Published in final edited form as:
Soc Sci Med. 2011 September ; 73(6): 912–921. doi:10.1016/j.socscimed.2011.06.038.

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

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Abstract

Studies in medical journals regarding the delivery of a cancer diagnosis typically focus on a single clinic episode where the definitive news is disclosed to the patient by the physician. 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 28 patients recently diagnosed with leukemia, myeloma, or lymphoma and 30 of their family caregivers. The participants, recruited at a large 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.

Keywords

United States; diagnosis; physician-patient communication; cancer; bad news; narrative; family caregiver

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).

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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 the task (Buckman, 1992; Girgis & Sanson-Fisher, 1995; Maynard, 2003; Rabow & McPhee, 1999; Baile & Buckman, 2000; Back, Arnold, Baile, Tulsky, & Fryer-Edwards, 2005). 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 (Butow, Kazemi, Beeney, Griffin, Dunn, & Tattersall, 1996; Fallowfield, Ford, & Lewis, 1995; Hagerty, Butow, Ellis, Lobb, Pendlebury, Leighl, et al., 2004; Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Cassileth, Zupkis, Suttonsmith, & March, 1980). 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 58 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 and Strauss, 1965), and the ways in which identities are transformed through the experience of chronic illness (Charmaz, 1993). Ethnomethodological 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; Perakyla, 2006; Maynard, 2003).

In addition, organizational studies have examined the medical professionals who have institutional authority to convey diagnoses (Freidson, 1970) and conceptual issues such as the medicalization of social conditions (Conrad and 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 35 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 33 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 (Dumit, 2006; Nettleton, 2006; Clarke & James 2003; Barker, 2002). 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 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 28 patients and 30 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 transplant (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 58 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-nine 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.

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 fieldwork 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. The weblogs followed in this study were maintained by caregivers somewhat more often than the patient and in either case 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 identify 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. (P12/1:1)

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 pin point 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! (P6/1:2)

Whether the process of "getting it" was slow or fast, a common pattern among patients was to review "previously ambiguous signals" (Maynard, 2003, p.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.'(P5/1:15)

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. (P21/1:9)

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?” (C9/1:4)

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.” (C3/1:6)

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, 13 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*[1] 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,

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[1] All proper nouns used in participant quotes are pseudonyms.

> 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? (C5/1:5)

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 (C12/1:15). 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 each 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. (C15/1:4)

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(...)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.' (C7/2:4)

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. (C7/3:8)

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 pain killer, 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." (P9/1:4)

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. (P9/1:7)

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. (P9/1:40)

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, Bynoe-Sutherland, and Coleman (2003) about 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. This connection was stated explicitly by the mother who was given inaccurate information about recurrence of her daughter’s sarcoma.

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 (Luhmann, 1979, 1988). Trust is also understood to be the outcome of situational predictability (Goffman, 1971; Berger, 1998; 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 18 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 (P12:1/23). 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.' (P5/1:18)

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 David Sudnow (1967) and Daniel Chambliss (1996) 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 eminent 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 (Buckman, 1992; Back et al. 2005). 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 used while disclosing the diagnosis that seemed to hold significance well beyond simply communicating information about the medical disorder. These “prognostic phrases” were nontechnical, 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” (P4/1:8) 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 (C5/1:7). Another recalled that his cancer was “very treatable” (P13/1:1), while another patient recalled hearing that he was in a “high risk” category (C18/1:20). 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 28 blood cancer patients and 30 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 interactions with medical staff. In this way, the news disclosure interview 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.

Acknowledgments

The author would like to thank Cameron Macdonald for generous access to the BMT Families Study project data. The author also thanks Doug Maynard and three anonymous Social Science & Medicine reviewers for their helpful comments. This research was supported by funding from the National Institutes of Health (NIH 1KL2RR025012-01), the University of Wisconsin Center for Demography of Health and Aging (P30 AG017266), and the University of Wisconsin Alumni Research Foundation.

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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			

Case number	Participant	Cancer*	Age	Sex	Disclosure Context	Who w/patient	Who disclosed
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			

Case number	Participant	Cancer*	Age	Sex	Disclosure Context	Who w/patient	Who disclosed
28	**Patient**	**AML**	**35**	**F**	**Recurrence**	**Alone**	**Oncologist**
	Husband		**35**	**M**			

[*] **Key:** 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).