AFFECTIVE COMMUNICATION: MANAGEMENT OF BAD NEWS FOLLOWING CANCER DIAGNOSIS & STEM CELL TRANSPLANT

By

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Fewer than one third of terminal cancer patients have ever had a conversation with their doctor about their values and treatment goals, according to recent studies. In the absence of these conversations, physicians more often administer futile therapies; patients are more likely to die in the hospital; and to suffer at the end of their lives. The purpose of my research is to examine how communication among patients, caregivers, and physicians addresses end-of-life decision-making. The research focuses on disclosures of bad news about a decline in health status in three contexts of importance to patients: (1) hearing the diagnosis for the first time; (2) sharing the diagnosis with family and friends; and (3) discussing changes in health status in the outpatient setting. I followed twenty-eight patients with leukemia, lymphoma, or myeloma from diagnosis until twenty-four months post stem cell transplant. My research suggests that more important than the skillfulness with which physicians handle the initial news disclosure is the sense of being supported by the medical system overall. Patients were most concerned with the level of coordination between medical staff and consistency of the information provided. Also overshadowing initial diagnosis is that, in the long haul, over ninety percent of the conversations in the outpatient setting focused on routine and short-term changes in health status. Explicit discussion of prognosis and serious changes in health status were, by contrast, rare. Accordingly, explicit discussions about end of life appear to be non-normative in the outpatient setting. These findings may help explain the paucity of end-of-life planning. Overall, my research contributes to the sociological literature on chronic illness and medical communication. My study, as a rare longitudinal ethnographic examination of disclosures of bad news, sets the stage for further such research not only in cancer clinics but also in other health care settings involving chronic illness.

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PREFACE

Shortly after concluding fieldwork, I attended a cancer symposium where oncologists and medical researchers discussed the challenges of communicating with patients. Most of the sessions focused on the problems that arise in clinical practice along with proposed interventions. The tone of the conference shifted noticeably however, during the last session when a well-known journalist took the stage and 'put a face' on issues discussed throughout the day. The speaker introduced herself as the spouse of a cancer survivor two years post stem cell transplant and introduced her husband seated in the front row. Then over the next forty minutes, through a mix of jokes and tears, she recounted her husband's diagnosis of lymphoma with metastases to the brain and traced the path by which her family came to take up residence in "Cancer Land."

While most of what she discussed I had heard before from cancer patients and families over the course of fieldwork, her account fixed my attention because of the emotion she used to convey her story. As I listened I thought how the oncologists and researchers in the audience could certainly understand, on a cognitive level, the issues she discussed, but embedded in the way she presented her story was a deeper emotional message I believed would only resonant with those in the audience who had "been there" too. This sub-textual something came through particularly in her discussion of three aspects of the experience, all influencing the quality of care but, sadly, having almost nothing to do with medicine as it is practiced in the United States today.

The first was the communal nature of the illness experience. "Cancer is the whole family's disease," the journalist said to explain her planned use of "we" throughout her talk. "Our whole family got cancer in 2008 and our whole family were patients." This sentiment is hardly foreign to the medical community and, in fact, the family is increasingly recognized as key to successful recovery. However, little about the organization of formal care takes the needs and strains on the whole family into account. Most family caregivers will say they do the work because they care and "because it's there to do," but over time caregivers often lose a sense of themselves as anything other than a caregiver and the blessing and burden of the situation becomes deeply and confusingly intertwined. Patients find the situation emotionally confusing as well. While valuing the comfort and support from family, the loss of independence coupled with an awareness of the negative impact of their illness on family is, research shows, among the most common causes of depression.

The speaker also noted the uneasy communication relationship between families and physicians. As an investigative journalist, she was accustomed to asking hard questions, but said that around her husband's oncology team she often was silent. Speaking directly to the oncologists in the audience at one point she said, only half joking: "We believe that you have the power to make our loved ones whole again but if we make you angry, you also have the power to kill them off." This might sound like an exaggeration, but there is a core of truth in it -- parents, spouses, and children of patients in my study *routinely* second-guessed their decision to ask or refrain from asking a question of the doctors or nurses, fearing that a misstep might alienate them and effect their loved one's care. Studies have shown, in fact, that doctors rarely convey detailed information about the diagnosis except in response to direct inquiries from patients and family members (Christakis 1999; Helft 2005). Thus, if questions are not explicitly posed, physicians may take this as an indication that the patient and family do not want, or are not ready for, more information. In line with these kinds of findings in the literature, the speaker said, "What scares us most is what you are not willing to tell us unless we ask. Please don't make us ask."

Third, as the primary caregiver, the speaker noted the inner conflict of simultaneously planning for "two futures": one with and one without her husband. Although grateful to her husband's oncology team for all they had done, she lamented not having received more guidance when making important "non-medical" decisions. Among other things, this included trying to decide whether to quit her job and draw down retirement savings to be with her husband in what could be his final months or to continue working because both of them would need the income down the road. Caregivers in the study, and in a number of online venues, have talked frequently about this dilemma.

What is the theme running through her discussion of these three issues? Thinking about it afterward, I believe it had to do with a feeling of liminality and living too long between ordered worlds. Cancer patients and families fear that almost anything could happen now that cancer is a reality and many are desperate to restore some kind of order. This subtext is likely to come through to someone who has been there, but remain invisible to those without personal experience. In fact, it is an emotion often interpreted as paranoia by clinicians, but important I think because it complicates everything about treatment, communication with doctors, and overall coping with the disease. I recognized this, in part because of my research with the families but also because of my personal experience as the primary caregiver for my mother during her cancer treatment twelve years ago. Like this journalist and the patients and families in the study, I also struggled to communicate with medical staff and often did not "get it" when something important was conveyed during a clinic visit. Like them, too, I assumed that an inability to grasp the information that the clinicians provided was due to being emotionally overwrought, unfamiliar with the medical terminology, and generally unprepared to negotiate the medical system. However, revisiting this scene as a researcher many years later I began to think that this phenomenon could and should be investigated to begin to specify what exactly about communication during a long illness makes it so confusing and difficult for so many patients and their families.

The phrase "affective communication" in the title is a play on words. Articles and books routinely use "effective communication" as part of the title to cue readers that the text will discuss ways to produce a desired effect on a specific audience through communication. *Affective* communication, by contrast, alludes to a symbolic interactionist inspired way of thinking about communication. In fact, it reaches back even farther to the early writings of William James (1884) who claimed that we learn to feel emotions through acting in the world and responding to external circumstances. Thus, from this perspective, skillful communication in the clinical context requires understanding conversations as not only a cognitive, rational process, but also a form of interaction that arouses an emotion strong enough to evoke certain kinds of responses. This dissertation title reflects the idea that communication research may benefit occasionally from a less utilitarian achievement-oriented approach ("effective") and more from beginning to see how communicators influence each other and co-produce understanding ("affectively").

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I dedicate this dissertation to the memory of my parents, Paul and Delores Schaepe, who in life and death have taught me much. I also dedicate this effort to my family Bruce, Barb, Rob, and Beth Schaepe who provided ongoing emotional support. (Andi and Cody, too.)

Introduction: The Sociology of Chronic Illness

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This dissertation analyzes disclosures of cancer news in three social contexts of particular importance to patients: (1) hearing the diagnosis for the first time, (2) sharing the diagnosis with family and friends, and (3) discussing changes in health status in the outpatient setting. In each context, the goal was to understand the experience from the patient's perspective. That is, by attending closely to how patients described these experiences and observing how patients managed these news episodes over time, my research seeks to explore the longitudinal dimension of coping with a serious chronic illness. This research contributes primarily to the literature on management of chronic conditions and to the cancer literature. It is one of the few studies to focus on cancer communication specifically, and it may be the only study to look at "bad news" as a longitudinal phenomenon in cancer care. I first review the sociological literature on chronic illness, positioning the current study within this literature. I then describe the research design and the data used to conduct the investigation. I conclude with a brief summary of the subsequent empirical chapters.

The Chronic Illness literature

In 1951, Talcott Parsons introduced the "sick role" in his book *The Social System* as an involuntary form of social deviance affording individuals temporary exemption from normal role obligations. Parsons' was the first sociological framing of the illness experience and sixty years later, it remains a key contribution in the field of medical sociology (Cockerham 2010). Over the years, however, Parson's model has been criticized as only applicable to acute conditions. Chronic illnesses such as cancer, heart disease, and diabetes require thinking of the "sick role" not a temporary status but a status "overlaid" on an individual's normal roles and responsibilities (Mechanic 1959).

Since Parsons, qualitative sociologists have investigated the chronic illness experience in several ways. One line of research builds on Parson's functionalist theory of roles and examines patient strategies for managing, among other things, an illness "career" (Zola 1973), "illness behavior" (Mechanic and Volkart 1960), and the medical system overall (Freidson 1960; Stimson and Webb 1975). Another line of research –

and the first substantial challenge to Parson's model – draws on symbolic interaction (SI), a theoretical approach to qualitative research that is based on the work of George Herbert Mead (1934) and Harold Blumer (1969). The SI tradition maintains that social reality is "constructed" through individuals in interaction and in the context of widely shared symbolic meanings.

Several early ethnographic SI studies identify dimensions of the chronic illness experience that remain central to the study of chronic illnesses today. Among these are Julius Roth's, *Timetables* (1963), which drew on his personal experience with tuberculosis as well as extensive field observations in three hospitals to highlight discrepancies in the way patients and doctors characterize the *passage of time.* The disparity between how physicians and patients conceptualized time proving critical to ongoing communication problems. Roth found that physicians spoke of time as a relative measure – defining "good progress" in terms of comparisons between patients. TB patients themselves experienced time emotionally, often resisting long periods of uncertainty about their condition. Based on fieldwork with fourteen pediatric polio sufferers and their parents, Fred Davis' *Passage through Crisis* (1963) revealed the role of families in management of polio, laying blame for communication breakdowns primarily on the medical staff. Like Roth, Davis also pointed to discrepant definitions of time as a key factor interfering with patient care, noting that conceptions of time in conjunction with what constituted "recovery" and "rehabilitation" for the child were primary areas of disagreement between doctors and parents. In addition, Davis points to ways that physicians engaged in evasive communication tactics and at times resorted to technical language out of impatience or defensiveness. Evasion and obfuscation were particularly counterproductive, because it eroded parental trust essential to maintaining a therapeutic relationship and managing the child's illness overall.

Erving Goffman's work, although not aimed at a specific disease, has also contributed a great deal to understanding of the chronic illness experience. In *Asylums* (1961) Goffman offers insight into the ways the organization and structure of medical care can affect patients. His dramaturgical conceptualization of 'life as a stage' in *Presentation of Self* (1959) led to development of the notion of "impression management" which, others have identified as an ongoing preoccupation for many coping with chronic illness (Strauss et al. 1984, Charmaz 1991). Goffman's *Stigma (*1963) has also been influential, revealing how individuals who are labeled as different for any number of reasons attempt to minimize the disruption to their lives by avoiding situations where they are likely to experience judgment. His work has aided understanding of the psychosocial challenges faced by patients coping with chronic illness and examined how these pressures can lead sufferers to retreat from social contact.

By far, the most comprehensive ethnographic investigations on the social and psychological experience of chronic illness to date are that of Anselm Strauss and colleagues. Strauss's work over the years not only considered time, family, the structure of medical care, identity, and stigma, but also integrated the patient's subjective experience into the broader organization of care. That is, his research has examined how patients cope with illness, manage self-care, and maintain professional and personal relationships. Strauss (1975) and Strauss et al. (1984) have also examined the effect of hospital and clinic schedules on patient's experience of a chronic illness. Conceptual and practical insights emerging from Strauss's work on chronic illness are numerous, but the notion of an "illness trajectory" has been particularly influential. Developed in collaboration with Juliet Corbin (Strauss and Corbin 1988; Corbin and Strauss 1985), the illness trajectory is an extension of previous research on the dying trajectory with Barney Glaser (Glaser and Strauss, 1965; 1968). The trajectory maps out expected temporal phases of a chronic illness, including the "acute phase" where effort centers on bringing the condition under control, the "comeback" phase (organized around reintegration into normal life), and the "stable" phase, which centers on management of ongoing symptoms. The "unstable" phase refers to disease spikes and uncontrolled symptoms that can lead relatively quickly to the "deterioration" phase, involving rapid or gradual physical decline along with increasing disability or escalating symptoms. The final stage is the "dying" phase referring to the period of weeks or days preceding death. Sociologists have used this normative model in many studies, while nursing and other medical personnel have employed it as a predictive tool.

Since the 1980s, narrative case studies have emerged as one of the dominant approaches to the study of the chronic illness experience. A number of sociologists argue that narrative offers a better basis for development of both theory and policy initiatives (Flyvbjerg 2011; Frank 1995) and it has proved useful in recent years in drawing further connections between the bodily and the psychosocial experience of disease. In 1982, Michael Bury introduced the idea of "biographical disruption" noting how chronic illness interferes with the order of everyday life. Sufferers, he argued, tend to develop a heightened state of bodily awareness, must rethink their identity and reevaluate life plans and expectations, and live with a tentative and reflexive stance regarding the future (Bury 1982). The changes that illness forces on patients and families have social repercussions as well, a premise that Gareth Williams (1984) used as the basis for examining patient's "narrative reconstruction" of their identities. He argued that chronic illness sufferers seek to manage the impressions of others primarily by developing and telling new stories of the self.

In the late 1980s, Arthur Kleinman's now classic study, *The Illness Narratives* (1988) served to empower the sufferer by drawing a distinction between "disease" and "illness." In particular, the book legitimized the analysis of patient illness narratives. Kleinman's distinction between "healing" (or caring for the patient) and the medical objective of "curing" the patient has gained a great deal of momentum, particularly within the medical humanities and among patient advocacy groups. Charmaz's (1991) *Good Days, Bad Days: The Self in Chronic Illness and Time*, a longitudinal interview project with chronic illness sufferers, builds on previous research on chronic illness and has extended the scope of narrative to consider the way a chronic illness reconfigures identity and social relationships. Charmaz suggests that the news disclosure process involving family and friends includes announcing and recounting what the physician has reported to the patient about the illness and its prognosis. Two specific postures associated with news sharing are protective disclosing (planning what to tell, to whom, and when) and spontaneous disclosing (minimal planning and sometimes impulsive telling). Charmaz (1991: 121-133) also explores "strategic" announcing, by which ill persons work to control information as well as their recipient's response, and "selective" informing or acknowledging aspects of illness while minimizing others, in an effort to protect their friends as well as themselves. Overall, this work explores the meaning of illness in terms of the affected person's self and identity, disclosure and identity being deeply intertwined.

One notable offshoot of the narrative literature has been the growth of autobiography and auto ethnography, a genre of investigation that removes the subject/object dualism and centers on intimate reflections of one's personal experience with chronic illness. A number of social scientists have written autobiographical accounts of their chronic illnesses over the years including Paget (1988) and Blaxter (2009), who write about their experiences with cancer, and Register's (1992) account of living with congenital liver disease. Arthur Frank has written both autobiographical (Frank 1991) and theoretical work (Frank 1995) based on his personal experiences with heart disease and cancer. In the last ten years, physicians and researchers in medical humanities have used the narrative literature to teach clinicians techniques for developing "narrative competency" which is viewed as a form of attending to the patient that is essential in long doctor-patient relationships (Charon 2006).

This brief overview of the development of the chronic illness literature reveals a rich (but eclectic) history. Over time, the emphasis on the subjective experience has become a primary focus, reflecting efforts to restore a holistic and longitudinal picture of the chronic illness experience by tracking individuals through time. Patient narratives are particularly useful for this goal. However, narrative poses substantial challenges as well, because patient accounts can serve such a wide a range of purposes. In recent years, the heavy emphasis on the subjective experience of patients has been criticized by sociologists leading some (Strauss in Baszanger 1989; Gerhard 1990;, Pierret 2003; Charmaz and Rosenfeld 2010) to argue for more integration of analysis of the social structure into qualitative research on chronic illness. Conrad in particular notes:

> It is not sufficient (…) to only present a description of how people experience and manage this or that illness. These types of studies – while interesting in their own right – do not contribute to the development of a sociology of the chronic illness experience. (Conrad 1990: 1260).

While sociologists often share the orientation toward analyzing subjective experience along with social structure, ways to conduct this kind of research have not yet developed. However, the early work of Roth (1963), Davis (1963) and others point to communication research as a promising vehicle for longitudinal analysis of chronic illnesses that integrates attention to structure and the subjective experience at the same time (IOM report 2001; Fallowfield et al. 2004; Epstein and Street 2007).

Context & Background

This dissertation examines the illness experience of cancer patients and their families from diagnosis through treatment, recovery and death. *Similar* to other chronic conditions, cancer is potentially life threatening; it is often stigmatizing and can lead to social isolation (Gray et al. 2000), as well as increased friction between family members (Adelsward and Sachs 2003; Beach 2002; 2009). Cancer is *distinct from* most other chronic diseases, however, in that it is potentially curable with certain kinds of aggressive therapy. Cancer is also a condition that involves sudden and extreme fluctuations between acute and sub-acute phases of the disease. In fact, it stands apart from most chronic conditions in that the treatment itself is a cause of long-term co-morbidities, secondary cancers, and the treatment can actually hasten the patient's death.

Ideally, research on communication in the cancer context would examine all the communication between doctors, cancer patients and family members over the course of the illness, but that would be an insurmountable task. Instead, this study focuses on one form of communication - the disclosure of bad news related to the disease. Much rides on "news" in terms of decision-making as well as coping with the ups and downs along the way. In the medical literature, bad news has been defined as "any news that drastically and negatively alters the patient's view of their future" (Buckman 1984: 97). The impact of the bad news generally depends on the distance between the patient's expectations and the biomedical reality conveyed by the news.[1]

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[1] Anecdotally, clinicians know this all too well, and in a recent historical cohort study of six million patients, Fang et al. (2012) found a substantially elevated risk of suicide and death from cardiovascular disease among patients who had received a cancer diagnosis during the previous year. The risk was particularly high for cancers with a poor prognosis.

Sociologically, bad news is an especially revealing form of communication because it exposes the taken-for-granted reality that is now breaking down (Maynard 2003). That is, through attention to how health related news is discussed, other features of the social context are also made visible.

This study focuses on twenty-eight blood cancer patients diagnosed with leukemia, lymphoma, or myeloma who have undergone a hematopoietic stem cell transplant (HSCT). HSCT is generally a multi-staged process that takes a year or more to move through, from preparation for the procedure, to the transplant itself and then through various stages of outpatient recovery. While transplant results in more cures and remissions than alternative treatments for blood cancer, the procedure is risky. The mortality rate can be as low as two percent for some autologous transplants (patients whose own stem cells are extracted, frozen, and later re-infused) and below ten percent for some allogeneic transplants (involving stem cells from a donor). However, forty percent of those with advanced cancer will ultimately die from complications related to transplantation (Copelan 2006). The outcome of treatment -- which include complete cure, long-term remission, or death – are contingent on a host of factors including the patient's genetic make-up, age, overall health, the specific diagnosis and stage, the type and duration of prior therapy, transplant type, the match between the donor and the patient, and the nature of complications that occur after the transplant. Thus, it is hard to predict with accuracy whether a particular patient will benefit from the treatment.

Because transplant patients are monitored closely for periods of a year or longer, this setting provides a good opportunity to witness the ebb and flow of communication between clinicians, patients, and caregivers over the course of an illness with a long recovery period. In the early phase of outpatient care, bad news revolves around issues such as a failure to engraft or the failure of the transplant to halt progression of disease. In late phases of recovery, news may center on fluctuations in blood counts that, in turn, may indicate relapse and require a discussion about transitioning from a curative to palliative mode of care.

The data used here was collected for a multi-year ethnographic project (2007-2010) conducted at a large comprehensive cancer center in the United States.[2] The research team tracked the medical and psycho-social experiences of blood and bone cancer patients and their family caregivers prior to and over the course of one year post HSCT using a purposive sample of twenty-eight patients and thirty family caregivers stratified by age, sex, diagnosis, type of stem cell transplant procedure, and socio-economic status. The sampling frame was designed to capture maximum variation within the pool of all transplant patients at the field site. The patients were recruited in coordination with the hospital staff. Efforts were made to include equal numbers of women and men, a representative number of adult cancer patients in each decade of life (20s - 60s), and individuals diagnosed with the most common range of blood cancers. During the initial intake prior to transplant, the transplant coordinators presented patients with a "consent to contact" form. Patients who agreed, were contacted in person in the waiting room or by phone. We further explained the purpose of the study and provided a brochure reiterating the central objective of the study.

The patients eligible for recruitment at the site were predominantly white, middle class, and possessed a high school or greater level of education. Five patients from lower SES income categories (on medical assistance) were included in the sample as well as two patients from minority populations (one African American and one Native American). Overall, sixty-one patients were approached for the study and forty-one agreed to participate. Six of these patients went to transplant too quickly to conduct the initial intake interview and seven others became ineligible because they were referred to hospice shortly after recruitment. Because the risk and recovery trajectories were distinct, patients undergoing both allogeneic transplant (stem cells infused from a matched donor) and autologous transplant (reinfusion of the patient's own stem cells) were included. The hospital's institutional review board approved the study for interviews and ethnographic fieldwork with all twenty-eight families throughout the treatment and recovery process. In addition, we were approved to conduct field observations in the hospital, clinic, in the oncology workrooms, and to attend the weekly patient rounds.

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[2] The Principal Investigator for the project was Professor Cameron Macdonald of the University of Wisconsin Department of Sociology. I was a Research Assistant along with another graduate student in the department.

Dissertation overview

The manuscript is comprised of three freestanding but interrelated empirical chapters, each intended for separate publication as journal articles. The first empirical chapter, ***Bad News and First Impressions*,** focuses on patient and caregiver accounts of "the day" of learning the diagnosis. The analysis examined the structure and content of complete narratives from each of the fifty-eight participants to reveal the way stories mediated the individual's understanding of the situation. Diagnosis was generally described as a *process* culminating in one episode where a physician definitively disclosed the diagnosis. Patients' experiences of the medical system prior to hearing the diagnosis played an important role in accepting the news. That is, my research shows that how well individuals came to terms with the news had less to do with one skillful disclosure by the physician and much more to do with a sense of being supported by the medical system overall – an impression that had been building up over the testing process. Patients in this study felt supported by the system if they experienced coordination between medical personnel in different clinic settings and consistency in the information provided on the way to the definitive diagnosis. The analysis offers evidence for the importance of routine organizational practices on the path to diagnosis and argues that events leading to diagnosis laid the foundation for either trust or distrust in the medical establishment.

This chapter offers recommendations for clinicians charged with disclosing the diagnosis to the patient just prior to commencing treatment. Because the events that have lead up to diagnosis are on the minds of patients already, and sets the tone for how patients are likely to react to the news, I recommend that prior to delivering the actual diagnosis, physicians feel out the emotional state of the patient first by asking a few "indirect" questions. This means that rather than eliciting what the patient fears or expects the news to be, it might be more helpful to inquire about where the patients have been for testing and what various clinicians have told them about their condition so far. These kinds of inquiries are less likely to elevate anxiety than direct questions about concerns patients have pertaining to the diagnosis. In addition, this approach to gaining the perspective of the patient not only gives doctors insight about the emotional state of the patient, but also positions doctors to allay fears by commenting on and perhaps reinterpreting the patient's perceived lack of support during one or more stages leading up to diagnosis. Thus, this kind of "indirect" conversation can actually aid physicians in conveying the diagnosis in a way that both contains anxiety and re-establishes a sense of support for patients and their families that may have been eroded in earlier encounters with the medical system.

The next chapter, ***The Second "Weight" of Diagnosis,*** examines how the news of cancer is disclosed by the patient to family, friends, and coworkers and reveals the deeply social nature of managing a serious illness. The act of sharing of the news is rarely the focus of published accounts in the medical literature or the social science literature, although theorists since Georg Simmel (1906) have argued for the value of analysis of self-disclosure practices for understanding a range of social phenomena. I describe one case in detail, trace the chronological path by which the patient shared the news with his family and others, and use this to highlight specific themes across all cases in the data set. In a word, I found that the act of sharing news could enhance or erode a sense of well-being among patients, *but it was never a neutral activity.* That is, verbalizing the diagnosis was part of the sense-making process and helped reinforce existing relationships but it also led to the weakening of some relationships. For all of the patients, sharing the diagnosis with family and friends was emotionally difficult and having to disclosure news about a change in health status remained a substantial concern throughout the course of managing the disease. Overall, I argue that our understanding of role of patients sharing the diagnosis needs to be revised. It is not a tangential activity occurring *between* important disease-related events but rather a significant social dimension of the illness experience in its own right. Patients all worked from the assumption that self-disclosure of the illness was an obligatory task that should begin with those closest to them but notably, it was in strategizing disclosure in the workplace that caused the most ongoing ambivalence about what, how or when to share health related news.

While the first two substantive chapters work primarily from interviews and field observations, the third chapter, ***Perilous Communication in Long Clinic Relationships,*** centers on analysis of audio-taped outpatient clinic visits between three oncologists, two nurse practitioners and ten patients to examine the conversational practices used to discuss serious changes in the patient's health status. I drew "news events" from forty-one audio-recorded clinic visits to reveal a number of conversational strategies used by patients and physicians to discuss a decline in health status. News events fell into three general categories: 1) "perilous" - serious or consequential - news about overall health status; 2) "routine" news about short-term changes; and 3) "social" news pertaining to the patient's social schedule. Routine news was the *lingua franca* between patients, family members, and physicians while the more consequential news was rarely discussed explicitly.

Overall, I characterize explicit communication about perilous news as "non-normative" in this outpatient setting, and I show how physicians and patients employ strategies to redirect or suppress explicit discussion of this kind of consequential news. Although indirect communication tended to preserve the social order of the clinic visit, in at least some cases, I point out that it came at the expense of helping patients and family members prepare materially and psychologically for end of life. My findings challenge assumptions (prevalent in the medical literature) that doctors are simply unskilled communicators who must practice to be effective at delivering bad news. Instead, this article argues that it is important to cast a sociological light on the phenomenon of indirect speech acts and train physicians to better leverage indirect communication to ensure that certain conversations occur when they are necessary.

The final chapter, ***New Approaches to the Study of Chronic Illness Communication***, summarizes the central findings throughout the dissertation and argues the need for more systematically designed qualitative longitudinal research. I discuss challenges to this kind of research as well as techniques that may minimize the obstacles. A central theme running through all three empirical chapters is that by looking more closely, and longitudinally, at how patients experience particular kinds of conversations, we can see why some of the current recommendations for training clinicians to communicate with patients may be inadequate and thus, should be tailored to reflect the actual circumstances of many of these conversations.

Generalizability. Each of the three empirical chapters in this study considers how patients with blood cancers, along with their families, experience complicated communication pertaining to care. How generalizable are the conversational patterns found between physicians and patients in the HSCT clinic to other patient populations managing different chronic conditions? To this, I would say that my research offers *one baseline* with which to examine chronic illness communication in other medical contexts. It is inevitable that chronic illnesses will share some aspects of communication and diverge in others. I would argue that taken together, my study and other studies could be used to build a *generalized framework* for understanding medical communication as a longitudinal phenomenon. In the meantime, my ethnographic methods may already suggest patterns that are generically relevant to the understanding of chronic illness and communication.

Chapter 1: Bad News and First Impressions: Patient and Family Caregiver Accounts of Learning the Cancer Diagnosis

Bad News and First Impressions: Patient and Family Caregiver Accounts of Learning the Cancer Diagnosis

Abstract

Studies in medical journals regarding the delivery of a cancer diagnosis typically focus on a single clinic episode where the physician discloses the definitive news to the patient. Far less research characterizes the diagnosis in the way patients and their family members often describe it: as a longitudinal, multi-sited search process culminating in a news-telling and realization event. This article analyzes lay accounts of learning a cancer diagnosis drawing on ethnographic interviews among a purposive sample of twenty-eight patients recently diagnosed with leukemia, myeloma, or lymphoma and thirty of their family caregivers. The participants, recruited at a regional cancer center in the United States, were asked to describe "the day" they learned the diagnosis. Narrative analysis revealed that in almost every case, detailed descriptions of preliminary events – such as the pace and sequence of testing; smooth or disorganized transitions between care providers; and the timeliness or delays in diagnosis – were used to contextualize the actual episode of hearing the diagnosis and reacting to the news. This study finds that patients' and caregivers' experience of the medical system prior to hearing the news played an important role in the way the news was ultimately internalized. The findings also provide empirical support for integrating lay perspectives on the diagnostic experience into future cancer disclosure guidelines.

Introduction

Each year an estimated 1.4 million new cancer cases are diagnosed in the United States, and although the 5-year survival rate for many forms of the disease has improved, cancer remains one of the most feared diagnoses. Euphemism and vague language are common in physician communication with patients (Chapman, Abraham, Jenkins, & Fallowfield, 2003) and research shows that even when the principles of informed consent obligate doctors to fully disclose the cancer diagnosis, terms such as "growth," "lump," "tumor," "abnormal cells" or "precancerous condition" are often used instead during initial consultations (Holland, Geary, Marchini, & Tross, 1987; Fallowfield, Jenkins, & Beveridge, 2002). Similarly, indirect referents to cancer predominate in discussions of transition from curative to palliative care (Lutfey & Maynard, 1998).

Practical concerns drive the research on disclosing diagnoses in the medical literature and in the last two decades a number of communication guidelines have been generated from this research to aid clinicians with this task ((Back, Arnold, Baile, Tulsky, & Fryer- Edwards, 2005; Baile et al., 2000; Buckman, 1992; Girgis & Sanson-Fisher, 1995; Maynard, 2003; Rabow & McPhee, 1999). Most of the research draws on self-reported data collected among physicians (Baile, Lenzi, Parker, Buckman, & Cohen, 2002; Ptacek, Ptacek, & Ellison, 2001) as well as survey data from patients about their preferences for hearing bad news (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Cassileth, Zupkis, Suttonsmith, & March, 1980; Butow et al., 1996; Fallowfield, Ford, & Lewis, 1995; Hagerty et al., 2004). Thus, the guidelines focus heavily on clinician behaviors during the encounter and advise doctors to find a suitable place to disclose the news; "forecast" (Maynard, 1996) and dose information to reduce the shock patients experience; respond to emotion with empathy; and minimize incomprehension by clarifying frequently and summarizing plans for treatment at the end of the visit. While adherence to recommendations such as these will undoubtedly enhance the quality of the therapeutic relationship, one problematic assumption embedded within most guidelines is that it is a single disclosure episode that needs to be handled skillfully. The current study challenges this assumption based on findings from fifty-eight patient and caregiver narrative accounts of learning the cancer diagnosis. Rather than focusing on "the moment" or "day" of learning the bad news, these accounts describe the diagnosis as a process or stepwise "journey" (Beach, 2009) encompassing a social context that includes events occurring before and surrounding the actual cancer diagnosis. This investigation examines the characterization of these surrounding events to better understand how early experiences affect patients' and caregivers' reception of the news.

As noted, published consensus guidelines serve as the basis for training physicians to deliver diagnostic news, but studies continue to find a wide gap between what doctors think they convey and what patients and caregivers actually understand of the cancer diagnosis and the treatment process (Back et al., 2005). Among a group of 181 patients diagnosed with advanced cancer and receiving palliative care, for example, Craft, Burns, Smith, and Broom (2005) found that only 45% correctly understood their terminal status and the goals for treatment. Similarly, Chan and Woodruff (1997) report that among 131 patients with an advanced malignancy, approximately 10% did not know they had cancer and 33% were unclear about the long-term prognosis.

The social science literature on diagnosis, by contrast, rarely evaluates the effectiveness of specific disclosure strategies and instead adopts a predominantly theoretical approach to the subject. Although diagnosis has not yet coalesced into a distinctive area of research (Blaxter, 1978; Brown, 1995; Jutel, 2009), it has been studied extensively within the literature on the social construction of illness, the social construction of medical knowledge, and in the disease theory literature Jutel, 2009; Conrad & Barker, 2010). Ethnographic studies, for example, have examined numerous theoretical constructs relevant to illness such as "biographical disruption" (Bury, 1982), "narrative reconstruction" (Williams, 1984), and other psycho-social phenomena by which an individual becomes a "patient" (Zola, 1973), a medical "case" (Glaser & Strauss, 1965), and the ways in which identities are transformed through the experience of chronic illness (Charmaz, 1993). Ethno- methodological research has examined medical action, such as diagnosis, as an "accountable" practice (Garfinkel, 1967) and conversation analysts, through close assessment of the sequential, turn-by-turn organization of talk, have examined a range of features associated with the delivery and reception of difficult diagnoses (Heath, 1992; Maynard, 2003; Perakyla, 2006).

In addition, organizational studies have examined the medical professionals who have institutional authority to convey diagnoses (Friedson,1970) and conceptual issues such as the medicalization of social conditions (Conrad & Schneider, 1980), ways of dealing with stigmatizing diagnoses (Goffman, 1963), and the logic by which a system of disease classification is developed (Blaxter,1978; Bowker & Star, 1999) have also been explored. Only a small number of studies within the medical or social science literature has focused on the cancer diagnosis itself as a longitudinal phenomenon.

In the cancer context, specifically, The, Hak, Koeter, and van der Wal (2000) conducted a four-year, two-phase ethnographic study of thirty-five lung cancer patients followed from diagnosis to death and observed what seemed to be a "don't ask, don't tell" style of collusion between doctors and patients regarding progression of the disease. In another study, Salander (2002) reviewed 138 written patient accounts of hearing the cancer diagnosis and found that rather than focusing on a single instance of hearing the news, patients routinely began their stories with the first contact with clinical staff and ended them at the conclusion of treatment. This suggests that access to coordinated medical services was an important means by which patients established a trusting relationship with their doctors. Similarly, Leydon, Bynoe-Sutherland and Coleman's (2003) analysis of interview and focus group data among thirty-three cancer patients found that the experience of the medical system up to the point of diagnosis colored patient's views of their doctor and profoundly influenced their expectations of future care. Each of these studies examines the cumulative effect of multiple clinic encounters on the patient's experience, but the findings from this type of research have not yet been extensively theorized. In fact, the most well-developed, best theorized research on diagnosis adopts a constructionist perspective and focuses specifically on contested illnesses (Barker, 2002; Clarke &James, 2003; Dumit, 2006; Nettleton, 2006). While this research has provided valuable insight into the emotional, and often longitudinal, negotiation process (Brown, 1995), less work has investigated the social construction process associated with relatively uncontested diagnoses.

Blood cancers – the diagnoses discussed in the accounts presented in this article – are rarely contested primarily because abnormal blood counts are hard to refute. From a constructionist perspective, the process leading up to diagnosis can shed light on how the patient's interaction with various organizational actors across a multi-staged testing sequence contributes to what comes to be accepted as social reality about the cancer diagnosis. In the accounts described here, clinicians often told the patient that cancer was suspected one or more stages before the definitive diagnosis, thereby "topicalizing" the diagnosis but presenting it as tentative. Because this process left a strong impression on many study participants about the medical system and about what the future held for them in coping with the disease, it certainly bears further investigation.

Methods

This article is based on data collected for a multi-year ethnographic project (2007-2010) conducted at a large regional comprehensive cancer center in the United States. The study tracked the medical and psycho-social experiences of blood and bone cancer patients and their family caregivers prior to and over the course of one year post hematopoietic stem cell transplant (HSCT) using a purposive sample of twenty-eight patients and thirty family caregivers stratified by age, sex, diagnosis, type of stem cell transplant procedure, and socio- economic status. That is to say, the sampling frame was designed to capture maximum variation within the pool of all transplant patients at the field site. Efforts were made to include equal numbers of women and men; a representative number of adult cancer patients in each decade of life (20s – 60s); and individuals diagnosed with the most common range of blood cancers. Also, because the risk and recovery trajectories were distinct, patients undergoing both allogeneic transplants (stem cells infused from a matched donor) and autologous transplant (reinfusion of the patient's own stem cells) were included. The patients at the field site were predominantly white, middle class, and possessed a high school or greater level of education. Even so, five patients from lower SES income categories (on medical assistance) were included in the sample as well as two patients from minority populations (1 = African American and 1 = Native American).

Overall, sixty-one patients were approached for the study and forty-one agreed to participate. Six of these patients, however, went to transplant too quickly to conduct the initial intake interview and seven others became ineligible because they were referred to hospice shortly after recruitment. The study was approved by the site hospital's institutional review board to conduct interviews with each of the remaining fifty-eight participants and to engage in ethnographic fieldwork with a subset of thirteen families throughout the treatment and recovery process. In total, seventeen patients in the study were male, eleven were female, and the majority were in their forties (n = 8) or fifties (n = 11). Twenty-seven patients had a designated caregiver; two- thirds of the caregivers were spouses (n = 20) and the other third were parents of the patient (n = 7). Seventeen of the patients had been diagnosed with leukemia, six with lymphoma, and five with multiple myeloma. (Demographic data are shown in Table 1.)

Table **1**
Participant demographics & diagnosis disclosure information (n =58).

Case number	Participant	Cancer•	Age	Sex	Disclosure context	Who w/patient	Who disclosed
1	Patient	ALL	58	M	Acute	Wife	ER doctor
	Wife		51	F			
2	Patient	AML	55	M	Sub-acute	Alone	Oncologist
	Wife		55	F			
3	Patient	AML	41	F	Acute	Husband	ER doctor
	Husband		43	M			
4	Patient	NHL	49	M	Secondary	Alone	Oncologist
	Wife		42	F			
5	Patient	AML	50	M	Sub-acute	Alone	Family doctor
	Wife		53	F			
6	Patient	AML	40	F	Sub-acute	Alone	ER doctor
	Husband		41	M			
7	Patient	ALL	24	F	Secondary	Family	Oncologist
	Mother		46	F			
8	Patient	MM	68	M	Sub-acute	Alone	Family doctor
	Wife		72	F			
9	Patient	AML	23	F	Acute	Fiancé	ER doctor
	Fiancée		27	M			
10	Patient	MDS	53	F	Sub-acute	Husband	Oncologist
	Husband		65	M			
11	Patient	MM	53	M	Sub-acute	Wife	Family doctor
	wife		51	F			
12	Patient	AML	50	M	Recurrence	Alone	Oncologist
	Wife		49	F			
13	Patient	HL	25	M	Recurrence	Alone	Oncologist
14	Patient	CML	32	M	Recurrence	Alone	Oncologist
	Mother		62	F			
15	Patient	MM	47	F	Acute	Husband	ER doctor
	Husband		46	M			
16	Patient	MCL	59	M	Sub-acute	Wife	Family doctor
	Wife		57	F			
17	Patient	ALL	46	M	Sub-acute	Wife	Medical Record
	Wife		46	F			
18	Patient	AML	21	M	Acute	Family	ER doctor
	Mother		43	F			
	Father		41	M			
19	Patient	HL	32	M	Sub-acute	Wife	Oncologist
	Wife		31	F			
20	Patient	FL	49	F	Recurrence	Alone	Oncologist
	Mother		75	F			
	Father		76	M			
21	Patient	MM	54	M	Acute	Girlfriend	ER doctor
	Fiancée		55	F			
22	Patient	MM	74	M	Sub-acute	Alone	Nephrologist
	Wife		71	F			
23	Patient	AML	22	F	Sub-acute	Alone	Family doctor
	Mother		40	F			
24	Patient	ALL	39	F	Sub-acute	Husband	Family doctor
	Husband		36	M			
	M-in-law		65	F			
25	Patient	AML	55	F	Secondary	Alone	Oncologist
	Husband		55	M			
26	Patient	ALL	43	M	Acute	Wife	ER doctor
	Wife		38	F			
27	Patient	NHL	49	M	Sub-acute	Alone	Family doctor
	Wife		48	F			
28	Patient	AML	35	F	Recurrence	Alone	Oncologist
	Husband		35	M			

• Leukemia: Acute lymphoblastic leukemia (ALL), Acute myeloid leukemia (AML), Myelodysplastic syndrome (MDS). Lymphoma: Follicular lymphoma (FL), Hodgkin's lymphoma (HL), Non-Hodgkin's lymphoma (NHL), Mantle cell lymphoma (MCL), Myeloma: Multiple myeloma (MM).

A semi-structured "guided" interview format was used (Denzin & Lincoln, 1994) and patients and caregivers were interviewed separately at four intervals: (1) prior to transplant, (2) several weeks following discharge from the hospital, (3) six months post transplant, and (4) at the end of one year. The observational field- work was based on a grounded theory methodology (Glaser & Strauss, 1967; Schatzman & Strauss, 1973) that involved observing and audio-recording patient clinic visits every three weeks following discharge from the hospital and also visiting patients and their families at home once a month to learn about the ongoing, day-to-day experience of living with cancer and recovering from transplant. Additional data was collected from *Caringbridge* or *Carepages* weblogs. These are hospital-sponsored websites that enable patients undergoing treatment for a range of conditions to share information with their support network through a password-protected portal. Caregivers maintained the weblogs followed in this study somewhat more often than by the patient but in either case, these logs provided textual, first-person accounts about the fluctuations in the health and mood of the patient and their families.

While the ethnographic data provided background for the overall project, the findings reported in this article focus primarily on one topic raised during the intake interview where participants was asked to describe "the day they learned the cancer diagnosis." Originally, this question was intended simply to establish some history about each patient. Because these accounts were so richly detailed, however, it became evident they merited attention in their own right. All interviews were transcribed and a combination of grounded theory coding and narrative analysis was used to examine them. Analysis began with "open" or substantive coding (Strauss & Corbin, 1990) of the transcripts to identity themes and patterned differences in the way that patients entered the medical system and received the cancer diagnosis. The accounts sorted naturally into three categories and each account was then analyzed as a single cohesive unit. *Thematic* narrative analysis was used to understand "what happened" from the participants' perspective (Riessman, 1993, 2008) and *structural* narrative analysis was used to examine the way participants ordered their stories and selected features for inclusion (Labov & Waletzky, 1967). Focused coding was later used to reveal the relationship patients and caregivers saw between the specific events leading up to diagnosis and to the diagnosis itself. The analysis conducted here builds directly on the interest in narrative that emerged subsequent to Arthur Kleinman's (1988) study of the patient experience of illness and extends the focus to examine both patient and family caregiver accounts of diagnosis in tandem.

Findings

Structural features of the accounts

Patients heard the cancer diagnosis in one of three circumstances: after an acute episode in the emergency room; during a clinic visit following presentation with sub-acute symptoms (such as rash or fatigue); or as part of routine blood work for a physical or ongoing monitoring of a previous cancer diagnosis. The medical specialist who conveyed the news and the individuals accompanying the patient when the news was delivered varied for each context (see Table 1). Regardless of circumstance, however, all patient and caregiver accounts shared the following features:

Accounts were "storied"

The experience of learning the cancer diagnosis was developed as a cohesive story with a beginning, middle, and an end, and most conformed to a narrative structure whereby a prefacing background was used to set up the account– either by describing first symptoms; normal life just before the diagnosis; or by describing episodes of a smooth or delayed diagnosis.

Stories were composed of two interrelated sub-topics

These were: (1) the patient’s multiple encounters with the medical system prior to diagnosis and (2) the moment when the patient or family caregiver realized the news.

Participants' stories devoted more attention to encounters with the medical system than to the diagnosis itself

Patients and caregivers offered detailed descriptions of the path leading up to diagnosis – including visits to various clinics, conversations with different physicians, and a listing of the diagnostic tests performed. Accounts also included descriptions of clinic conversations about ambiguous findings and phone conversations with staff on a range of sensitive and mundane topics. By contrast, accounts of the realization process and descriptions of the actual diagnostic news exchange were typically brief paraphrases of what the doctor has said:

> That evening he called and he said that I had to go in for a bone marrow transplant because he thought I had leukemia.

Narrative content

"Diagnosis" is essentially the process of determining the nature and cause of a disease by its symptoms and signs. The symptoms of many blood cancers are often little more than complaints of fatigue, bone and joint pain, fever, and difficulty breathing. Physical signs are equally unremarkable and include bruising, swelling, and petechiae (a form of intra-dermal hemorrhage that manifests as pinpoint red spots under the skin).

When presented to a doctor, these signs are never sufficient to make a diagnosis, but patients and family members frequently reported that doctors did offer a tentative "likely" diagnosis after laboratory tests showed blood counts beyond normal ranges. In all cases, however, it was the bone marrow biopsy that served as the basis for disclosing a definitive cancer diagnosis to the patient and initiating a discussion of treatment options.

Realization

Patients and caregivers described absorbing the diagnosis as a two-fold process. That is, an intellectual understanding of the cancer news often came shortly after hearing it, but a deeper emotional realization was a separate event – sometimes occurring well after treatment had commenced. For example, one 40-year leukemia patient recalled being so overwhelmed by the conversations with different specialists about abnormalities in her blood that nothing seemed real for some time.

> I was down there probably halfway through the first week of chemo before I even realized - well, you know, before it really sunk in. Like holy man, I'm sick! And oh, I can't change my mind on anything now because they're already pumping drugs in me!

Whether the process of "getting it" was slow or fast, a common pattern among patients was to review "previously ambiguous signals" (Maynard, 2003: 12) surrounding events and, thereby, make sense of the experience and come to terms with a new reality. One 50- year old engineer diagnosed with leukemia illustrated this kind of cognitive processing as he recounted the visit with his primary care doctor where he learned the results of blood work done at a walk-in clinic the previous evening.

> No height, no weight, no blood pressure, no temperature. I mean, that's *always* done. You go through everything (...) afterwards. I'm analyzing it going, 'You boob! You should have known that (...) there was something up.'

In essence, this man looked for clues that he missed earlier about the news to come and finds them in the absence of the clinical routine that normally occurs when he visits his family doctor. Earlier in the interview, he noted that his first reaction to the news had been denial – that the doctor was mistaken. In this extract, however, the patient considers the possibility that the mistake may have been, in part, his own.

Realizing the news in different clinical contexts

While the presence of a two-part realization process was consistent across accounts, each of the three contexts reflected a distinctive pattern of realization. In the *acute context,* where patients and family learned the diagnosis following a visit to the emergency department (ED), none recalled hearing the diagnosis with much clarity or even feeling strong emotion when the word "cancer" was used. This kind of reaction was captured quite well by a 54-year old man recalling his myeloma diagnosis:

> Well, I don't know if I was shocked (...) I guess I describe it as [similar to my experience of] (...) one winter storm in late April (...)with about eight or nine inches of heavy snow(...) I went into a spin at sixty [mph] down the road and there was nothing coming. When that happens and you have the seat belt on, it's like a ride at an amusement park except that you could die. There's this taste that comes into your mouth and your heart beats fast and you lose feeling in your arms even though you're holding on. I went off the road and into a cornfield full of snow, upright. It didn't flip or anything. I was fine. But at the end of that I had this numb feeling. The same kind of feeling [after hearing the diagnosis] came over me and that was about all I felt. I just kind of digested what he [the doctor] was saying without a reaction.

Most patients in the acute context described a similar deficit of emotion in reaction to the news. In all seven cases, in fact, realization of the deeper impact of the diagnosis seeped into consciousness slowly, culminating in some graphically meaningful event such as finding clumps of hair on their pillow or sitting in a waiting room with other cancer patients and realizing that they were one of "them."

By contrast, family members who accompanied the patient to the ED described feeling the full force of the diagnosis almost immediately. In four instances, caregivers actually recalled learning the diagnosis *before* the patient, either because one of the medical staff had taken them aside or because the caregiver had guessed what was happening from observing activities and overhearing the conversation between clinicians. All described feeling like bystanders and thus, looked to medical staff for guidance as to how to understand the situation. Caregivers also typically expressed feeling very alone with the news and overwhelmed by the possibility of losing their loved one. One 28-year old construction worker, for example, noted this when his fiancée was transported by ambulance from a local hospital to the regional cancer center for additional tests.

> The EMTs were taking her away, and then [the nurse] gave me a huge hug and then she told me (...) she said "Good luck."(...) And I said, "Well, what's wrong?" She said, "We think it's leukemia." So then I knew and I didn't say anything (...) I cried my eyes out as I drove home, just me and [my infant daughter] you know. And I'm like "Now, what do I do?"

Interestingly, none of the caregivers who learned the news before the patient disclosed it to the patient themselves, but instead waited for the doctor to do so. Few explicit reasons were given for this, but one husband's account provides some insight. This 43-year old man recalled that after overhearing a discussion of "leukemia" in the hospital corridor among several doctors he sat in a chair watching his wife sleep thinking about how the news would impact their four children. As he got more upset, he decided he'd better go home before his wife picked up on it.

> I just thought (...) I'm going to go, and I'll come back in the morning, because we had to wait for the hematologist to come in the morning to speak with us and to look at her and stuff. And right before I left I said goodbye. She said, "What's up with you?" and I said, "Nothing."

The need to contain emotion and the belief that the doctor would be able to present the whole picture and make sense of it was a thread running through other caregiver accounts as well.

In the *sub-acute* context, thirteen patients learned the diagnosis after a scheduled visit to the doctor for persistent symptoms. Seven of these patients were alone when hearing the news for the first time and most noted that prior to the biopsy they believed a mistake *must* have been made. Even so, these patients disclosed the unconfirmed diagnosis to their spouses but waited for the biopsy confirmation before telling other family members and friends. These patients described the diagnosis as a two-stage trauma: first, having to absorb the news themselves and second, having to convey the news to their spouse or someone else close to them.

As a corollary, the caregivers who learned the news from the patient described feeling "shocked" or "blindsided" by the news because it came in an otherwise ordinary context. One participant, for example, recounted that she did not even know her husband had been to the doctor. He simply came home one evening from work and told her the news at the kitchen table.

> I said, 'What's going on?' He goes, 'Well' he said- he couldn't tell me! So he pulls this card out of his pocket (...) and he handed me this card and here it has *Med Plus Cancer Center* on the top of it with Dr. Fleming's name, address, you know, the address of the cancer clinic (...) and I'm looking at this and I'm...I'm looking up at him and I'm...I'm going, 'Cancer!?' I'm going, 'Cancer!?' I'm thinking, oh, my God, that's the worst news that I could hear, other than somebody coming up to the door and telling me that he's dead, you know?

Clearly, the pattern of news delivery in the clinic is distinct from disclosures in the hospital or ED. In acute settings, patients and family heard the news at roughly the same time but in vastly different emotional states. Patients were often incapacitated by pain and/or drugs and unable to fully process the information. Caregivers, by contrast, were on high alert, watching events transpire and thus, learning the diagnosis by deduction or from a clinician taking them aside. As bystanders, they also had time to think about the implications for themselves and their family.

In the sub-acute context, patients more often learned the cancer diagnosis first and alone and experienced a heavy emotional burden of having to move quickly from news *recipient* to news *deliverer.* The act of telling family about the cancer diagnosis was invariably described with the most emotion.

In the third context, patients and caregivers had already received one cancer diagnosis and now learned that either the primary cancer had recurred or that a secondary cancer had developed. None of these respondents used the word "shocking" to describe their reaction to the news. Instead, the news was often described as a "blow" – a description retaining the sense of assault, but absent the sudden reversal of fortune. Several of those a year or more out from the original diagnosis, in fact, used "devastating" to describe their reaction. This suggests a certain battle-weariness in the face of yet another advance of the disease. Those hearing cancer news for the second time often indicated that the latter was harder news to hear because the odds were longer, fewer treatment options were available, and the patient would be less able to tolerate aggressive therapy in any event. For the five patients who received news of recurrence and the three where news of a secondary cancer was disclosed, only one patient was with family. The other seven were told by their oncologist during an office visit or by telephone.

One other feature that distinguishes accounts of a secondary cancer or relapse from acute and sub-acute accounts is that although interviewed separately, the patient and caregiver narratives more closely matched each other in content and the personal referents used. That is, these accounts included more expressions such as "we felt," "we were devastated," "our family was..." making clear that the news was now received by a team facing a challenge together.

Overall, these accounts illustrate how the realization of the diagnosis was influenced by the context in which the news was disclosed. The "context" refers, essentially, to the physical surroundings, what members of the patient's social network were present, and what clinicians were involved in disclosing the diagnosis. Depending on the specific context, initial reactions of patients and family were somewhat predictable. In the acute care setting patients absorbed the news slowly while the caregiver understood the news immediately and often in a highly anxious state. In the sub-acute setting, the caregiver heard the news from the patient and more often expressed being "blindsided" while the patient recalled feeling burdened by having to transition quickly from recipient to deliverer of the news. In the situations of recurrence, the patient and family experienced the news as a collective blow on the family unit.

The path to diagnosis

As noted earlier, the path to the cancer diagnosis involved two or more encounters with clinicians in various settings and accounts generally focused greater attention on the process leading up to the diagnosis rather than on the diagnosis itself. In this section three examples are used to illustrate the range of circumstances that affected patient and caregiver reception of the news. In the first situation a "bad news" disclosure (cancer) is delivered through a "good" (efficient) means in the emergency department; the second account illustrates "good news" (no evidence of cancer) received through a bad process (inconsistent and contradictory information), and the third is an account of a bad experience moving through the system leading up to a badly handled disclosure of the cancer diagnosis. The central focus in this section is on the way respondents speak about the process and the diagnosis in the same account which, in turn, lends insight into how the patients and caregivers experienced the cancer diagnosis overall.

"Bad news" by a good process

Some participants described an expedient path to the cancer diagnosis and these narratives generally conveyed a sense of having to navigate a bad situation but having confidence in the professionals helping them through it. One account of this type involved a 49-year old female office worker who had delayed seeing a doctor for many months, attributing her fatigue to chronic depression. When she began to hemorrhage one evening at home her husband rushed her to the ED where doctors found she was in near complete kidney failure. The husband described the whirlwind hospital admission experience this way:

> I heard somebody say it was the "mystery ward" going up there (...) We had the hematology team, renal team, what else did we have? Oncology team. I think they showed up after the renal and hematology team. Oh, general medicine. Who else would we have had? It seems like there was four or five. There were a lot of teams. At any rate, by, I think, Wednesday afternoon, I don't remember which doctor it was, one of the doctors came in and said they had a pretty good idea what it was. They wanted to do some more tests (...) but they thought it was cancer (...)The one true test was a bone marrow biopsy. So they did that Thursday afternoon (...)it took about 24 hours to get the results back from that. So we found out for sure, absolutely sure on Friday, about three o'clock, four o'clock. By seven o'clock they had her first round of chemo in.

The central theme in the narrative is one of quick and coordinated medical care. The experience of learning the diagnosis of cancer was secondary and segued quickly into a discussion of treatment. Without saying it explicitly, the organization of this caregiver's narrative suggests that the feeling of support from a range of specialists, all working together to diagnose his wife and initiate treatment, made the actual diagnosis less traumatic than it might have been.

"Good news" by a bad process

In this account, drawn from the six-month interview, miscommunication and a lack of coordination led to an irrevocable sense of alienation for the patient and her family. The 24-year old patient had developed leukemia as a result of the chemotherapy used to treat her sarcoma. Three months following a stem cell transplant to treat the leukemia, a false reading of an X-ray indicated that the patient's original sarcoma had returned. During the interview, the mother of the patient went over the events that led first to news that the cancer was back and then to news that a mistake had been made in reading the X-ray; the cancer had not, in fact, recurred. Rather than experiencing relief when the mistake was discovered, the family felt re-traumatized. The mother described it this way:

> We were actually celebrating her '100 days' (...)and two days before, Sarah called Dr. Y and said (...) 'I've got this pain in my hip and I don't know if I pulled something or what.' He said, 'Well, you know, to play it safe, why don't you get an X-ray'(...) and rather than run back to Albany [home clinic], just have an X-ray done and have them fax it (...) So she did that and then the doctor that read it was actually a nurse practitioner and had told us that the radiologist had read it. But long story short, she read it. She read it backwards. And even though Sarah and I both explained that on her (...)one hip it's going to look like she's got a tumor, but it's a dead tumor. And the pain was actually on the other side (...)Anyway, she read it wrong and called us the next day at the resort we were at and told Sarah right there on the phone that, you know, 'Sorry. Your cancer's back.'

The celebration at the resort was cut short, the family returned home that day and another X-ray was done at the home clinic in Albany where the mistake was subsequently revealed. The dominant feeling afterward for the patient and her family was a sense of betrayal. As the mother noted:

> I actually had talked to the nurse practitioner (...) I just grabbed the phone from Sarah because she was screaming and crying and saying, "No, not again! Not again! Not again!" When I talked to her [the nurse practitioner] I said, "Are you sure? Are you absolutely sure?" "Yes, I'm sure." And, you know, you trust them.

Trust is the operative word here and while it might be said that trust was misplaced in this situation, what is also revealed is how this trust depends on doctor, radiologist, and nurse acting in concert to provide reliable information to the patient and family members.

"Bad news" following a bad process

This account highlights the relative importance of the process leading up to diagnosis for the patient and her family over the skillful handling of the cancer disclosure itself. In this instance, a 23-year old woman began to experience back pain a month after giving birth to her first child. When the pain intensified, she went to the emergency room where a doctor told her she probably had arthritis. She was prescribed ibuprofen and the painkiller, Vicodin. In a matter of hours, her nose began to bleed uncontrollably.

> I called later in the afternoon on Saturday, spoke to the same doctor, and I'm like, "Listen, I've had a bloody nose for three hours straight." You know, "What am I supposed to do?" He's like, "Well, let me up you to Percocet and we'll see if we can get you through the weekend and then go in on Monday and see your family doctor."

The woman was able to schedule an appointment for Monday morning and based on the laboratory results she was transported to a regional comprehensive cancer center that evening. On Tuesday morning the patient learned the diagnosis from a new resident who came into her hospital room to prep her for treatment.

> Like this doctor guy, he came in and he was saying "leukemia" and "cancer." And I'm like, wait, you know. He wasn't my attending physician (...) I'm not sure what he was, but he's the one who told me, and I'm like, "Whatever. You don't know nothing (...) I'm not listening to you because you're not my doctor."(...) He's like, "Okay, whatever." I'm like, "I don't need to hear that I have cancer from you" you know.

Reflecting on the poor process leading up to diagnosis and the disclosure itself, the patient noted that the resident who inadvertently disclosed the news later apologized and she felt the situation, despite her initial frustration with the doctor, was satisfactorily resolved. However, she and her family continued to express anger and planned to file a complaint about the doctor who attributed her symptoms to arthritis. It was the failure to conscientiously investigate the symptoms rather than the poor conveyance of the leukemia diagnosis that the family remembered. Charles Bosk (1979) describes "moral errors" in medical settings as a situation where a physician fails to discharge role obligations in a responsible fashion, noting that other physicians assess these errors as evidence of a flawed character. This characterization may also explain why the family assessed the ER doctor's behavior as they did and why it was judged inexcusable or "unforgivable" (Paget, 1988). As the patient said later:

> I'm 23 years old. How the heck can I have arthritis? And how did it come on this fast? You know, it started off with low back pain, but it went away and it went into my arms.

In sum, consistent across all three situations was the idea that support or lack of support from the medical system influenced coping with the diagnosis. Where individuals felt support – particularly in terms of a sense of coordination of care across distinct locations – the diagnosis was hard but less traumatic than when miscommunication and a lack of coordination prevailed.

Discussion

A key finding from this research is that while hearing the diagnosis and realizing the news were significant moments to participants, the ability to cope with the news was tied only tangentially to one well-executed disclosure. This finding is consistent with Salander (2002), whose review of patients' written accounts of the diagnosis found that stories typically began with first symptoms and included multiple clinic interactions, suggesting a broader understanding of diagnosis for both patients and their families. The research also correlates with the findings from Leydon et al. (2003) regarding the way in which the interactions up to the point of diagnosis influenced patient *expectations* about future care. Difficulty getting a clinic appointment or delays in receiving a cancer diagnosis led patients to expect their care to be subject to similar problems in the future.

The notion of expectations emerged as a particularly salient aspect of the current study. Essentially, the *outcome* of initial impressions about the coordination of care within the medical system led to positive or negative expectations brought to subsequent clinic visits and proved integral to the level of trust patients and caregivers had in their providers. The mother who was given inaccurate information about recurrence of her daughter's sarcoma stated this connection explicitly.

Trust

Sociologists view trust as a feature of enduring personal and public relationships (Seligman, 1997) that functions to stabilize the social order by reducing its complexity (Luhman, 1979, 1988). Trust is also understood to be the outcome of situational predictability (Berger, 1998; Goffman, 1971; Habermas, 1999; Misztal, 1996; 2001). Because the stakes were so high for the cancer patients and family caregivers in this study, many seemed to want to believe that the system was predictable and the clinicians were competent

(Hughes, 1951). Patients and families often closely scrutinized the functioning of the organization for evidence that they could trust staff. Trust is something sociologists understand to be actively negotiated between doctor and patient and reproduced through routine organizational practices and this study reveals that the medical encounters early in the diagnostic process served as a defining trust-building or distrust-building experience.

In the illustration of learning "bad news through a good process," the spouse was able to relinquish control and trust the system because several specialized medical teams converged to diagnose his wife. Despite fluctuations in his wife's disease status over the next two years, this baseline trust persisted. The situation of "good news by a bad process" where the patient's X-ray was misread resulted in distrust in the medical system for the patient and her family and over the next eighteen months this patient continued to travel the hour and a half to the hospital for exams rather than returning to a local provider which was more customary. In the third situation, where the patient experienced both a "bad process and a bad news delivery," the patient moved past the awkward news delivery fairly quickly, but as with the previous case, she and her family remained distrustful of the care provided by the medical system for many months afterward.

The role of organizational routines in disclosing a diagnosis

The patient and caregiver accounts reveal that there was often unspoken coordination between clinicians in different settings regarding the diagnosis. One disclosure seemed to build on the previous one delivered by someone else and might be as simple as two exchanges illustrated in one account where the patient was told by the transplant doctor that his blood work looked "off" and later learned from his local oncologist that he had relapsed. The disclosure process can also involve multiple stages. Another patient recalled being told by a doctor at a walk-in clinic that his labs were "inconclusive" and so the patient was scheduled to see his family doctor the next day. The family doctor told the patient that it "looked like" he had leukemia, but noted that to rule out a "false positive" he would need an appointment with an oncologist. The oncologist told the patient:

> Just to let you know I am probably ninety percent sure that you do have AML (...) based on (...) the results from the walk-in clinic (...) 'But,' he says, 'what will really confirm it will be the bone marrow biopsy.'

The biopsy results confirmed leukemia, news delivered by phone to a patient now largely expecting to hear this bad news. In both cases, each clinician had a role in the process and as Everett Hughes notes, the fact that there *are* roles implies a system of social arrangements (Hughes, 1951). Where clinicians understand and execute their specific roles in relation to one another – as well as patients and families – the latter learns the cancer diagnosis systemically.

Medical sociologists Chambliss (1996) and Sudnow (1967) have examined this phenomenon of system level action in terms of distributed organizational routines. Routines, both authors note, can be a means to accomplish difficult professional tasks. Sudnow's ethnomethodological study of medical practices surrounding death in one public and one private hospital finds that in the public hospital particularly, staff adjusted treatment protocols and rationed attention for terminal patients in the absence of a formal decision-making process. This, Sudnow argued, initiated a "social death" sometimes long before biological death occurred. Chambliss's ethnographic field study similarly finds that the handling of ethical issues in hospitals is rarely the decision of one or two people. Much more often, Chambliss argues, ethical decisions are "organizational acts." He illustrates this using the phenomenon of a "slow code." When DNR (do not resuscitate) orders are not in place and the medical staff believes that death is imminent and inevitable, the speed usually associated with a resuscitation effort may not be exercised and all therapeutic means may not be deployed. In this way, Chambliss notes, the decision-making process remains tacit and is simply infused into routine organizational practice.

However, where both Sudnow and Chambliss emphasize how organizational routines distribute unpleasant tasks in order to diffuse responsibility and accountability, in this study of diagnostic news disclosures the incremental release of information throughout the testing phase functioned less to *pass off* a difficult task of disclosing the news and more to *begin the process,* and prepare the patient and the family for a shocking new reality. Through a conversation about the reason for specific tests and discussion about what the sequence of testing would be, clinicians shine a light down the path to reveal what lies ahead. In fact, in this situation, one could say that a *failure* of clinicians to offer some kind of preliminary assessment prior to the definitive diagnosis would have been more accountable than doing so and would likely have caused patients much more stress.

This kind of advanced indication of bad news to come has been described by Maynard as "forecasting" (1996, 2003) and as "firing a warning shot" in the medical literature (Back et al., 2005; Buckman, 1992). The idea is that through verbal and non-verbal behavior physicians try to lessen the shock, easing the recipient into realization. This strategy for delivering news refers primarily to the exchange between two participants during a single encounter; however, this paper argues that a similar process is involved where more than one clinician in more than one clinic setting is providing the news. The desired outcome is also similar: to prepare the patient for the definitive diagnosis of cancer after testing is complete. The effectiveness of this process can be seen particularly well in the multi-sited disclosure described above, where the patient ultimately heard the definitive diagnosis by phone, and notably, without incident.

While this study suggests that a single disclosure was not the make or break event, one feature of the definitive diagnostic episode did emerge as quite important. Patients and caregivers (if they were present) almost always could recall verbatim one or two specific phrases that the doctor while disclosing the diagnosis that seemed to hold significance well beyond simply communicating information about the medical disorder. These "prognostic phrases" were non-technical, often vague, but noted by study participants either during their account of the diagnosis or in the early phases of treatment. From close narrative analysis, it became apparent that these phrases provided patients and caregivers with a method of thinking, not only about the type of cancer, but also about the prognosis and the nature of the challenges that lay ahead. For example, one man diagnosed with a particular form of lymphoma, recalled his doctor saying that his was the "cancer of choice" because of the slow development of the disease. The spouse of another patient remembers the oncologist saying that if you have to get leukemia this is the "good kind" to get because the odds of long-term survival were better. Another recalled that his cancer was “very treatable”, while another patient recalled hearing that he was in a "high risk" category. By alluding to what the future might hold without making explicit prognostic guarantees, it seems that the doctor is able to offer, and the patient is able to take up, a "bright side" (Holt, 1993) while still remaining cognizant of the fundamental risks. Thus, even in the case where the patient was described as "high risk" the term implies some chance for a positive outcome, however slim.

Conclusion

Summary

The research finds that patients and families experienced the diagnostic informing as a longitudinal process and the presence or absence of support from members of the medical system prior to diagnosis mattered a great deal. "Support" was described as the consistency of communication across settings, variability or consistency in clinician competence, and in terms of whether the doctor was knowledgeable about their specific medical case. These initial impressions about the level of support, in turn, influenced patients' and caregivers' trust in the doctor's recommendations for treatment and affected patients' sense of equanimity or apprehension about the future. The ethnographic data further revealed that these initial impressions often had a long-lasting effect on the doctor-patient relationship.

Limitations

In a statistical sense, generalizing from a purposive sample of twenty-eight blood cancer patients and thirty family caregivers to a representative population-based sample of patients and caregivers is unwarranted. However, because the testing protocol leading to a blood cancer diagnosis is relatively standardized across the United States, the experiences described here undoubtedly bear similarities to those of other blood cancer patients and could find parallels to a variety of conditions that rely on multiple stages of testing. The use of narrative analysis was appropriate for a small sample in order to reveal the patient and family perspective about diagnosis and the ethnographic data collected using established procedures (Glaser & Strauss, 1967) helped draw connections between events and revealed residual emotion related to this experience even after two years.

Development of future diagnostic news delivery guidelines

The SPIKES protocol (Baile et al., 2000) is one of the most widely used models in medical training curriculums for delivery of bad news to cancer patients. This six-step approach uses each letter of the acronym as a mnemonic for specific tasks that, if included and well-executed, is expected to enhance good communication with patients about the cancer diagnosis.

The SPIKES protocol advises physicians to create a **S**ituation that ensures privacy and facilitates attention to the patient's needs; to draw out the patient's **P**erspective on the health condition and diagnosis and to **I**nvite the patient to set the terms about what information and in what way they would like the news disclosed. The guideline also recommends that doctors provide **K**nowledge to the patient using various devices, such as "warning" patients about the news to come and adopting non-technical language. Clinicians should demonstrate **E**mpathy for the patient when disclosing news and **S**ummarize the topics covered at the close of the news disclosure interview. While this study is not suggesting that guidelines such as this are misguided, it is arguing that they are not enough and the findings from this research would offer three modifications:

Situation

Patients and caregivers in this study often described diagnostic news being dispensed incrementally by various clinicians in different locations prior to the definitive conversation with the oncologist and coordination between settings appeared to be inadvertent. The SPIKES model could be modified to recognize the importance of conscious coordination across clinical, laboratory, and phone communications with patients pertaining to their diagnosis.

Perception

The protocol might be improved by extending the focus of the query beyond asking "What have you been told about your medical condition so far?" (Baile et al., 2000, p. 106) to include a query about the patient's and caregiver's experience of previous encounters, listening particularly for fears revealed in light of previous inter- actions with medical staff. In this way, the news disclosure inter- view offers an opportunity for physicians to not just correct misunderstandings about the medical situation, but to learn about expectations or desires families may have about future interactions and reassure the patient and family in a more targeted way.

Knowledge

Although the protocol encourages the use of non-technical language, the findings from this study suggest that a "bilingual" approach might be the best strategy for presenting a diagnosis. The "prognostic phrases" recalled by participants offered a hopeful lay interpretation of what was, in essence, a technical diagnosis. This kind of pairing facilitated patient and caregiver understanding in the moment, yet allowed families to seek additional information later – querying "metastases" rather than "spread," for example (Baile et al., 2000, p. 306).

While most claims about ways to disclose bad diagnostic news come from expert opinion of what constitutes a "diagnosis," the findings in this paper suggest the importance of understanding how patients and families experience the medical system prior to diagnosis. This experience – both positive and negative – plays a critical role in acceptance of the news and lays the foundation for the therapeutic relationship. Adopting a broader view of the diagnosis and developing guidelines grounded in both clinical experience and in the experiences of patients and family caregivers could lead to innovations in organizing services as well as new policy recommendations for prioritizing communication to improve continuity of care and enhance patient trust in the system.

Chapter 2: The Second “Weight” of a Cancer Diagnosis: Sharing the News with Family and Friends

The Second “Weight” of a Cancer Diagnosis:

Sharing the News with Family and Friends

Abstract: This paper examines patient’s initial self-disclosures of a cancer diagnosis to family and coworkers drawing on fieldwork and interviews with twenty-eight blood cancer patients and their family caregivers followed from diagnosis through twenty-four months post stem cell transplant. One patient case is examined in detail tracking the way the patient first noticed symptoms, decided to seek medical care; learned the diagnosis and then disclosed the diagnosis to others who will be affected by the news. Across cases, participants shared the assumption that self-disclosure of the illness was an obligatory event; it should begin with those closest; it was difficult to prepare recipients for and, equally, if not more emotionally challenging than learning the diagnosis itself. The greatest variation across cases pertained to how individuals shared their diagnosis in the workplace and patients described much ambivalence about how to undertake the task. Overall, the study offers insight about how patterns of self-disclosure about a serious diagnosis transform patient identity and social relationships that, in turn, influence patient coping and decision-making.

Introduction

> Imagine yourself in this situation: last week you had a biopsy, today you’re going back to find out the results. You took the day off, drive to the clinic, check in (…) get to the exam room, wait, the doctor walks in, warm smile, nice handshake and tells you those words that will change your life: “You have cancer.” Immediately there is a huge weight on your shoulders thinking, ‘What do I have to do to get myself well?’ You spend twenty minutes with the doctor making treatment decisions (…) then you leave the clinic, numb. Driving back home all of a sudden another whole weight falls on your shoulders, ‘I’ve got to start telling people. How am I going to communicate? How can I tell my friends and family what’s going on? The last thing I want to do is pick up the phone and tell this story over and over.’
>
> Sona Mehring, creator of *CaringBridge,* Transform 2010 conference, Mayo Clinic, Rochester, Minnesota.

A cancer diagnosis is a dramatic event marking the boundary between the last moments of one life and the beginning of a new life where good health cannot be taken-for-granted. From the physician’s perspective, naming the condition and disclosing the diagnosis are the two critical tasks necessary to establish the clinical relationship and set the stage for the discussion of therapeutic options (Jutel 2011). From the patient’s perspective, however, the diagnosis is a different enterprise and the quote above offers a condensed version of an important way in which it is distinct. An individual goes to a clinic appointment to hear test results. If the news is bad, after absorbing it and discussing treatment options, a patient’s thoughts naturally turn to the other people who must be told.

The difficulties patients encounter sharing the diagnosis with family and friends are generally assumed to pale in comparison to the task of grappling with the diagnosis itself. However, for cancer patients and patients coping with other serious diseases, self-disclosing the diagnosis is integral to the overall adjustment process. Social theorists note that humans do not process serious events in isolation (Rimes 2007) but rather as members of social groups (Mannheim 1936; Berger and Luckmann 1966). Research shows that the way individuals are embedded in social networks (Giddens 1984; Granovetter 1985) matters for both the patient's recovery and the health of the social group (Christakis and Fowler 2009).

For patients, sharing the news diffuses the psychological burden of the diagnosis. In the act of verbalizing it, patients come to terms with the situation (Maynard 2003: 43) and are then able to redirect energy toward other aspects of the disease (Schneider and Conrad 1980; Davis 1961). Sharing the news, however, also adds new burdens by exposing the patient's sense of vulnerability and loss of control (Cozby 1973). Management of a "spoiled" identity often takes a central role in the illness experience (Goffman 1963) as does coping with changing personal relationships (Charmaz 1991). For these and other reasons, self-disclosure of a serious illness is something that a subset of patients manages successfully, others do not, but either way, it is an extremely stressful part of the illness experience (Charmaz 1991: 276; Wortman & Dunkel-Schetter 1979).

Although diagnosis as a lived experience is an expanding area of research in science studies and medical sociology (Jutel 2011; Cockerham 2012), the patient's experience of disclosing the diagnosis to those others for whom the news will have personal consequences is rarely any part of the analysis. In this paper, I focus specifically on the *patient's perspective* in an effort to recast diagnosis and sharing the news as two closely related phenomena – essentially two moments in the same experience -- both integral to coping with illness and making treatment decisions.

In what follows, I review the literature on self-disclosure in the medical and social science literature noting the near absence of attention to how patients experience this process. To highlight the significance I describe one case in detail, tracing the chronological path of sharing the news and then discuss specific themes and areas of variability within the set of cases in the larger data set. The paper concludes with recommendations for future research on the issue of self-disclosure in clinical contexts.

Literature

The medical literature that examines patients' self-disclosure practices is situated primarily in journals of health psychology, psycho-oncology, health communication, HIV-AIDS care, STD management, and preventative health. Both the quantitative and qualitative research tends to correlate one or more independent variables to patient outcomes and long-term survival (Burns et al. 2005; Larson and Chastian 1990). Studies have looked at differential survival of AIDS patients who disclose or conceal their condition (Cole et al. 1996); the health benefits of sharing disease-related news (Degi 2009; Gray et al. 2000); and the likelihood to disclose a diagnosis as a product of age (Henderson et al. 2002). Research has also compared disclosure practices by gender (Cecil 2010; Hilton et al. 2009), by quality of marital relationship (Goldsmith 2009); and in terms of the emotional impact of disclosure at different points in an illness trajectory (Wortman and Dunkel-Schetter 1979). Increasingly, studies have also begun to consider the disclosure behavior of family caregivers as well, to aid understanding of how it may affect caregivers' physical and emotional health (Beattie and Lebel 2011; Olsen 2011).

One provocative line of research in the medical literature has examined the interpersonal consequences of family members' disclosure of a hereditary predisposition to cancer and other serious disease (Adelsward and Sachs 2003; Aktan-Collan, et al. 2011). The Swedish study by Adelsward and Sachs in particular nicely illustrates the significance of disclosure on relationships. The study draws on thirty-one audiotaped consultations from a genetic specialty clinic and reveals how individuals who voluntarily submit to genetic testing subsequently find themselves in two uncomfortable roles that threaten interpersonal relationships within the family. First, by requesting information about family history from parents and other extended family, individuals breach social norms about appropriate and "unspeakable topics." Second, these individuals further threaten familial relationships when it becomes necessary to follow up and convey bad news to family members after testing is complete. From this study, one can see just how disruptive health related news can be on close family relationships.

Little consensus is evident in the medical literature about which "states" and "traits" most influence the likelihood that an individual will self-disclose news of a serious diagnosis. Gray et al. (2000), for example, find gender to be a significant determinant with women more likely to disclose than men, while Hilton et al. (2009) find men disclose the diagnosis at rates equal to women. Likewise, some studies indicate that young people are more likely to share their health-related news while other research finds that older people discuss their health with family and friends both more often and more openly (Henderson et al. 2002). Across the board, the effects of disclosure practices on long-term clinical outcomes have been difficult to establish due to the complex and unique circumstances surrounding each patient.

Much of the literature on self-disclosure in the field of sociology builds on symbolic interactionism and the phenomenological tradition in philosophy. Theorists from Georg Simmel to Erving Goffman to Anthony Giddens have long regarded self-disclosure to be an important class of social behavior. Simmel (1906), for example, wrote about how patterns of self-revelation and self-restraint reveal social norms within personal relationships. Goffman (1959; 1967) analyzed how individuals manage the impressions others through the strategic packaging of personal information (deciding what to highlight and what to omit about the self). Giddens (1992) argued forcefully that self-disclosure is, in fact, essential to any kind of socially intimate relationship.

Over the years, empirical studies have enhanced understanding of the central role of self-disclosure in the development, maintenance, and dissolution of personal relationships. One of the first extensive investigations on self-disclosure practices was that of sociologist Mirra Komarovsky. Her examination of marital relationships, in *Blue-Collar Marriage* (1964), drew on case study data with fifty-eight married couples, in an effort to fill a gap in the family relationship literature. Previously, studies had focused on either middle class white Protestants or families living in poverty but Komarovsky interviewed working class couples to specify ways in which the norms governing their marital relationships might be distinct from those of the middle class. She examined norms regarding mutuality in disclosure, the scope of taboo topics, and behaviors that reinforced rigid sex roles and found that working-class partners did not value self-disclosure as highly as middle-class couples did. In fact, a lower level of self-disclosure seemed to stabilize rather than de-stabilize many working class marital relationships. Another study exploring disclosure in marital relationships is Diane Vaughn's *Uncoupling: Turning Points in Intimate Relationships* (1986). Rather than focusing on bonding mechanisms, Vaughn examines patterns of self-disclosure during the process of separation or "uncoupling." The research focused on middle class marital relationships and found that dissolving a relationship typically begins as a "quiet unilateral process" (Vaughn 1986: 13) whereby the partner initiating the separation progressively withholds information about the self, beginning with the first secret of unhappiness in the relationship. Over time, Vaughn notes, an individual will begin to conceal information while simultaneously enhancing autonomy through greater self-disclosure to others outside of the marital relationship thereby better accomplishing the separation.

Both Komarovsky and Vaughn work from ethnographic data and focus on particular kinds of social relationships. Another important investigation on disclosure is Douglas Maynard's *Bad News, Good News: Conversational Order in Everyday Talk and Clinical Settings* (2003). In the tradition of conversation analysis (CA), Maynard focuses not on the specific kind of social relationship but rather on the interaction itself. The nature of a relationship is revealed empirically through concrete disclosure practices visible "on the surface, in our overt doings and sayings" (Maynard 2003: 121). Referred to as "first-party" news, Maynard examines a range of self-disclosures in various contexts, and within the subset of disclosures with consequences for the recipient (such as is the focus of the current chapter), several strategies are identified. The first party, for example, may announce the relevance to the recipient by prefacing the news with statements such as 'I thought you would like to know' (Maynard 2003:140). Alternatively, relevance may be presumed, prefacing will be absent and conveyed primarily through structural decisions about who, when, and how to disclose the news. Maynard also notes that explicit announcements of relevance do not automatically translate into actual strong relevance to the recipient. In fact, these announcements may instead signify an unstable relationship that the deliverer is working to restore or reflect a desired future state of intimacy in a relationship (Maynard 2003:143). Reflexively, recipients of the news also display the nature of relationship through how they ratify or fail to ratify the assertion of relevance by the first party, and the degree to which they personalize (i.e., 'this is awful') or do not personalize the news (i.e., 'I'm so sorry').

Self-disclosure comprises an extensive literature in psychology and the behavioral sciences. This work has roots in phenomenological philosophy and is premised on the idea that analysis of disclosure behavior reveals relationships in a way that other forms of analysis cannot. Distinct from CA, however, psychologists studying patterns of self-disclosure focus less on the observable behavior and more on the content for how it facilitates changes in relationships. That is, disclosure patterns are assumed to reflect the quality of existing relationships and play a central role in shaping the kind of relationship individuals will have with each other in the future (Harvey & Omarzu 1997). Among other things, researchers study the mechanisms by which forms of self-disclosure help establish new relationships, maintain existing relationships or contribute to the deterioration of ongoing relationships (Derlega et al. 2008; Greene, Derlega and Mathews 2006; Derlega, et al., 1993).

Both sensitive and mundane information, personal as well as relational disclosures are the object of investigation in the social psychological literature. Self-disclosure is also analyzed in terms of "transactional outcomes" such as building intimacy or self-worth; level of "informativeness," degree of truthfulness, normative appropriateness, and the effectiveness of self-disclosure (Derlega & Chaikin 1977; Greene et al. 2006; Derlega et al. 2008). While patterns of self-disclosure and relationship quality are not assumed to reflect a one-to-one correspondence, there is an assumption in this literature that self-disclosure generally proceeds in a gradual and orderly fashion over the course of a relationship moving from less-intimate to increasingly more intimate disclosures. Violations of this order pointing to a failure to establish a relationship or deterioration of an existing relationship. Ryan (2006: 229) examines these "norms of notification" and "circles of knowing and non- knowing" explicitly, considering who is expected to tell what kind of information to whom and when. His analysis reveals the larger meaning derived by individuals about the standing of personal and professional relationships based on these learned, tacit, rules of notification. Individuals ritually reenact solidarity as well as manipulate social structures through decisions about the disclosure of information. The aggregate effect of these notification norms is what Ryan refers to as an "information order."

The social psychological literature also includes a number of disclosure decision-making models that map the way that individuals weigh risks associated with self-disclosure in light of particular motivations. Derlega (2008) and Green et al. (2006) have analyzed *self-focused motivations* such as help-seeking, catharsis or sense making; *other-focused motivations* such as a sense of obligation to inform and a desire to test the reactions of others; and *relationship-focused motivations* for divulging news. All three motivations center on being in or desiring to create a close intimate relationship. *Situationally-focused motivations,* by contrast, refer to mere physical proximity and the fact that a recipient may be asking questions (Park and Abels 2010). Once the decision to disclose has been made, a number of psychometric scales have been developed drawing on Social Penetration Theory (Altman and Taylor 1973) and Incremental Exchange Theory (Levinger and Snoek 1972) to assess the timing, best mode of delivery, most appropriate setting, and the specific content of a range of disclosures. One important contribution from this literature has been to draw attention to normative expectations or what Rubin et al. (1980) describe as an "ethic of openness." This refers to the way that disclosures of particular types may be expected and necessary to the maintenance of intimate relationships in a way that they are not in less personal relationships. A second important contribution has been detailed examination of sharing news of highly emotional events. Rime et al. (2007) argue that decision-making is an entirely different task with highly emotional news because there are unique pressures to disclose and these experiences are difficult to conceal indefinitely. Usually, events such as news of a serious illness, will need to be shared in the near term (a matter of hours, days, or weeks following the event). Once the barrier of sharing this information with one person for the first time has been broken, the self-disclosure process tends to be modally repetitive across an expanding circle of social contacts.

To this point, the literature considers illness just one of many types of self-disclosure but a small literature in medical sociology has examined diagnostic self-disclosures specifically. In their accounts of serious chronic illness Strauss et al. (1975, 1984); Glaser and Strauss (1965) and Schneider and Conrad (1980, 1983) have all described self-disclosure as among the important factors influencing the ability to cope with a disease or disability. However, the most thorough treatment of self-disclosure of illness is undoubtedly Kathy Charmaz,' *Good Days, Bad Days: The Self in Chronic Illness and Time* (1991) in which she examines the impact of chronic disease on identity. Drawing on interviews conducted over fifteen years with patients coping with a range of chronic conditions, Charmaz describes how patterns of self-disclosure, reveal much about the illness experience and shifting personal identities noting how patients engage in various strategies to preserve a sense of self. This includes "protective disclosing" a strategy involving calculated decisions about what, to whom, and over what time period to convey news about health and "spontaneous disclosing" which is motivated by immediate circumstances and the need for catharsis. Charmaz notes that obstacles that most discourage individuals from self-disclosing their illness to others are situations characterized by "low trust"-- where the sufferer fears harsh judgment or where there is a sense that recipients are weary of the ongoing conversation about illness.

Summary

Although the literature on self-disclosure is rich and varied, research on illness disclosures have not been set apart and studied as a unique category of self-disclosure in the medical, sociological, or psychological literature. The medical literature examines patterns of self-disclosure with an eye to organizational priorities such as clinical outcomes; the sociology and psychology literatures focus primarily on the behavioral phenomenon itself. In the medical sociology literature although it has been a focus of attention, it is rarely studied in terms of the way patients experience this event: as a part of the overall diagnostic experience. Instead, the research tends to discuss self-disclosure as one of many challenges facing patients.[3]

Medical anthropologist Arthur Kleinman (1988) notes that a "disease" and an "illness" comprise two very different sets of problems for patients. The disease is the biomedical label for the physiological condition that is bestowed on patients and serves as the master narrative for care. Illness, by contrast, interconnects the "physiological processes, meanings, and relationships so that our social world is linked recursively to inner experience (…) acting like a sponge, illness soaks up personal and social significance from the world of the sick person" (Kleinman 1988: 31). Self-disclosure of the diagnosis is where the patient and others take up the social significance of the diagnosis as an illness experience. Patients "enact" the diagnosis when they choose whom they will inform and when. Family and friends contribute to this enactment through their questions and other reactions to the news.

Compelling evidence of the impact of diagnosis on identity (Charmaz 1991) can be seen in the explosion in use of new "compassion technology," which channels the impulse to share the news into the blogosphere. Health news sharing websites such as *CaringBridge* (1997) and *CarePages* (1998) emerged before *Facebook* and at a time when *Google* was in early development, allowing patients undergoing treatment for a range of diseases to convey the diagnosis and other health information with members of their social network. Contrary to expectations, the niche of this technology was never subsumed or in substantial competition with other social media[4] and today, *CarePages* has over three million members worldwide, while *CaringBridge* has over seven million registered members, becoming the third largest non-profit dot-orgs in the world (Merhing 2010).

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[3] Notable exceptions to this would be with regard to conditions associated with considerable stigmatization such as AIDS, homosexuality, and mental illness (Chaudoir, Fisher, et al. 2011).

[4] According to one nonprofit-brand advisor, this kind of technology fills a unique need to share news about the progress of a medical condition and the platforms are different in that: "You don't go to the barbecue and tell everyone that you have cancer. You do it in a private room, you do it on your own terms, and you do it in a way that deepens relationships. Users understand that *Facebook* is the barbecue, *CaringBridge* is that private room" (Logeland and Rash 2010: 5).

What might explain this radical trend in managing self-disclosure? How can attention to disclosure practices offer new insight into the illness experience? What might attention to sharing the news reveal about the social nature of serious disease? This paper examines these questions and offers a new view of diagnosis as simultaneously an event, a process, and a transition to reveal how acts of self-disclosure are a key part of the unfolding of illness for patients and families.

Data & Methods

The data on sharing news comes from a larger project based on longitudinal ethnographic fieldwork (2007-2010). Twenty-eight blood and bone cancer patients and thirty of their family caregivers were followed from shortly after diagnosis up to twenty-four months post hematopoietic stem cell transplant (HSCT) in coordination with a large comprehensive cancer center in the United States. The cancer center's institutional review board approved the study. A purposive sampling frame was used to recruit candidates stratified by age, sex, socio-economic status, diagnosis, and type of transplant procedure in order to achieve a distribution that roughly paralleled the general patient population at the cancer center. Of sixty-one patients approached for the study, forty-one consented to participate. However, six went to transplant before an intake interview could be conducted and seven others were referred to hospice shortly after recruitment. Of the remaining twenty-eight participants, seventeen were men and eleven women. Five patients were in their 20s; four in their 30s; eight in their 40s; eleven in their 50s; one in his 60s; and one in his70s.

Each patient and their caregivers were interviewed separately at four points: prior to transplant, three weeks post-discharge, six months following transplant, and at the end of one year. Thirteen of the twenty-eight families also took part in more intensive ethnographic research that involved monthly visits to the patient's home and observation and audio-recording of patient clinic visits every three weeks. Patients and caregivers received a $25 gift card as compensation for each interview and families participating in the home study received an additional $100. Contact beyond eighteen months post-transplant was maintained primarily through home visits, telephone, e-mail, and monitoring of patient hospital-sponsored weblogs.

The phenomenon of sharing diagnostic news with family and friends was not a focus of the original investigation but emerged in the first few months of fieldwork. During intake interviews, patient accounts of the diagnosis often segued naturally into a discussion of sharing the news with family, friends, and co-workers. While the topic usually came up as an aside or an afterthought, it was notable that it could evoke a great deal of emotion for the interviewee. I became sensitized to the issue going forward with fieldwork and later determined that sharing the news was not a tangential phenomenon but rather an event that deserved sustained attention in its own right. It offered a new window on the lay experience of a protracted serious illness.

As I reviewed each of the twenty-eight patient cases, I organized all reports and observations of sharing news into a collection. The data sources include interviews, telephone calls, weblogs, e-mail and field observations. Each instance of disclosure was first coded according to contextual information including: (1) who conveyed the news, (2) the nature of the relationship between the teller and the recipient, (3) the circumstance of the disclosure, (4) the type of news is disclosed and (5) where the patient was in the overall illness trajectory. Using a thematic grounded theory approach (Strauss and Corbin 1988; Schatzman and Strauss 1973) additional coding included attention to what precipitated the disclosure and the strategy used to decide with whom to share the news. These data sometimes involved long narratives but many were short statements and partial phrases. For example, one husband and wife in an informal conversation with me in the waiting room prior to a clinic appointment stated, "We called to tell her about the recurrence [of the husband's cancer], but she doesn't get it." While short, this comment reveals that the patient and his wife had specific expectations about how someone *should* react to such ominous news. As an expression of disapproval, the comment suggests that the act of sharing increased the social distance between the couple and this member of their social network.

My analytic strategy for this chapter is to describe one case in detail to convey the chronological unfolding of how a patient first learned about his cancer, and systematically proceeded to share it with others, including, initially, his wife. In its detail, the case captures patterns in other accounts in my data and therefore is "typical" – or at least not extraordinary to any significant degree. The patient and his spouse reviewed their transcribed interviews with me and offered further commentary. I was also able to observe their interactions in each of the clinic settings they visited over an eighteen-month period.

Case Study

In the account that follows, "Harry" [5] describes learning and then sharing his leukemia diagnosis with his family and co-workers. In a separate interview his wife, Sheila describes her experience hearing the diagnosis from her husband for the first time and then sharing the news with her colleagues at work.

Context and background

Harry is a fifty-year-old product engineer for a large ventilation company in the Midwest. He is married and has a grown son and daughter from a previous marriage and he has worked for the same employer since graduating from college nearly thirty years ago. He is one of the youngest of a close cohort of men who started working at the company at roughly the same time and together these men have watched the business grow from several hundred to several thousand employees. Many of the men are nearing or have recently retired but at just fifty years old, Harry is still years away from retirement. In fact, in the last year, he took a promotion within the company that required frequent international travel and it was during this first year in the new position that Harry began to experience vague symptoms that ultimately led to a diagnosis of acute myelogenous leukemia.

Pre-diagnosis

In late June of 2007, Harry returned home from his second trip in eight weeks to Shanghai. Changing his clothes after the flight, he more closely examined the rash he noticed while traveling. In the bathroom mirror, it looked like "a million miniature mosquito bites" and seemed to be spreading further

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[5] All proper names have been changed and all details in this account are from the patient and caregiver accounts and from my field notes drawn from observation.

across his chest and ribs. Harry assumed it was probably an allergic reaction to the detergent his clothes had been laundered overseas, so he used a hydrocortisone cream on his chest and threw his clothes into the wash. His wife suggested he make an appointment with his doctor but Harry did not feel like he could spare the time. He was scheduled to fly to North Carolina in a couple of days to evaluate a quality issue with some industrial kitchen hoods already packed into crates and ready to be shipped overseas.

> The rash could wait. I had bigger fish to fry (...) I wanted to make sure that we didn't have forty mistakes that I was going to have to worry about when I flew back to Taiwan in August.

Later in the week, on the flight back from North Carolina, however, the rash was no better and Harry had now developed flu-like symptoms. Shortly after returning he tried to make an appointment with his regular doctor. However, the doctor was on vacation so Harry planned to stop at a walk- in clinic after work the next day.

The preliminary diagnosis

The following day after work Harry arrived at the walk-in clinic shortly after 4 p.m. A nurse took information about his symptoms, some blood work was done, and then Harry was ushered into an exam room to wait for the doctor. A few minutes later, a doctor entered, reviewing the nurse's notes and introducing herself:

> 'How're you feeling?' and I said, 'Eh, a little bit of a low grade.' She says, 'Yeah, I noticed that, based on what the nurse took.'

The doctor examined the rash, asked about symptoms mentioned in the notes, and after a more thorough physical exam, prescribed an oral antibiotic and a topical cream, calling it in to Harry's pharmacy. Because the lab work was not back, the doctor told Harry she would call him if anything else turned up. On the way home from the walk-in clinic, Harry stopped at the pharmacy to pick up the prescriptions. He gave his name to the pharmacist and just as he took a seat, the phone behind the counter rang. After a brief exchange, the pharmacist motioned to Harry that the phone was for him. Surprised, Harry took the phone. It was the doctor from the walk-in clinic.

> 'Mr. Powell?' 'Yes. Yes.' 'This is doctor so-and-so. (…) um, based on the test results I have, there's a few things that were inconclusive on here. I would prefer- I'll call over to Eastview clinic for you and I'll get you set up on an appointment right away. They are going to want to run a couple of tests. We're already closed down here, but you probably should see your family doctor.'

The doctor continued:

> 'I'm going to tell the pharmacist not to fill those prescriptions.' I says, 'Oh, neither one?' She said, 'Well, the one would be okay but (...)well - why don't you let your doctor - if they run a complete - more complete blood screen and stuff like that, they'll, they might prescribe something different, so we'll just let them go.' (…) So I thought, okay, no big deal.

Harry did not mention the clinic visit to his wife that night. The next morning the clinic called him at work to confirm an appointment in the early afternoon.

> I thought (…) I'll just work a little longer and then go to lunch, and then run in there (...) I had told the staff -- the people I work with -- I said, 'I don't know, Doc wants to see me. I got a little rash. I think it's from the stuff that they washed my clothes in (…) but evidently the Doc picked up something in the blood work yesterday, so I don't know how long I'll be.' Just left it at that.

This time Harry went to his regular clinic. It was a hot day and Harry recalls walking across the parking lot as waves of heat came off the asphalt making him feel lightheaded. Still, he did not suspect anything serious.

> I mean, I had no inkling and when I got in there (…) The nurse just walked me in, and she says, 'The doctor will be right in to see you.'

In just a few minutes, a colleague of his regular doctor entered the room.

> She came in and she looked a little bit solemn and, you know, reading faces I should have known that there was something really wrong. But I says, 'Doc, how're you doing? You having a good day?' And she's (…) looking down at the piece of paper she's holding on to and she says, 'No, no I'm not.' Then she says, 'I need to tell you something that you're probably not going to want to hear.'

The doctor told Harry that the blood work showed abnormalities suggesting leukemia. Immediately, Harry questioned whether there had been a mistake, prompting the doctor to add:

> 'This is what they're telling us from these counts but sometimes we get false positives.' She said, 'I don't - I want to be very thorough. This is what it *appears* to be based on the results that you have, but let's not jump the gun.'

The doctor told Harry she wanted to schedule him with a specialist later this afternoon. With the words "leukemia" and "false positive" fixed in Harry's mind, he reacted to something else the doctor said:

> She says, 'Before I go [make arrangements], do you want to call somebody?' And I looked at her and I said 'What?' And she says, 'Well, you're married, right?' And I said, 'Yes.' 'Well, do you want me to call your wife?' And I says, 'And tell her what? If you're not sure, I don't want to get her excited. She's at work. That's the *last* place I want to call her and say I think I have cancer.'

Bringing his wife into things sounded to Harry like he actually did have cancer, even though the doctor also said it might be a false positive. As he waited for the doctor to return, his confusion escalates to panic:

> Every bad thought comes through your mind, "I'm not going to make it, I'm going to barely walk out of here," and all that kind of stuff, because you just don't know . . .

After the doctor set up an appointment, she asked Harry if he was okay to drive or if he would like an ambulance ride. Harry told the doctor that he was fine to drive, but as with her previous comment about calling his wife, he is confused about the reason she is asking. Stepping outside the clinic again, the heat coming off the asphalt reminded him of where he was but now everything familiar had become surreal: "I felt like I was in a bad movie or something." As Harry drove the ten miles to the regional hospital, his sense of urgency built:

> I was still thinking - boy, this better be a false positive (…) I'm too young. I'm fifty years old, fifty and a half. I can't be dealing with this.

At the hospital, blood was drawn again and Harry was put in yet another exam room. A dark-haired man in his mid-thirties, Dr. Robertson, who would become Harry's primary local oncologist, walked in and introduced himself as "John" shaking Harry's hand. After Dr. Robertson reviewed the information from the walk-in, he described the bone marrow biopsy and told Harry he would call on Friday morning with the results of the procedure noting:

> 'Just to let you know I am probably ninety percent sure that you do have AML (...) based on (...) the results from the walk-in clinic (...) but' he says, 'what will really confirm it will be the bone marrow biopsy.'

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After the biopsy, Harry looked at the clock for the first time all afternoon and realized his wife would be wondering where he was. Harry's wife worked at a bank on the far side of town and usually got home after him. She knew nothing of the visit to the walk-in clinic yesterday or the two clinic visits today so when she came home and found that Harry was not there yet, she changed into shorts and a T-shirt and started planning dinner, noticing they were short on several staples. She recalls:

> When it got to be about twenty to six, I was getting a little bit more worried and so I finally called him on the cell phone and I said, 'Hey,' (…) I said, 'Well, what are you doing? You're on the way home?' He goes, 'Yep, I'm on my way home right now.' Thinking he was coming from work I said (…) 'Well, you know, I just checked it' I said, 'We're running low on bread and milk.' I said, 'Could you pick some up on the way home? (...) He goes, with kind of a hesitation in his voice, he goes, 'Well, can I come home first?' And I thought to myself, well, what does he have to come home for that he can't stop and pick up bread and milk? Well, then I'm thinking, oh, my god, something happened at work. He lost his job; all these things are running through my head.

Sheila stopped planning dinner thinking about what might be going on with Harry; instead, she gets a glass of water and decides to wait for him outside.

> So I'm (…) sitting out in the lawn chair in the mouth of the garage and he comes pulling up in the truck, and he parks the truck, and he gets out, and I said, 'Well, hi' I said. 'What's going on?' He goes, 'We need to go in the house.' I thought, okay, what do we need to go in the house for, you know? So we get in the house, and at this point I'm getting a little nervous, you know, wondering what the heck's going on. Again, thinking that something happened at work -- that he lost his job or, I didn't know, somebody died that he worked with.

Sheila recalls:

> I get in the kitchen and I sit down at the kitchen table, and he's standing in front of me. And I said, 'What's going on?' He goes, 'Well' he said - he couldn't tell me! So he pulls this card out of his pocket. He didn't say anything, he just stood there. And he kind of was - just had this look on his face like he didn't know what to say.

Similarly, Harry recalls:

> In the house (…) she said, 'What's up?' And I said that 'I need you to sit down.' She says, 'You're not leaving for China again.' And I said, 'No. No, as a matter of fact, I won't be going for quite a long time.' 'You didn't lose your job?' 'No, no, I didn't lose my job.' I reached in my pocket, and I had John's business card in my pocket (…) and I handed her his card and she read the card.

Sheila says:

> He handed me this card and here it has *High Point Regional Cancer Center* on the top of it with Doctor Robinson's name, address, you know, the address of the cancer clinic and (…) I'm looking at this and I'm, I'm looking up at him and I'm going, 'Cancer!?' I'm going, 'Cancer!?' I'm thinking, oh, my god, that's the worst news that I could hear, other than somebody coming up to the door and telling me that he's dead, you know. So I just - I said, 'Oh, my god' I said, 'What' I didn't know what to say, I, I think I was speechless for probably a few seconds. I stood up and I went, 'Oh, my god.' I said, 'Well, what kind of cancer do you have?' And he said, 'Leukemia.' And I w—I just- well, he lost it, and I lost it and we started hugging and I was crying and he was crying. And I said, 'Oh, my god' I said. So then he told me the whole [story of] going to the clinic.

They sat at the kitchen table talking for hours -- looking out of the sliding glass doors onto the new deck they had recently built themselves. The retirement they planned, just a few years off, was now uncertain. Harry recalls, "We cried for quite a while. I don't even know if we ate dinner that night." Harry thought they should not discuss the situation with anyone on Thursday.

> I said, 'We won't know anything 'til Friday morning, so don't say anything.' One of my co-workers was married to one of her co-workers(…) even if you tell his wife in confidence, it'll be around the company." And I says, 'I don't want to have to explain it to anybody right now until we have all the cards exposed. We've got to know a hundred percent because this isn't something you just blurt out.'

Thursday was a strange day for both Harry and Sheila because it was so "normal." In fact, after dinner that evening, Sheila suggested that perhaps they had overreacted. Maybe tomorrow the doctor would tell Harry that someone misread the lab results. Although this was a comforting idea, when Friday morning came, Dr. Robinson called Harry at work and confirmed the diagnosis of acute myelogenous leukemia (AML). While disappointing, the news was not unexpected and Harry followed through with their plan.

> I called Sheila and told her that it was confirmed and (…) she could go around and tell specific co-workers or her boss and that kind of stuff, and let it filter out that way.

Harry thought about how he was going to break the news where he worked. He knew he needed to tell his immediate supervisor, but before that, he approached another co-worker.

> Chet and I have been very close friends for (...) the twenty-eight years that I've been there. I went into his office and I closed the door and he kind of looked up at me. He said, "Harry, how're you doing?" I says, "I need somebody to talk to. The walls don't have ears, do they?" He looked at me and he goes, "No." He says, "Confidential?" and I said, "Extremely." So I explained what happened and he just sat back in his chair. He says, "I can't believe this." I said, "Neither can I! I had to tell somebody here at the company." He said, "Well, Rob [Harry's boss] is here. You know that." And I says, "I know, I've got to go tell him. How do I do it?"

Since Harry's promotion, his new direct supervisor was Rob, a man based in Singapore. Coincidentally, Rob happened to be at the corporate office that week for a series of meetings.

> I composed myself the best I could and I was going to go into his office, and [upon entering] Rob looked up at me and said, 'This looks like it's going to be awhile, and I have a very important telephone call to make. Uh, I'll talk to you at ten o'clock?'

Harry said "Sure." Back at his desk, he began thinking past the conversation with his boss toward the conversation he'd ultimately need to have with other colleagues at work:

> So (…) I sat down and I just started thinking about it (…) and I started composing an e-mail that was to friends and co-workers. I basically went through the whole thing, outlining that I was diagnosed with leukemia and that I was just diagnosed with it and this was what was going to be happening. I put it all together (…) scurried over to the printer real quick so nobody else could find it (...)I read through it (...)and it basically took it down from a story that you'd want to go around and tell your best friends (…) But it condensed it down to give everybody the factual information. Then they could ask questions (…) or do whatever they wanted to do. And it obviously was going to make it a lot easier on me than to have to go around and hit twenty offices of my closest peers that I've been working with for so many years, and repeating the story time and time again. It's hard enough to talk about it the first time, you know, let alone nineteen more times.

Harry's boss found him after his phone call and invited him back into his office.

> 'Come on in (…) What do you want to talk about?' And I said, 'This is the best way I can talk about this,' and I handed it [the draft] to him.

His boss took the paper. When he finished reading, he looked at Harry and said, "Are you sure?" Rob went on to explain that a year ago he, too, had been diagnosed with cancer about a year ago, but it turned out to be a mistake. Harry was taken aback and even felt momentary hope, but then said, "No, they were sure."

Harry's boss said:

> 'You've done a great job here. You've explained it to everybody (…) so, yeah, go ahead and send it out. I'll talk to HR and find out what we need to do, and I'll take care of that end of the things for you.' And he said um, 'Let's do lunch.' He said, 'Let's do lunch. We'll talk about this more.' And I said, 'Okay.' So, you know, it was already like (…) 10:30 that morning by the time I'm finishing this up with him. I went back to my desk and pshhsssew [sound of sending the e-mail to everyone].

Harry sat in front of his computer after sending the e-mail waiting, without being sure what he was waiting for. In the next hours, it was evident that people had received the note. "You know, in an office, you can hear the office chatter, but then dead silence. They got it." "I was getting these blind hugs from behind." Harry sighed recalling events noting

> It was a tough day, … a tough day. Matter of fact I only made it until about three o'clock. It's one of those kind of things, you just, you never know what's coming. All of a sudden, POW! Here it is. (…) Deal with it.

Sheila sharing the news. At the bank, Sheila hung up the phone after Harry told her the news. It was official: The biopsy confirmed that Harry has leukemia. A wave of nausea came over her and not quite sure what to do next, she walked toward her supervisor's office. Her supervisor was preparing for a department meeting and Sheila barely waited for her to look up before blurting out that they just found out that Harry has cancer. Her supervisor was silent for a moment and then went around her desk to hug Sheila. She said she couldn't believe it. They were both heading into a department meeting in a few minutes, so her boss suggested that, after they got through the central business, Sheila should let everyone know what was going on.

> All through the meeting all I could think about was how do I tell the girls? You know how do I - but then I started getting upset. In the meeting, I started crying and everybody could tell, I mean everybody kept looking at me (…) like what's going on? Well, the more I thought about that and telling the girls and how I was going to tell it and the more I thought about Harry having cancer the more upset I got (…) and I just started crying in the meeting. And I was just sitting there and I know I must of looked like hell. But um it – she [her boss] got done with the meeting and she said, 'Okay, Sheila (…) the floor is yours.'

Sheila told the group that Harry had been diagnosed with leukemia.

> Everybody was (…) just shocked "Well, how did he know?" "What did he go in for?" "How did he find out?" "What were the symptoms?"

As people started asking questions and talking about their own experiences, Sheila felt lifted up. As though she was being brought into a community of cancer patients and survivors that she never knew existed.

> My supervisor had contact with people that she knew, people that had leukemia. It seemed like everybody (…) either had a brother or a sister or an uncle or an aunt and it seemed to be randomly all these people in the bank that I work with knew somebody that had leukemia.

Back home at the end of the day, both Harry and Sheila were drained, and the last thing they wanted to do was entertain. However, because Harry was scheduled to check into the hospital on Monday morning, they began discussing logistics of a get together with Harry's adult children. Sheila noted:

> He almost had to because once he's in the hospital, what are you going to do? "Well, hey, I'm in the hospital. I'm having chemo treatments, I have cancer," you know?

They planned to have Harry's son and daughter over for a barbeque the next evening - Saturday night. However, Harry's son called on Saturday morning with an emergency of his own and Harry decided this would not be a good time to talk about his cancer diagnosis. His daughter, Sara, and her family came over for the barbeque and before they all sat down to eat, Harry took Sara away from the group to tell her the news. Sheila recalls feeling helpless as she observed them from a distance. Harry's daughter dropped to her knees on the driveway sobbing and then Harry knelt beside her and they hugged and cried together. Over dinner, the whole family discussed the diagnosis and the logistics of chemotherapy. Harry and Sheila noted that, in an odd sort of role reversal, they found themselves reassuring Sara and her family of something they were not sure of themselves: that Harry would be all right.

Discussion

What has been presented here is a chronological account of the process by which Harry learns and then shares his cancer diagnosis before entering the hospital for induction chemotherapy. The story follows Harry's decision-making process as he discloses the news to his wife, his co-workers, and his children and through the step-by-step description of what he actually did, we are also able to trace to some degree, his cognitive transformation as he absorbs the news and prepares for the task of disclosure. By including Harry's experience of first noticing symptoms we see the combination of factors that ultimately led him to seek medical care. From his discussion of first hearing the *possible* diagnosis and then, incrementally, learning that it was the *probable* diagnosis, we also gain insight about Harry's interpretation of the situation; fears about sharing the news, and his presumptions and expectations about his personal relationships.

Harry's journey began as an interior, psychological experience where he rationalizes early symptoms using a 'symptom discovery narrative' (Halkowski 2006), beginning with a series of "noticings" of a bodily experience out of the ordinary. Over a period of weeks, the rash across his chest and mild fatigue develop into a low-grade fever and more pronounced fatigue. Harry's lay causal hypothesis at the outset was that the rash was probably a reaction to the detergent his clothes had been laundered in overseas – a physical reaction aggravated by work-related stress.

While symptom recognition is a necessary step prior to seeking medical care, Mechanic (1978) notes, it is never sufficient in and of itself. That is, with symptoms such as those Harry experienced; the cause could be attributed to any number of illnesses. The decision to see a physician required Harry weighing how disruptive and dangerous he believed the symptoms to be in light of competing obligations at work. When his symptoms began to emerge, Harry was under considerable pressure and had time-sensitive responsibilities at work that could he could not hand off to someone else easily. Under these circumstances, Harry assessed his symptoms as likely due to a minor ailment – a reasonable assumption that would insure minimal disruption in other areas of his life.

However, as Halkowski (2006) and Mechanic and Volhart (1960) point out, in the event that symptoms *do not* resolve over some period of time, individuals re-evaluate their initial assessments of the situation. When Harry came back from North Carolina, he begins to believe that the condition will not resolve on its own and thus, his decision to seek medical care was ultimately due to the persistence and the escalation of his symptoms and the fact that these symptoms began to intrude on his ability to perform his job.

Harry's account also depicts a diagnosis spread across several clinic visits. That is, physicians in different settings throughout the testing process offered partial information about a likely cause culminating in a definitive diagnosis of cancer conveyed by the oncologist, Dr. Robinson, on the phone. Harry's description suggests that several clinicians tried to avoid offering a diagnosis until testing is complete.[6] Reluctance to proffer a diagnosis until all of the information is available is a common practice in oncology and other specialties. However, as Harry's account illustrates, given the multiple stages of testing required prior to a conclusive diagnosis, part of the communication challenge for physicians becomes one of tempering patient fear throughout the process and containing patient alarm without appearing to be concealing medical information (Rousseau 2000; Christakis 1999).

While physicians often meter the amount and control the valence of information pertaining to the diagnosis, in a parallel fashion, during this testing process Harry seems to hold off on disclosing his situation to his wife at several points. There are at least three moments when Harry arguably might have discussed his health situation with his wife, but chose not to do so. The first opportunity was after having gone to the walk-in clinic. His failure to mention the visit is notable given the somewhat unusual events that transpired afterward – where the physician surprised Harry by calling him at the pharmacy to cancels the prescriptions she had previously called in and, instead suggests that he see his regular doctor the next day. Harry saw this event as "no big deal" and thus, unnecessary to discuss with his wife but perhaps there is more to this than he let on. The second opportunity for disclosure was after the news of leukemia based on abnormal blood work

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[6] Just how much each physician knew is not clear, but from another part of the interview we learn that the ER doctor at the start of this process knew because she came to the hospital and apologized to Harry: "She came up because she felt bad about not telling me over the phone, the one at the walk-in. And I...you know, I...I told her, I says "Well, I wouldn't want to do that either. And I probably wouldn't have wanted you to over the phone, that, you know, (…) for me to come back to the clinic and have you sit down and talk to me about it probably would have been way out of (…) the league of what was going on, and [I'd be thinking] why are you doing this?"

and it is here that he is explicit about the decision not to tell his wife, suggesting he feared that disclosing too soon could upset his wife. Harry recalls saying: "If you're not sure, I don't want to get her excited. She's at work." A third opportunity for disclosure was when Harry's wife called him to find out why he is not home yet and asks that he stop at the store. This could have been a point where he "forecasts" (Maynard 1996) the bad news by telling his wife that he wanted to come home which put his wife on alert that something was going on. Overall, it seemed that Harry wanted control over the disclosure in order to protect his wife (and himself) from reacting prematurely to the situation. His strategy of stalling, paradoxically, put Sheila on alert that Harry was concealing some important news. Stalling, as Maynard (1996; 2003) notes, can occasion a kind of disorientation on the recipient's part, and this seemed true for Sheila:

> . . . I thought to myself, well, what does he have to come home for that he can't stop and pick up bread and milk? Well, then I'm thinking, oh, my god, something happened at work. He lost his job; all these things are running through my head.

Summary

As Harry begins to share his cancer news, the act of disclosure alters his own understanding of the diagnosis, moving it from an abstraction into a reality. That is, early, tentative disclosures to Harry by various clinicians were in some sense, unreal. Harry adopted a "no big deal" approach to ambiguous signs and initial findings. In retrospect, however, he views these same events as clear signs of a serious problem: "I should have known that there was something really wrong." Harry held onto the possibility of a false positive for several days. Only in the process of self-disclosure, first to his wife and then to co-workers does the diagnosis become a reality with concrete personal and social consequences. As the diagnosis moves from a possible "false positive" to "ninety percent sure that you do have cancer," Harry began to orient toward an obligation to share his clinic visits with his wife.

This increasing pressure to disclosure raises a more general issue about concealment versus disclosure in personal relationships. Maynard (2003), building on Gans (1962) classic discussion, describes both public and personal situations where the failure to "appropriately" share good and bad news with specific others often precipitates a decline in the relationship more generally. Non-disclosure after a certain point was likely to have negative consequences for Harry's relationship with his wife independent of the news itself. Intimate relationships involve a high level of mutuality and reciprocity (Altman and Taylor 1973) and there are normative expectations regarding self-disclosure for relationship maintenance (Derlega and Chaikin 1977). Disclosure or concealment behavior provides a gauge of the quality and the level of trust in the relationship (Charmaz 1991; Rubin at al. 1980). By the standard of appropriateness for self-disclosure shared by Harry and his wife, even though a definitive diagnosis was still several days away, for Harry to delay much longer would arguably be "accountable" and reflect something unhealthy about state of intimacy with his wife.

The sequence of disclosures in Harry's account occurred in three waves: First Harry tells his wife, then Harry and Shelia each tell co-workers separately, and then, together, they share the news with Harry's daughter and her family. As Harry initiates his disclosure of the diagnosis in each context, we see a modally repetitive process by which he conveys the diagnostic news. A reflexive interplay between his individual experience and the social experience as others become involved in his diagnosis is also evident.

In each wave, Harry follows a pattern and tells one person the news first and alone. He tells his wife face-to-face in a private setting where there will be time to discuss the situation at length. At work, he first speaks privately to a one co-worker who he has known for a long time leading with "The walls don't have ears, do they?" This kind of opening suggests that the information is serious, but as Maynard notes (2003), the request for the recipient's time and attention also suggests a desire not to intrude until the recipient concurs that the information has time and the news will be held in confidence. In the third wave of the initial disclosure, Harry takes his daughter away from the group to tell her alone before discussing the situation as a family. The tendency to create similar contexts for sharing highly emotional news is, as Rime (2007) notes, often initiated early and through repetition helps the individual manage the emotions of others. This approach also moves the diagnosis to a kind of informing rather than confessional experience. Further, Harry's way of sharing the news reflects what Charmaz (1991:119) describes as "protective disclosing"– where one fears losing control and seeks a means by which to buffer their own and the emotions of others. Sharing too much with too many at the same time is one context that can lead to shock and other strong emotions from others with ramifications for the disclosure as well.

A second pattern in Harry's disclosures was that at three points in the process the recipient of the news is given something to read rather than Harry verbalizing the cancer diagnosis himself. That is, Harry hands his wife the business card of the oncologist and it is Shelia who verbalizes the diagnosis -- "Cancer?" He also hands a draft e-mail to his boss as a means of disclosing the diagnosis and sends a broadcast e-mail to other colleagues at work. Researchers have noted the preference for written communication of news where there is fear of losing composure during the delivery is common. Even if face-to-face with the recipient, a written statement allows an individual to disclose catastrophic news by confirming rather than telling the news (Maynard 2003:41-42). This mode of disclosure offers the additional advantage of avoiding a display of their own emotional state through a wavering voice, tears or other signs. Since the ball is in the recipient's court, so to speak, the erstwhile messenger can gauge the extent and depth of the relationship by the kind of reaction the recipient manifests.

A third pattern relates to the sequence of disclosures. In the account, we see overt and tacit ways in which Harry invokes the assistance of others as he discloses the news. In telling his wife before a definitive diagnosis has been made, it becomes clear that the two of them will be facing what comes next together – both waiting for the definitive diagnosis from the doctor on Friday and together strategizing ongoing disclosures to others about Harry's health. In consulting with Chet, a trusted friend and co-worker, Harry seeks both a sounding board and advice about how he should disclosure the news to others at work. In this way Harry is somewhat more grounded psychically when he "goes public" to the wider audience of co-workers. When he talks with Rob (his boss who is in town from Singapore), he volunteers to take on part of the task of disclosure by talking with HR and making arrangements for Harry's absence.

Overall, the orderly process and sensitivity to the timing of the disclosures lend insight into the meaning of the experience for Harry as well as revealing his relationships to various individuals in his environment. The fact that none of those receiving the news responds with anger or hurt feelings suggests that he has conformed to normative expectations shared by those in his social network for when and how to convey news. [7]

Comparison to other cases in the study

Accounts of sharing the news were, in many respects, as unique as the twenty-eight patients in the study. Thus, comparison of "themes" and "variables" across cases must be done cautiously. However, because thirteen patients learned the diagnosis in a sub-acute context similar to Harry's case this subset is used as the basis for comparison to understand how other patients handled the disclosure of the diagnosis to family and friends.[8] In all thirteen cases, four patterns were evident:

First, *disclosure was socially expected.* In interviews and observational data, sharing the diagnosis was characterized by patients as obligatory as revealed by frequent comments such as "I had to tell . . ." and "I

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[7] Contrast this with two other accounts from a separate pilot project conducted by the author. In one case the wife of a pastor of a small congregation did not disclose her multiple sclerosis symptoms until they impinged on her ability to work on various church committees. In another, an actor opted to disclose her diagnosis to family and friends in the form of a public staged reading. In both cases, family and friends reacted with anger; many expressed feeling hurt by the patient's manner of disclosure and interpreted it as commentary on the quality of their one-on-one relationship.

[8] Seven patients learned the news in the context of an emergency room visit. These patients were either with a family member when the diagnosis was disclosed or the caregiver was told the news by the doctor separately -- often, before the patient. In eight cases, the patient had already received one cancer diagnosis and now learned that either the primary cancer had recurred or that a secondary cancer had developed. In only one of these cases was the patient with family. The other seven were told by their oncologist either by phone or during an office visit (Schaepe 2011). In most cases, learning the diagnosis in the ER occurred in the presence of both patient or family or, frequently, because the patient was incapacitated, the family member heard the news before the patient. This changed the nature of the disclosure context substantially and thus is not included for comparison here. Also, having to disclose news of recurrence while valuable is a different kind of event in that there is history and often the disclosure to intimates is more akin to conveying news to a team of people facing the diagnosis together.

knew this was something I could not keep to myself."[9] The duty to disclose derives, in part, from a genuine concern for the feelings of the other party, but it was also a means for stabilizing relationships and limiting the degree to which previous decisions about when and what to share required explanation (Brown and Levinson 1978). When Harry's wife Sheila describes the urgency they felt to tell the children, for example, she said: "He almost had to because once he's in the hospital, what are you going to do?" In her view, it was better to anticipate and preempt his children's expectation that they be told about his diagnosis and upcoming hospitalization rather than deal with their reactions if the situation was explained to them after the fact. The negative consequences Harry and his wife sought to avoid was experienced by another patient who noted that news of his diagnosis had "gotten out" to a friend by way of a third party communication. This inappropriate path of notification caused a rift in the patient's relationship with his friend that took many months to repair.

A second pattern was *not being able to prepare the recipient for the news.* Leukemia often has a rapid onset with few visible markers and, as in Harry's case, symptoms can be taken as signs of other, more benign conditions that are hardly worth discussing. Consequently, recipients such as spouses and other close family members noted that the news seemed to "come out of nowhere." As Maynard (1996) points out, disclosures in an "unprepared context" are often perceived as being blunt which may or may not facilitate realization but will definitely add to friction in the relationship for a time.

A third pattern was that *self-disclosure was at least as emotionally draining for the patient as hearing the diagnosis itself.* Charmaz' (1991: 276) noted that she was surprised to find that in her research among patients coping with chronic illnesses a number described sharing health-related news as one of the most difficult aspects of dealing with their condition. Likewise, in this study, the emotional trauma of sharing the news remained high for many participants even months and years later. One male patient, for example, months after diagnosis broke down in tears when recalling the experience of first telling his wife and his children. In another instance a man one year after diagnosis also broke down, waving his hand away and saying, "Nope, I still

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[9] This "have to" type of comment is relational and should not be confused with the self-oriented "fever" model of disclosure (Stiles 1992) whereby the level of psychological distress is characterized as analogous to a fever and disclosure is part of regaining balance.

can't go there." He explained that just the thought of all his wife has been through since hearing that news and recalling that moment when he first told her was still beyond his emotional capacity to confront.

A final pattern was that patients assumed the *appropriate path of disclosure begins with the individual closest to them.* This is not surprising. In the social psychology literature, people generally disclose highly personal information to those they feel will be most concerned and who they can trust (Green 2009; Petronio 2002). What makes this tendency notable, however, is that this recipient often is expected and will share more fully in the experience than others told later. Thoits (1984, 1996) notes that coping with a serious illness is something "done together," and that means those close to the patient share the experience in a deep way and patients often delegate a number of tasks to these individuals. In Harry's case, as well as a number of the other cases in the study, the patient and their spouse or parent or child become symbolically one -- as "I have cancer" morphs into "we are/our family is facing cancer together."

Self-disclosure in the workplace

The greatest variation in the data pertained to how individuals shared their diagnosis at work. It is telling that even in this small set of cases, there was a wide range of approaches to disclosure suggesting that this context raised issues of trust and vulnerability not associated with disclosure to intimates. The workplace was an important step in "going public" about cancer, and a number of patients pointed out that personal disclosure about a serious illness (or anything else) was not something they had ever had to do at work before. Some worried about losing their job. For others, the prospect of having to disclose their illness introduced an uncomfortable and unwanted intimacy. As one man noted, "Before all this, most of my co-workers didn't know a damn about me outside of work (…) and that was just fine with me."

Common explanations used to account for variability in the likelihood to disclose serious news at work include factors such as personal style (Fesko 2001; Mendelson2006), the nature of one's profession (Beatty and Kirby 2006), the duration of employment (Charmaz 2010; Munir et al. 2005), and the length of time needed off from work. These factors undoubtedly played a role in my study but it was hard to discern systematic patterns in just twenty-eight cases.

That is, some individuals with high investment in their career disclosed the news in a linear, comprehensive way – such as Harry did. Others relied on electronic channels and colleagues as a primary means of passing the news onto others, and still others withdrew from most contact. In terms of the duration of employment influencing the likelihood to disclose, there were several cases where long-term employees avoided disclosure. By contrast, two individuals who had been employed in their job a very short time were quick to fully disclose their situation. In one case, the individual was a seasonal worker, in another, the individual had been diagnosed just a few months after starting his job. In both cases, the patients were young and perhaps because of their age, both experienced substantial (unexpected) support from their employer and colleagues who were relative strangers.

Personal disposition undoubtedly plays a role as well, but, once again, with my data it was difficult to categorize these differences in a meaningful and predictive way. Harry and Sheila, for example, each disclosed the news to supervisors and colleagues, even though their personal styles were quite different. Harry's approach fit with Charmaz's (1991) notion of "protective disclosing," involving planning and strategy. Shelia, by contrast, engaged in a form of "spontaneous disclosing" (Schneider and Conrad 1983) where there is no planning but rather just an outpouring of emotion.

The practical reason for variation in disclosure patterns were due to how long the patient would need to be off work did show up in the data. When the time off work would be longer than six months as it often is with an allogeneic transplant (stem cells from a donor), it was more likely that individuals talked with co-workers as well as supervisors. With an autologous transplant (reinfusion of one's own stem cells), however, more study participants felt it was not necessary to disclose the diagnosis until it had a direct impact on their work.

What was meaningful in this context and, I would argue, offers a more targeted explanation for variability had to do with ambiguity about the status of relationships at work. Study participants all seemed to struggle with whether a relationship was primarily personal or professional. Thus, participants also struggled with finding the appropriate social script (Shank and Abelson 1971) or frame (Goffman 1967; 1974) to guide their behavior and expectations in this setting. Often, the nature of the relationship was revealed only in the act of disclosure itself, a phenomenon noted by Charmaz (1991: 123). For example, one woman in the study, who worked in the front office for a building supply company, lamented the seemingly cool response she received from co-workers noting, "I've worked there a pretty long time but I guess since I've always been in the front office, maybe I wasn't viewed as part of the 'family." An engineer noted that he was not sure how to "read" the reactions of others when he first told them, which caused him to reflect on whether sharing might have been a mistake because it was, after all, "just a work setting." An electrician recalled feeling surprised but good that his supervisor was relating to him more as a friend when he first told him. The supervisor graciously reduced his workload to aid with recovery. Subsequently, though, the electrician felt that these gestures might actually have been more of a professional response and a means by which to first demote him and ultimately ease him out of his job.

The study participants also alluded to strategies they used to manage their emotions during the disclosure process. Harry, as noted, took one person aside first in the work setting and he relied on written information as a means by which to manage his emotions. A few others in the study noted that they did this too. Patients also reported downplaying the severity of the situation simply to get through the conversation and more than a few recalled saying something to the effect that, 'Compared to others, I'm much better off.' Some patients who would need to be out of work for six to twelve months, also admitted giving the shortest likely time off from work as part of the disclosure as a way to make it seem less serious.

I would argue that the tendency toward underestimating the needed time off was exacerbated by physician, many favored giving patients shortest time off estimates as well. When questioned, one oncologist explained, “It gives them [patients] something to shoot for.” That is, offering an ambitious and optimistic estimate rather than a less ambitious and pessimistic recovery trajectory was thought to lead to a favorable self-fulfilling prophesy and a better long-term outcome.[10] Patients even used the doctor’s optimistic phrases when sharing the news with co-workers -- “You have the good kind of cancer” becoming “I have the good kind of cancer” or the “cancer of choice” (Schaepe 2011).

One surprising consequence some patients mentioned was that they believed they had been perhaps ‘too good’ at conveying a rosy picture when first telling others their diagnosis. That is, several noted having conveyed the initial diagnosis in such positive terms that family and friends came away thinking the diagnosis was no big deal and the cancer was an easily treated condition. To correct this misperception, some individuals reported later being quite blunt at times to make others understand that the condition was actually serious and with no guarantee of survival much less full recovery. One patient in particular recalled his rationale for making dire statements about his health to friends after the diagnosis:

> I mean part of this is because I want sympathy. But I think a big part of it is because I want them to realize how serious - potentially - it was or is. Because they don’t see it. It’s not like I have a big gash on my forehead or anything. The ones who aren’t medical don’t realize that it’s pretty dangerous.

Conclusion

The analysis presented here illustrates the way in which self-disclosure is integral to the patient’s experience of a cancer diagnosis and how the act of sharing the diagnosis helps it become real. The study also shows the way in which the experience of illness is through and through a social and collective one. Self-disclosure is never a neutral act but rather one with inevitable positive and negative consequences. On the up side, self-disclosure offers patients support, catharsis, and an opportunity for sense-making and clarification.

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[10] Ironically, this tendency was reversed for patients undergoing transplant. While in the hospital, estimates of the time patients would be inpatients were often longer than most patients ended up staying. This had the same sort of uplifting effect. Many patients who were told they could leave sooner than expected were buoyed but this turn of events. And many read this as a very good sign about their ability to cope with the procedure and perhaps even speaking to long term outcomes.

On the down side, however, disclosure poses an additional burden or, as noted at the outset, a second "weight." Decisions about when, who, and how to self-disclose the news is often experienced as obligatory and fraught with the potential for missteps because how one discloses and how others respond inevitably conveys information about the status (or changing status) of relationships with family and friends.

Generalizability. The findings in this account are not generalizable in a statistical sense but as Conrad (1990) argued, the generalizability of qualitative research is better assessed in terms of how rigorously the analytic concepts apply to other contexts and conditions. Understanding the significance of self-disclosure in coping with a serious diagnosis requires attending to how individuals convey their experiences and how recipients take up these disclosures. This study describes a phenomenon that is not necessarily limited to populations of blood cancer patients or cancer patients, but can be used to explain self-disclosure of many other medical conditions and possibly other circumstances deriving from different institutional contexts (such as law and criminal justice).

Future research. Two fertile areas for future research useful for understanding how self-disclosure of illness is socially regulated might focus on (1) the workplace and (2) online forums such as *Caring Bridge* and *CarePages*.

Disclosures at work. Charmaz (2010) and Munir, et al. (2005) have begun to examine patterns of self-disclosure of illness in the workplace, and additional research might aid understanding of the complex ways in which disclosure is influenced by fear of stigma, concerns about a loss of employment, and fear of setting in motion a cycle of unwanted attention from co-workers. Given the cost of chronic illness in the labor force, it seems both timely and important to understand more about how individuals make decisions about self-disclosure in this context and, likewise, how co-workers and management respond to these disclosures.

"Compassion technology." A second useful area of research might look at the rising use of websites such as *CaringBridge* and *Carepages* to understand the degree to which a technology that reduces physical barriers may (or may not) be fostering a new kind of "social order" (Goffman 1983) around illness disclosure.

Already it is evident that this kind of technology has allowed patients and families to think differently about their illness experience, and the technology has made it possible to convene an online "community" in a way that would not be possible offline. It is now common, for example, for *CaringBridge* and *Carepages* forums to survive the death of the patient. In several cases in my study, the online entries became something of a memorial and two families actually took the patient and caregiver entries and photos and developed an offline scrapbook. At the same time, this technology raises questions about the degree to which dissemination of personal health information has been merely a technological problem. Turkel (2010) and Anderson (2011) have argued that, paradoxically, online platforms are popular not only for what they facilitate but for what they guard against. That is, these web portals offer a means by which to maintain relationships and cultivate new ones without the full range of burdens and demands associated with face-to-face encounters.

Chapter 3: Perilous Communication in Long Clinic Relationships:

Case Study in the Oncology Outpatient Setting

Perilous Communication in Long Clinic Relationships:

Case Study in the Oncology Outpatient Setting

Abstract: Aggressive treatment of terminal cancer patients has been a subject of intense debate in the medical literature in recent years. Studies show that when end of life conversations between patients and their doctors have not occurred, futile therapies are more often administered; patients are more likely to die in the hospital; and to suffer at the end of their lives. Family members, in turn, are more likely to experience one or more episodes of major depression during the six months following a loved one's death. Increasingly, physicians are encouraged to initiate discussions with patients about their values earlier in the clinical relationship. This study analyses audio-taped outpatient clinic visits between three oncologists, two nurse practitioners and ten patients (diagnosed with leukemia, myeloma, or lymphoma) over two years post stem cell transplant at a large comprehensive cancer center in the United States. The study reveals nuanced conversational strategies used by patients and physicians to discuss a decline in the patient's health status. News events fell into three general categories: 1) "Perilous news" with serious implications about health status; 2) "routine news" about short-term changes; and 3) "social news" pertaining to the patient's social schedule. "Routine news" was the dominant form of communication between patients and physicians while "perilous news" was rarely discussed explicitly and, in fact, seemed to be "non-normative" in the oncology outpatient setting. Patients and clinicians frequently employed strategies to redirect or suppress explicit discussion of perilous news. The study concludes that while clarity was not an interactional imperative and indirect communication actually helped preserve the social order of the clinic visit, it came at the expense of psychological preparation and good decision-making for a number of patients near the end of life.

Introduction

A "bad death"

> *As the ambulance sped down the highway, Linda coached her husband, "Hang in there, honey, you're doing good." But John, the 58-year-old cancer patient curled up on the stretcher kept repeating, "No I'm not." Hours earlier, John had gone to the Emergency Department near the family's summer cabin with severe stomach cramps, and Linda called her husband's oncologist back home to find out whether John needed an adjustment to his medications. To Linda, this was just one of many routine emergencies the family had been through over the last 18 months. However, this time Doctor J sighed and said, "We should have had this conversation." Linda was bewildered. What conversation?! Was the doctor implying they should not have gone to the cabin? That John needed to go back to the cancer clinic? Doctor J told Linda that John did not need to come back to the clinic. It was time for Comfort Care - hospice. Linda was stunned as she hung up the phone. She told the ER doctor, "He's dying and there's nothing they could do." The ER doctor, however, gave Linda a strange look and said, "His kidneys are having problems, but he doesn't need dialysis at this time. He's stable. Don't give – there's no reason to give up." Linda said, "I don't want to give up.' The doctor and Linda arranged to have John transported to a care facility near the cancer center several hours away. The ER doctor confirmed with Linda, "We'll put down full code."*
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> *In transit, John became agitated, repeating that something was wrong and apologizing to his wife for all the trouble. "I shouldn't have let myself get so constipated. I shouldn't have waited so long." Linda wiped away tears and said, "It's not your fault. Just hang in there. You're doing good." Ten minutes later, however, the EMT monitoring John's condition shouted, "He's coding!" The driver immediately pulled onto the gravel shoulder of the highway, jumped out, threw open the back doors of the van and the two paramedics commenced CPR. John's daughter watched from a dashboard monitor in the front seat and whispered, "Help him, please help him." Just two days earlier, she and her dad talked about him walking her down the aisle. He can't be dying now. The paramedics continued to take turns pumping on John's chest, fracturing ribs in the process, but still no heartbeat. Finally, they stopped. Linda, her son, and daughter said nothing as the driver called John's status into the hospital. The Friday night traffic continued to whiz by. John was covered, the doors of the van slammed shut, and the ambulance turned around and headed back to the hospital.*

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Four months later, the traumatic nature of this experience was still raw for Linda and her children as they recounted the circumstances of John's death. All three were now coping with stress-aggravated conditions of their own. Linda had experienced rapid weight gain and the escalation of symptoms associated with fibromyalgia during the last months of John's life. Since his death she had also developed severe migraines and was diagnosed with new complications associated with a heart arrhythmia. John's daughter was struggling with her college coursework due to anxiety and an inability to concentrate, and John's son had not been managing his Type I diabetes, and according to Linda, her son's symptoms of autism had become more pronounced.

The primary lingering question the family had was this: Why did John have to die in the manner that he did? John had what many would describe as a situation conducive to good decision-making, even as he approached end of life. He had a supportive wife and children, an oncologist who was accessible and willing to discuss John's condition in detail over the many months of his follow-up care. In addition, John was a "good patient" and had diligently followed the doctor's orders throughout the course of his illness. While no one could control the course of the disease itself, in such a supportive environment of open communication, the family now wondered why John ended up dying in an ambulance on the side of the highway with his whole family as horrified witnesses to the traumatic event.

"We had no idea," Linda said. "The doctor never, ever brought up hospice ever, and I was kind of waiting for that to happen because then I figured, okay, then we have six weeks." Instead, the last office visit with John's oncologist focused on medication adjustments - albeit, radically increasing some of them - to slow the growth of the cancer. Linda said, "Now that I look back at it, it was all progressing." The increase in medication dosages and the alarming results of lab work shortly before leaving for the cabin, she now believed, should have tipped her off:

> [He had] no neutrophils[11] at all. I said how long can he go on like this? I didn't get any answer or response [from the clinical staff] and so we figured John had lumber in the van and projects he brought up [to the cabin] and there were things he was in the middle of.

Crises had become routine for this family and John had always bounced back, but months after his death Linda now regretted many things. She wished she had not kept telling John that he was "doing good." Had he been trying to tell her in the ambulance that he knew he was dying and she ignored him? She also wondered if John had been admitted the day his counts were bad, might the outcome have been different?

> I wish that we would, he would have gone in the hospital that Thursday night and just been in a place where he knew. But at that point, he wasn't bad enough, I guess.

John's daughter and son wondered whether the medical staff at the ER -- who did not know much about their father's cancer history -- had given him too much pain medication to stabilize him in transit. Was that the reason he went into cardiac arrest?

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[11] Neutrophils are the infection-fighting white blood cells.

Linda also second-guessed her decision to go with the ER doctor's recommendation of a full code status, "Originally, he [John] didn't want the resuscitation thing…" John's daughter tried to summarize why her father's death continued to haunt them noting, "It's not so much that we didn't get to be with him when he died or, like, spend time." What made the death so hard, she said, was that her father had gone to great lengths to protect the family from seeing him weak and in pain. The scene in the ambulance was the opposite of what he would have wanted:

> I still remember the entire event (…). It's just hard with how like traumatic of an experience it was. Like, I don't know. I still have a hard time sometimes because I can still like see it in my head and sometimes before I go to sleep, like I can't stop thinking about it.

Linda noted that the family had worked closely with John's medical team throughout his treatment because they wanted to plan carefully and be prepared for what lay ahead. To have John die suddenly, in agony and under such inauspicious circumstances anyway caused Linda to think there was no way for *anyone* to plan a good ending: "I just don't know how that ever happens."

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The circumstances surrounding the end of John's life are what clinicians generally describe as a "bad death" -- one with little opportunity for the patient and family to prepare, occurring outside of the confines of home or a peaceful institutional context and where the patient experiences pain and other unrelieved symptoms. Making a bad death worse, is a situation where the family is witness to their loved ones suffering and/or aggressive resuscitation efforts, and where the end is chaotic.

Deaths like John's are not seen as a one off event in the palliative care literature, but rather part of an increasingly common systematic problem in health care. Statistics show that one in five Americans now dies in intensive care, and most will die after either episodic organ failure or after a year or more of slow decline (Nelson et al. 2006). In addition, Wright et al. (2008), found that less than one third of all seriously ill patients in the United States, even when they do have time to prepare, have had a conversation with their doctor at any point about their values and treatment goals. In the absence of these conversations, futile therapies are more often administered and patients die more often in the hospital in intensive care and suffer at the end of their lives. Family members, such as in the case described here, are also more likely to experience one or more episodes of major depression during the six months following their loved one's death.

Findings like these raise more questions than they answer. That is, while there may be a correlation between end of life communication and the quality of the end of life experience, how does this happen? How exactly do physicians come to provide treatment that does not improve survival and instead, often has negative consequences? Likewise, what are the factors that go into patient decisions to undergo more treatment near the end of life? Studies are increasingly pointing out that good terminal stage care requires good communication, but as Roscoe et al. (2013) note in analysis of interviews with end stage head and neck cancers, most of the communication difficulties experienced by patients do not originate at or near the end of life but are part of a more sustained dynamic. Among other things, physicians in the study generally preferred to answer patient questions only as they would arise rather than planning for and initiating an end of life conversation. Fagerlind et al. (2008) studied clinic conversations among patients with gastrointestinal cancer and found that physicians communicated about responses to treatment and the severity of side effects and generally avoided discussions about quality of life, coping, and psychosocial concerns even when patients near end of life raised these issues explicitly. The physician-journalist Atul Gawande (2010), in his *New Yorker* article "Letting Go," brought widespread attention to how cancer patients, families, and physicians may all know that the patient is terminal but even so, little is done by any of these parties to prepare for the final stages. As one physician quoted in the article pointed out: "We are having more conversation now about what patients want for the end of life, by far, than they have had in all their lives to this point. The problem is that's way too late" (Gawande 2010:3).

In an effort to understand more about the process that leads to particular end of life dynamics and clinical outcomes, a small body of research has analyzed the nature of clinical relationships and, specifically focused on the communication between doctors and patients as a longitudinal phenomenon. These qualitative studies while few in number; offer a better understanding of ongoing relationships between doctors and cancer patients. Some of this research has focused on routinized behavior and the way in which routines can undermine frank discussion about treatment and prognosis. Taylor (1988), for example, found that routinized ways of communicating with patients may be established unilaterally. Drawing on observation of seventeen surgeons delivering positive breast biopsy results to 118 women Taylor found that surgeons adopted one of several approaches to disclosure: 1) "truth-telling, where the surgeon revealed just what they know about the cancer prognosis; 2) expressions of uncertainty and 3) "dissimulation," offering a diagnosis/prognosis that could not be substantiated clinically. Notably, nearly half - forty-five percent - of all of the encounters that she observed involved evasion of some kind, particularly in an effort to avoid discussion of information about long-term survival. Clinicians and patients may also work together to establish routines which was a finding of Sanden et al. (2001) in his examination of three doctors and twenty-one male patients after surgery for testicular cancer. In this study, routinization of particular communication patterns effectively preserved the social order of the clinic relationship. Regardless of whatever was happening bio-medically, it reinforced a sense among patients that things were still "okay." However, Sanden et al. notes that routinization also makes it more difficult to address some serious health issues as they came up over the course of care.

One particularly ambitious ethnographic study by The (2002) examined a population of patients with small-cell lung cancer and tracked the evolution of doctor-patient communication over time. On the front end of research, The was struck by how many terminal patients expressed optimism about their chances for recovery even relatively close to death. To understand how patients may have come to hold these views, she engaged in intensive field observation following 30 patients (two cycles of 15 patients each) from the point of learning of an incurable lung cancer diagnosis to death. She attended outpatient clinic consultations as well as conducting many informal conversations with patients, visiting them at home when patients had become terminal in an effort to tease out the process of decision-making about treatment and end of life care. She also attended funerals and interviewed bereaved spouses. Ultimately, she concluded that the interaction between the doctor and the patient that led to false optimism was a subtle process. It emerged at particular points in the disease trajectory such as shortly after the first round of chemotherapy when patients frequently told relatives and friends that the doctor had "cured" them, when in fact, life expectancy was in all cases less than two years.

One of the few longitudinal cancer studies that draws on conversation analysis specifically, was conducted by Pilnick (1998) who examined multiple clinic visits between the same clinicians and leukemia patients drawing on forty-one audio-taped follow-up consultations between pharmacists, patients, and their companions in a leukemia pediatric outpatient clinic over a two-month period. Pilnick's research challenges previous one-dimensional assessments of "asymmetry" in provider-patient communication noting that what may *look* asymmetric (i.e., physician-dominated) during one encounter may look very different if considering multiple encounters over time. Leukemia patients, she found, often brought a substantial amount of lay expertise to the encounter and the nature of interaction between these patients and medical professionals tended to wax and wane depending heavily on the specific issues discussed.

My study extends the findings from this previous communication research and centers attention on multiple clinic conversations between doctor and patients following stem cell transplant. In addition to examination of cumulative changes in the conversation, my analysis focuses particular attention to what Giddens (1991) calls certain "fateful moments" -- times when events come together or a person learns information with important consequences. I isolate these potentially "fateful moments" through analysis of one particular kind of clinic communication: "bad news" about a change in health status. I analyze this kind of news across multiple clinic encounters with the same clinicians and patients in an effort to understand how decisions to administer or suspend treatment are made at various points over the course of a long illness.

News

> **news, n.** (nüz, nyüz) n.pl. [with sing.v.] **1.** New things; novelties. *Obs.***2.** The report or account of recent (esp. important or interesting) events or occurrences, brought or coming to one as new information; new occurrences as a subject of report or talk; tidings. **news, v.** (nüz, nyüz) v. **1.** *trans.* To tell or spread as news. *Obs.* **2.** *intr.* To exchange or tell news; to gossip.

Webster's dictionary offers a practical working definition of "news." As a noun, it refers to events that have transpired but are still unknown to some individual or group; as a verb, news is simply the act of disclosing new information. With regard to news of a serious health condition, oncologist, Robert Buckman points out that bad news goes beyond learning something unknown. It is a holistic experience and the qualitative degree of "badness" depends on the gap between the new reality and preexisting expectations. Bad diagnostic news, Buckman argues is "Any news that drastically and negatively alters the patient's view of their future" (1984: 1597). This more contextualized definition is the foundation of classical Greek tragedy where the experience of learning bad news hinges on both a sudden reversal of fortune– *peripeteia,* and on the process of discovery – *anagnorisis*, the moment of realization producing strong emotion for the recipient and altering relationships between social actors destined for a particular fate (Bruner 1986). Likewise, momentous health news is more than learning something unknown, it is highly emotional and catalyzes an internal shift of perspective, identity, as well as transforming personal relationships. Whether the bad news is Oedipus Rex realizing the woman he's been sleeping with is his mother; Luke Skywalker discovering that Darth Vader is his father; or Bruce Willis as the psychiatrist in *The Sixth Sense* treating a patient who sees dead people and ultimately realizes he's the one who is dead, it is the *transformative experience* that is at issue. For patients coping with a serious illness, "Bad and good news represent disruptions of quotidian life to the extent of jeopardizing participants' sense of what is real" (Maynard 2003:11). Thus, news of a serious negative turn in one's health goes beyond learning, "I have cancer" or "I have relapsed." It catalyzes a profound psychic transformation, the realization that "I'm not going to live forever;" "My children will grow up without me;" or other dire realities.

In this paper, I consider serious bad news after the initial diagnosis in this broader sense with consequences for the social group as well as the individual. My research expands on approaches to bad news that treat episodes as singular, marked events, often introduced by pre-announcements, and consisting of discrete components of what Maynard (1997, 2003, chapter 4) has called a "News Delivery Sequence." In my data, information is delivered but it is not often formulated or recognizably "news" as such. Rather, it leaks through and permeates the clinical conversation in subtle ways. That is, disclosures about a serious negative change in health status is first sidestepped, suppressed, alluded to and then eventually parceled out over time.

In what follows, I describe the context of news in the outpatient stem cell transplant clinic. I then describe the kind of news about the patient's health status that is disclosed during visits. Next, I examine the way serious news emerges during clinic discussions and outline strategies used by clinicians to disclose this news as well as techniques employed by patients and family to re-interpret verbal and non-verbal phenomena (and thereby 'recover' some sense of serious health news). In closing, I discuss the ramifications of a tendency to avoid explicit conversations about a negative prognosis and the implications for good decision-making by patients who are approaching the end of life.

Hematologic cancers as a chronically managed condition

This case study focuses on blood cancer patients who have undergone stem cell transplant as part of their treatment. For perspective, of the 1.6 million people who are newly diagnosed with cancer in the United States each year,[12] roughly one hundred thousand (9.6%) are cancers of the blood, bone marrow, and lymph nodes.[13] Of this hundred thousand, each year approximately seventeen thousand are treated with autologous and allogeneic HSCT.[14]

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[12] American Cancer Society. *Cancer Facts & Figures* 2013. Atlanta: American Cancer Society.

[13] *Blood Cancers: Leukemia, Lymphoma, and Myeloma*, Centers for Disease Control and Prevention. http://www.cdc.gov/features/hematologiccancers/ Also taken from *Leukemia, Lymphoma, Myeloma Facts 2009-2010*, June 2009 http://www.leukemia-lymphoma.org/attachments/National/br_1247234696.pdf

Autologous HSCT is not technically a "transplant" but rather reinfusion of previously extracted stem cells from the patient themselves. This form of transplant procedure is used to bridge the period after the patient's stem cells have been destroyed by the high dose chemotherapy used to treat their blood cancer. Allogeneic HSCT, by contrast, involves infusion of healthy stem cells from a biological relative or an unrelated donor. The procedure is used to treat congenital or "acquired marrow failure" most often due to cancer. The main advantage of allogeneic over autologous transplant is that it is potentially curative due to the "graft versus tumor" effect whereby the donor's stem cells attack and destroy residual cancer cells following chemotherapy. Because of the punishing nature of the procedure as well as the high treatment-related mortality, HSCT is limited to disorders that are themselves life-threatening.[15] Blood cancer patients who are recommended for HSCT typically have refractory disease, resistant to standard treatment, or their history and genetic risk factors make them unlikely to achieve a lasting remission with chemotherapy and radiation alone.

While a relatively small proportion of cancer patients undergo HSCT, this kind of treatment context provides a good opportunity to study bad news as a longitudinal process, capturing both more broadly and more intensively the kind of news disclosure episodes that play a role in management of many chronic illnesses. That is, the recovery process is slow, multi-staged, and anything but guaranteed. Individuals may live

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[14] In 2009, 16,790 patients in the United States were treated with HSCT (7012 allogeneic and 9778 autologous HSCT). United States Department of Health and Human Services. Reported to the CIBMTR by disease and year of transplants through the C.W. Bill Young Cell Transplantation Program Website at http://bloodcell.transplant.hrsa.gov/RESEARCH/Transplant_Data/US_Tx_Data/Data_by_Disease/national.aspx

[15] Transplantation survival rates vary dramatically depending on the patient's age, disease type, stage of disease, type of transplantation and type of donor cells. For example, patients with Hodgkin's lymphoma who are in remission prior to autologous transplantation have the best survival rates, achieving about 70 percent survival at six years. Conversely, adult patients with advanced acute lymphocytic leukemia (ALL) treated with unrelated donor transplantations have approximately a 10 to 20 percent survival rate at six years after transplantation. Transplantation-related deaths are primarily due to either graft-versus-host disease (GVHD) or infections but sometimes they are due to organ damage from high dose chemotherapy. With GVHD, the donor HSCs (the graft) recognizes the patient's tissues (the host) as "foreign," and attack those tissues. GVHD can produce a large number of complications affecting several different parts of the body, such as the gastrointestinal tract and skin, and some of these complications can be fatal. Transplantation-related death due to infection is more likely to occur with allogeneic than autologous transplantations, due to immunosuppression *(Leukemia, Lymphoma, Myeloma Facts 2009-2010*, June 2009).

only a short time but can also live with for many years following transplant. In either case, follow up and management requires substantial infrastructure and coordination among a network of specialists. Along the way patients experience frequent crises, short and long-term disability and dissipated effectiveness in treatment. The effort required of patients and family members to effectively manage symptoms and avert crises can hardly be sketched out in advance. Thus, this subpopulation of patients - who are neither permanently well nor permanently ill - captures well the heightened importance of news to all of those living in some form of "remission society" (Frank 1997).

Field Setting & Data

Data. The data used in this paper focuses on a subset of ten patients and their families who participated in a "home study" portion of a larger multi-year project (2007-2010) conducted at a comprehensive cancer center in the United States. The parent study tracked the medical and psychosocial experiences of twenty-eight blood cancer patients who had undergone HSCT. Thirty family caregivers were involved in the study. The patient population was stratified by age, sex, diagnosis, type of stem cell transplant procedure, and socio-economic status. In addition to four interviews: 1) prior to transplant, 2) several weeks following discharge from the hospital, 3) six months post-transplant, and 4) at the end of one year, the subset of ten patients were followed closely to understand the day-to-day experience of living with cancer and recovering from transplant. This involved visiting these patients at home once a month and accompanying them to clinic visits every three weeks. The sub-sample includes five men and five women aged 21 – 58, seven had been diagnosed with various forms of leukemia, two with lymphoma and one with multiple myeloma. Six received stem cells from an unrelated donor, three from a related donor, and one was re-infused with his own cells. The patients were all white, mostly middle class and possessed a high school or greater level of education. The site hospital's institutional review board approved the study. Five clinicians were involved in these clinic visits: three oncologists and two nurse practitioners specializing in oncology.

Data analysis focused on forty-one audio-recorded clinic visits between the patients, family members and clinicians collected from March of 2008 through June of 2009. Tape recorded interviews and extensive ethnographic field data supplemented the analysis by providing a timeline of significant events for each family. In addition, observation of the weekly medical rounds and activities in the oncology workroom before and after clinic visits lent insight into clinicians' views regarding the patient's health status.

Each of the forty-one clinic visits was initially reviewed with an eye to any statements that involved: 1) discussion of a change in physical condition, 2) a lack of change in condition, 3) expression of an inability to conclude anything because of the absence of data (from laboratory or radiology results), or 4) expressions of uncertainty about overall health status. Once gathered, particular news sequences within the overall collection were analyzed more carefully to review just how clinicians introduced news as well as how patients and companions responded to it.

Background on the clinic visits. The central purpose of the outpatient clinic visits was to monitor the patient's recovery post-stem cell transplant. For the first three months, patients generally met with the clinician on a weekly basis. Good and bad news disclosures during the early and middle phases of outpatient care (roughly the first three months or 100 days) pertained to the success of the transplant and recovery status of the immune system. In late phases of recovery (approximately six months and longer), bad news involved coming to terms with the likely extent of recovery; conversations about relapse; or news of fewer alternative treatments left to try. When alternative treatments were no longer feasible, discussion centered on transitioning from curative to palliative care.

Where patients are in the treatment and recovery process is easy to discern -- even without verbal cues. A glance around the waiting room on any given day, for example, reveals a mix of patients in different stages of recovery. Pre-transplant patients generally look "normal." They wear street clothes and exhibit little evidence of illness. Patients recently discharged post-transplant are bald from the chemotherapy and puffy from steroids, and their skin is the color of raw pie dough. These patients usually wear clothing that does not bind, such as sweat pants, and shoes that slip on. Many, because of their immuno-compromised state, wear masks in the waiting room. In the later stages of recovery, patients do not wear masks, some wear scarves, hats, or wigs to cover bald heads and some wear no head coverings as their hair begins to grow in. Patients are often with a companion during the early stages of follow up, and it is the companion who may be caring bags, medications, and notebooks. Between three and six months after transplantation, "self-expression" in clothing becomes a more prominent feature of recovery. That is, patients who are clearly on the road to recovery but still not recovered are those most likely to wear t-shirts and hats conveying defiant and/or proud testimony to the cancer ordeal. For example, one young woman with new growth of blond hair wore a t-shirt that said, "I'm too sexy for my hair." A man in jeans and steel-toed boots wore a baseball cap stenciled with "Open Season on Cancer" and an elderly woman had a pink sweatshirt that said, "I have chemo brain. What's your excuse?"

Patients at this field site were from both urban areas and rural locations – some from as far as two hundred miles away. Whatever their distances, many patients found it exhausting to prepare for a trip to the clinic each week. Those who were temporally distanced from transplant and still unable to work were often most weary of the isolation at home. Clinic visits, in fact, provided the one bit of structure in what was an otherwise shapeless day-to-day schedule.

Patients arrive at the clinic about an hour before their scheduled appointment so that blood can be drawn in the lab[16] and then wait until a nurse calls them to the examination room; usually greeting them with a cheerful "How are you today?" Patients get to know others in the waiting room that have similar appointment schedules and some recognize each other, having been hospitalized for their transplant at the same time. Generally, they talk about their recovery, side effects, the oncologists and nurses and other matters. Even though there is a good deal of friendly conversation, patients appear anxious and many are fidgety – unable to read or watch T.V. and just look around the waiting room.

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[16] The lab work or complete blood count (CBC) is a central part of the clinic conversation with the oncologist.

Lay accounts about the anxiety and confusion experienced when coming to see the oncologist are common in published literature, weblogs and online support groups. It was frequently discussed during this fieldwork as well. Patients with recent diagnoses and transplants, along with caregivers, tended to engage in "restitution narratives" (Frank 1995) where cancer is characterized, as one patient referred to it, as a "speed bump" -- a hurdle that that one gets through and then back to a normal life. Over time, the idea of full recovery is replaced with the characterization of cancer as a "marathon, not a sprint." This metaphor of a marathon is only somewhat apt, because many patients discover that cancer is a "marathon" with no specified length. There are no mile markers to indicate where you are in the race and, thus, no way to pace yourself along the way. In addition, progress may be hard to recognize and at any time, things can change for the worse. This is the context in which patients and family members hear news about setbacks and recovery.

Three kinds of news about the patient's health status

As mentioned, informing the patient and the family about the health status of the patient post-transplant is a central focus of the weekly meetings. These discussions fell into three general categories: 1) "perilous news," 2) routine updates, and 3) social, health-related news.

"Perilous news" refers to news about the patient's health that is consequential, uncertain and threatening. This term roughly parallels Christakis's (1999) notion of "serious" news and The's (2002) discussion of "long-term" news. The phrase is used here to refer to formal discussions of life-threatening changes in the status of the disease and/or the long-term likelihood and timing of a fatal outcome. Perilous news during the first 100 days is based on findings in blood work pertaining to the speed of engraftment;[17] immune system reconstitution;[18] "chimerism" [19] and relapse.[20] Discussions of symptoms and signs can also be quite serious in the first 100 days (less so farther out) and many of these discussions can focus on the development of various kinds of fungal and bacterial infections and/or development of acute GVHD. In the

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[17] The reestablishment of neutrophils, the infection-fighting white cells.

[18] The number of donor lymphocytes, circulating antibodies and cells that assist in killing invaders.

[19] The ratio of donor to patient stem cells which is an indicator of impending graft rejection.

[20] Cancer blast cells are present making disease recurrence eminent.

later phases of recovery (three to six months or longer), news pertains to the development of chronic GVHD,[21] "late effects" (such as permanent damage to organs, vision issues, and sterility); evidence of relapse and news of transitioning to palliative care.

"Routine updates" also rely heavily on blood work and the assessment of symptoms and signs but with less immediate or dire consequences for overall recovery and life expectancy. This kind of news is embedded in the general business of the clinic encounter and focuses on issues such as how particular drugs will act on the body, assessments of side effects or symptoms, the need to adjust medications and the need for transfusions or changes in the clinic appointment schedule. The focus tends to be on medical news—for example, regarding treatment—and includes side effects as well as other physical ailments: episodes of nausea, vomiting, mucocitus,[22] hair loss, fatigue, boredom, depression, weight gain, and the overall pace of recovery.

Such news may drift into *social, health-related news* and lead to discussions about resuming normal activities (including work), reengaging in social life, taking on a normal diet or activities such as mowing the lawn and grocery shopping, whether and when the patient can have visitors at home, attend weddings, take vacations, and participate in family reunions. Patients and caregivers generally were the ones who introduced social news through their questions. The exchanges, therefore, were very important to patients. However, when clinicians disclosed news of this type, they did so somewhat casually and haphazardly in the course of conversation, suggesting that clinicians did not necessarily recognize or appreciate the impact of the news on the patient. Consider this example of a 52-year-old male patient who had been planning his life in terms of a specific date that he believed he could expect to return to work. This date was based on a conversation he had had with one of the medical staff during an intake exam prior to transplant. The patient locked in on the initial one-year estimate as a firm date, and had told family and friends and made arrangements at work in

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[21] In the clinical setting, graft-versus-host disease (GVHD) refers to the phenomenon of the transplanted cells attacking the hosts cells. GVHD is divided into an acute and chronic form. Acute occurs in first 100 days and associated with short-term elevated mortality. Chronic often occurs after 100 days but can interfere with long-term survival as well.

[22] Debilitating mouth sores -- making it difficult to eat, drink, and swallow.

terms of it. However, he understood this to refer to one year after the original diagnosis, not one year after transplant. He was devastated when he learned six months after transplant that he was mistaken.

> I did ask the question last week about going back to work or something like that, 'When would other things like that happen?' in conjunction with, you know, "When are we going to stop, you know, the every week kind of thing?" And they said, well, generally, again, from the date of transplant, the earliest that they would see anything happen like that would be six months. And it could go on to maybe even upwards of a year. And Betty [nurse practitioner] said, 'That's probably what it's going to be in this case, probably going to be about a year.' And I looked at her and I said, 'You're serious?' She said, 'Yeah.' And I said, 'You're saying that...like Christmas I still won't be back at work? I'll 'still be doing what we're doing here?" And she says, 'Yeah, probably.' And I just like, 'Holy cow.' (…) From a work standpoint (…) I'm climbing up on a year and after that year's time there's no guarantee they're going to hold my position open, you know. We're shifting on the fly and it's like, "Oookaaay. This is the middle of May. You're now telling me that it could be (…) February of next year?

After the seemingly casual correction of the date by the nurse practitioner, the patient went into a period of depression and wondered if he would ever recover. He was prescribed a higher dose of antidepressants following complaints of restlessness and insomnia, but the impact of this particular bit of news was never discussed during subsequent clinic visits.

While the physicians and nurse practitioners view different kinds of news disclosures as more or less significant, for patients and family members "perilous news," "routine updates," and "social news" are part of the same search for evidence about long-term prognosis and thus, in some sense all news is personally threatening or "perilous." So regardless of the specific content of the discussion, the larger implications are never far from the surface.

Patients often described their orientation to clinic visits as tentative, and as though they were "waiting for the other shoe to drop." One patient who had recently had a pulmonary embolism described his stance toward the outpatient clinic visits this way:

> My psychology-- I don't know if that has influenced me at all – maybe just reinforcing just how fragile everything is in terms of my health. Knowing that it [the pulmonary embolism] could have killed me but it didn't and there is something else that could be around the corner that could kill me.

> But you can't spend too much of your energy thinking about that -- the unanticipated, *unanticipatable* events. Pulmonary embolism, fungal infection, or blood in stool [this week] and who knows what it will be next week.

Routine news dominated nearly every clinic conversation and patients, physicians and family members together laid the foundation for ritualized forms of communication pertaining to all news during the first 100 days post-transplant.

In general, patients seemed to feel betrayed or abandoned by their bodies because of the strange and unprecedented things they were doing, and sometimes complained that it was hard to discern whether their symptoms were due to therapy or due to underlying disease. With little ability to interpret bodily phenomena on their own, patients had to rely on external authority (clinicians) to make sense of what was happening to them physically. In this way, clinicians essentially "socialized" patients during the early stage of recovery about how to interpret unfamiliar symptoms and side effects. This process was both frustrating and confusing for patients. Sometimes they came to the clinic feeling good only to learn that their "numbers" (blood counts) were not good or, alternatively, feel bad and learn that the numbers were good. Physician also shaped patient's understanding of how to distinguish between physical changes that were significant and those that were not. That is, doctors would sometimes listen to the complaint but not support the patient's interpretation of what was going on making comments such as "the drugs won't do that" or "that isn't related to your disease." Even comments such as "that's normal" -- which is intended to reassure patients that their recovery is proceeding as expected –could be confusing for patients. Some mentioned that after talking to the doctor or the nurse about severely debilitating symptoms (such as mucositis), being told this was normal felt dismissive and that they were complaining inappropriately about minor symptoms.

Ways of discussing health news during clinic visits

Although I have delineated three separate categories of news in the outpatient setting for analytical purposes, in reality, these different types of news are over-lapping domains, and there seemed to be a kind of "ecological" relationship between them. That is, explicit discussions of perilous news was akin to a rare and dangerous species and physicians disclosed this news cautiously, using veiled language or only divulging information in response to direct questions from patients or family members. Routine updates, by contrast, composed the majority of outpatient conversations, and were characteristically explicit about treatments, blood tests and scans. Discussions about the patient's ability to participate in various social activities were initiated most through patient and caregiver inquiries and doctors seemed to treat these conversations somewhat incidentally or as small talk of low consequence (Maynard and Hudak 2008).

Overall, the relationship between these categories of news seemed to be that routine news served both as a reassuring default and might actually be initiated to avoid discussion of news of greater import. Likewise, social news might be used to reroute a discussion but this news was also where the discrepancy between the worldview of the patient and the physician was most apparent. When patients expressed disappointment that the physician advised against plans to attend some social gathering, on occasion the doctor later described the patient's reaction as out of proportion to what the situation merited. Patients and families were, in fact, sometimes blamed for their own disappointment in that they had misunderstood what the medical staff believed had been a consistent message all along.

What is particularly notable about the rhythm of routine news discussions is that these were usually unproblematic exchanges. For example, in a clinic visit six weeks post-transplant the doctor was reviewing the blood work and offered this update:

Doctor : So the bone marrow's calming down now (…) These are all just a picture of things that give us a general sense.

In another clinic conversation, referring to the results of a liver function test to assess potential toxicity due to immunosuppressive drugs the doctor said:

Doctor: Yeah liver tests are all perfect. No - no GVH [graft versus host disease] so -

Patient: All right!

Concerning routine news, patients are also more often treated as collaborators and autonomous decision-makers in the relationship. In the following situation, a multiple myeloma patient had an autologous transplant six months earlier. There is evidence of minimal residual disease [23] and the patient was being considered for additional chemotherapy. The doctor tells the patient that the percentage of cancer cells is still a bit low to justify initiating more treatment and it might make sense to wait until the percentage goes up (to 0.5 or 0.6). This news is presented to the patient as a full participant in the decision-making:

Doctor: No they're, they're great looking [blood counts]. Um, then do you want to just and leave it this way and we'll say that if you are in that ball park, .5 probably even a .6 that we would just sort of sit tight until March? And then sort of re-address this again?

In the last example below the news is presented in a straightforward manner to the patient in terms of general progress. Eliminating Fluconazol,[24] is an indication that the patient is moving to a later stage of recovery:

Doctor: Okay. So, I'm going to go back and we're gonna, we're going to stop a few medicines. We stopped the Fluconazol and the folic acid. You can put both of these prescriptions - finish what you have and be off it.

Patient: Yeah.

Doctor: Okay. So two fewer pills, but one new medicine.

Perilous news that is good. When the news was very consequential but good, the announcement followed a prototypical news delivery sequence with an announcement, response, elaboration and assessment (Sacks (1992b) as reported in Maynard 1997). For example, when one patient's new stem cells had begun to engraft (indicating that things were going the way they should), the doctor entered the patient's hospital room smiling broadly and without preamble said: "I'm cutting you loose today!" This is an example of what Maynard

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[23] This means a small percentage of cancer cells are still circulating in the blood -- which is common for this disease (multiple myeloma) and this type of transplant (autologous).

[24] It is standard practice to administer a prophylactic anti-fungal for the first few months post transplant.

(1996) calls being blunt and it also fits the pattern of asymmetries between bad news and good news, whereby good news is regularly "exposed" more forthrightly than bad news (Maynard 2003: chapter 6).

In another case, the news was disclosed as a summary of overall health four months post transplant:

Doctor:	You've had beautiful blood counts through this. On the fourteenth you did all your labs. There's no sign of graft versus host disease of the liver. There aren't any concerns that I have about a lot of bleeding risks. You're making plenty of platelets – 100,000 are a normal count.

Notably, while quite positive, good news even if it is important is still short of making a prediction about the future. It focuses primarily on short-term gains and thus, points to a positive trend but without making guarantees.

Perilous news that is bad. During the clinic visits that transpire in the months following transplant it is exceedingly rare that there is one moment when the physician offers definitive bad news. In fact, in the outpatient context disclosures of this type may not even be straightforwardly recognizable; instead of being exposed, the news is "shrouded" in various ways (Maynard, 2003: chapter 6). In my data, there is a moment that alludes to an untoward situation for the patient, or there may be repetition of vague references over multiple clinic visits. Doctors may, for example, preface their comments with terms like "Unfortunately," or say, "This is not what we want to see," or suggest that results of a lab test are "concerning" or "disappointing."

In one conversation, the doctor told the patient that a drug had not slowed the growth of the patient's cancer and other treatment options may not be worth pursuing. In essence, this was a conversation about the transition from a curative to a palliative mode of care:

Doctor:	Well, we want to kind of juggle as best we can. We don't want to give you any false information or false hopes
Patient:	No no
Doctor:	All of us feel so deflated when we see this happen
Caregiver:	Yeah.

Doctor: We want the possibilities to seem endless but -

Caregiver: Yeah

Patient: But they're not

Caregiver: Yeah

Some doctor-initiated news is followed by a clarification question by the patient or (more often) a family caregiver and this is how discussion of the bad news goes forward. In the extract below, the patient has a sudden drastic change in health and the doctor offers the news but uses terms that are not necessarily self-explanatory. In this case, the caregiver asked for further explanation in an effort to reveal the news:

Doctor: When you think about the time frame in which this is occurring, this [cancer] must be fairly chemotherapy resistant

Patient: Yeah, that was a short …

Doctor: You were in, you didn't have a long period of time
(long pause)

Caregiver: So what do you mean by "chemotherapy resistant?"

Doctor: Getting things like Adriamycin and Vincristin again aren't probably not going to help a whole lot

Caregiver: And they're just going to decrease his quality of life?

Doctor: They … will take away your good - they'll take away … the good cells

Even here, the doctor stops well short of explicit discussion of the prognosis or the larger meaning of these changes. He focuses on the short term and why he would not recommend additional chemotherapy with different drugs.

Patients and doctors often developed a friendly relationship such that *joking as understatement* was another way to navigate bad news. The following was from the first outpatient clinic visit between the oncologist and the patient following a hospitalization. The patient had become extremely ill and for a time, there was concern that he would die. Testing in the hospital revealed that the donor stem cells had not led to a desired "graft versus tumor" effect, whereby the donor's stem cells would attack and destroy residual cancer cells in the patient's body. The extract below was from the opening moments of the visit where the doctor sees the patient for the first time since hospitalization:

Doctor: (Sitting down and facing patient) So anyway, you've had a few adventures in...

Patient: Yeah, yeah, (laughs) slight little change in plans here. Those, those stem cells aren't angry. They don't want to -

Doctor: You and your brother have a lot in common and then a little bit of -

Patient: Yeah, maybe too much

Farther into this same encounter, the caregiver initiated discussion of where things stood now given that the transplant had failed. She asks whether her husband's health might be better now had he stayed with a regime of chemotherapy and not undergone transplant:

Caregiver: So he's still better off...?

Doctor: To have them [the stem cells]?

Caregiver: Because of the transplant than if he wouldn't have had the transplant?

Doctor: Oh and that's my strong opinion.

This kind of question could be taken as a pointed criticism of the transplant doctor and it is likely that the caregiver wanted some explanation as well as reassurance. The doctor, however, does not elaborate but moves the conversation past whether previous decisions were the right ones and toward a discussion of future options for treatment to slow the re-growth of the cancer.

Patient assumptions and *"letting it pass."* It is also common for patients and family members to verbalize assumptions about their condition as an indirect way to pose a question. If the doctor does not challenge the assumption, patients take this to mean that the doctor supports it. For example, one 23-year old woman had been told (and presented with written material stating) that after high dose induction chemotherapy she would be infertile. During a routine visit, fourteen months after transplant this patient, who had made a wonderful recovery, said to the doctor that "when I get pregnant" she would have to make adjustments in light of her fiancée's work schedule. The doctor smiled but let this pass without comment. The patient was in high spirits after this clinic visit, but in the clinic workroom, the doctor mentioned the patient's comment to a colleague shaking his head. Depending on the circumstance, rather than withholding comment and "letting it pass," physicians may use comportment and gesture to communicate what they do not verbalize. One physician joked to his colleagues that when a terminal patient asked about an experimental option that he did not think was a good idea, he "put on my sad face."

Time. Clinicians also use time as one important means to disclose perilous news gradually. In the workroom after a clinic visit, for example, one nurse practitioner noted that the patient did not understand a significant development yet and said to a colleague: "I'm giving her a week to figure it out."

Physicians often used time in conjunction with geographic space (multiple clinic visits in different locations) and multiple people (enlisting other physicians) in the disclosure of perilous news as well. One middle-aged leukemia patient had made slow but steady progress in the months following his transplant. "Eight months to the day" according to the patient, he and his wife went to a routine clinic visit with his transplant oncologist, "Dr. G," several hours distance from his home and expected to hear that soon he could come less frequently to the clinic. Prior to the visit, he recalled thinking:

> I was looking forward to hearing "Hey, let's stretch this out to three weeks or a month." We had actually talked about it a little bit [in a previous clinic visit] because [Doctor G] goes 'You're one of those deer hunters aren't ya?' and I said, 'Yes I am. I do live up north.' And he says probably by November we'll get into that. So we were already kind of talking about what was going on for the future.

The patient's wife recalled that the mood during the visit where the transplant oncologist, Dr. G. alluded to bad news in the lab work as otherwise very upbeat:

> I remember him [Dr. G.] walking in that day that he told us the news and the first thing that he said was "Well, there's the happy couple." I remember him saying that. And then he told us that – well he said "Your numbers aren't real good today." Or something about the numbers – the numbers are off I think he said. (...) but we didn't think much of it (…)

Dr. G. did not elaborate and neither the patient nor his wife inquired further, thinking that whatever the transplant oncologist saw with the laboratory reports was probably due to some excessive partying they had done on a recent trip. On Monday while the patient's wife was at work, Dr. G. called the patient at home.

> [W]hen the doctor called on Monday and he said he had talked to hematology that's when I thought that there might be something wrong. I grabbed that report [they had received during their clinic visit] and I opened it up and when I opened it (…) it was on there and the percentage was on there - the blast cells. It showed blast cells. As soon as I saw "blasts" I went, "Oh, no" and I knew.

If the presence of blast cells were on the report, the transplant doctor also knew this during the clinic visit. Because the patient's transplant oncologist was located at a regional cancer center 150 miles away, another physician - the patient's local cancer doctor, Dr. B - who communicated with Dr. G about the lab results, arranged additional testing and a follow-up visit. In this way, completing the disclosure begun by Dr. G. at the regional cancer center the previous week:

> I remember Dr. B [the local doctor] coming into the [exam] room after the testing and says "This is the worst part of my job is telling somebody that the cancer is back." He just didn't want to have to tell us that and it's not an easy thing to hear. It was almost like, it was almost like getting, like hearing it for the first time.

In sum, doctors, nurse practitioners and other clinical staff had a good deal of prognostic information that was shared matter-of-factly with each other (and with our project team), but selectively disclosed this information to the patient and the family. Although the patient in the excerpt above suggests that getting the news about recurrence was like "hearing it for the first time," the experience is different from initial deliveries of news because the patient and his wife do not so much experience the "shock" associated with diagnosis and a sudden reversal of fortune. Instead, the news of recurrence is more often described as a "blow," alluding to battle-weariness in the face of an again advancing disease (Schaepe 2011).

Overall, while the long-term prognosis may be altered based on changes in fixed short-term developments, for the most part, discussions about the short-term prevailed in the clinic. The patients and families seemed to get accustomed to this short-term focus and questions about the long-term were often redirected by physicians as dependent on what happened in the short term. ("Let's see how upping the dosage works first.") In this way, if patients are constantly anticipating some specific result from a particular treatment they are not worrying about (or preparing for) end of life.

The "breach" of posing direct questions about perilous news

Patient and family initiated questions about perilous news often seemed a breach to the smooth functioning of the clinic conversation. According to Garfinkel (1967), breaches can render tacit understandings of a local social order of a setting more transparent. Maynard's (2006) study of "meaning assessment" in the contexts of diagnostic news deliveries is in this vein, showing how a patient's blunt question, "Does it mean I'm gonna die?," after being told of a stomach cancer, suggested the absence of physician interpretation and prognosis regarding expected sequelae. In the present study when a patient initiates a question about prognosis it can be tough for clinicians to hit head on and everything about the interaction suggests that this questioning goes against the grain of the encounter. In the extract below, the patient's first transplant had failed and while in the hospital, the possibility of a second transplant was mentioned by a colleague of the patient's oncologist who was overseeing all the patients on the inpatient unit during a scheduled rotation. Based on a conversation with the second rotating oncologist, the patient assumed a second transplant was a viable next step and raised the issue with his own oncologist. It is the patient's wife who pursues the possibility even when the patient's oncologist tells them this is not an option:

Extract 1: "Second transplant"

Patient: Well, then...yeah, if we do another transplant, will it be done with his [brother/ the donor's] cells modified or what?

Doctor: I don’t think there’s any plan to do a …. second transplant.

Patient: Okay.

Spouse: There’s no plan ever? Dr. Smith talked about it.

Patient: Well, I guess...would there be a benefit or not, yeah.

Doctor: (pause) What might be considered here is this. If the - if you go into remission with this drug, we’ll do what’s called a “short tandem repeat” where we study the DNA and know how much is your brother and how much is yours. If there is residual of your immune system, we’ll ask your dear brother to give us some of his t-cells, his lymphocytes. And we’ll try to push-

Spouse: An infusion, a lymphocyte infusion?

Doctor: But that’s not a second transplant.

Spouse: But then...but she [Dr. Smith] also talked about doing a second transplant. She said...at one point they said that um, they would do a different donor because he might have better luck. And then she said that they might go ahead and use his brother and just put more cells in and withdraw the tacrolimus sooner so that you don’t suppress it, that they still had -

Doctor: If -

Spouse: (speaking rapidly) I mean, she said we had to get through all these hurdles first, he has to - I mean, that’s -

Doctor: What (sigh) is a realistic possibility - as you know the second transplant would accomplish acquisition of your brother’s immune system.

Patient: Yeah. But we’ve already done that once.

Doctor: (said slowly) We’ve already done that.

Patient: Been there, done that.

Doctor: I mean, Dr. Smith in her zeal to want to offer options --

Spouse: **(**cuts doctor off) But isn’t that the only cure?

Doctor: If there’s graft versus tumor in effect that can lead to a cure. And that’s what I was saying, if we treat now and this reverts and regresses, it doesn’t mean the bad cells are gone.

This conversation was a direct confrontation with very perilous news. Without a second transplant, the patient had no chance of cure. The doctor was saying that a second transplant was not an option. This means that the patient would ultimately die of his cancer. The exchange was quite difficult and left the family shaken. In the doctor's final comment above, he is trying to make clear that what they can expect to achieve with additional treatment is qualitatively different than if the transplant had been successful and the donor cells had begun to attack the remaining cancer cells through a graft versus tumor effect.

After this meeting, in an adjacent room the patient and his wife got into a fight about the wife's pursuit of the issue during the clinic visit. This exchange reveals how profoundly disruptive confrontation with perilous news can be, not just to the order of the clinic visit but to the family unit as well:

Patient: What Doctor Smith said is -- she is not my doctor! And when you were saying you know "Doctor Smith said this" "Doctor Smith said that" -

Spouse: Well, I'm just trying to understand, honey.

Patient: No, that's -- he [doctor] was very offended that you made that -- and he tried to gloss it over by – he wasn't very happy.

Spouse: Well, I get – I guess I don't care

Patient: Okay.

Spouse: Because I need to understand (starts to cry) what's going on.

Patient: Okay. But that's – that was an awkward situation.

Spouse: Well, it's awkward for everybody but you were under the same impression. That you could have another transplant. You told your family, you told your brother.

Patient: As a *possibility*. We still knew –

Spouse: We knew it was a possibility that you had to go through hoops

Patient: if you're going to – I'm not going to get into a – it's not, it's not going to change what's going on so I mean we have to look at this realistically. Extended life is what we're going to get.

Spouse: Well, Doctor Smith didn't say that. It was a thing that they were going to go out to do like she said it was a 'steeple chase.' You had to go through hoops and a – but she did say it was a possibility.

Patient: But also -- they told us, they've also told us there's differing philosophies within doctors

Extract 2: "How to think about success of an experimental therapy"

Another patient had a surprisingly good response to an experimental chemotherapy and felt better than she has for a long time. She tells the doctor that a couple days ago she was merging onto the highway between two semi- trailers and said, " I'm thinking I'm feeling good, I ripped off the DNR bracelet. I don't want to get smooshed by a truck now!" She comes to the clinic visit asking about whether this treatment might suggest that her prognosis has changed.

Patient: Okay are you at some point going to say, you know, we can't keep this effect going?

Doctor: Well I don't know e e . . . I don't want to a … a portray myself as somehow being in control of what happened here.

Patient: Oh, no, no, no. I was just

Doctor: This is just a wonderful thing

Patient: If you see that it will hold

Doctor: Well, sure um

Patient: Yeah?

Doctor: Sure. Yeah it – so I don't know where things are going to go here and --

Patient: (laugh)

Doctor: I don't even want to try to …

Patient: project?

Doctor: project

Here the patient is thrilled by the effect of the experimental treatment and wants to know whether it might be a game changer. The doctor hesitates and essentially defers to uncertainty when he tells her he cannot project.

How patients and family re-interpret verbal and non-verbal phenomena

As noted previously, along with, or following the lead of, their clinicians, patients and families learn to focus on immediate concerns. However, they are capable of inferring conclusions about the longer term and prognosis through re-interpretation of verbal and non-verbal cues. This happened in a number of ways but two “passive” and two “active” ways of getting a sense of how things were going are described here. Passive ways of assessing health status included comparisons with other patients who have gone through a transplant, and drawing conclusions based on changes in the scheduling of their clinic visits. Actively, patients and caregivers solicited information through reframing questions as medical inquiries and through end-of-the-encounter “doorknob” questions.

Passive Interpretation A: Comparison to other patients. Social comparison theory (Festinger 1954) explains how individuals, in environments of uncertainty, evaluate their own opinions and abilities by viewing others in relation to themselves. Patients may select (a) targets who are similar to themselves, (b) those who are relatively advantaged or superior, or (c) people who are inferior or less fortunate, which can enhance self-esteem (Wills 1981). Patients in this study tended to engage in (c), in a manner that Wood et al. (1985) found among seventy-eight breast cancer patients. Patients were often demoralized by media “supercopers” and favored “downward comparison.” In my study, patients tended to focus on others who were struggling more severely because of the disease. In one discussion, a patient described another: “He’s got bones in his back breaking down. I have had none of that.” Patients would also allude to other patients more generally, “I’m lucky compared to some of these people.” This kind of comparison may have been self-enhancing but probably was not an accurate gauge of health status.

Passive interpretation B: Clinic schedule. Patients described a change in their clinic schedule as a milestone or an achievement. “I’m only coming to the clinic every three months now.” The clinical staff manipulated this symbol as well. When the clinic schedule is changed to have less frequent visits, it is the same as disclosing good news for many patients and clinicians. Davis (1963), Roth (1963) and others also note how schedules are taken as proxies for progress and note that discrepant definitions of time may emerge through appointment scheduling. In one instance in my research, the patient and his wife noted that the patient’s brother was coming for a visit and said, as the date for a next clinic appointment was being settled, that of course the clinic appointment would be their priority. The doctor countered that the visit with the patent’s brother "should be the priority at this point." "You need to enjoy your family." The subtext here for the physician was to convey terminal status. For the patient and caregiver, the patient was still on a curative track.

Active Pursuit A: reframing questions about prognosis. Patients and family members broached serious issues about health status through an indirect approach to inquiry, using medical jargon (technical language about their disease and its treatment) to assess where the disease was heading. This patient, a 54-year-old man increasingly initiated technical discussions to get at issues of prognosis.

Patient: I'd like to see an MRI at some later date to see if the spine is deteriorating at all. Because I'm always –

Doctor: We can do that – that can be helpful if you're looking for other reasons or other tools.

Patient: Well that's one thing that I know about a disease that can do me in

Doctor: Yeah, if you, if you've got other tools to say sort of "how am I doing?" I mean that is one thing that you can use.

Patient: The osteoclassic thing [25] that's not proven to be part of the benefit of the transplant, that could still be going on all through –

Doctor: Well, I think, I think um, certainly people feel like they - the osteoclastic activity would ramp down after you've, you know, been successfully treated but certainly you should make sure that you get adequate calcium and vitamin D in your diet (…)

Although this exchange is quite technical, essentially the patient is concerned about changes in health status in the long term. His bones were progressively weakening and he knows this is one thing that "can do me in." He does not express this worry directly. Instead, he requests an MRI which would facilitate a discussion with the doctor about his long-term prognosis in light of information from the scan.

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[25] An "osteoclast" is from the Greek words for bone ("osteo") and broken ("clast"). It refers to a type of cell that removes bone tissue by mineralizing it and transferring the calcium from the bone fluid into the blood – a process known as "bone resorption." Osteo "clasts" an osteo "blasts" are instrumental in controlling the amount of bone tissue in the body. Osteoblasts form bone, osteoclasts resorb bone (Netter 1987). Resorption is a valuable process in healthy individuals but because treatment has compromised this patient's bones substantially, its value is dubious.

Active Pursuit-B: the "Doorknob" question. End of the clinic visit questions do not fit into a category of "news" so much as a patient strategy for getting at "news" -- some deeper layer of truth about health status. Traditionally, "doorknob questions" refer to the dreaded inquiry that doctors hear as they place their hands on the doorknob to leave the treatment room at the end of the encounter. This is the point when a patient will disclose a different reason for the visit than the official complaint. It is a phenomenon occurring with some regularity, especially in primary care, and questions of this type have the potential to disrupt the doctor's schedule for the rest of the day (Baker et al. 2005; Jackson 2005).

In the cancer outpatient context, doorknob questions are a slightly different phenomenon. Patients aren't so much withholding a key symptom or holding back a different agenda from the official one. Rather, they reveal an underlying worry or anxiety about the long-term direction of the disease, and it is as if this concern bubbles up at the end of the visit to be blurted out in the form of a last-minute question. This phenomenon was easiest to see across many patient visits rather than from tracking individual cases longitudinally. In this study, in fact, it was most apparent while shadowing physicians as they met with a series of patients (many not part of the study) over half day observation periods. The sheer range of things asked of the physician at the end of the encounters was striking. On first blush there seems little that tied these questions together other than where they occurred in clinic conversation, the fact that they were prefaced with phrases such as: "I have one other question" or "by the way" or "I just wanted to be sure to ask . . ." or "I've been wondering; and patients rarely seemed satisfied with the answer. For example, during one observation period these were three of the questions that were asked by three different patients at the end of his or her encounter: "Should I take a job in health care?" "Can I eat salsa?" "Can I donate my organs?" Below I describe each of these doorknob questions briefly to reveal the embedded theme about prognosis.

- A twenty-year old female twelve months post-transplant has recovered well. After the doctor hands a prescription to her, she says there is something she's been meaning to ask. She is thinking of taking a position as a receptionist at a cancer clinic near her home. She says that this whole cancer experience has made her feel like she might have something valuable to contribute to other people going through cancer. The doctor says 'Sure, it is a great idea.' The girl seems as though she was hoping he would say more and follows by saying she wanted to ask because she wondered if there might be any reason that she shouldn't do this. The doctor said, 'no, it should be fine.'

- A fifty-year-old man is told by the doctor that things are going well with his recovery, and they can plan to schedule his next appointment farther out. The man does not seem happy and says that it would be helpful if they could schedule appointments earlier in the day because today he ended up waiting two and a half hours and he and his wife still have to drive home. The doctor sympathizes and says they can figure out another arrangement and reiterates that at least his visits will be much less often. The doctor is standing and ready to leave and the man says he has one question he's been wanting to ask. The doctor says 'go ahead.' "Can I eat salsa?" The doctor smiles and says commercial salsa is okay but he should avoid anything homemade. The response from the doctor does not seem to satisfy the patient. He goes on to say that it is frustrating to not know what is okay or not okay for him to do. The doctor says that he can eat a lot of fresh food if the skins are removed or washed thoroughly, but he should avoid things like blackberries and raspberries. The man says that he doesn't know how careful he needs to be around sick people, dirty areas, basements, wood. "Can I burn stuff outside without a mask?" "I want to lift weights but I don't know how much is too heavy" and "I live in a neighborhood full of dogs." He said he has a 90 pound chocolate lab. "Can I be around him?" The doctor ticks off yes and no for each item but the patient still seems unsatisfied.
- A 50-year-old woman four months out is very shaky and frail. She came to the clinic visit with her mother-in-law. Near the end of the visit the woman says she does not like the "tremor" and the "fog" she is experiencing in recent weeks and would like to start feeling better and have more energy. The doctor agrees and says that he wants to start seeing her appetite return. He gets up to leave and opens the door and asks her if she has any other questions. She says, "yes, one thing." The woman has a serious look on her face and says that she has been getting different answers from people she's

> talked to but wanted to ask him: "Can I donate any of my organs?" Without pause, the doctor answered literally. She might be able to donate tissue, but as for her organs, probably not - certainly not her spleen. The woman appears emotional now and her eyes are glistening. The doctor says that they can talk about this later and not to worry about it. He said that there is a number they call when the time is right. The mother-in-law smiles and says thank you.

Substantively, questions about employment, salsa, and one's suitability to be an organ donor have little in common. However, structural features of these exchanges -- placement in the conversation, prefacing the question and dissatisfaction with the doctor's answer – do reveal a pattern and suggest that the real meaning of the question was something other than the one verbalized. In the first case, the female patient may have wanted confirmation that she was out of the woods and had crossed over from a patient to someone who not only could seek employment but also could be helpful to other cancer patients. By asking the doctor if there was any reason this may not be a good idea she alludes to a more global question about her future.

In the case of the man's question about salsa, the doctor has told him he is doing well and plans to push out the clinic schedule – both indicators of a positive direction in health status. When the man asks about salsa the doctor offers a straightforward answer but the man went on to express frustration about whether he could engage in any number of "normal" activities. The doctor methodically answers each of the questions, but again a more global concern seems to be at issue here -- the overall quality of life and prospects for improvement. In the third case, the question is the most transparent. The woman is likely inquiring about just how sick she is. She may be attempting to discern whether donating her organs is reasonable discussion to have in her state of health. The doctor's response leaves the patient shaken because he validates the appropriateness of such a question and worse, points out that most of her organs are probably too damaged by chemotherapy to donate.

Discussion & Conclusion

The “bad death” presented at the beginning of this paper closed with questions about how such a death can occur when patients, family and physicians are actively involved and trying to do the best things. Although this chapter may not be able to answer any those questions definitively, close analysis of multiple clinic visits from this and nine other cases in the study revealed nuanced strategies by which patients and clinicians give a wide berth to direct discussions of serious bad news and its long term consequences for the patient’s health. Patients, physicians and family members develop the ability to vary their language along the spectrum from explicitness to indirect communication depending on their reading of each other and the specifics of the situation.

In recent years, the quality of communication in the cancer outpatient setting has taken on greater relevance in light of advances in technology that offer therapeutic options to manage late stage disease. But many have noted that with medical progress has come a trend toward administering a “tech tonic” or futile treatments to terminal patients. As Atul Gawande (2010:3) notes, “Our medical system is excellent at trying to stave off death with eight-thousand-dollar-a-month chemotherapy, three-thousand-dollar-a-day intensive care, five-thousand-dollar-an-hour surgery. But, ultimately, death comes, and no one is good at knowing when to stop." (Gawande 2010). Smith and Swisher (1998) make a similar point in the article, “Telling the Truth about Terminal Cancer,” noting that too many patients are fighting a battle they cannot win but because explicit conversations are missing about when to stop treatment and prepare for dying, most patients do not draw on the available resources for good end of life care. The "traditional open-ended model" that assumes medical advances will continue unabated, they argue, must be replaced by more realistic priorities, namely a good death for the patient and improving the quality of life for everyone involved in the process.

My study provided an overview of how clinic conversations are organized and showed a number of reasons for indirect communication. When confronted with difficult decisions or when there are no longer options for treatment, physicians must juggle multiple goals, such as helping patients remain hopeful while still easing them into new and more modest expectations for care. Juggling these goals often involves using indirect language, being intentionally vague, and leaving key news implicit. It is made explicit only if the patient or family members pursue it. On one hand, inexplicitness reduces the potential for tension in the relationship with patients and physicians may view it as a way to lessen the anxiety of patients and family members. On the other hand, indirect communication about perilous news can make it difficult to engage in informed decision-making, thereby contributing to futile treatment and bad deaths. Vague language allows patients and family members to "fill in" their understanding of the situation and leaves open the possibility that what a patient believes about the situation is also deniable as a message sent by the physician later on (Eisenberg 1984). Thus, a comment like, "We should have had this conversation" may suggest that the family projected a meaning from previous discussions and test results that the clinician never intended.

The British philosopher of language, H. Paul Grice (1975) formulated maxims of communication based on the ideals of clarity and cooperation. That is, where possible:

a. Do not say what you believe to be false.
b. Do not say that for which you lack evidence.
c. Avoid obscurity of expression.
d. Avoid ambiguity.
e. Be brief.

The actual norms in the cancer outpatient clinic (as opposed to Grice's ideals) are more in line with Searle's (1975) proposal that indirect speech acts (speaking idiomatically) are the social norm and direct speech acts are the exception. The following might reflect the "real" implicit maxims:

a. Do not say what you believe to be false but do not say the complete truth.
b. Given the possible ambiguity of evidence, never be forthright in conveying bad news.
c. Focus on the here and now even though it may obscure long-term concerns.
d. Do not appear to be ambiguous, but use indirect means to get at serious bad news.

e. Be brief, and persevere with optimism, no matter what.

Do these implicit maxims reflect a failing of some kind? Should these norms be changed? If these maxims suggest that new norms are needed, I would argue that encouraging direct communication is perhaps too simple a recommendation. In fact, clarity of expression in the outpatient clinic is not a good measure of communication competence. Drawing more deliberately on what is known about how communication actually works in clinical contexts may be of much more use. As Sanden et al. (2001) observed, routine forms of communication are useful for upholding a certain order and getting through the encounter smoothly, as long as both patients and physicians also recognize the right time to raise sensitive issues. The therapeutic relationship can also be undermined by routinization if doctors, patients and family members silently collaborate to side-step difficult issues. Future research could help develop recommendations about how to leverage indirectness while also recognizing when direct discussions need to surface.

Chapter 4: New Approaches to the Study of Chronic Illness Communication

New Approaches to the Study of Chronic Illness Communication

In the midst of the fieldwork, analysis, and writing up the findings, it is easy to get lost in the "trees" -- the specific phenomena at issue in each chapter – and lose sight of the "forest" – the larger persistent theme running through each chapter. The broad objective of this dissertation was to learn about ongoing communication between doctors and patients and their families as they develop and sustain therapeutic relationships. Many cancer patients seem to "lose their way" going through cancer treatment, and research shows, somewhat counter-intuitively, that patients experience *more* rather than *less* confusion and misunderstanding the longer they live with their disease (The 2002; Prigerson 1992). Through a longitudinal analysis of one type of communication, this study sought to reveal patterns influencing patient and family decision-making.

As noted earlier in the dissertation, recommendations for better communication between doctors and patients in the medical literature tends to rely on a common sense understanding drawing on anecdotal experiences of physicians in clinical practice. Firsthand experience, as sociologists would argue, is not the same as an empirically grounded analysis however, and thus systematic examination of these relationships is a better means by which to identify patterns in both patient and physician thinking and behavior.

The analysis conducted here revealed a number of patterns that offer insight about the nature of bad news communication as a longitudinal phenomenon with ramifications for future sociological research as well as clinical practice. The first empirical chapter, ***Bad News and First Impressions***, focused on patient and caregiver accounts of "the day" of learning the cancer diagnosis. The study found that the experience of coordinated or uncoordinated care prior to disclosure of diagnostic news played an important role in elevating or reducing patient anxiety. While this finding seems a subtle insight, it is one with not-so-subtle consequences for physicians cultivating a relationship with patients and delivering difficult news in the cancer setting. The chapter concludes that prior to delivering the diagnosis; physicians would do well to feel out the emotional state of the patient by asking a few questions about the experience of the medical system to this point. This may help contain anxiety and at the same time serve to re-establish a sense of support for patients and their families that may have been damaged in earlier encounters with physicians and clinicians in other parts of the medical system.

The next chapter, ***The Second "Weight" of Diagnosis,*** examined how the news of cancer is disclosed by the patient him or herself, to family members, friends, and coworkers. By paying attention to an activity that has generally be viewed as tangential to the disease experience, the chapter revealed the social meaning of cancer – specifically through analysis of decisions about who and what to tell to others. Cancer patients think a lot about how others will react to the news, and often express concerns about how to function if people in various parts of their life know about the diagnosis. Thus, sharing the diagnosis is anything but a small event for patients and, in fact, remains central to the overall experience of cancer. I make no specific recommendations here about how care might be delivered differently in light of the findings from the study, but I argue that analysis of self-disclosure patterns can be a valuable way to understand the social experience of serious illness for patients. The third chapter, ***Perilous Communication in Long Clinic Relationships,*** examined the conversational practices used by physicians, patients, and family members to discuss serious changes in the patient's health status in the outpatient clinic during many months of follow-up care. In my data, there were few direct disclosures of highly consequential bad news, leading to my argument that direct discussions of serious bad news, in fact, may be "non-normative" in this context and more research is needed to learn how widespread this phenomenon may be.

Longitudinal qualitative research

This study has reinforced my sense that longitudinal research designs are essential to understanding therapeutic relationships in chronic care settings and the only means by which to address rigorously some of the emerging questions about less than optimal communication, which has been noted in the literature. Unfortunately, as Conrad (1990: 1258) has observed, contemporary qualitative researchers have not seemed to show "the staying power necessary for conducting longitudinal qualitative research." In part, qualitative longitudinal research – especially in medical settings – remains rare because it is time consuming, difficult to systematize, and offers no guarantee beforehand that the effort will be worthwhile scientifically or otherwise. In addition, at every stage from data collection to data analysis there are ways that the researcher may "lose" the study. For example, data collection over long periods of time among a population of seriously ill individuals, almost by definition will involve attrition or the threat of attrition, and there are many reasons and moments when participants choose to drop out of a study. In my project, it would have been nearly impossible for study subjects to anticipate all of the contingencies that may affect participation in light of their life-threatening condition. Cultivating and sustaining relationships with participants is also a bigger task than qualitative research of short duration. It requires working within a framework of ongoing "process consent" (Holland, Thomson, Henderson 2006) that makes available to participants the option to stop at any time and at any number of logical intervals (Lawton 2001). Data analysis with longitudinal qualitative research is a somewhat different enterprise as well and requires tracking one or more separate cases chronologically and simultaneously conducting comparisons across cases. Finally, the mere passage of time has an effect on the analysis and interpretation process. Participant perspectives change, the researcher's interpretations evolve, and, thus, findings are necessarily provisional (Thomson, Pulmridge and Holland 2003).[26]

Longitudinal qualitative research in medical settings also amplifies ethical issues associated with other forms of qualitative research. For one thing, the longer the relationship and the greater the intensity of the personal change for subjects, the more difficult it is to maintain professional boundaries. A situation that is confusing for both researchers and study participants. The blurring of boundaries is further aggravated by the fact that research subjects are asked to articulate intimate and often still unprocessed or "raw" experiences. In this context, the agendas of researcher, patient, and clinician tend to coalesce in what Dickson-Swift et al. (2006) call "therapeutic means to research ends." Patients with serious illnesses often appreciate the chance to

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[26] In fact, in comparison to other qualitative research the notion of "saturation" (Glaser and Strauss 1967) - where the researcher is no longer hearing or seeing new information – is far less apt than Stanley's metaphor of a "kaleidoscope" (Stanley 1992: 158). Where some of the same elements persist as the study continues to unfold, but new elements and new configurations and possibilities for interpretation are added.

talk about the experience and frequently find conversations with researchers more therapeutic than actual counselling (Gale 1992). Medical staff recognize the value of a listening ear for their patients too, and may actually direct patients toward ongoing qualitative studies for this reason.[27] In addition, for good or bad, qualitative researchers often define a "successful" interview as one with a great deal of intimate information, a kind of private narrative that may not have been previously told to anyone else (Birch and Miller 2000). Overall, the confluence of these factors make the research process uniquely challenging and prone to much ethical ambiguity -- yet it is these very features that reveal much about the nature of living with a chronic and potentially fatal illness.

Building a longitudinal methodology

The ideas discussed in the remainder of this chapter pertain to developing an approach to longitudinal communication research using ethnography. The ideas are preliminary at best, but I would argue that future studies of chronic illness communication require exploring the haphazard ways that events unfold and the often-conflicting rationalities that play a role in doctor-patient communication. Longitudinal qualitative research (LQR) is usually assumed to be just another label for ethnographic research of some duration or the process of re-interviewing subjects at intervals over many months or years. However, in the last fifteen years or so LQR has emerged as methodology that focuses on analysis of some form of change (adaptation, transition, etc.) as it happens over time. Relatively specific research questions are posed to assess differences between some Time 1 and Time 2. Inquiries in the literature center on questions such as whether the phenomenon increases or decreases over time; whether the change is sudden or slow; and the degree to which the changes substantive or symbolic (Holland, Thomson & Henderson 2006). Under what conditions do changes occur? Which changes occur in conjunction with or preceding others? In what ways are the changes meaningful to the individuals affected? In the case of a serious illness, research might involve

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[27] In the research for this study, on more than one occasion a patient referral by a transplant coordinator came with a comment such as this one, "This person REALLY needs to be in your study."The implication is that this person needs some sort of talk therapy.

considering just how previously taken-for-granted assumptions about life and expectations for the future are altered.

To date, ethnography has been good at describing the social framing of the chronic illness context, but has not been particularly good at capturing the details of interaction or how change in communication patterns occurs over time. Communication research, such as conversation analysis (CA), by contrast, has been very good at closely examining verbal exchanges in clinical settings to understand how participants create a "locally meaningful" level social organization (Sacks, 1992). Although my study is not a conversation analytic one per se, it does incorporate recordings of doctor-patient interaction and the use of recordings to enhance the ethnography. My argument is that, in the future, as Corsaro (1996) and Maynard (2003: chapter 3) have suggested, skillful integration of these two methodologies might prove a particularly powerful (and yet efficient) form of LQR yielding new insight about communication across a number of chronically managed conditions. Although mixed methods are encouraged in LQR, none of the existing research involves the integration of ethnography and conversation analysis specifically.

My vision for the integration of these two types of analysis is driven strictly by my experience working on this project rather than stemming from a particular theoretical commitment.[28] That is, early on in the research, my objective was to analyze bad news about prognosis in the audio-taped clinic date just as it might be done for disclosures of a diagnosis. However, I found few examples of explicit "bad news" disclosures in the audio-recordings. From the field research, however, I knew that the status of a number of patients had changed dramatically over the course of the clinic visits, even though the discussion of these changes were not immediately apparent from review of the tapes. Drawing on a timeline of significant events that I had developed for each of the ten patients, I could pinpoint health downturns, which paralleled physician discussions of patients during clinical rounds during the same period. But the news was not often

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[28] That is to say, there has been a good deal of controversy surrounding CA's approach to "context" and/or "talk extrinsic data" (via ethnography and interviews) for conducting an analysis. On one end, some conversation analysts argue that CA and ethnography can be complementary methods but others view them as incommensurable paradigms.

discussed explicitly with patients, which prompted this question: How are these changes in status communicated? Additional review of the tapes caused me to attend more to the many conversations focused on what I thought of as medical and social trivia. As I spent more time reviewing the conversations, I began to see allusions to changes and ambiguous references where I might have expected an explicit discussion about negative changes in health status. Thus, I began to focus on strategies for avoiding explicit discussion of particular kinds of bad news.

Without the ethnographic data, it would have been difficult to identify the nature of the indirect communication so prevalent in the outpatient setting. Future research from a CA perspective may be able to establish patterns more quickly and concretely (relying less on interpretation). Through the fieldwork, I found that doctors, patients and family members orient and hold each other accountable for discussing consequential news in particular ways as though reflecting unspoken normative assumptions. But is it an assertion that CA could do much more to explicate.

Future LQR on communication could begin by thinking about the scope of the phenomenon. What is the "reach" of the study? The length of time would be relative to the phenomenon observed and study could vary based on the specific research question. A relatively *short term* longitudinal inquiry, might involve intensive tracking through an organisational process (e.g. following patients through a hospital procedure). A *longer term* investigation might track a patient from admission to the hospital through discharge. An e*ven longer* study might follow individuals through a life course. L*ong term* research might involve extensive tracking over decades in an effort to discern changing life styles, practices, attitudes and values.

Although longitudinal studies integrating CA and ethnography are few, another potential for this combination centers on tracking how medical professionals learn in ongoing clinical relationships with patients. Nguyen (2008), for example, considers how new pharmacists develop interactional competence in dealings with patients over time. The research integrates CA and ethnography to reveal the changes one pharmacy intern makes to the organization of the clinic encounter as both a local and longitudinal interactional accomplishment. The data include twenty-one patient consultations and conversation analysis of the pharmacist's interaction with patients over the course of several months revealed how the intern learned and modified her process by reordering particular actions. Among other things, she adjusted the "openings" and "advice sequences," and changed the way she transitioned from one part of the conversation to the next. The data provided a nice picture of the way patient consultations transpired as well as how the pharmacist adjusted her approach over repeat encounters.

The examination of serious news in light of the experience of chronic degenerative conditions, reveals that news is not altogether about disease and pathology but also about relationships. To study these relationships requires a form of qualitative longitudinal research that is robust enough to be able to incorporate new findings that may challenge initial interpretations. I think that a mix of ethnographic research and conversation analysis offers this possibility.

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