to deal with.” (Krause, personal diary, 2015)

This narrative illustrates the pervasiveness of decision-making in healthcare; indeed, decision-making is a constant in a health crisis. Further, it illustrates how the plethora of decision-making episodes, both major and minor, are experienced as lived stories, and through the living and telling of those stories, they are woven together into a tapestry of meaning that provides the foundation out of which future decisions are made. As new decisions arise, they are woven out of and into the fabric of the pre-existing stories.

In our meta-analytical discussions, we realized that there were many other instances where this was true. The metaphor of a train on a track came up to describe this: “Once you were in the hospital and the insurance company had given its ok, it was like the train left the station, and we never even thought about getting off. It never even occurred to us that we could.” Another metaphor that emerged in our conversations about our cancer journey was the image of the ripples caused by a stone thrown into a body of water. “When your doctor

says, “You have cancer,” she is throwing a stone into the pond that is your life, and the ripples that spread out from that reach more people than one realizes.”

Part of the disruption caused by illness is to pre-existing decision-making structures and processes within the relational system. This is a finding that crystalized only after the fact, in our meta-level conversations about decision-making. An effective way to set the stage is to share a vignette written by Andrea about the patient’s first chemo infusion:

It’s difficult to think of this as a narrative, even though there was always a sequence of events – a plot, in a sense. My memory, however, is more in terms of snapshots – when suddenly a spotlight on high beam plunged things into searing brightness for me to see what I didn’t want to see, as I am rather a “looker-awayer” in most things medical!

Generally speaking, one difference definitely was that when we got to the States, I felt that Beth was back in charge. In Germany, I was the one native to the way doctors’ offices and hospitals work – down to the “you need a bathrobe and slippers and your own towel and washcloth” type stuff. I was not terribly knowledgeable, however, since I am rather phobic of medical facilities. Still, through relatives being in the hospital, I knew enough of the script to take over and be in charge of negotiating the German healthcare situation.

In Indy, Beth (now physically a bit stronger and recovering from her operation) was back in the driver’s seat – literally, as she drove us to the clinics, and figuratively as she did most of the negotiating of the healthcare situations related to her follow-up treatment. Since Beth needed no translating or language help here, my role was less well defined. One constant between

Germany and American: I functioned as a clothes rack and bag holder (in all the meanings that can take on!). I have rather vivid memories of sitting perched on – often uncomfortable – stools or chairs, clutching our coats and Beth’s clothes when she had to undress for an examination. I also rummaged in bags to pull out various forms and medical reports to hand to Beth when needed. In some ways, this feels like (and did then, too) focusing on irrelevancies, but clutching our stuff perhaps gave me a small measure of control and familiarity in the alien and anxiety-producing territory. (Krause 2014)

Decisions are routinely made within primary relational systems. Families do not just fall into decision-making mode when health issues arise. Instead, relational systems regularly make decision about everything from what to have for dinner to where to go on vacation to how to manage finances. Within these decision-making systems, members play different roles, and system-specific norms for making decisions are generally followed. One of the disruptions caused by health crises can be to the normative patterns for decision-making within the relationship, as illustrated in the above narrative. In our meta-analytical discussions about decision-making, we were surprised to realize that these shifts had occurred without our being aware of it. Once again, the story lived was a story untold until we made a point of telling it to one another.

6. Discussion and Implications

This study set out to explore the potential of utilizing CMM’s LUUUTT model to expand our understanding of the ways in which individuals in a relational system make sense of health-related information and then translate that into decisions. In keeping with findings reported by Tardy and Hale (1998) and Dohan et al. (2016), this study reinforces the

important role primary relational networks play in that process. In this section, we will recap some of the key findings from our research and discuss their implications for health related decision-making.

The autoethnographic vignettes analyzed for this study reveal close friends and family members are influential in constructing the social reality in which health-related decisions are made. CMM's LUUUTT model provides a useful framework for conceptualizing this coordinated meaning-making process. Both of the participants in this study entered the health crisis with individual and shared lived stories – experiences they had had individually or as a dyad related to health and health management. In addition, both had stories that had been told to them, stories that helped to shape their individual belief systems and perspectives related to healthcare. When the crisis hit, these stories became the foundation for the conversations within the relational system related to decision-making. These foundational stories shaped the meaning-making in this situation, whether the participants were aware of it or not. The meta-analytical discussions that took place after the treatment was completed reveal that the stories that were not told were just as important in meaning-making as the stories that were told. Those conversations also revealed that, generally, meaning-making and the coordination of meaning are not transparent actions, even though these processes play a constant role within the relational system.

Another conclusion supported by these data, and one that has implications for communication education for healthcare professionals, is that generally the stories that influence decision-making are not shared. Decision-making frameworks and the past experiences that have shaped the way an individual perceives and responds to an event are generally not talked about. In this case they certainly were not part of the decision-making conversations between doctor and patient. Surprisingly, decision-making frameworks were

not even shared within the primary relational system when decisions were being made. They were only discussed during the meta-analytical discussions the participants engaged after the fact. Knowing the “stories untold” is potentially very valuable. In general, an increased meta-level awareness of the factors affecting decision-making would be beneficial. Perhaps training that promotes this meta-level awareness and the sharing of untold stories should be embedded in curricula that teach communication skills to healthcare professionals and in general health/interpersonal communication courses so that both patient and healthcare provider can be better prepared to engage in shared decision-making.

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