The Social Order of Oncology Clinics:
Co-Constructing End-Of-Life Care and Treatment

By

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ABSTRACT

This study examines the processes by which terminal lung cancer patients, their family members, and oncologists attempt to treat cancer and plan for death. I focus on the network of forces that influence end-of-life care, illness trajectories, and the dying experience. To that end, I document patients' illness experiences, examine how treatment decisions are made, observe how participants deal with problems associated with treating terminal cancer, analyze how participants talk about death (or ignore the subject), and detail how participants come to some sort of consensus about future goals considering their dire medical circumstances. Using a multi-method qualitative research design, I explore the interactional and organizational (at the hospital level) aspects of providing medical care at the end of someone's life.

In the first empirical chapter, *Uncertainty and Certain Death: Interactions Surrounding Clinical Trials in Terminal Cancer Care*, I analyze the phenomenon of uncertainty as it surrounds the consideration of clinical trials for terminal lung cancer patients. This chapter shows how terminally-ill patients experience tension due to the uncertainty they confront when faced with the choice of transitioning to palliative care or volunteering for experimental medications to postpone death. I detail how the consideration of clinical trials manifests the phenomenon of uncertainty through discussions about the trials' efficacy, descriptions of the physiological consequences of clinical trial medications, and exchanges surrounding prognoses. My analysis focuses on a central paradox—patients (and their family members) may have high prognostic certainty, i.e., they know that the disease is fatal, yet they experience elevated levels of uncertainty in relation to making the crucial choice about participation in clinical trials.

In the second empirical chapter, *Do you want to talk about it?: Asking questions, supporting patient agency, and discussing death*, I examine how oncologists initiate discussions

of prognostic-talk. Drawing on the field of conversation analysis, I analyze the use of a *"what this means inquiry"* (WTMI) to suggest prognosis as the next topic of discussion. My analysis illustrates the collaboratively organized beginnings of prognostic-talk. I show how participants build an interactional environment that supports both the physician's agenda (to discuss prognosis) and the patient's preferences. WTMIs work to set the topical agenda (prognosis), but also forecast the valence of the news, and work towards an acceptance of the nominated next action. While WTMIs are topic-proffering actions that present in a manner that transmit a preferred positive response, patients and caregivers still have opportunities to shape the proceeding talk.

In the final empirical chapter, *Invoking Incurability to Socially Calibrate and Process Death*, I analyze how prognostic-talk is "done" in clinical interactions. Drawing on two years of ethnographic research, I examine how oncologists balance patients' concerns, goals, and treatment preferences with open discussions about limited treatment options and death. I argue that oncologists "invoke incurability" to talk about death and dying and help patients process impending death. Looking at cases where oncologists invoke incurability, I demonstrate how this conversational strategy updates diagnosis and confirms the terminal prognosis, tempers unrealistic expectations about the overall efficacy of treatments, and improves prognostic awareness and knowledge. I show how doctors invoke incurability as a way of calibrating what "terminal" or "incurable" means for each patient at that particular time in their illness trajectory.

CHAPTER 1: INTRODUCTION

The Issue

It is early in the morning and Dr. Blackwell[1] is looking at his computer screen in the large U-shaped workroom at the Lorne Cancer Center. The workroom was built in the middle of the cancer clinic. It houses all of the oncologists, medical residents, nurses, and medical assistants. There are no assigned workstations, walls, or dividers in the workroom. Workstations are comprised of long tables that are built directly into the walls of the room. Every three feet there is a desktop computer and an ergonomic chair. Storage shelves and bins are directly above the tables, approximately a foot above the computers. There are two heavy doors on each side of the U-shaped room that keeps it relatively soundproof, a design that insulates the workroom from surrounding clinical rooms—where the doctors see patients. The lack of privacy and division of workspaces contributes to a collaborative and collegial atmosphere, as clinicians routinely swivel in their chair and ask someone else a question, ask for help interpreting a diagnostic scan, or remind the person there is cake today because it is someone’s birthday. This also means that the workroom can also become extremely crowded and noisy, depending on the day and time and which clinics are in session. The Lorne Cancer Center treats 25 different types of cancer. Depending on the day and the time, there might be six oncologists treating six different types of cancer sharing the space.

On this September morning, the workroom is rather empty, housing three oncologists, all of whom treat lung cancer. Dr. Blackwell is getting ready to see Jennifer, who has stage IV disease. Jennifer is short with wiry brown hair and was a slight woman prior to her illness. Now, after many rounds of chemotherapy and radiation, she has lost a great deal of weight and looks

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[1] All of the names that reference people, places, or facilities are pseudonyms.

incredibly small and very sick. She was in the clinic a week ago but called and asked to see Dr. Blackwell today. As he reviews her chart and his clinical notes from the previous visit, he turns to me and states that she is probably back to tell him she wants to re-start chemotherapy. In Jennifer's prior visit she and Dr. Blackwell discussed her latest scans, which showed continued tumor growth—her treatment had become ineffective and her cancer grew. Together, Jennifer and Dr. Blackwell decided that it was probably best to stop all "standard treatment[2]" and contact hospice—not only had none of the chemotherapies slowed the cancer, but also she was ineligible for any clinical trials and was suffering from terrible side-effects. Her cancer had progressed to the point that she might not live to see the new year. Dr. Blackwell expected that he would probably never see Jennifer again. He was wrong.

When we step into the clinic room, we see that Jennifer is accompanied by her daughter Mary. As the conversation begins, Jennifer tells Dr. Blackwell that she wants to re-start chemotherapy. With a confused look on his face, Dr. Blackwell moves closer to Jennifer and asks her if she can help him understand why she wants to continue therapy that has been ineffective and extremely toxic. Jennifer's voice shakes as she holds back tears and looks at Mary and slightly nods her head towards her daughter, "for her and for my other kids." She tells her doctor that she is also a foster mother to a six-month-old baby and a seven-year-old, "I need to fight for them, they need a mother." She tells Dr. Blackwell that she was "selfish" and that when she went home after last week's clinic visit, she realized that her life's meaning was directly tied to her family. She goes on to say that she made arrangements so that her foster children have a good home to go to once she is gone. However, she still wants to keep "fighting" for her kids, and if there any chance that chemotherapy gave her extra time with them, then it

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[2] This is a general term for all treatments that are used to try to stop, slow down, or reduce the size of tumors. Oncologists also use "standard care" or "curative" treatments, although "curative" is somewhat of a misnomer.

would be worth the pain and discomfort. Dr. Blackwell tells her that he highly doubts that chemotherapy will give her more time, but that it is very likely that the treatment will severely impact the last weeks and days of her life in terms of quality. Nevertheless, Jennifer conveys her wish to re-start treatment, despite the toxicity of the chemotherapy, and the impact it might have on her body.

Jennifer's statements indicate that her commitment to her family outweighs the physical discomfort and increased financial cost that comes with re-starting anti-cancer treatment. She also seems to ignore, or at least act against, her doctor's medical advice and what the diagnostic scans are showing—the tumors are growing and the treatments that have been used are not slowing that growth. Jennifer's decision-making process is complex and amounts to much more than simply weighing financial and physical costs. Her final decision also changed over time; interactions with family and reflections about her life seemed to sway her willingness to continue treatment.

Jennifer's case highlights some of the difficulties associated with terminal cancer care. It gives us a glimpse into the dynamic nature of medical decision-making and clinical interactions. This visit also generates questions about the way clinicians, patients, and family members discuss death and dying.

Research Questions

My fieldwork is motivated by two central questions:

1) Considering a patient's incurable diagnosis, how do oncologists, terminally-ill lung cancer patients, and their family members make treatment decisions?

2) How do participants discuss (or ignore) end-of-life issues and/or the prospects of impending death?

Addressing these questions includes documenting patients' illness experiences and the struggles family members face when providing care for their loved one. Additionally, answering these questions involves making sense of how these participants collectively weigh (or ignore) the patients' perspectives, treatment preferences, needs, and goals against the dire medical circumstances—i.e., limited efficacy of treatment available for terminally-ill patients, the aggressiveness of lung cancer, and biophysical limits of the human body. This project examines the structure of clinical interactions and the social mechanisms by which terminal cancer care is carried out.

Previous sociological research details how difficult it is to talk about death and dying (Glaser and Strauss 1965; Lutfey and Maynard 1998; Schaepe 2013), how end-of-life issues are avoided (Schaepe and D. W. Maynard 2014), the reluctance of doctors to prognosticate with terminally-ill patients (Christakis 1999), and the way doctors withhold information and patients ignore clear signs of impending death, which leads to overly optimistic expectations (The et al. 2000). I build on this research by identifying the structure of clinical interactions and detailing both the interactional barriers and potential mechanisms through which open discussions of death are possible. My initial analysis of ethnographic data from the clinic suggests that the integration of information made available by the use of medical technology, such as diagnostic scans and laboratory tests, makes it easier to track disease progression. This offers opportunities for participants to discuss, with some precision, the physical risks of continuing treatment, the efficacy of treatment options, and how long patients might live. However, there is not much research that examines these matters. Ethnographic research provides one way of studying these subjects close up. I address empirical and theoretical issues connected to the mechanisms by which open discussions of death and dying are or are not carried out.

Cancer

An estimated 1.68 million new cancer cases are identified in the United States each year (Siegel, Miller, and Jemal 2016) and approximately 224,390 of those cases are diagnosed as lung cancer (American Cancer Society 2016). Cancer is the second leading cause of death in the United States, while lung cancer comprises 27% of all cancer deaths (American Cancer Society 2016; Siegel et al. 2016). Non-small cell lung cancer (from now on referred to as lung cancer) makes up the majority (approximately 85%) of all lung cancer cases. While new therapies are starting to make a modest difference in 5-year survival rates[3], especially in earlier stages (i.e., stages 0, I, and II) the prognosis of patients with advanced disease (stages III and IV) is still dire. For instance, the median survival time for advanced lung cancer is approximately 8–10 months (Abbasi and Badheeb 2011; Ali et al. 2013). Patients who are told they have incurable lung cancer are quickly forced to come to terms with a limited battery of treatments and tempered expectations.

Further complicating matters, research shows that even after patients are told that they have incurable cancer, they still believe their treatment is curative in intent, thus misunderstanding their own diagnosis (Pronzato et al. 1994; Rocque et al. 2015; Weeks et al. 1998, 2012). In the case of incurable lung cancer, chemotherapy and radiation can help alleviate

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[3] Survival rates tell us what portion of people with a certain kind of cancer, and stage of that type of disease, are still alive a certain amount of time after the initial diagnosis. These statistical projections vary depending on the kind of cancer and are often given as 5-year survival rates. The 5-year survival rate is the percentage of people who are projected to survive at least 5 years after being diagnosed with cancer. For example, a 5-year survival rate for someone with stage IVB non-small cell lung cancer is about 1%, which means that an estimated 1 out of 100 people are still alive 5 years after being diagnosed with that illness and stage.

or control pain and may extend life by weeks or months, but those treatments will not cure the disease. Misunderstanding the intent or purpose of treatments can lead to poor illness understanding, which is thought to negatively impact decision-making and can lead to unrealistic expectations about medical care and survival outcomes(Singh et al. 2017; Weeks et al. 2012). For example, Weeks and her colleagues show that 69% of patients with metastatic (late-stage) lung cancer and 81% of patients with metastatic colorectal cancer incorrectly believe their chemotherapy is curative in intent (2012). This research points to the importance of patient-doctor interactions and the potential of these interactions to either muddle or potentially improve prognostic understanding and informed decision-making. This is why patient-doctor interactions and relationships are a major focus of patient-centered care, which is a model of care that has come into prominence over the last three decades (Committee on Quality of Health Care in America 2001; Mead and Bower 2000). Patient-centered care stresses respect for and responsiveness to, "individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (Institute of Medicine 2001, p. 6). This is also why research that sociologically inspects interactions up close in the oncology clinic (via ethnography and conversation analysis) is extremely important.

Lung cancer is the second most likely diagnosis of new cancer cases in the US, but it leads all types of cancer in deaths for both men and women (Siegel, Miller, and Jemal 2018). By 2020, the annual cost of cancer care is projected to reach $175 billion, which will be an increase of 40% from 2010 (American Society of Clinical Oncology 2014). This is not surprising when we consider that the prices for the drugs to treat cancer have more than doubled. For example, in 2012, of the 12 cancer drugs that the Food and Drug Administration (FDA) approved, 11 of them cost more than $100,000 per year (Kantarjian et al. 2013). Prices for anticancer drugs have risen from an average of $5,000 per month to more than $10,000 per month (Fojo, Mailankody, and Lo 2014; Kantarjian et al. 2013; Smith and Hillner 2011), and this trend shows no signs of slowing. The costs of cancer patients who die of their disease essentially follow a “U-shaped” curve, with the highest costs incurred following initial diagnosis and the few months before death (Mariotto et al. 2011).

This is not just a public expenditure issue, however, because while having medical insurance or being covered by Medicare and Medicaid help cover much of the cost of treating cancer, patients still face a great deal of cost. Cancer patients on Medicare face an average out-of-pocket expense of $4,727 a year (Davidoff et al. 2013). A recent study from a group of researchers at Duke found that 16% of their 300 participants reported high or overwhelming financial distress. On average, their participants were paying 11% of their cancer treatment out-of-pocket (Chino et al. 2017).

The cost of cancer is high at the end of someone’s life, with monthly costs increasing as patients near death (Bremner et al. 2015). Unfortunately, treatment at the end of someone’s life does not translate to a higher quality-of-life (Zhang et al. 2009). Cancer drugs are getting more expensive but are not radically improving the survival time of patients. Of the 12 drugs the FDA approved in 2012, only three were shown to improve survival, and of those three, only one drug (out of the 12) improved a patient’s survival more than two months (Kantarjian et al. 2013). Other studies in the US and Europe support this finding. Fojo and colleagues (2014) found that of the 71 anticancer drugs approved by the FDA to treat treatment solid tumors the median improvement in the duration of overall survival was 2.1 months. While Davis et al. (2017) found that the European Medicines Agency (EMA) approved the use of 48 cancer drugs, the median prolongation of survival was 2.7 months. Two additional months of life may be considered a positive impact for some patients, but treatment for patients nearing death comes with terrible physical side effects, reduced quality-of-life (QOL), and increased costs.

Transitioning to palliative care and enrollment in hospice services, earlier in a patient's illness trajectory, not only reduces cost (Dalal and Bruera 2017; Morrison et al. 2008; Penrod et al. 2010). It also shows signs of increased QOL measures[4]. Moreover, a growing body of literature shows that patients that are told they are close to death prefer to a treatment protocol that focusing on alleviating pain and discomfort over curative-based treatment (Barnato et al. 2007; Dalal and Bruera 2017; Gott et al. 2004; Pritchard et al. 1998; Rose et al. 2004; Townsend et al. 1990). These findings and trends suggest that cancer care is getting more expensive for patients and for the US healthcare system even though the quality of patients' lives decreases the longer anti-cancer (curative) treatments are used. Yet, discontinuing anti-cancer treatment and fully switching to a palliative care regimen is difficult to negotiate. These conversations are replete with interactional difficulties that make medical decisions more complicated than simply weighing the financial cost and physical impact of the treatment against the likelihood of the treatment's efficacy.

Entering the Field, Research Design, Methods

My entrance into the field happened in stages, over a two-year timespan. Prior to entering the field, I was hired to work as a project assistant on a research project that focused on end-of-life conversations. The two co-PIs on the project were Dr. Blackwell and my advisor, Prof. Douglas Maynard. The project conducted a secondary analysis of audio-recorded conversations

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[4] There are numerous QOL measures, all of which range in how they measure QOL and in the amount validity and reliability issues found in each measurement tool (see Cohen and Mount 1992). More recently, however, researchers have attempted to address the multidimensional and highly subjective concept (Jocham et al. 2006). Generally, QOL measures assess the physical, functional, financial, emotional, social, and spiritual aspects of patients' lives.

among terminal lung cancer patients, their family members, and their oncologists to examine how participants communicated about death and end-of-life issues. Dr. Blackwell would later become one of my participants and gatekeeper. This project produced important findings of health communication, including the fact that there were very few explicit conversations about death, dying, or end-of-life issues in the data (see Maynard, Cortez, and Campbell 2016). After this project was completed (also see Cortez, Maynard, and Campbell forthcoming; Singh et al. 2017), I expressed an interest in conducting further research to explicitly look at how end-of-life conversations were organized and the ways conversations about death and dying were carried out. Dr. Blackwell was very supportive of this idea and helped facilitate entrance into my field site.

With the permission of Dr. Blackwell, I observed his clinical practice for a semester in 2015. I showed up to observe what he did during his clinic hours. He introduced me to his colleagues and allowed me to accompany him during clinic visits. At the end of the semester, I shared what I had noticed with Dr. Blackwell. During that semester, Dr. Blackwell introduced me to two other oncologists who focused on lung cancer. After the semester ended and my Institutional Review Board application was approved, I approached the oncologists I met during my independent study and asked if they would be interested in participating in my study. Fortunately, each one agreed.

My research design included two central objects of study: 1) the interactional dynamics of clinic visits – particularly how participants talk about death and make treatment decisions, and 2) the illness experiences of patients and caregivers. The original design involved three methods to carry out these endeavors: ethnographic observations, conversation analysis, and in-depth semi-structured interviews. As the study developed, I would rely primarily on ethnographic observations and conversation analysis, dropping the semi-structured interviews from my design because participants were not receptive to being interviewed and routinely declined to consent to that part of the study (see below where I discuss this matter further).

At the time I conducted my study, the institutional review board prohibited video recordings in the hospital clinics where I did my research. I was able to collect audio recordings, and the purpose of my ethnographic observations of clinic visits was to further examine the interactional dynamics of oncology visits. Digital audio recordings captured everything that is said, thereby facilitating analysis of the social organization of what Goffman (1983) calls the interaction order in everyday situations. Conversation analysis captures how participants exhibit their understandings of what is being said. My detailed ethnographic fieldnotes on the conversation enabled capturing some of the non-vocal aspects of the talk, and the use of artifacts (e.g., charts, handouts, images on a computer screen). Finally, I planned on using in-depth semi-structured interviews to talk to oncologists, patients, and caregivers. However, after having difficulties consenting participants for the interview portion of the study, I abandoned this method and decided to focus on more informal conversations while patients were in the clinic.

Ethnographic Observations

I conducted observations at an oncology clinic over a 24-month period. The clinic is attached to a large university hospital. Ethnographic fieldwork was necessary since one of my primary objects of study is the interactional nature of oncological visits. As noted, there are many non-vocal features to conversations and interactions that cannot be adequately captured by audio recordings alone. Furthermore, ethnography takes as its unit of analysis the “collective act,” wherein social action is carried out by two or more people (Becker 2004; Jerolmack and Khan 2014; Katz 2002). As such, ethnography is an effective tool for studying socially-organized objects such as medical decision-making and oncologist-patient-caregiver interactions. Face-to-face interactions are central to understanding human activity (Goffman 1983), so direct observation of these face-to-face encounters in clinic visiting rooms was essential to understanding how death is discussed.

After obtaining approval from both the Health Science Institutional Review Board and the research site's internal research review committee, I started recruiting participants. I spent my time at the Lorne Cancer Clinic, observing three (of the four) oncologists that specialize in lung cancer. Inclusion criteria required that each participant was at least 18 years of age. Patients must have been *previously* diagnosed with incurable non-small cell lung cancer, at stages IIIA, IIIB, IVA, or IVB and receiving treatment at the Lorne Cancer Center.

Sampling

Research participants were recruited using a purposeful sampling design that also relied on theoretical sampling (Glaser and Strauss 1967). Purposeful sampling keys into the need for "information-rich" cases (Patton 2014). This kind of sampling involves identifying and selecting research participants that are particularly suited to provide information or experiential knowledge, given the research questions and study aims. In other words, purposeful sampling helps researchers recruit people that are "especially knowledgeable about or experienced with the phenomenon of interest" (Palinkas et al. 2015, p. 2). While there are many types of purposeful sampling strategies, see Table 1 in Palinkas et al. 2015 for an extensive list, I relied on a strict criteria-based purposeful sampling strategy (i.e., criterion-i). I predetermined the criteria and attempted to recruit as many participants that met that criteria. For example, patients in my study had to be at least 18 years old, have been previously diagnosed with incurable non-small cell lung cancer (stages III-A, III-B, IV-A, or IV-B), and had to be patients at the cancer clinic that I was observing. Purposeful sampling can also help refine the selection criteria prior to data collection. By using the phenomenon of interest or research question(s) as guides, researchers can be thoughtful about what qualities, characteristics, experiences, and perspectives they want to access. Purposive sampling can be combined with theoretical sampling to help collect rich data and facilitate theory building.

Theoretical sampling may be best understood as using a sampling strategy that maximizes the potential for researchers to produce theory. While this sampling strategy's name may suggest deductive theory-testing, theoretical sampling is generally used in an inductive manner to refine concepts and emerging themes. According to Corbin and Strauss (2014), theoretical sampling is particularly suited to "maximize opportunities to develop concepts" by specifically selecting cases or participants that can help unearth variation, tease out the relationship between concepts, and detail the properties of the analytic strands that comprise theory (p. 143). This type of sampling was chosen for two reasons. First, as Williamson (2006) notes, it provided a form of selecting subjects and cases that "represent the important characteristics that researchers consider of interest to the study" (p.89). Second, as my data collection advanced, theoretical sampling helped me "refine ideas" and "identify conceptual boundaries and pinpoint the fit and relevance of the emerging categories" (Charmaz 2003, p. 265). This strategy is uniquely suited for inductive research because it responds to the data that are collected and the analyses that researchers produce. Once concepts emerged, theoretical sampling helped select participants (or cases) that helped explore the analytic dimensions of concepts, construct the boundaries of codes, explored disconfirming cases, or capture dthe variation of themes. All of this is done to construct robust inductively produced theory.

Combing these two sampling approaches helped me ensure an iterative approach to data collection that follows the logic and strengths of inductive qualitative research. I initially used purposive sampling to make sure I was recruiting the participants that could help me understand terminal cancer care and clinical interactions in a cancer clinic. I became less concerned with recruiting every single participant that fulfilled my study's criteria as my sample size grew and I started analyzing data. Instead, I started sampling based on what my analyses gleaned. As data are analyzed and theoretical strands emerge, researchers may indeed feel that "re-sampling" or changing sampling strategies will help fully explore the theory that is generated from analysis (Miles and Huberman 1994). Inductively grounded studies that start out with a sort of purposeful sampling strategy and later transition to theoretical sampling are common (Sandelowski, Holditch-Davis, and Harris 1992). This is especially true in health research and inductive qualitative studies that are interested in understanding a phenomenon that is not widely understood or common.

Observations and Recordings

I audio recorded clinic visits with a digital voice recorder and made initial jottings and detailed field notes in a notebook to capture other features of patient-doctor interactions. Relying on the digital recorder to capture everything that is said during clinic visits also allows for the use of ethnographic observations to better attend to what Emerson and colleagues (1995) described as the "active processes of interpretation and sense-making" (p. 8-10). Audio recordings were transcribed verbatim. Jottings and field notes include descriptions of each setting, the oncologists' preparations prior to meeting each patient, and the behavior of each participant during clinic visits—including non-vocal communication and the use of artifacts such as hand-drawn graphs and computers.

My participation during clinic visits purposely varied depending on the context. During the actual clinic visit, I took a passive approach. Staying as unobtrusive as possible in this setting minimized the potential for me to interfere with the natural flow of the conversation or possibly influence the topics covered during the clinic visit. Accomplishing this task was easier than expected since the cancer center is housed in a large teaching hospital. In this setting, it is common to have medical students, clinical trial specialists, and medical residents present in the room, simply observing, while patients are meeting with their oncologist. Palliative care and psychology specialists would also show up to clinic visits and acted as floating staff. They would come into the workroom at the beginning of clinic hours and let oncologists know that they were there in case any patient wanted to talk to them. Sometimes these specialists would see patients separately or join with the oncologist in the clinic room. Patients and caregivers did not seem to behave differently when observers were in the room.

Prior to and after clinic visits, however, I took a more active approach to participation. This included informal conversations with participants, caregivers, and oncologists. I asked oncologists about the interaction that just took place or to reflect on different topics—e.g., conversational approach, medical decision-making, the difficulty of the conversation, treatment options discussed or avoided. Engaging in "shop talk" with oncologists and observing "shop work" (Maynard and Clayman 1991), provided a deeper understanding of how clinicians accomplish cancer care. I also had informal conversations with patients and caregivers before and after clinic visits, depending on their treatment schedules that day and their willingness to talk.

Conversation Analysis

I drew on conversation analysis (CA) to examine the audio recorded clinic visits collected while conducting ethnographic observations. CA is an examination of what Harvey Sacks called “naturally occurring social activities” (1989, p. 211). CA incorporates the analysis of both vocal and non-vocal communication. It is an inductive and empirically-driven approach that captures minute interactional features, such as prosody, micro-inflections, and silences, all while identifying reoccurring interactional patterns. CA is primarily interested in the interactional organization of social activities, human communication being its focus. Complementary to ethnographic inquiry, CA allows me to examine detailed transcriptions along with recordings to analyze the negotiated social tasks of and actions in medical care.

This approach assumes that human interaction is orderly and highly organized, which can be tracked and uncovered by focusing on the micro-interactional features of interaction. This “orderliness” is co-constructed. It is a product of the methods and practices people employ in interactions (Stivers and Sidnell 2013). As such, conversation analysts are particularly interested in identifying the actions that participants undertake, the procedures used to achieve those actions, and the ways they work with other participants to make themselves understood. This approach starts with a detailed transcript of conversations. To give a sense of the detail involved, to turn a conventional transcript of an audio file into a CA transcript requires approximately 10 times the length of the audio file (Chatwin 2004). As an example, a 30-minute audio recording could take up to 30 hours to transcribe using symbols that track the pitch of a person’s voice, turn-taking, silences (measured in tenths of a second), overlapping utterances, inflections of words, the stretching of sounds, intonations, and the changing volume of a person’s voice. This “fine-grained” analysis is meant to unearth the organization and structure social interaction that makes up the bedrock of social action (Sidnell 2013). The analysis results in a detailed description of the practices by which participants achieve the organization of human interactions.

CA examines, in rich detail, the tasks of medical care and make sense of participants' emic perspectives. More specifically, CA helps me systematically unearth and describe the organization and order of clinic visits (Heritage and Maynard 2006a; Maynard and Heritage 2005). In other words, CA helps me identify the "underlying machinery" (Seedhouse 2004, p. 14) that allows oncologists, patients, and caregivers to collectively make sense of each other's actions during each clinic visit and come to some agreement about how to proceed with medical care.

Interviews

Finally, I planned on conducting in-depth semi-structured interviews with oncologists, patients, and family caregivers. Interview participants were to be recruited from the participants that consented to participate in the ethnographic component of this project. Additionally, interview participants were to be recruited using the same sampling design employed in the ethnographic component of this project—i.e., a purposeful sampling design that also relied on theoretical sampling in order to select subjects that have important characteristics given my study's objectives.

The use of a semi-structured interview protocol creates more of a "guided conversation" (Lofland and Lofland 1995) and less of the rigid call-and-response type of interview. This method is important because it helps reconstruct and recall conversations and events that I could not observe. Since I am interested in patients' illness experiences, interviews are essential because I cannot observe patients as they live their daily lives. Interviews help me access the "emotional landscape" (Pugh 2013, p. 50) that patients occupy. As Charmaz and Belgrave (2012) note, in-depth interviewing is an incredibly useful method for generating data on difficult subjects such as illness, grief, and disrupted lives. A second purpose for interviewing participants was to gather data on what each participant remembers and how they perceive clinic visits. I wanted to collect data on how each participant experienced the interaction, how they made sense of the conversation post-visit, and how they felt about the latest diagnostic report and/or treatment decision. In a sense, the interviews attempted to reconstruct each participant's emic perspective.

Recruiting interview participants was more difficult than I expected. I made it possible for patients to consent to the observation and audio recording but decline the interview when I drafted my initial consent form. In the first year of data collection I did not recruit a single participant for a formal interview. After six months of failing to recruit participants for interviews, I started gently asking some of the participants I had built a relationship with why they thought potential participants were opting out. Patients did not want to be further burdened since they already had to deal with pharmacies, general practitioner visits, oncology visits, and insurance conversations or forms. Having to coordinate another appointment or time commitment was not appealing. According to one participant, an interview would be "just another thing to do." On the other hand, my observations and recordings of clinic visits did not alter their routine or extend the time they had to spend at the hospital.

I decided to change my plan. Rather than trying to recruit patients for 90-minute semi-structured interviews, I simply spent more informal time having conversations with patients and caregivers prior to visits. Scrapping my interview protocol meant that I had to adjust my expectations. I might not be able to ask participants about how they perceived past clinic visits or discuss the ways they discuss treatment options at home but talking to patients and caregivers prior to visits helped me better understand who my participants were. These conversations were as often about what my participants enjoyed doing—e.g., the plans they had for the weekend, where they grew up, travel plans, events that were coming—as they were about their illness and treatment.

Data Analysis

I analyzed audio transcripts and field observations of clinic visits using MAXQDA-18, which is software specifically designed for qualitative data analysis. I used an inductive analytic approach. Initial coding of transcripts and field notes of interviews and ethnographic observations relied on the type of line-by-line analysis outlined by Charmaz (2006). Preliminary analysis lead to "focused coding" as initial codes collapsed into new ones, and categories and themes emerged. I diagramed the relationships between individual codes, categories, and larger themes using the MAXQDA-18 "code relations browser" and "Maxmaps" functions. These diagrams, along with other MAXQDA functions (e.g., "document comparison chart" and "Smart Publisher") kept data organized and assistant in creating a constantly evolving codebook.

Using a *constant comparative approach* outlined by Glaser and Strauss (1967) allowed me to "establish analytic distinction" (Charmaz 2006:54) between (and within) segments of data, categories, and themes. Comparing different segments of data within the same transcript, data from the same person at different times and across each participant in the data set helps establish the conceptual cornerstones of the study. Constantly comparing not only infuses rigor into the analytic process—by detailing differences, similarities, connections, and disjunctions across and between segments of data—it also provided a way to dismantle and detail the features, and then reassemble the various components of each emerging phenomenon. Memos helped detail the features of the connections that developed between the constellations of codes and categories, and the relationships that were forged between (and among) categories and themes. As such, memo writing was important throughout the research process, especially considering my use of this kind of comparative approach. Furthermore, extended analytic memos helped keep an ongoing log about the broader interpretations and sense-making activities the ethnographic observations and in-depth interviews produce (Emerson et al. 1995).

I started analysis for my second empirical chapter, which draws on CA, in the same way I approach the rest of my data. The first step included broadly coding transcripts of clinic visits and keeping a running log of recurring interactional patterns of behavior. I then further transcribed the transcripts using conversation analytic conventions (see Sacks, Schegloff, and Jefferson 1974). The point here is to produce a highly detailed transcript, which is used to further investigate and continue to log observations and patterns. By creating different collections for each interactional pattern, I could then analyze each case within a particular collection and compare that case with all the other cases in that collection. I used a case-by-case analytic strategy to build generalization across cases, while making sure to analyze the distinctness of each case (Sidnell 2013). The idea was to create a detailed examination of each case and generate a clear understanding of the way each particular case fits with the rest in the collection.

I looked closely at the sequencing of the conversations, with an eye on the way these clinic visits are structured. My goal was to make sense of: 1) how a speaker formulated their current turn to talk; 2) how the listeners made sense of what they just heard (both verbally and non-verbally)[5]; and, 3) how all participants co-created a shared understanding of what was being talked about. This kind of analysis attempts to uncover the endogenously produced organization of human interaction (Maynard and Clayman 2003). The idea is to understand the kind of

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[5] This means focusing on how participants listen and how they respond once the speaker stops talking.

conversational devices used to “do” cancer care. It also maps the ways patients and caregivers shape cancer care. For example, CA research helps us understand the ways doctors discuss bad news (Heritage and Maynard 2006b; Holt 1993; Maynard 2003; Schaepe and Maynard 2014), how conversational devices shape and curb patients’ expectations (Maynard, Cortez, and Campbell 2016), how patients and caregivers exhibit agency during clinic visits (Koenig 2011; Stivers 2005), and how patients and caregivers influence treatment regimens (Bergen and Stivers 2013; Costello and Roberts 2001; Stivers 2002) and diagnostic testing (Gill 2005; Stivers 2002).

This dissertation is written in a three-article format. My idea is to construct a general umbrella that covers each papers’ related concerns. The conclusion will briefly summarize my dissertation’s major findings, discussion, and limitations. I discuss the connections between the papers and show how each paper is part of a coherent body of work. In the following section, I present the empirical chapters that make up each paper.

Overview of the Dissertation

In the chapters that follow, I analyze how cancer care is collaboratively shaped. By examining clinical interactions are organized, and the social resources participants use to make themselves understood, I detail the tasks associated with terminal cancer care.

In Chapter 2, I use ethnographic observations and audio recordings of clinic visits to analyze the phenomenon of uncertainty as it surrounds the consideration of clinical trials for terminal lung cancer patients. My analysis shows how terminally-ill patients experience tension due to the uncertainty they confront when faced with the choice of transitioning to palliative care or volunteering for experimental medications to postpone death. I detail how the consideration of clinical trials manifest the phenomenon of uncertainty through discussions about the trials’ efficacy, descriptions of the physiological consequences of clinical trial medications, and exchanges surrounding prognoses. My analysis focuses on a central paradox—patients (and their family members) may have high prognostic certainty, i.e., they know that the disease is fatal, yet they experience elevated levels of uncertainty in relation to making the crucial choice about participation in clinical trials.

This chapter provides empirical evidence of the ways uncertainty and risk are introduced into patients' lives. Rather than presenting an abstracted or detached theoretical concept, I detail the specific social actions that cause uncertainty. For example, I show how physicians frequently employ probabilistic language and rely on highly technical jargon to discuss trial drugs and their effects. Far from clarifying how any particular trial works or how a patient's body might react with the trial medication, the use of quantitative and technical language to describe experimental drugs muddle explanations of potential outcomes and biophysical side-effects. In these cases, patients and caregivers must navigate a combination of interactional hedging (e.g., "if," "might," or "maybe"), a dizzying use of probabilities, and often abstruse medical language. The result is that patients experience a disruption in their lives and illness experiences (Bury 1982; Pietilä et al. 2018), with a once clear prognosis now made more ambiguous by interactionally generated uncertainty. In effect, discussions of clinical trials reintroduce "unorganized" illness (Balint 1957; Brown 1995; Mishler 1981) into a secure diagnosis and certain prognosis, i.e., death.

In chapter 3, I draw on the field of conversation analysis to analyze how oncologists initiate discussions of prognostic-talk. Specifically, I analyze the use of a *"what this means inquiry"* (WTMI) to suggest prognosis as the next topic of discussion. This mechanism works towards proferring the next topic. In other words, WTMIs work to set the topical agenda (prognosis), but also forecast the valence of the news, and work towards an acceptance of the nominated next action. While WTMIs are topic-proffering actions that present in a manner that transmit a preferred positive response, patients and caregivers still have opportunities to shape the proceeding talk. My analysis illustrates the collaboratively organized beginnings of prognostic-talk. I show how participants build an interactional environment that supports both the physician’s agenda (to discuss prognosis) and the patient’s preferences.

WTMIs provide oncologists a mechanism with which to carve out space within the typical phase structure common to oncology visits in order to discuss prognosis. This chapter builds on previous work by showing how prognostic-talk can occur in a manner that does not radically alter the sequential order of other components of the oncology visit. This practical insight can inform future clinical practice in a manner of ways. First, discussing bad news is difficult. As established in social scientific research that is heavily cited throughout the preceding chapters, clinicians and patients alike avoid discussing issues that point to bad news or the suggestion of impending death (see Christakis 1999; Glaser and Strauss 1965; Luftey and Maynard 1998).

Second, WTMIs initiate discussions of prognosis, which provide important information that can help patients and caregivers make treatment decisions. This point holds particular weight considering previous research that suggests prognostic clarity leads to higher satisfaction of medical care (Jackson, Chamberlin, and Kroenke 2001; Jackson and Kroenke 2001), lower reported stress and anxiety (Bakitas et al. 2009; Temel et al. 2010), and higher reported quality-of-life measures (Detering et al. 2010; Gade et al. 2008; Teno et al. 2004, 2013; Wright et al. 2008). Despite the importance of prognosis, patients and doctors dread discussions of prognosis that point to bad news. WTMIs provide physicians as well as patients and caregivers a distinct way of clearly marking the initiation of prognosis.

Finally, WTMIs align with the goals of patient-centered care. Seen as paradigm with a set of core values that prioritize clinical practice that respects “individual patient preferences, needs, and values” (Institute of Medicine 2001, p. 6; Levit et al. 2013), patient-centered care promotes collaborative clinical interactions. WTMIs particularly respond to suggestions by Stewart and colleagues (2000) to build a supportive patient-doctor relationship and realistically discuss resources, options, and the current state of a patient’s illness. WTMIs can be the foundation and an ongoing interactional touchstone for conversations related to treatment planning and goal-setting (Paterniti et al. 2010). When all participants have a clear sense of prognosis, they can move forward with treatment planning by allowing the prognostic landscape to shape the appropriateness of one particular treatment over another.

In chapter 4, I analyze how prognostic-talk is “done” in clinical interactions. Whereas chapter 3 primarily focuses on the interactional mechanism that introduces prognosis as the next potential topic, chapter 4 shows how oncologists “invoke incurability” to talk about death and dying and help patients process impending death. Oncologists invoke the incurable nature of a patient’s disease in an attempt to provide an updated diagnosis and confirm the terminal prognosis. Throughout this chapter, I show how oncologists “invoke incurability” to talk about death and dying and help patients process impending death. Looking at cases where oncologists invoke incurability, I demonstrate how this conversational strategy updates diagnosis and confirms the terminal prognosis, tempers unrealistic expectations about the overall efficacy of treatments, and improves prognostic awareness and knowledge. I show how doctors invoke incurability as a way of calibrating what “terminal” or “incurable” means for each patient at that particular time in their illness trajectory.

A great deal of the sociological literature on prognosis details the various interactional difficulties preventing clear communication about prognosis (Christakis 1999; Cortez, Maynard, and Campbell 2019; Luftey and Maynard 1998; Singh et al. 2017; Thulesius, Håkansson, and Petersson 2003; Timmermans and Stivers 2018). This chapter contributes to this literature by focusing on how participants accomplish prognosis. In a sense, prognosis is as much a part of the "language of medicine" (Brown 1995, p. 39) as other clinical tasks. Yet this task, like others (e.g., diagnosis), takes place and is negotiated in a social (albeit institutional/clinical) realm, despite the fact that it is understood and measured using technical skills in a highly medical realm. Oncologists attempt to provide an accurate prognosis based on medical evidence while patients and caregivers attempt to listen and understand the prognostic news that is based on medical science. And yet, oncologists and patients also attempt to collectively make sense of the prognostic landscape, with its technical and highly medicalized features (Clarke et al. 2010; Conrad 2007), through social interaction. We see oncologists invoke incurability to translate medical understandings of "incurable" and "terminal" for patients, while also attempting to negotiate a social understanding of the illness. Chapter 4, details how participants come to discuss the incurable nature of a patient's disease and then participants negotiate what terminal or incurable truly means for patients and caregivers.

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CHAPTER 2 – Experiencing Uncertainty and Certain Death: Paradoxical Interactions Surrounding Clinical Trials in Terminal Cancer Care[6]

Abstract

I consider the phenomenon of uncertainty as it surrounds the consideration of clinical trials for terminal non-small cell lung cancer patients. Using grounded theory to analyze 85 clinical interactions between doctors, patients, and family members. I argue that uncertainty is a major source of tension for terminally-ill patients, with individuals confronting a choice between transitioning to palliative care or volunteering for an experimental/trial medication that might postpone death. Regardless of the trial's efficacy, patients must also consider how such experimental treatments might affect their quality-of-life. I show how the consideration of clinical trials manifests the phenomenon of uncertainty through 1) discussions about their efficacy; 2) descriptions of the physiological consequences of clinical trial medications; and, 3) dialogues surrounding prognoses. A paradox in this kind of cancer care is that although patients (and their family members) may have high prognostic certainty (i.e., they know that the disease is fatal), they experience elevated levels of uncertainty in relation to making the crucial choice about the patient's participation in clinical trials.

Introduction

Emerging technoscience is altering how diseases are tracked and treated (e.g., through imaging technologies, see Joyce 2008, for an example). The increase in defining conditions via medical technologies is also linked with concerns about the management and control of health (Conrad 2007), as well as an escalating tendency to define health and illness in precise and technical terminology (e.g., Clarke and Shim 2011). Meanwhile, the expanding dominance of biomedicine (Clarke et al. 2003; Sulik 2009) contains narratives of choice, responsibility, uncertainty, and risk (see Clarke et al. 2003; Clarke and Shim 2011; Hofmann and Svenaeus 2018; Sulik 2009). As social scientific studies have demonstrated, developments in science and technology are consequential for professionals, patients, and caregivers, in that biomedicine is simultaneously associated with risk and uncertainty on the one hand (Clarke et al. 2010; Clarke

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[6] This chapter is based on a co-authored article with Michael Halpin. The chapter is presented here with my co-author's knowledge. My chapter contains a longer methods section and additional data in the results. The discussion and introduction sections have also been edited and rewritten at certain sections.

and Shim 2011; Hofmann and Svenaeus 2018; Sulik 2009), while connected to precision and control on the other (Clarke et al. 2003; Conrad 2007; Joyce 2008; Sulik 2009). Indeed, the tensions between precision and uncertainty are evident within discrete studies and frameworks (Armstrong 1995; Clarke et al. 2010; Rose 2007). My analysis focuses on the tension between precision and uncertainty, as it manifests in cases in which patients have a clear prognosis (impending death due to cancer-related illness), but yet experience a good deal of uncertainty when discussing clinical trials.

Cancer kills more people worldwide than any other disease and is the 2nd leading cause of death in the United States (Siegel, Miller, and Jemal 2018). An estimated 1.68 million cases of cancer are identified each year in the US, with lung cancer accounting for 25% – 30% of all cancer deaths in the country, which is more than the next three types of cancer combined (Lindeman *et al.* 2013; American Cancer Society 2016). Lung cancer is generally classified into two classes, non-small cell lung carcinomas (NSCLC) and small-cell lung carcinomas (SCLC). Non-small cell lung cancer, the focus of this paper, makes up the majority (approximately 85%) of total lung cancer cases.

Cancer treatment is intimately linked with research (Keating and Cambrosio 2012). In the last ten years, there has been a 61% increase in the number of oncological clinical trials initiated worldwide (U.S. National Library of Medicine 2019), with the United States operating as a major hub for experimental cancer medications (Hirsch et al. 2013; U.S. National Library of Medicine 2019). In the United States, sponsoring companies (e.g., pharmaceutical companies) often cover the cost of medications, laboratory and tests, and diagnostic scans associated with the clinical trials. Additionally, the Patient Protection and Affordable Care Act, often called “Obamacare” (statute 42 U.S.C.A § 300gg-8 under PPACA Section 2709), mandates that insurance companies must cover routine care costs for trial participants. While terminal lung cancer patients have increased access to medications, evidence suggests that end of life treatment is associated with worse quality-of-life (Dalal and Bruera 2017; Zhang et al. 2009), and that many clinical trials and experimental treatment options fail to extend life.

In this paper, I demonstrate that clinical trials result in heightened medical uncertainty for patients who have been told they have terminal cancer. Such uncertainty derives, in part, from the use of precise and quantitative language (*Efficacy*). It also has to do with how doctors handle the unknown impact of trial drugs (*Consequences*), and the potential for trial treatments to eliminate patients' cancers (Prognosis). Paradoxically, patients live with a high degree of prognostic certainty since they are all diagnosed with terminal cancer, yet their discussions of clinical trials produce uncertainty. This analysis demonstrates the influence that patient-doctor interactions have to dissolve, mitigate, or challenge the certainty of a terminal diagnosis. I also discuss how my findings might guide future analysis of medical uncertainty regarding doctor-patient interactions and the clinical care of terminally-ill cancer patients.

Literature Review

Macro sociological theories suggest that uncertainty and risk are central elements of both modern social structures and experiences (Beck 1992; Giddens 1990, 1991). That is, increasingly complex technological breakthroughs, fragmented knowledge systems, and consumeristic market-based economies create environmental risks and threats to social order. These features of modernity disrupt identities and destabilize self-perceptions. While numerous scholars question the conceptual and analytic utility of risk and uncertainty (Alexander and Smith 1996; Dingwall 1999; Green 2009; Mythen 2005; Scott 2000), and others take a macro or social structural view of risk and uncertainty (Giddens 1990, 1991), I consider how interactions surrounding clinical trials produce uncertainty in the context of terminal cancer.

Uncertainty is also a central element of social scientific theories and studies of health (Clarke et al., 2010; Davis 1960; Fox 1957; Rose 2007). Most relevant to my study, there is renewed interest in relation to the institutional management of medical risk and prognostic (un)certainty. While many doctors do struggle to discuss prognostic uncertainty (e.g., estimated life duration) with terminally-ill patients (Schuster et al. 2012), studies also suggest that physicians avoid prognostic observations, as they might be poorly evaluated for making errors (Christakis and Iwashyna 1998). As well, it is demonstrated that discussing prognostic certainty (Halpin 2018; Konrad 2005) and uncertainty (Nettleton 2006; Timmermans and Buchbinder 2010) is distressing for patients.

In the popular media (Markoff 2012; Morrissey 2019), emerging technologies and the associated development of personalized medicine are positioned as a means of alleviating medical uncertainty. While developing medical technologies provide opportunities to quantify, test, and measure, social scientific research suggests that such technologies might (Reed, Kochetkova, and Whitby 2016) or might not alleviate prognostic uncertainty (Fox 1980; Pilnick and Zayts 2014; Sulik 2009). Rather than resolving uncertainty by revealing an “objective” or “real” phenomena, sociologists of science suggest that new technologies often create or translate controversies and debates (e.g., Garfinkel, Lynch, and Livingston 1981; Joyce 2008). Indeed, Collins (1975) suggests that scientific debates and uncertainty can only be resolved by social, rather than technological, means. Engaging with this debate, I argue that emerging trial drugs disrupt the certainty of a terminal cancer diagnosis. My concern here is not the materiality of the trial drugs but the instead interactions and micro-processes surrounding such medical encounters (see also Stivers and Timmermans 2016).

As numerous scholars observe, medical risk and uncertainty are primarily expressed in quantitative terms (Fosket 2004; Greene 2007; Rose 2007). Indeed, such quantification is central to major conceptual work in medical sociology, such as biomedicalization theory (Clarke et al. 2010) and studies of surveillance medicine (Armstrong 1995). That is, health and illness prospects are increasingly communicated via percentages, odds ratios, and relative risk. However, research in numeracy—the ability to understand numbers and mathematical concepts—shows that patients do not respond well to such numerical representations (Fagerlin and Peters 2011; Peters et al. 2007). Patients not only report difficulties understanding highly quantitative health information, but also they have difficulty recalling quantitative information even when it is initially understood. My study also builds on previous work addressing how uncertainty and risk are discursively presented (e.g., Littlejohn and Kimport 2017) and how patient-doctor interactions influence the ways patients understand their prognoses(Maynard, Cortez, and Campbell 2016; Singh et al. 2017). Once again, employing an interactionist perspective, I consider the relationship between precision and uncertainty by examining both the medical language and probabilistic terminology surrounding patient-doctor interactions about clinical trials.

Methods

Data for this paper comes from 85 clinic visits that range from 12 to 69 minutes (M=22). After obtaining approval from both the Health Science Institutional Review Board and the research site’s internal research review committee, I observed interactions at the “Lorne Cancer

Center" (all names are pseudonyms) housed in an American university hospital. I also audio recorded clinic visits and collected ethnographic observations. Relying on the digital recorder to capture everything being said during clinic visits allowed the researcher to focus on non-verbal behavior, the use of artifacts (e.g., hand dawn charts, computer screens, printed lab results), and to better attend to what Emerson and colleagues (1995) described as the "active processes of interpretation and sense-making" (p. 8-10). Audio recordings were transcribed verbatim. Data collection occurred in exam rooms and the clinicians' workroom—a large room closed off to the public in the middle of the clinic that oncologists used to look at scans, review patients' charts, and prepare for clinic visits.

All of the participants in this study have insurance. They have coverage through Medicare, private insurance, or through a program offered by their employer. And while medication costs still factor into US patient's out of pocket expenses (Chino et al. 2017), especially for those covered through Medicare (Davidoff et al. 2013), my analysis suggests that the hope that the medication might extend life is the main motivating factor for trial enrollment. There are no instances in which a patient cites the cost of standard treatments or clinical trial medications as a reason to participate in a clinical trial. In the 85 visits I analyzed, there are no instances in which a patient or caregiver brings up the cost of clinical trials, either as an inducement or prohibition. In fact, patients and caregivers rarely bring up the cost of standard cancer treatment (anti-cancer medication) at all. There are nine cases in which participants discuss the cost of medication. In three of the nine cases, the patient complains about the cost of prescriptions associated with cancer growth (non-treatment related symptoms). For example, one patient complains that his salt tablets are expensive. In another example, a patient complains about the cost of Albuterol, which controls coughing and wheezing that is likely associated with that patient's cancer growth. In the remaining six cases, it is the doctor that brings up the cost of standard cancer drugs. In half of these cases, the patient expresses surprise at their cancer treatment's expense. One patient mentions that their insurance must be paying for all of this because they have not seen the charges, while another responds that this is why he is "paying for insurance."

My participation during clinic visits purposely varied depending on the context. During the actual clinic visit, I took a passive approach by standing in the corner of the clinic room writing notes. Staying as unobtrusive as possible in this setting minimized the potential to interfere with the natural flow of the conversation or possibly influence the topics covered during the clinic visit. Accomplishing this task was easier than expected since the cancer center is housed in a large teaching hospital. In this setting, it is common to have medical students, clinical trial specialists, and medical residents present in the room, simply observing, while patients are meeting with their oncologist. Yet, prior to and right after clinic visits, the researcher took a more active approach to participation. This included informal interviews and conversations with participants, caregivers, and oncologists. After clinic visits ended, oncologists were regularly asked questions about the interaction that just took place or asked to reflect on a variety of topics—e.g., conversational approach, medical decision-making, the difficulty of the conversation, treatment options discussed or avoided. Engaging in "shop talk" with oncologists and observing "shop work" (Maynard and Clayman 1991), provided a deeper understanding of how clinicians accomplish cancer care. I also had informal conversations with patients and caregivers before and after clinic visits, but these were completely dependent on peoples' treatment schedules that day and their willingness to talk.

Study participants include 65 lung cancer patients (35 female, 30 male), 48 family members (26 male, 22 female), 3 oncologists (2 female, 1 male), five nurses (all female), three medical assistants (1 female, 2 male), four medical residents (all female), and one clinical trial liaison (female). Research participants were recruited using a purposeful sampling design. Purposeful sampling allows for obtaining “information-rich” cases (Patton 2014). This kind of sampling involves identifying and selecting research participants that are uniquely suited to provide information or experiential knowledge, given the research questions and study aims. In other words, purposeful sampling helps researchers recruit people that are “especially knowledgeable about or experienced with the phenomenon of interest” (Palinkas et al. 2015, p. 2). While there are many types of purposeful sampling strategies—for an extensive list see Palinkas et al.’s *table 1* (2016)—this study initially relied on a strict criteria-based purposeful sampling strategy (Palinkas et al.’s criterion-i). Patients in the study had to be at least 18 years old, previously diagnosed with incurable non-small cell lung cancer (stages III-A, III-B, IV-A, or IV-B), and had to be patients at the cancer clinic that I was observing. I used these criteria because the larger study’s aims are to better understand discussions around death and dying and end-of-life issues.

The patients in this paper were either enrolled, or were contemplating enrolling, in a mix of double-blinded, blinded, and non-blinded studies. Additionally, some of the trials were single-arm studies. As such, some of the patients knew that they were receiving the drug from the onset of the treatment. The trials referenced in my data are not curative.

I also relied on theoretical sampling as data collection advanced. Theoretical sampling is particularly suited to “maximize opportunities to develop concepts” by specifically selecting cases or participants that can help unearth variation, tease out the relationship between concepts, and detail the properties of the analytic strands that comprise theory (Corbin and Strauss 2014, p. 143). Early data analysis revealed instances in which patients and caregivers discussed “curing” cancer. When these cases were further analyzed, one key constant was that patients were either discussing clinical trials or were enrolled in trials. I then adjusted the sampling strategy using theoretical sampling to specifically recruit participants that were discussing, enrolling, or enrolled in clinical trials. I did not exclusively recruit using this criterion, but rather integrated clinical trial “cases” into the larger sampling strategy. Theoretical sampling helps explore the analytic dimensions of concepts, construct the boundaries of codes, explore disconfirming cases, or capture the variation of themes (Charmaz 2003). As such, clinical trial cases were analyzed along with, and compared to, cases in which standard treatment options (e.g., chemotherapy, radiation, surgery) and palliative regimens were used. This helps me further understand the differences and similarities between trial-talk and clinic visits in which standard treatments were discussed.

Transcribed audio files were analyzed using the MAXQDA-18 software for qualitative data analysis. Initial coding of transcripts and fieldnotes relied on line-by-line analysis (Charmaz 2006), with preliminary analysis leading to “focused coding” as initial codes collapsed into new codes, and categories and themes emerged. This process also used a constant comparative approach (Charmz 2006) allowing me to compare between—and within—segments of data, categories, and themes. As an example, in the early stages of analysis of the larger project “optimistic hope” initially emerged as a code. As more cases of “optimistic hope” appeared and compared to one another, there seemed to be differences based on the kinds of treatments patients were getting or discussing. The ways patients and caregivers ascribed hope statements to standard treatments (e.g., chemotherapy) differed considerably from the ways they attribute optimistic hope statements to clinical trial drugs, and also differed considerably from their descriptions of palliative treatment and hospice care. Statements of hope for standard treatments tend to be bound to the perceived (in)curability of patient's cancer. Participants discuss getting "more mileage" out of the treatments and "continued" or "durable response." For patients, the implication is that standard treatments were "keeping the cancer at bay" but that they had no hope of curing the cancer. In these cases, "optimistic hope" attaches to the expectation or desire for treatments to extend life. Meanwhile, in early clinical trial cases, some participants were discussing the possibilities of experimental drugs being a "miracle" and potentially curing the cancer.

After comparing across different treatments, clinical trial cases were isolated and further analyzed. Upon further analysis, "optimistic hope" remains a larger theme, with clinical trial cases emerging as having distinct properties. Continued analysis shows participants struggling to make sense of clinical trials, and "uncertainty" emerges as a constant property during these interactions. Analytic memos also helped detail the features of the connections that developed between the constellations of codes (e.g., "numeracy," "qualitative mitigation," "statements of hope," "unknown risk") and categories (e.g., "enrolling in trial," "pulled from trial," deciding not to enroll") and fleshed out the relationships between (and among) categories, codes, and themes. This kind of analysis forms the basis for the subsequent findings section, which details uncertainty and clinical trials in relation to 1) efficacy, 2) consequences, 3) prognosis.

Findings

My findings consider how clinical trials produce uncertainty in the context of a terminal diagnosis. Here, I am not detailing that experimental drugs themselves are risky, unpredictable, or uncertain (e.g., that they might have unknown or unknowable effects). Rather, focusing on *in situ* patient-doctor interactions, I explain how perceptions of clinical trials are shaped via clinical interactions and how those perceptions influence the lived illness experiences of terminally-ill patients. As such, I illustrate how clinical trials produce uncertainty through the use of precise and quantitative language (*Efficacy*), the unknown impact of trial drugs (*Treatment Consequences*), and the potential for trial treatments to eliminate patients' cancers (*Prognosis*). While I examine these sources of uncertainty independently, they are related and occur across these three areas. For example, while I focus on the use of quantitative language in *Efficacy*, examples of highly medicalized and technical language are also seen in *Treatment Consequences* and *Prognosis*.

The Uncertain Efficacy of Trail Drugs

It is necessary to establish the certainty of patients' diagnoses before demonstrating how clinical trials might disrupt such certainty. In my study, patients have been explicitly and repeatedly informed that their cancer is terminal. For example, in a conversation with Kat (a patient) and Ben (patient's husband), doctor Blackwell states:

> I always indicate [to patients] that one option is to not use any anti-cancer drugs. To focus on your symptoms. At some point. When it is that I decide [that is] either you saying, "It's not for me anymore." Or I say, "I don't think there's any good options anymore." Here the door is open to bringing more resources to you at home like hospice for example.

Dr. Blackwell reminds Kat that she will eventually exhaust her limited treatment options and even before then, transitioning to hospice care might be her best option. In this interaction, as well as many others in my dataset, death is clearly "on the table." In contrast to Glaser and Strauss' (1965) classic work on death and dying, doctors and patients in this study openly discuss death, and patients' terminal prognoses are routinely mentioned. As such, all patients in this study are informed of the severity of their diagnoses.

My focus in this analysis is how interactions surrounding clinical trials disrupt the reality of certain death and re-introduce uncertainty. For instance, while Dr. Blackwell first discusses hospice as a real option, he also suggests that clinical trials are still an option for Kat, modulating her transition to hospice care. While death is "on the table" for Kat, her transition to hospice care will occur as some ambiguous point in the future, after trial drugs cease working or Kat decides to refrain from treatment. Therefore, Kat has a certain prognosis (i.e., her cancer is terminal) but when she transitions to hospice care, and what treatments she pursues, are uncertain.

Accordingly, patient-doctor interactions regarding clinical trials are one avenue for introducing such uncertainty in the context of certain death. One means by which trial interactions create uncertainty is via physicians' use of probabilistic language to describe the efficacy of trial drugs. Medications "might or might not" have an impact, the impact might be "modest" or "substantial," and "clinically significant" improvement might occur for 10%, 20%, or 30% of enrollees. Through this discourse, trials muddle the prognostic certainty of terminal illness, as patients might or might not be one of the few to receive "clinically significant" results. For instance, Dr. Blackwell explains to Kat how one trial works:

> When you give [drug one] to 10 people with lung cancer, it shrinks the cancer in two or two and a half of them. So roughly 25 people out of a hundred, 2 to 3 out of 10… That's a better number, believe it or not than [drug two]. The number for [drug two] is closer to 10 out of a hundred. This difference is meaningful, but actually, the most meaningful thing is that when drugs like [drug one] work they tend to work for much longer than [drug two]. And so if you were to take those 100 people of those 25, somewhere around 15 or 20 of them get what I call a "durable response," which might last months and actually sometimes it's even measured in years.

Dr. Blackwell's discussion of these trial drugs is characterized by probabilistic language as he reviews both rates of success and duration of response. Although couched in seemingly precise quantitative terminology, the impact either drug might have on a specific patient (e.g., Kat) are difficult to discern. If she takes the drug, Kat might be among the majority that experience no beneficial side-effects. She would also have to choose between the two trials, which covey different risks and outcomes. Additionally, Dr. Blackwell has previously discussed transitioning to hospice care with Kat (see above), while now presenting a drug that might provide a "durable response" that might be "measured in years." In this sense, interactions surrounding clinical trials introduce uncertainty in the context of Kat's more assured prognosis, with her choices adding considerable complexity to when she might die.

In an effort to add some certainty to this discussion of probabilities, Kat asks Dr. Blackwell if there are genetic tests or similar diagnostic exams that might indicate if she will benefit from either drug before she chooses a trial. Dr. Blackwell responds:

> Well, no, you asked the perfect question. I mean, if you knew you were one of the 75% who it wasn't going to work for then I could just avoid giving it to you. That would be lovely. Things like [test name] for example are attempts to try to figure out who's that group, but the bottom line is "no." I don't have a good way of predicting who will respond and who won't. Maybe someday I will.

Later in their interaction, Dr. Blackwell adds that, only after multiple rounds of treatment, will they know if a treatment is working for her, "I would do two rounds. So two months and then I would take a look… so basically you get four doses and then I get our scan." Put simply, the only way for Kat to know if a drug works (or does not work) is to spend several months taking it.

As with the potential success rate, Kat similarly asks Dr. Blackwell to provide additional certainty in relation to the duration of the impact of the trial drug. Dr. Blackwell responds by explaining how the specific chemical agent acts in a body. Still unsure, Kat asks how the drug will impact her life span if she is not in the 25% who experience a benefit:

> Kat: Okay. And so if I'm not part of the 25%, then, um, do you have a sense of how much more? How many more months or whatever I get?
>
> Dr. B: So, um, in the worst case, if I see again that treatment [clinical trial drug] isn't working, I think that probably makes it clear that time is measured in months.

However, Dr. Blackwell adds that he also will not know how the drug might impact morality until Kat takes it. Accordingly, although Dr. Blackwell provides a thorough review of her options, the probabilistic language surrounding trials produces considerable uncertainty: she might respond to only drug 1 or only drug 2, or she might not respond to either drug. If she does have a response, this might last months or years, substantial time for someone considering hospice care. Despite the medical statistics and novel technologies used to assess her progress (e.g., genetic tests, scans), Kat’s choice amounts to opting for “trial and error” or not, with the difference between a correct and incorrect choice potentially being years of additional life.

As with probabilistic language, medical terminology also introduces uncertainty in clinical trial interactions, particularly in relation to how drugs might work. That is, when patients question physicians about the operation of a drug, physicians respond with extensive medical terminology that is simultaneously precise and inaccessible. For example, Luther (a caregiver), asks Dr. Souza if there are non-invasive ways to produce lung samples required for a trial. Dr. Souza responds with biomedical detail:

> So, they just approved genetic testing of the blood for T790M. But in your case, I want to go beyond T790M. So, my impression would be that I would need to do tissue testing first to identify, well, what is the mechanism of resistance here? It's possible that she still has the T790M, but something else is also popping up. I don't know if you remember, when I first talked about your molecular results. You had the T790M mutation and you also had another one called the PIK3CA mutation, which is two resistance mutations. So, it may be that we’ve suppressing the T790M and the PIK3CA is sort of now acting up. But I have no way of targeting both mutations at the same time because there's no approved therapy that I can give that will target both mutations. So, that's my guess that that might be what's going on. But I'd only know if I really checked the tumor.

While many Lorne patients have considerable lay expertise (Epstein 1995; Wynne 1992) and Lorne physicians emphasize collaborative patient-doctor communication, Dr. Souza's response is nonetheless embedded in a long list of medical terms. Indeed, while Dr. Souza answers Luther (i.e., "I'd only know if I really checked the tumor"), the answer is embedded in extensive terminology that references specific mutations (i.e., T790M and PIK3CA), "mechanisms of resistance," and "molecular results."

The medical terminology in Dr. Souza's response also includes potentially negative news, suggesting that if both mutations (T790M and PIK3CA) are active, there is "no approved therapy" that will help Luther's loved one. That is, while they are discussing trial drugs, a lung sample might reveal that even the trials Dr. Souza is aware of will not be of help. Further complicating matters, Luther receives this information orally and without the benefit of the text I provide here. Indeed, the opaqueness of Dr. Souza's response is indicated in Luther's follow-up:

> Should I be waiting for the results of whether they'll radiate her head? Or should I be searching the internet for clinical trials, or you searching for clinical trials? Or let's just wait to see what we're gonna do with her head first?

Luther raises two potential courses of action. First, he suggests that they could wait for more diagnostic information and see if the brain tumors are small enough that radiotherapy might still slow their growth. Second, he suggests that they could move forward with "searching the internet" for clinical trials. It is unclear if Luther's "searching the internet" is literal or somewhat euphemistic. Doctors at the Lorne Cancer Center frequently use databases to look for ongoing trials. Often, oncologists do this work "backstage" in their workroom, but sometimes they show their patients the "results" from searches to discuss the options (or lack thereof). In more than one case, an oncologist brings up the list of open trials to discuss whether a patient is willing to move to a city across the country for a few months to take part in a trial. Luther's question at the end (“or let’s wait and see what we’re gonna do with the head first?”) seems to re-emphasize the first course of action.

Responding to this series of questions, Dr. Souza simply states, “I would do that first,” which endorses the suggestion to wait and see if they can use radiotherapy on the brain tumors (“radiate her head”) or if they have grown to such an extent that radiotherapy will not be advisable. Now the interaction has moved from a topic of relative simplicity (i.e., taking a tissue sample) to a situation wherein intervention options, their consequences, and prognostic certainty are no longer clear. Accordingly, as with probabilistic language, the medical terminology that can surround clinical trials produces uncertainty in the context of terminal cancer. And, despite the precision of Dr. Souza talk, Luther is left with more, rather than fewer, questions.

The Uncertain Consequences of Trial Drugs

At the Lorne Cancer Center, clinical trial specialists frequently visit clinicians to discuss trials. These specialists inform oncologists about new studies, monitor patients that are “on study,” and help enroll and consent new trial participants. Monitoring patients depends on the specific protocol of each trial, but general monitoring mechanisms include laboratory tests (e.g., blood draw analysis, urine tests, or tissue sample examination), closed and open-ended questionnaires, and diagnostic imaging results (e.g., magnetic resonance imaging, computed tomography scan, x-ray, or positron emission tomography scan). Despite the highly regimented and extensive review of physical risks involved, the consequences of trial drugs produce considerable uncertainty for terminally ill patients. Accordingly, in this section, I detail how clinical trial interactions influence participants’ perceptions of the consequences of experimental drugs and experience biophysical risk.

Between oncologists and clinical trial specialists, the potential side-effects are carefully reviewed before patients enroll. For instance, as Dr. Souza and Richard are discussing a trial, they review a list of common side-effects, such as the dropping of white blood cells, fatigue, and blood clotting issues. Since Richard’s father also had terminal cancer and enrolled in a trial, Richard asks about the potential to develop diarrhea and neuropathy. As Dr. Souza starts explaining the potential to develop neuropathy, which results in the damage of the peripheral nervous system and can cause a great deal of nerve pain and harm, she uses statistical language:

> I would say about 10% to 20% [of patients develop neuropathy] so it's an important one. It tends to be the more you get, the more the risk. So, it's something that I just have to monitor and see if you have it. If you have it, then sometimes I need to, again, dose modify or change things around or stop it if it's happening.

Although Richard’s interest in the trial partly hinges on his risk of developing neuropathy (and diarrhea), Dr. Souza can only provide estimates of his risk, adding that if he does develop neuropathy, it is likely to increase in severity throughout the trial. Resonating with data above (*Efficacy*) and previous studies (see Lipkus and Peters, 2009; Peters *et al.* 2009; Fagerlin and Peters 2011), Lorne physicians discuss these side-effects in terms of probabilistic ranges and quantitative assessments. Here, a source of interactional uncertainty is a clinician’s inability to predict which side-effects a patient might develop among a constellation of possibilities, mixed with the difficulty in describing the extent to which these side-effects might affect their overall health. This uncertainty surrounding the trial side-effects compounds the already difficult task of explaining uncertainty to patients during clinic visits. That is, when patients receive broad presentations of probabilistic outcomes, uncertainty surrounds their anticipated, specific encounter with a drug, how it might disturb their physiology, and how they may understand the risks and aims of clinical trials.

Not all of the potential biophysical reactions are known prior to a patient's participation in a trial. Indeed, part of the work of clinical trials is distilling the precise adverse effects of medications. The opaque consequences of trial medications are apparent in an interaction between Dr. Blackwell and Kristen (a patient). Dr. Blackwell states Kristen has three options: transition to hospice, try the latest Food and Drug Administration (FDA) approved drug, or enroll in a trial. He then lists the side-effects of the experimental drug, including "bleeding because you are altering blood vessel growth and development." Kristen is immediately worried about bleeding, asking "bleeding from where? Where? What, if you cut yourself? Will it come out my ears, nose, or mouth? Where? I mean, what kind of bleeding are you talking about?" Dr. Blackwell says it is difficult to say where she might bleed from, but previous enrollees report nosebleeds and blooding in the gastrointestinal tract. Dr. Blackwell adds, "theoretically, you could bleed from anywhere. You have blood vessels everywhere." Although Dr. Blackwell is able to list an adverse effect (i.e., bleeding), how, where, and to what extent the drug causes bleeding is not currently known. Indeed, the experiences of potential enrollees (like Kristen) are necessary to ascertain the extent of such effects, in addition to whether or not the drug is useful in treating cancers. Despite her terminal diagnosis, Kristen decides that the seemingly unspecified yet comprehensive possibility of bleeding is too risky in relation to her potential longevity and quality of life, and she declines to participate in the trial.

The interactional uncertainty surrounding trial drugs is heightened by the uncertainty of disease advancement, as a previously tolerable side-effect can become unmanageable and hazardous as cancers change. Indeed, while constant biomedical surveillance might provide positive news on tumor shrinkage, it can also facilitate negative news on tumor growth (see Pietilä *et al.* 2018). For example, Sofia enrolls in the same phase-1 clinical trial that Kristen declines (see above). Through the first round of treatment, the drug slows the growth of her tumor, with both lab results and self-reports indicating no major side-effects. However, the latest round of diagnostic scans reveals that the cancer spread to her brain. For Dr. Souza, this development completely alters the drug's risks:

> I know it's disappointing and I'm not, you know, I'm not downplaying. But I think safety first and because there isn't enough safety data with this, when people have, you know, brain tumors and they're worried about bleeding because this affects blood vessels… And it's even possible, you know, that you've had this, and I just didn't pick it up… So, I don't think that you failed the regimen. The reason to stop it is for safety.

While Dr. Souza and Sofia were willing to navigate the side-effects when Sofia first enrolls, the risks increase once Sofia's cancer metastasizes to her brain, which is a relatively common development for lung cancers (see Ali *et al.* 2013; Greenspoon *et al.* 2017). This case highlights how difficult it is to communicate the uncertainty and risk of clinical trials when also trying to account for cancer progression. Dr. Souza hints at this by expressing her surprise that the experimental drug stopped working and started hurting Sofia because the initial decrease, "was more than I'm used to seeing." Throughout the visit, it is clear that Sofia's brain bleeding is unexpected, especially since the previous diagnostic scans and laboratory results showed the experimental drug to be working.

In the section above (*Efficacy*), I detailed how clinical trial interactions produce uncertainty by potentially obscuring the prognostic landscape, i.e., when a patient might die. Here, the consequences of trial drugs similarly produce temporal uncertainty vis-à-vis terminal diagnoses, as patients might die from the adverse effects of a cancer drug, rather than the cancer itself. While clinical trial interactions addressing side-effects often revolve around probabilistic outcomes, these probabilities are transitory as cancer development intersects with drug effects to produce unknown and potentially unknowable risks, elevating the interactional difficulty for both patients and doctors in discussing outcomes that are so uncertain.

Prognostic Uncertainty and Trial Drugs

Biomedicine is rife with promissory notes (Fortun 2008), or the potential benefits of emerging technologies. Such promises are not foreign to advertisements regarding experimental cancer medications (Markoff 2012), with drugs situated as “silver bullets” and miracle cures. However, in contrast to Fortun’s (2008) description of physicians, researchers, and corporate actors emphasizing the promises of emerging medications, in my study, it is patients that primarily laud the potential of trial drugs, while physicians struggle to assuage their optimism with realistic expectations. In the sections above (*Efficacy* and *Consequences*), I detail how clinical trial interactions disrupt certainty in regards to when a patient might die, and here I describe how trials question *if* a patient will succumb to their terminal cancer.

The potential of trial drugs is demonstrated in an interaction between Richard (a patient) and Dr. Souza. Richard has been informed that his cancer might be growing. Dr. Souza reports there is a 10% chance that this growth is “pseudo-progression,” wherein scans show a larger tumor but the cancer has not actually grown. There is also a 90% chance the progression is genuine, which means that Richard is facing a difficult decision to either switch to another trial or transition to hospice care. Dr. Souza adds that the new trial will at best “extend” or “stretch” Richard’s life span, and the drug also carries a new set of side-effects. After consulting with his wife, Richard decides to begin the new trial, “I think that you're right and I think that I need something that's stronger and I want something that goes after it. Kicks its butt to be totally honest.” Despite Dr. Souza’s emphasis that the trial drug is not curative, Richard proposes that the drug will “kick [the] butt” of his cancer. Accordingly, while Dr. Souza is careful concerning the efficacy of the drug, Richard exhibits an interpretation that this new medication may potentially eliminate his terminal cancer.

In clinical trial interactions, physicians encounter difficulties managing such optimism. Patients have a difficult diagnosis and medications sometimes provide tangible and measurable benefits (e.g., tumor shrinkage). Nonetheless, these improvements need to be communicated in realistic terms. Responding to Richard, Dr. Souza attempts to manage his expectations:

> In general, the goal of this treatment would be to try to shrink the cancer in that area, to delay or slow down further progression, and hopefully, despite managing chemo side-effects, you could have an overall better quality of life if the symptoms are manageable from the cancer and the side-effects are also manageable. Okay?

Dr. Souza downgrades Richard’s “kick its butt” assertion by emphasizing that the new drug will only “shrink,” “delay,” or slow the progression of his cancer. While these outcomes are beneficial, per Dr. Souza’s message, she is also tacitly conveying that they are not curative. Despite the reframing, Richard responds, “I mean hopefully it's a ticket to kill the cancer and have a miracle – but the side-effects that I would most probably get, what would they be, besides hair loss?” Here, Richard’s “I-mean” does not indicate that Dr. Souza misheard or misunderstood what Richard said, instead it is used in a way to repair his previous statement and attempt to build alignment with the doctor (Maynard 2013). Richard once more situates the drug as curative, with even the extent of side-effects being minimized. Here we see the paradox at the heart of my phenomenon plays out in action. Richard’s impending death from cancer is prognostically certain. Yet, the availability of a trial and its ambivalent outcomes allows him to interrupt that certainty with notions of a “silver bullet” or “lottery ticket.” Uncertainty re-enters the field of otherwise certain death.

Other participants were similarly optimistic vis-à-vis experimental drugs. For instance, Gary (a patient) asks his physician about the treatment potential of medical marijuana. Gary's wife adds he thinks marijuana "sounds like a miracle" because online sources report it is "curing" cancers. Another patient asks his doctor if he has "heard of Watson," IBM's Question and Answer software that has been reported to outperform clinicians in diagnostic challenges, and whether that software might discover a trial drug to treat his cancer. In both circumstances, "outside the box" and experimental approaches are situated as disrupting patients' terminal prognoses.

Although doctors struggle to navigate patients' optimism they too, at times, emphasize the promising potential of trial drugs. For example, Dr. Blackwell tells Mary (a patient) of a drug that is showing "pretty impressive differences in what I call progression free survival," meaning that "I can't even see the cancer." Dr. Blackwell adds that the drug has not received FDA approval and is "not yet reporting cure rates" but if the results continue, "I may just lay claim to curing more people." Clearly, any drug with such results is appealing to someone living with terminal cancer. Although this description of the medication can disrupt the certainty of Mary's death, the actual impact of this medication remains ambiguous, since the trial, while showing promise, had not yet begun to report official results. The drug has since received FDA approval and while it does seem to extend life by several months it falls short of delivering "progression free survival." Nonetheless, during these clinical interactions, this trial drug is the type of "miracle" that Richard, Gary, and other participants are pursuing, with Dr. Blackwell's description of the drug disrupting the certainty of Mary and other participants' terminal cancers.

Discussion

Clinical trial medications are *de facto* uncertain. Indeed, part of the work of clinical trials is to better ascertain how these experimental compounds operate in the body (Corrigan 2002). In this paper, I demonstrate how patient-doctor interactions regarding clinical trials paradoxically introduce uncertainty in the context of terminal cancer. As study participants face a stark prognosis, they navigate extensive uncertainty, with their health and future described in an ever-fluctuating combination of probabilities, "mights," and "ifs" associated with experimental medications. Such uncertainty is deeply implicated in the clinical encounters I describe, even though these encounters occur exceptionally close to the end of the life course and in the context of impending or close-to-impending death. In contrast to social structural theories of uncertainty and risk (Beck 1992; Giddens 1990), I argue that such uncertainty is locally produced and managed through clinical interactions as participants consider the risks surrounding the curative potential of experimental medications.

Physicians in my study frequently employ probabilistic language to discuss trial drugs, which supports prior findings regarding quantitative language, risk, and uncertainty (Lautenbach et al. 2013; Lobb and Gaff 2010; Pilnick and Zayts 2014). Here, physicians' quantitative and seemingly precise language describing clinical trial studies has the paradoxical effect of exacerbating uncertainty, as all outcomes are qualified by statistical language, unknown variables, and mitigating factors. In this regard, clinical encounters can be ambiguous and uncertain, even when physicians rely on empirical findings consistent with an evidence-based medicine approach (see also Babrow, Kasch, and Ford 1998; Gigerenzer and Edwards 2003; Segalowitz et al. 2016). How patients deal with uncertainty is important because it affects how they make treatment decisions (Littlejohn and Kimport 2017). For example, both Kristen and

Richard’s perception of side effect risk was a determining factor in whether or not they would enter a clinical trial. As participants routinely worry about the quality and quantity of their remaining life, the uncertainty of clinical trials has implications for both themselves and their families.

This paper also traces the various ways participants “manage” uncertainty and make medical decisions under increased uncertainty and risk (Zinn 2008, 2009). Consider, for example, my analysis of Sofia’s experience (in *Consequences*) with a trial drug. Sofia’s bleeding becomes a serious and imminent risk to her health only after her cancer spreads and continues to grow. The way patients come to experience and understand uncertainty and risk are not bound to the ways trials are discussed and understood at the time of enrollment. In fact, the risk of experimental medications is in constant flux, intersecting with the level of aggressiveness of a patients’ cancer. As such, any conversations about the potential of clinical trial drugs to be effective or cause a serious health risk are difficult to fully explain or predict, further muddling prognosis. That is, uncertainty and risk are dynamic and emergent aspects of clinical encounters that are not temporally bound to single interactions or simply products of the biochemical agents interacting with peoples’ bodies. Instead, patients’ lived experiences are made more confusing and complex because the discussion of trials needs constant tending. With every new clinic visit, patients and doctors need new discussions about trials, keeping in mind how tumors are growing (or not) and how the trial drugs are interacting with peoples’ bodies. Further studies could look at clinical trial discussion throughout patients’ entire enrollment in a given trial, paying attention to the ways patients and doctors discuss the continued risk and uncertainty as the patients move through a trial’s course. Analyzing ways discussions of trials change or stay the same over time can contribute to recent conceptual debates over the analytic utility of uncertainty and risk (for a review on this debate see Brown 2013).

The interactional components relevant to uncertainty and clinical trials that I detail are also salient for physicians' practices. Based on my findings, physicians might discuss the temporal features of uncertainty, noting how the benefits and risks of trial medications unfold over time and intersect with cancer growth or shrinkage. Similarly, while probabilistic language might accurately reflect clinical trial data, the current study suggests probabilistic language also complicates patients' perceptions of prognostic certainty. Understanding the components of clinical trial interactions might also help identify avenues for discussing other options (e.g., palliative care), which is especially salient for patients that are enrolling in trials because there are no other viable anti-cancer treatments. By using examples of interactional misunderstandings or challenges, physicians might prepare all conversational parties for the difficulties associated with clinical trials.

Future research might employ other qualitative methods (e.g., conversation analysis, in-depth interviews). Complementarity to my study, conversation analysis might identify the micro-features of interactions characterized by uncertainty, or detail specific conversational sequences and language use that facilitate the joint management of uncertainty to strengthen patient-doctor interactions. Likewise, in-depth interviews might better reflect the feelings, thoughts, and experiences of patients that surround clinical trial interactions. By employing a micro-level approach and interactionist frame, I provide one demonstration of the analytic potential of such studies vis-à-vis health, medicine, and uncertainty.

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CHAPTER 3 - Do you want to talk about what this means?: Initiating difficult conversations, supporting patient agency, and discussing death

Abstract

This chapter draws on the field of conversation analysis to examine audio recordings of terminal lung cancer patients, their family members, and their oncologist as they initiate discussions of prognosis. I find that the oncologist in this study uses different types of inquiries to set the topical agenda (discussion of prognosis), forecast the valence of the news, and work towards an acceptance of the nominated next action. Specifically I call these "what this means inquiries" (WTMIs). These inquires also serve as a confirming strategy when a patient or caregiver initiates prognostic-talk or expresses "readiness" to discuss prognosis. I argue that despite a preferred positive response, WTMIs help diminish physicians' asymmetrical influence on patient-doctor interactions and promote patient and caregiver agency. Participants collaboratively build interactional spaces to gather information and express conversational preferences. By responding to WTM inquiries, patients and caregivers have opportunities to shape prognostic-talk.

Introduction

Discussing prognosis with terminally-ill cancer patients is an immensely difficult, yet essential task for oncologists. As a patient's health deteriorates and the person gets closer to death, discussing prognosis becomes increasingly important. Patients with clear prognostic understandings are more likely to engage in end-of-life discussions and planning (Applebaum et al. 2014). Openly discussing issues related to prognosis, such as life expectancy, palliative care, hospice care, and illness progression helps patients prepare for death (Bradley et al. 2001; Detering et al. 2010) and improves bereavement outcomes for family members (Wright et al. 2008). Open communication towards the end of a patient's life helps create opportunities to lay out final treatment preferences, settle personal and legal affairs, enable patients and family members to discuss feelings, and collaboratively construct expectations. These kinds of conversations can also lead to earlier involvement in palliative care, which reduces anxiety and depression and increases quality of life measures (Bakitas et al. 2009; Temel et al. 2010) and shows higher satisfaction with the care patients receive and lower care costs (Gade et al. 2008;

Teno et al. 2004; Teno and Gozalo 2014). Furthermore, it is generally accepted that physicians should endeavor to provide accurate and open prognostic information. In fact, an honest discussion of prognosis is considered one of the foundational components of providing modern healthcare (Epstein and Street 2007, 2011).

Despite the importance of building a clear prognostic understanding and patients' reported preferences for discussing topics related to prognosis (Gaston and Mitchell 2005; Innes and Payne 2009), clinic visits that include prognostic discussions are replete with interactional difficulties. First, as patients get closer to death it becomes more difficult to openly update the prognostic landscape. As Maynard (2003) shows, disclosing bad news is a dispreferred social action (cf. Pomerantz and Heritage 2013), and one which clinicians tend to avoid (Fagerlind et al. 2008; Sandén et al. 2001), bypass (Cortez, Maynard, and Campbell 2019), or only discuss after direct questions (Christakis 1999; Helft 2005). Even when patients and doctors discuss bad news, doctors will still allusively discuss or shroud the news (Maynard 2003; The et al. 2000). Additionally, while patients report wanting updated prognostic information (Hagerty et al. 2004; Parker et al. 2007), there is a great deal of variation in patients' preferences for how prognosis is to be discussed and what topics are to be covered. Further complicating matters, the amount of information patients and caregivers want may change as patients' diseases progress (Parker et al. 2007). Recent research, however, shows signs that despite the difficulties associated with discussing prognosis, participants are trying to use different interactional tools to gather specific information related to prognosis (Parry, Land, and Seymour 2014; Pino and Parry 2019). Yet more research is needed to understand the ways such prognostic discussions start.

The central task of this chapter is to analyze a set of inquiries that physicians use to ask patients if they would like to discuss their prognosis. I term these formulations "what this means inquiries” (WTMIs). I argue that WTMIs set a topical agenda (discussing the meaning of bad news) by suggesting that there is something serious to discuss, while also forecasting the valence of the news. Similar to polar questions also known as yes/no interrogatives, WTM formulations act as an invitation for patients (and/or caregivers) to either accept or decline (Bolinger 1978; Heritage and Raymond 2012). Notwithstanding the preferred affirmative response, WTM inquiries help create an “interactional environment” (Luftey and Maynard 1998; Pino and Parry 2019) in which patients can assert a type of agency and influence the trajectory of prognostic-talk. These WTM formulations also serve as a confirming strategy. During instances in which doctors suspect that patients are indicating “readiness” to talk about prognosis, a WTM formulation can check to see whether the patient is truly demonstrating a desire to initiate prognostic-talk. I argue that WTMIs help diminish physicians’ asymmetrically-strong influence on patient-doctor interactions and promote patient and caregiver agency.

Literature Review

Questions

Conversation analytic literature has a long tradition of investigating question-type utterances (Boyd and Heritage 2006; Raymond 2003; Sacks 1995; Schegloff 1985). A considerable amount of research shows that questions do more than simply ask for information. For example, statements that are lexically organized like questions make requests (Curl and Drew 2008), relate a particular point of view (Heritage 2002), or can declare or assert information rather than ask for it (Bolinger 1978; Clayman and Heritage 2002). And even when questions are presented in the interrogative form (i.e., when they do ask an information-seeking question) they can also work towards achieving other interactional goals beyond answering the question as such, by soliciting patients’ unmet needs or concerns (Robinson and Heritage 2016), or attempting to resolve misunderstandings by initiating “repairs” (Drew 1997; Koshik 2005).

Turning to medical encounters, Heritage (2009) notes that communication in healthcare is full of questions. Roter and Hall (2006) also note physicians’ high usage of questions, particularly the use of close-ended polar (yes/no) questions to gather health information and patients’ medical histories. In the interrogative form, questions help set agendas in clinical settings, but even slight alterations to the formulation of a question can have a demonstrable effect on how patients hear and respond to questions. As an example, research by Heritage and colleagues (2007) and Robinson and Heritage (2016) shows that asking a patient if they have “some” other issues they would like to address versus “any” other issues they would like to address is more likely to garner a response, since the “some” version has positive polarity while the “any” formulation has negative polarity, which discourages the listener from naming further issues. These findings point to the need for careful analysis of the way questions are formed since questions play a major part in patient-doctor interactions. This last point is particularly true when we consider that not all utterances that initially present as questions ask are inquiring or interrogating.

As mentioned above, utterances that present as questions can do much more than simply ask for information. Speakers can organize their questions to work towards more than one interactional goal, or what Schegloff (2007) refers to as pulling “double duty” (p. 169). Schegloff suggests that utterance that initially present as yes/no questions can engage in “topic proferring” (p. 169-170). By bringing up (proferring) a topic as the next potential action, a speaker does not simply jump into discussing the proposed topic, rather they offer the topic for other participants to embrace or reject, accept or decline, the topic that the speaker proposes (Schegloff 2007, p.171). Because topic proffering inquiries present a topic as a *potential* next action, rather than simply diving into the topic, recipients (people listening to the speaker) have room to influence the initial speaker's next action. That is, recipients can influence the conversation by embracing or rejecting the proposed topical agenda. As such, topic proferring sequences are "distinct" from other forms of inquiries in that they are organized to garner a response from the listener(s), which the speaker then uses to go ahead with or withdraw from what their initial turn of talk was adumbrating as a topic.

My research contributes to the literature by demonstrating how WTMIs work to introduce a potential next topic (agenda setting) for discussion, i.e., prognosis. I detail how these formulations build in preferred affirmative response, which is seen in the structural organization of these inquiries. I show how WTMI simultaneously work towards more than one interactional goal. So while WTMIs do work towards an affirmative response, acceptance, or at the very least non-disalignment, they also provide interactional opportunities for patients to guide the direction of prognostic-talk. This chapter details the ways WTMIs display a structural preference—to discuss what the diagnostic news means.

Prognosis

Timmermans and Stivers (2018, p.19) suggest that the "sociology of prognosis" is primarily built on investigations of conversations about terminal, rather than non-terminal illnesses. Glaser and Strauss' *Awareness of Dying* (1965) makes a substantial contribution to the social scientific study of prognosis. Their analysis of death awareness contexts provides an important empirical look at the ways in which physicians avoid prognosticating, especially when patients are close to death. A number of studies confirm and build on Glaser and Strauss' central finding that some patients in their study died without a clear understanding of their terminal prognosis. Since *Awareness of Dying*, social scientific literature confirms that physicians avoid prognosticating, especially about impending death. As Schaepe and Maynard (2014) have reiterated, clinicians use evasion (Taylor 1988) and distancing techniques (Fagerlind et al. 2008; Sandén et al. 2001) to avoid difficult topics like prognosis. Ethnographic research finds that physicians purposely withhold important diagnostic and prognostic information from patients (The et al. 2000). However, The and colleagues (2000) also argue that patients discourage prognosis, by "gratefully" accepting "opportunities" to skip over discussions of bad news. Similarly, patients prioritize the maintenance of hope over prognostic clarity, so they purposely do not seek information that would contradict their coping mechanism (Leydon et al. 2000).

One major barrier to discussing prognosis that points to death is that such talk does not have the organizational space in typical clinical encounters that other forms of "talk" have. That is, research that focuses on the interactional phases of medical visits shows that the temporal area committed to prognosis, is minimal compared to the time for reviewing symptoms, disclosing diagnostic scans and laboratory results, and discussing treatment options (Cortez et al. 2019; Maynard, Cortez, and Campbell 2016; Singh et al. 2017)[7]. Clinicians hesitate to prognosticate because they worry about harsh judgment by colleagues and by patients for predictive mistakes (Christakis 1999). Doctors also fear that honest prognostication can destroy coping mechanisms and crush patients' "existential hope" (Thulesius, Håkansson, and Petersson 2003, p. 1361) so they might frame news optimistically (Maynard et al. 2016) in order to provide a good news exit (Holt 1993).

Even when participants do talk about prognosis, discussions are vague. Instead of concretely elucidating prognostic landscapes, using vague terms obscures the meaning of

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[7] These findings build on research that similarly finds a clear organization structure to patient-doctor interactions (see Byrne and Long 1978; Frankel 1990; Heritage and Maynard 2006; Robinson 2003).

diagnostic and prognostic news. Luftey and Maynard (1998) provide clear examples of the ways that physicians initially “shroud” prognostic news. However, the examples Luftey and Maynard (p. 339) provide show that it is not just doctors who may obscure things by way of vague and non-direct language, but also that patients cooperate, and may use such tactics themselves. Doctors also tend to provide a positive spin or a “bright side” to bad news (Holt 1993) so they accentuate “silver lining[s]” to bring indisputably bad news back towards a “bivalent equilibrium” in which really bad news is partly balanced with some good news (Maynard 2003: chapter 6; Stivers and Timmermans 2017, p. 405). Additionally, studies also illustrate less direct strategies for providing “good news exits” or “silver lining[s],” such as citing the past efficacy of treatment (Maynard et al. 2016) or pivoting towards available treatment options when current treatments of been “exhausted” in terms of effectiveness (Cortez et al. 2019). My addition to this literature consists of analyzing interactional moves on the part of doctors that can facilitate prognosis as an appropriate next topic, for both the doctors’ explanations and patients’ and caregivers’ shaping of such explanations.

Methods

My approach in this chapter is conversation analytic. Conversation analysis (CA) is primarily concerned with social action. CA looks to examine and understand how people interact with one another in an intelligible and collaborative way. One of CA’s main assumptions is that human interaction is not random, but rather it is ordered and full of technical lexical choices that labor to “do” something (ten Have 2007). CA is the study of how people endeavor to make themselves understood by detailing and examining one of the main building blocks of social action—talk and its sequential organization.

Data come from 85 audio recorded clinic visits at the Lorne Cancer Center (a pseudonym). After transcribing audio files, I started analyzing data using an inductive approach. Initial analysis revealed the reoccurring use of WTM inquiries. Consistent with a conversation analytic approach, I started a collection of episodes in which patients and caregivers are asked, via a WTM inquiry, if they would like to discuss prognosis. This collection includes four cases in which WTM formulations are found. While a collection of four WTM cases may not seem like a large corpus of data by other research standards, CA has a long tradition of working with a smaller number of episodes or cases. For example, Schegloff's (1987) influential treatment of single episodes of interaction displays the analytic power CA has to find order in a singular instance of talk-in-interaction. My collection of four cases allows comparison across these cases, but the main point of single episode of analysis is that, as Schegloff observes, "past work [in the field of conversation analysis] on a range of phenomena and organizational domains are brought to bear on the analytic explication of a single fragment of talk" (1987, p. 108).

After organizing my collection, I then further transcribed each case using the transcription conventions commonly used in CA. I closely followed a Jeffersonian approach (Jefferson 1974, 2004). This type of detail-oriented transcription and analytic approach helped me concentrate on the "practices" of talk. I paid close attention to the micro-features of human interactions, such as overlapping turns-at-talk, shifts in tone, increased or decreased speed of speech, rising and falling intonation, pauses in between words and turns of talk (measured in tenths of a second), and elongation of words. For a list and description of the CA transcription conventions used in this chapter please see *Appendix A*. Chatwin (2004) posits that transcribing an audio file using CA conventions requires anywhere between 10 to 100 times the length of the audio file. By way of an example, a 60-second exchange between a patient and doctor may take anywhere between 10 minutes to over an hour and a half to transcribe using CA conventions.

After getting a sense of the larger components of oncology visits and transcribing each case in my new collection using CA conventions, I focused on the organized ways participants produced social action. I looked at the internal components of each turn-at-talk making sure to note how each person formed their turn at talking (Luftey and Maynard 1998), how each participant responded to previous participants' turns of talk, how participants together established mutual understanding, and how they worked to deal with interactional problems that arose (ten Have 2007; Hoey and Kendrick 2017). Most relevant for this chapter, I looked at the structural components of each WTM inquiry, paying attention to both the similarities and differences across cases.

Findings

Similar to past research, my initial analysis of 85 audio recorded clinic visits shows that patient-doctor interactions have a clear organizational structure (Byrne and Long 1978; Frankel 1990; Heritage and Maynard 2006; Robinson 2003). Lung cancer visits at the Lorne Clinic follow a sequential phase structure (*see Appendix B*) similar to what previous research on oncological visits report (Cortez, Maynard, and Campbell 2019; Maynard, Cortez, and Campbell 2016; Singh et al. 2017). The main components[8] of lung cancer visits follow a "typical phase structure" that generally includes a discussion of symptoms ("symptom-talk"), disclosure and discussion of new diagnostic scan results or a review of previous results ("scan-talk"), then a review of available treatment options (treatment-talk), and finally planning future visits or

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[8] For a detailed discussion of what type of topics are discussed during each phase see (Cortez et al. 2019).

discussions around planning scans or chemotherapy (Singh et al. 2017, p. 3). Singh et al. (2017, p.4) also show that explicit prognostic discussions are limited and almost exclusively initiated by patients. This chapter shows that when oncologists use “what this means” (WTM) inquiries, the formulation is situated within the typical phase structure of clinic visits; this means that WTMIs fit within the organization of a “typical” clinic visits and do not reorder or supplant the phases (*see Appendix C for a diagram*). WTMIs use the typical phase structure to build in opportunities to discuss prognosis (prognostic-talk). Specifically, WTMIs come immediately after scan-talk, extending the time spent discussing scan results to address prognosis). These formulations do not supplant treatment-talk, rather they insert prognostic-talk before discussions of treatment options.

What This Means Inquiries

This chapter’s main analytic task is to examine a set of inquiries that ask patients and caregivers whether they would like to discuss prognosis. As mentioned above, we see these types of inquires after patients discuss scan results. WTMIs are not uniform in that they are differently organized, yet they have the same function. In terms of structure, they are close to what Schegloff (2007) calls “topic proffers” (p. 170), in that the speaker offers a topic for others to accept or reject. In this context, it is up to patients or caregivers to provide a “go-ahead” or “block”—i.e., decline—the topic the oncologist mentions in their utterance (Schegloff 2007, p. 170). Moreover, Schegloff posits that, “in the turns following these topic proffers, that is, in second position, the key issue is whether the recipient [patient or caregiver in this chapter] displays a stance which encourages or discourages the proffered topic, embraces it or rejects it, accepts or declines what has been proposed” (2007, p. 171). Overall, WTMIs work towards one general goal, which is to interactionally pivot into discussing a patient’s prognosis.

Setting the Topical Agenda and Forecasting Prognostic Information

WTMIs suggest a new topical agenda—mainly the prognostic implications of recently discussed diagnostic news or information. The formulation of WTMIs forecasts the valence[9] of upcoming prognostic information. The organization of these inquires provide context cues that indicate that the news is going to be difficult to hear (i.e., negative valence), which gives patients and caregivers advanced warning. As Maynard (1996) suggests, forecasting helps prepare a "social psychological environment" in which recipients (patients and caregivers) can start preparing for the difficult news to come (p. 110). Furthermore, the format of WTMIs provides a preview of the topical agenda. In other words, the way the oncologist uses the inquiries provides clues as to why the news is going to be "bad." We see this feature in extract 1, which shows Betty (patient), Tom (husband) and Dr. Blackwell discussing recent diagnostic scans.

Betty and Tom are in the clinic to discuss her new diagnostic image (chest x-ray) and laboratory tests. Betty recently had radiotherapy to try to slow down the lung cancer that spread to her brain. She is also missing a lung, which was removed because of the location of her tumors and the aggressive progression of the cancer. After initial greetings, Tom quickly asks about the new chest x-ray and the doctor tells them that that the x-ray "looks good." However, what Betty and Tom will soon be told is that despite the x-ray looking good, the real concern is the progression of Betty's lung cancer to her brain. At this point in Betty's illness trajectory, her lung cancer will not kill her. From a medical perspective, Betty's brain tumors are more lethal than the cancer in her lung. Even if the x-ray had shown that the cancer in the lungs had

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[9] The word "valence" here refers to the degree of negative or positive attribution something like prognostic news or information has (Roberts, Margutti, and Takano 2011). See also Maynard's (Maynard 2003) usage of this term in his analysis of bad and good news in conversation as well as clinical settings.

worsened, the aggressiveness of brain tumors would still threaten her life much more. At this point in the conversation, however, Betty and Tom only know that the x-ray shows that the cancer in Betty's lung looks good.

Dr. Blackwell briefly discusses the x-ray of the lung before moving on and telling Betty, "the cancer was mean in what it did, showing up in your brain like that." Betty simply responds by saying that she guesses so. Dr. Blackwell then says, "felt mean to me. Does it feel mean to you?" As Betty tells him that she does not feel anything because "there's no pain with it," Tom quickly changes the topic by talking about how well Betty did with her treatment. After Tom starts an extended exchange about how well Betty did while she was in the hospital for her radiotherapy, the doctor tells Betty that she is "tough," which is where the transcript picks up the first extract.

At line 1, Betty responds to her doctor's assessment (that she is tough) and the doctor quickly closes out that turn-at-talk at the second line. We see the doctor start his WTMI at line 6. He begins to formulate the inquiry in a straightforward way, but restarts his inquiry and uses a repair that is related to what are known as pre-announcements, and, in this case, "forecasting" the bad news to come (Maynard 1996). More precisely, the pre-announcement is also a topic proffer as formulated by a WTM inquiry (line 6). The doctor uses a "do you" formulation, but quickly stops and restarts his question by switching to a "did anybody" formulation, which he says at a faster speed than any other words during this turn-at-talk.

Extract 1, Setting Topical Agenda and Forecasting Valence

```
1   Betty:     Well my body seems to be=
2   Doc:       =Yea:h=
3   Betty:     =(°Mmhm°)=
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4 Doc: =Tch .hhh=
5 Betty: =°Mm°=
6 Doc: → **=Do you- >did anybody< talk about what this me:ans that the**
7 **cancer came back in the brain?**
8 (0.2)
9 Betty: → **>No<**
10 (0.2)
11 Doc: → **Do you want to?**
12 (0.7)
13 Betty: → **Well sure**.
14 (1.3)
15 Doc: .hh It's a little bit serious::
16 (0.2)
17 Betty: Yes, I thought >it might be.<

There are a number of things that stand out in the doctor's utterance at lines 6-7. First, the doctor decides not to be so straightforward, or "blunt" (Maynard 1996), with his initial question. Rather than directly asking Betty if she would like to discuss what it means that her cancer "came back in the brain"—a question that "do you" possibly projects, as at line 11—he asks her if anyone has talked to her about what that means. This can be considered as a topic proffer, and, with its reference to "anybody," it prefers a confirmation, which would align with that polarity. Betty produces such a response at line 9, and, even though it is brief, it encourages the doctor's further proffer to address the issue of what the metastasis means (line 11). Betty pauses briefly (line 12) but aligns to this proffer (line 13) as well.

The original proffer contains a marker that signals the seriousness of the possible agenda. By asking Betty if anybody talked to her about what it means "that the cancer came back in the brain," the doctor transmits the implication that there is something *beyond* her new scan results that needs discussing. As the proffers are accepted, their naming of the subject (cancer in the brain) means that the matter is now officially to be the center of discussion. Although the 0.7 second hesitation (line 12) is longer than the average silence between turns of talk[10] found in

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[10] The mean response time between peoples' turns-of-talk is approximately 0.25 seconds. Stivers and colleagues (2009) measured response times between turns of talk in 10 languages. They used data from

English speakers (Stivers et al. 2009), after Betty's mostly aligning (ala the "well"-preface) line 13 response, the topic proferring sequences are complete. At this point, the doctor has the "go-ahead" to start prognostic-talk. We see the oncologist hesitate with a long pause (1.3 seconds) and an inbreath (.hh), both of which can pre-indicate bad news (Maynard and Frankel 2006), he then tells Betty that it is a "little bit serious." Betty quickly provides a my-side affirmation, and the participants go into the specifics of the news.

In the conversation that follows the exchange captured in the extract, Betty learns that she has entered into a different stage of her illness trajectory. The doctor tells her that her medical team will routinely scan her body, but that the cancer in her brain is the primary concern. They then discuss her ability to travel and the biophysical changes she might experience due to her brain tumors. Betty also learns that her past treatment protocols, which Tom enthusiastically wants to continue, will no longer be an option since her cancer spread through the bloodstream into her brain. All this information is important but is difficult to transmit. However, the WTM formulation creates the space for Betty and Tom to decide whether it is time to discuss the news while offering an advanced warning that difficult news is coming. Across multiple institutional contexts, vocal forecasting strategies often include some sort of prefacing (Bies 2013). For Betty and Tom, the doctor's prefacing is not as direct as seen in other studies, e.g., "I have some bad news" (Clark and LaBeff 1982, p. 382); instead, Dr. Blackwell seems to ease the participants into the news.

There are two key features in this WTMI that display the preferred positive response (confirmation or acceptance) of the utterance. First, the doctor's inquiry takes a lexical stance by directly naming the next potential topic (cancer in her brain). Dr. Blackwell's inquiry invites an

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traditional indigenous communities to major world languages: ǂAkhoe Hai||om (Namibia), Danish, Dutch, English (United States), Italian, Japanese, Korean, Lao, Tzeltal (Mexico), and Yélî-Dnye (Papua New Guinea).

acceptance of the new topic precisely because of the way he formulates it. Naming the topic lexically builds in the legitimacy of the topic and implies the importance of discussing the now named topic, suggesting that the news that the cancer is back in Betty's brain is important (Raymond 2010). Given that the cancer in Betty's lung "looked good," but the doctor brings up her new brain tumors rather than continue to discuss the good news, suggests that this other news (brain tumors) might be more pressing, which further invites the positive acceptance of the proposed topic (Heritage and Raymond 2012). As mentioned above, lines 6-7 have the properties of a pre-announcement as well as a topic proffer. One characteristic of a pre-announcement is that it makes the expansion of the thing it is announcing the "contingent next step" in a conversation (see Schegloff 2007, p. 39). As such, explicitly naming the topic (cancer in the brain) and pre-announcing the potential next topic work towards building an interactional setting in which acceptance is the socially preferred response.

While Betty displays some slight hesitation and resistance, a common feature of WTMIs is the almost immediate uptake by the next speaker with an affirmative answer, which is a "go-ahead" that accepts the proposed topic. As we will see in subsequent examples, WTM inquiries are answered affirmatively, either with minimal hesitation, well within the range noted by Stivers and colleagues (2009), or more immediately answered with no discernible pause between the first speaker (doctor) and the next (patient or caregiver). We see an immediate answer in the next example.

Accepting WTM Formulations with Immediate Uptake

Patients may respond quickly and accept WTM inquiries, typically with little to no delay. An example of these two features of WTMIs is seen when Ester and Neil are at the clinic to meet with Dr. Blackwell on a June morning. After initial greetings and small-talk, the doctor brings up the recent scan results. He mentions that the latest magnetic resonance images (MRI) show that Ester’s tumor grew. In the recent past, they tried treating the tumors with radiation, but it seems that the largest of those tumors has grown large enough that it is now very close to her spinal cord. The doctor then mentions that Ester’s platelets are low. Ester tells her doctor that she had a feeling that her scans would not show “anything good” because she was in more pain the past few months.

Doctor Blackwell posits that her low platelets are either because of the medication or because the cancer is “living in so many” of her bones that her marrow is unable to “make stuff.” Throughout scan-talk, Ester looks somber, avoiding eye contact, and saying “okay” to most of what her doctor is telling her. The doctor tells Ester, “ You're saying ‘okay’ a lot, none of what is coming out my mouth is okay, Ester,” to which Ester simply responds with “yeah.” When Dr. Blackwell asks Ester how she is dealing with “all of this,” she responds by saying that she came back to “realization” that god determined her fate “a long time ago” and that while she might not know how much time she has left, “that day has never changed.” She then tells her doctor that she knew the odds that her current medication would work “were not good.”

After the doctor states that he is impressed with how Ester is coping with all the bad news she keeps getting, she tells him that she has not been feeling well the last two weeks so she felt that something might be wrong. Neil, Ester’s husband, then mentions that it is more difficult for them to stay in hotels when they come into the city for her treatments and clinic visits. He then asks a question about Ester’s feet. During the doctor’s response to the question about Ester’s feet, the doctor pivots and suggests a different topical agenda—a discussion of time and what the scans are showing, i.e., what the scan results mean. We pick up the conversation with Neil asking about Ester's feet.

Extract 2, Preferred Acceptance

Neil: Uhm (.) what do >you think< of the swe:lling in her feet, is
that part a the:
(0.5)
Doc: Tch
(0.2)
Neil: °Uh° pa- part a the drug th↑ing too:: or is that a lack a
steroids:: a body rejection or:
(0.2)
Doc: No:: I th- (.) my guess: is that that's:: n:othing serious
but rather related to: the::: (0.7) cancer:: a:nd its
impacts on your: n- nutrition and the stero↑ids and its
impacts on your nutrition an::- .hh (   ) ye↓ah. I- I- th-
(2.5) it's about the same on both fee:t (0.4) you know.
(0.5)
Neil: °°Yeah°°=
Doc: =I think that's just (0.8) a sign of what's happening. Not
anything: (0.7) particularly serious or >anything we need to
do anything< about.
(1.2)
Neil: (°>M kay<°)
(1.5)
Doc: → **W:hile we're at it, should we t↑alk about what all this**
means, I mean, you sortta said, I don't know how many days::
a::nd that sort of thing, I mean, do: yo- is that stuff you
wanna talk about?
(0.1)
Ester: → **Yeah. Absolutely. I- (.) I mean (0.5) we need to know.**
(0.2)
Neil: Yeah. What I'm hearing so far is: radiation didn't work
here: a:nd it's probably not going to be an option for us
again?
(0.5)
Doc: .hh (1.5) more radiation, I don't think is (0.2) gonna be an
option. hh For starters ((Ester coughing)) when we radiated
previously, and help me remember, did we radiate >that part
of your neck< (.) twice?
(0.3)

In the first 20 lines, Neil restarts symptom-talk and asks if Ester's problems with her feet are due to side effects from her treatment. Dr. Blackwell posits that her swelling is "nothing serious" and is something that they should not worry about. While the doctor assures Ester and Neil that her swelling is not of concern, he does state that her feet are a "sign of what's happening," which is a callback or reference to what the scan results show (lines 9-13). Neil offers a closing at line 20 (“M kay”), and with the 1.5 second silence that follows, the matter of Ester’s feet seems closed.

We see the WTM formulation start at line 22. Doctor Blackwell begins by uttering, “while we’re at it,” which initially appears loosely connected to Neil’s question about Ester’s feet; it seems to indicate that the doctor is continuing the restarted symptom-talk. As we will see, however, doctor Blackwell’s “while we’re at it” is actually proposing to move past Neil’s symptom-talk. This component (at line 22) of his turn-at-talk holds some of the essential parts of WTMIs, such as the euphemistic return to the bad news, and a preferred affirmative answer. By line 23, the doctor offers an I-mean utterance as a repair[11]. At the start of line 23, the doctor shifts from displaying epistemic modality (“should we” at line 22) to offering a kind of justification for why he is proffering this topic (“I mean, you sortta said”). In repeating what Ester said about time and “days left” (lines 23-24), the doctor shifts the domain of the topic to one that Ester creates, related to her concerns, rather than something that he is bringing up due to his agenda. Also, the totality of the I-mean statement (“I mean” + “you sortta said…”), establishes that he is offering to discuss what the scan results mean and this will include discussing time left to live. By line 24, doctor Blackwell latches onto Ester’s comment about time, bridging over Neil’s symptom-talk restart, using “while we’re at it” to do so.

Doctor Blackwell moves to complete his WTMI by the middle of line 24—“I mean, do: yo- is that stuff you wanna talk about?” We see another I-mean utterance, effectively connecting all of the different components from lines 22-24, to the final inquiry. This final question initially starts as a “do you” formulation, but is repaired to ask if that “stuff” is something Ester wants to talk about. Here the use of “stuff” links back to Ester’s previous statements about time, as

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[11] I-mean utterance seems to simply act as a preemptive self-repair as a way of completing the intended action (Maynard 2016; Schegloff 2013), i.e., asking the patient if she would like to discuss what the scan results mean.

evidenced by the doctor’s recollection of Ester’s recent statement (“you sortta said, I don't know how many days:: a::nd that sort of thing). The use of “stuff” also subtly indicates that they can discuss topics beyond “how many days” Ester may have. If Ester agrees to discuss time, she is agreeing to start prognostic-talk since discussing time left to live is a major feature of prognosis (Daugherty and Hlubocky 2008; Hagerty et al. 2005; Lamont and Christakis 1999).

Almost immediately, Ester agrees with the doctor’s suggested topical agenda (line 27). In fact, her “Absolutely” intensifies the initial agreement (“Yeah”). Ester’s “we need to know” might also be orienting to her doctor’s strong presentation of preference and his subtle epistemic modality, or it could relate to her “Yeah. Absolutely,” emphasizing (repairing) what she meant by her agreement. Her quick response to the doctor’s inquiry (topic proferring) provides evidence of Ester fully embracing the topic her doctor offers (i.e., prognosis). Ester’s quick and short response displays a positive “stance” to the topic offered, in the same way a longer response that does not offer a quick positive response might show a rejection or “negative stance” to a topic (Schegloff 2007, p. 173). As it stands, Ester’s short and positive answer, followed by her intensified initial agreement displays a clear “go ahead,” acting as a signal to her doctor that she gives permission to start prognostic-talk.

The doctor’s use of “should we talk” at lines 22-23 instead of “would you like to talk” indicates, and lays the foundation for, the appropriateness of the action (i.e., discussing what all this means is an appropriate next step). In fact, the verb “should” reflects epistemic modality which displays a kind of professional claim to discuss what “all this means.” At the very least, “should” indicates that the oncologist determines that discussing what “all this” means is appropriate or permissible at this point in the visit (Coates 1983; Palmer 2001). We also see that this part of the formulation holds a key component of the preference structure. The use of a modal verb indicates that the doctor knows there is something beyond the scan results that needs to be discussed (Olaniyan and Adeniji 2015) and expresses a kind of desirability to discuss what “all this” means (Lillian 2008). If the other participants in the room decide not to take up this topical agenda, they are presumably missing out on what the doctor has to say, but also misaligning with what the doctor presents as the preferred next action.

We see misalignment is Neal’s next action. After Ester agrees to discuss what “all this means,” Neil summarizes what he understands from the previous exchanges. He brings up radiation and launches into treatment-talk, which is traditionally the next phase in the clinic visit structure, but is not exactly what the doctor was suggesting as the next topic of discussion. An indication that there is misalignment occurs when the doctor quickly answers Neil’s question but comes back to what “all this means” by suggesting that the radiation will not hold back the cancer near the spine and that the spinal cord does not “forgive” doses of radiation. The doctor tells Ester and Neil that the spinal cord has a certain limit of radiation it can handle and if that limit is reached then further radiation will permanently damage the spine. The doctor then pivots and tries to start prognostic-talk, similar to other “second tries” during topic proferring sequences (Schegloff 2007, p. 174). The extract picks up shortly after the transcript above leaves off.

Extract 3, Using a WTMI to re-start prognostic-talk

```
Doc:          We’↑ve not been able to hold your cancer for very long
             (1.0) with ↑any of the things that we've thrown at it.
             ((Sniffs))
             (1.6)
Doc:      →  .h I could describe >a little bit< about what I think (.)
             the future's gonna look like (0.4) <if you want me to.>
             (0.3) I could talk about- (1.0) my best guesses about time,
          →  if you want me to::
             (2.8)
Neil:               >It's up to you ((looks at Ester)).
                                      (0.6)
Ester:                   It's up to you.=
```

```
57  Neil:        =Naw, I'm good with that, $yeah. ((starts quietly
58              laughing))
59  Doc:               $Not really, but:=
60  Neil:        =((laughing)) No, I'm not good with that, but I haven't
61              been for a whi:le.
62              (0.2)
63  Doc:         ↓Yeah.
64              (1.2)
65  Doc:        So this is all shitty.(0.8) Uh::m, I think the reality is
66              time is getting pretty sh:ort. (1.1) I think this thing is
67              marching: pretty fast. And I think the pain that you're
68              having means I'm gonna (.) need ta work harder to keep your
69              pain under control, which means more medicine. (0.9) Which
70              means probably more sleepy. (1.1) .h I think the:: tumor up
71              next to the spinal cord (0.2) is very serious (0.6)uhm: I
72              think in the worst case (0.3) it could cause your arms and
73              your legs not to work very well (0.8) uh:m, if it really
74              pushed on that part of your spinal cord (0.6) uhm:: ↓youknow,
75              I think it would take your LIFE.
```

At line 45, Dr. Blackwell takes Ester’s permission to discuss “what all this means” and launches into describing the prognostic landscape. At lines 48 and 49, after a brief summation of the ineffectiveness of their treatment regimen, the doctor circles back to his first WTMI (see lines 22-25). Doctor Blackwell suggests that he can describe what the future might look like for Ester. The doctor’s “if you want me to” at line 49 does not have rising intonation, but is clearly a second attempt at a WTMI. At lines 50 and 51, after a brief pause, he goes on to suggest that a sub-topic of this larger topical agenda (i.e., prognosis) could be a discussion of time. Like other “second tries” of topic proffering sequences (see Schegloff 2007, pgs. 173-174), Dr. Blackwell’s turn of talk (lines 48-51) narrows in on what he is proposing with his WTMI—talking what the future is going to look like and also discussing time. Like the description of Ester’s prognostic landscape, the doctor presents the discussion of this sub-topic (i.e., time) as a choice. Ester can reject or accept this topic.

While the doctor’s turn-at-talk does not have the same organization as the first WTMI, it seems to call-back to that initial WTM inquiry, by re-stating the potential topics. Despite the clear preferred affirmative response, this larger topical agenda presents as a choice for Ester and

Neil. After Ester and Neil produce an exchange about responsibility for allowing the topic proffer (lines 52-55), Neil accepts the topic (line 56). He turns his response into a joke (lines 57-59) by implying that he is not really “good with that” but that he is “good” with starting prognostic-talk. The doctor then explains that time is getting short and that the tumor growing so close to the spinal cord is very concerning (lines 68-69). Dr. Blackwell explains what Ester’s probable physical symptoms might be if the tumor gets bigger (lines 69-73). It is only after prognostic-talk that the doctor moves into treatment-talk, explaining why other treatment options are no longer available, and discussing the different options for controlling the pain at the end of Ester’s life. In this example, the doctor inserts prognosis between scan-talk and treatment-talk. Singh and colleagues (2017) suggest that prognostic-talk can be added at the end of either scan-talk or treatment-talk and it not only works with the traditional phase structure found in clinical visits, but it also extends the time participants discuss scans and can bring a better understanding of what a patient’s future illness trajectory might look like.

Collaboratively Shaping Prognostic-Talk

WTM inquiries present in a way that indicate a need for an answer. The formulation of WTMIs signal the appropriateness of an answer, much like other forms of requests, offers, and questions. That is, patients and caregivers recognize that WTMIs are utterances that “require” a response. Similar to the way we recognize that an initial “hello” from a friend you are meeting for coffee “requires” some sort response in turn, what Schegloff and Sacks (1973) call a second pair part. However, WTM formulations differ from greetings in that the second speaker has a choice to accept or reject the proposed next topic (discussing prognosis). This type of choice, which is built into WTM inquiries by virtue of their suggesting the topic and not directly launching into the topic, helps set an interactional environment that supports patient and caregiver agency.

Bruce and Julie provide an example of how patients act within this supportive interactional environment. The clinic visit starts by slightly deviating from the typical phase structure. Dr. Blackwell asks Bruce to “catch” him up on things. After Bruce briefly outlines his recent conversations with his radiation oncologist. Together, Bruce and Dr. Blackwell piece together the updated diagnosis—Bruce’s cancer traveled through his blood into his bones. Bruce then tells his doctor that his recent treatment caused him discomfort. Julie tells Dr. Blackwell that the radiation immediately affected Bruce. Dr. Blackwell expresses his surprise since it usually takes one to two weeks for radiation to start to affect patients.

Extract 4 starts with Bruce responding to Dr. Blackwell’s comments about the radiation’s “lag” with an assessment of his immune system. Bruce offers one last assessment of his immune system and the topic seems to end by line 8. Dr. Blackwell starts to formulate his WTM inquiry with a pre-announcement, similar to what we see in extract 1. The doctor starts with “Has anybo-,” similar to how he starts to ask Betty, “did anybody.” Dr. Blackwell elects to abruptly abandon his initial formulation. After some restarts (“b:- d:- d-“), the doctor repairs his turn and finishes his WTMI (lines 9-12). At line 9, we see Dr. Blackwell start to form a pre-announcement (“do you have some sense, did doctor Tessio or others…”). Unlike the example in extract 1, this pre-announcement does not end Dr. Blackwell’s turn. Dr. Blackwell’s pre-announcement does not wait for Bruce’s confirmation or rejection of the first question (did others talk to Bruce about the meaning of the latest diagnostic news?). Instead, the doctor continues with his turn and attaches the final component of the WTM formulation (“is that sumtin you wanna talk about?”) to the pre-announcement.

Extract 4, Guiding Prognostic-Talk

1 Bruce: I've always had a hell of an immune system.((researcher
2 chuckling)) I real[ly do]
3 Doc: [Maybe] yo[u-]
4 Bruce: [I]
5 he[al really fast, if-]
6 Doc: [Well, that might f-]
7 that might fare well=
8 Bruce: =And I seldom get sick.
9 (0.3)
10 Doc: → **Has anybo::- b:- d:- d- do, do you have some sense, did**
11 **Doctor Tessio >or others< talk about what it means that the**
12 **cancer went from the lung to the bo::ne, is that sumtin yo:u**
13 **wan:na talk abou:t?=**
14 Bruce: → **=That- I'd like to learn as much as pos:sible. I'd (0.5)**
15 **just as soon you be as straight as you can be with [me**]
16 Doc:
17 [↓O]kay. (0.6) .hhh in some of the things you're saying
18 make me- e::h susp↑ect this isn't ne:ws:, but the::, what
19 it means: is:: when a cancer spreads from one place to
20 another place through the (.) bloodstream is that (0.3) t-
21 to the best of our kno::wledge (0.4) we might be able ta
22 contro::l ↑it (1.0) maybe help (.) find more ti::me, but
23 not make it go awa::y=
24 Bruce: =Right. I understand that=
25 Doc: =Oka:y.

Even though Dr. Blackwell's pre-announcement (lines 9-11) does not fully turn into a question, it still builds up the WTM formulation. Like other WTMIs, Dr. Blackwell's talk forecasts the valence of the news. Mentioning the cancer's progression again, after Bruce and Dr. Blackwell already reviewed the updated diagnosis towards the beginning of the clinic visit, provides further cues that this development is not positive. Progression at any point in someone's illness trajectory is a point of concern, but it is particularly troubling for terminal patients. Directly bringing up Bruce's progression at this juncture hints at bad news to come.

The doctor further elevates the importance of the cancer's progression by asking Bruce if he's discussed "what it means that the cancer went from the lung to the bone" with Dr. Tessio (his radiation oncologist) "or others" (lines 9-12). The indication here is that the news is important enough that someone other than Dr. Blackwell might have already broached the subject with Bruce. As mentioned above, Dr. Blackwell ends his turn (lines 11-12) by combining the pre-sequence with the final component of the WTM inquiry ("is that sumtin yo:u wan:na talk abou:t?"). Bruce's affirmative response comes with no hesitation. Yet, Bruce's response is more complex than a simple yes or no. Bruce decides to respond to Dr. Blackwell's inquiry by detailing how he prefers to discuss the proposed topic, rather than simply agreeing to "talk about" the cancer spreading to his bones. Bruce's "I'd like to learn as much as possible" gives his doctor a primer for how to proceed; he wants to understand the full prognostic landscape. Bruce goes further and gives Dr. Blackwell additional instructions—"I'd just as soon you be as straight as you can be with me." Dr. Blackwell quickly orients to Bruce's cues, even overlapping with the last part of Bruce's (lines 14 and 15). Here, Bruce clearly displays his preference for the doctor to be as direct as possible.

Together, Bruce, Julie, and Dr. Blackwell proceed by unpacking what it means that the cancer spread through the bloodstream and started growing in his bones. They deconstruct what incurable means and they discuss the difficulty in predicting how much time Bruce has left to live. It is only after Bruce and Julie get a detailed description of the prognostic landscape that they finally transition to discussing treatment options.

Amy and Dr. Blackwell provide another example of the ways WTMIs help create an interactional environment that supports patient's opportunities to assert their agency and shape prognostic-talk. The extract below, starts after Amy learns that the cancer in her lung has grown and that growth contributed to her lung collapsing. The doctor also tells Amy that he suspects the cancer in her brain has grown as well. Amy then asks if her brain tumors are the reason she is having memory issues. Dr. Blackwell posits that her memory issues might actually be a side effect of her radiation treatment (lines 1-6). By line 12, Amy seems to be satisfied with the answer and the matter of her memory issues comes to an end. After a long silence (line 13), Amy picks up the next turn and asks at lines 14-17 if in the future some of her physical symptoms (e.g., trouble walking) are going to inhibit her mobility. While Amy is not asking how long she has left to live, she is clearly asking the doctor for some sort of prognostication—she wants to know how her body will react as her cancer grows.

Before she can finish her turn, the doctor at line 18 latches on to her “less” and starts his turn. After a tongue click, the doctor’s “yeah” at line 18 acts as a pre-shift acknowledgment (Jefferson 1984) that signals the doctor is ready to shift from being a listener to taking the position of the speaker. Unlike other “yeahs” that indicate a shift in topic (see the analysis of Lottie and Emma's exchanges in Jefferson 1984), the doctor’s yeah-lead utterance at lines 18-19 shows that he is ready to take his turn and that he will continue the topical agenda that Amy initiated (“let me:: (0.4) >take a step back< an:d > the questions you're asking are perfect ones”). He links Amy’s questions to his own interpretation of what Amy’s questions are indicating, “it sounds like you wanna< talk about kinda what this means for yo[u:],” starting his WTMI by way of producing a candidate question on Amy’s behalf. The doctor takes Amy’s concerns and lexically ties them to the doctor’s pre-announcement which builds towards his WTMI.

Extract 5, Asserting Agency and Shaping Prognostic-talk

```
 1   Doc:      You know, Amy, it could be that, or that actually (0.2) even
 2             more likely, is the radiation that they: (0.4) delivered?
 3             (0.5) >Not< (.) >I don't mean to put it on someone else<=
 4   Amy:      Ye[ah
 5   Doc:        [The radiation that we: delivered↓ u:[hm]
 6   Amy:
 7
 8             [Mm]hm
 9   Doc:      .hh Radiation definitely causes memory impairment.=
10   Amy:      =Mm hmm=
11   Doc:      =Um, and so:: (0.3) .h tch, that might not be the cancer,
12             that actually might be what we did because the cancer was up
13             th[ere.]
14   Amy:        [Yeah] (0.2) yeah.
15             (1.0)
```

16 Amy: → ((Sniff)) (0.4) tch, U::hm, tch, (.) any:: (0.4) f:uture,
17 → like (0.3) I- I'm having a hard time wa:lking, does
18 that
19 → (0.2) mean I'm going to be (0.2) come less able ta (0.4) get
20 → aro::und or: (.) eh- ehm- (.) less energetic, less:=
21 Doc: **=Tch (.) yeah, so let me:: (0.4) >take a step back< an:d >the**
22 **questions you're asking are perfect ones, it sounds like you**
23 **wanna< talk about kinda what this means for yo[u:]**
24 Amy:
25 **[Mm] [hm]**
26 Doc: **[an]d**
27 **how you're gonna >be feeling< an:d (.) like, what happens.=**
28 Amy: **=Right.**
29 **(0.5)**
30 Doc: **Is that what you want to talk about?**
31 Amy: **=Right=**
32 Doc: =I will talk about that. .hhh To do that, >would it be< (0.3)
33 <helpful> or- o- okay anyway for me to kinda describe (1.0)
34 ((doctor audible swallows)) how your body might fe::el, in:
35 (1.2) in the coming::: ↑period of time? (0.6) An:d >I guess,
36 → another question< is **do you wanna talk about time too:?**
37 (0.3)
38 Amy: → **Tch .hh u:hm I'm no:t so: s:ure about talking about T:ime**
39 → **because I think that (0.3) is a- (.) every person and gO:D**
40 → **that's gonna make the decision on (0.8) how much time.**
41 (0.2)
42 Doc: Yeah=
43 Amy: =So I'm not worried about that so much, b[ut]
44 Doc:
45 [Ok]ay.
46
47 (0.2)
48 Amy: W:hat I'm going to fee:l that I'm >gonna say,< "O::h, okay,
49 well I knew: this was going to ha::ppen."
50 Doc: Yeah.=
51 Amy: =Ye[ah.]
52 Doc: [Ok]ay (0.2) alright. (0.7) A little bit of preparation
53 about what you might feel.=
54 Amy: =Right.

By line 20, Dr. Blackwell is well into his WTM formulation. The doctor takes "a step back" and we see him start to put Amy's questions into the broader context (prognosis), which his "what this means for you" implies at the end of line 20. Here the doctor specifically proffers a topic, "what this means for you". However, before he finishes his turn, Amy overlaps and offers a continuation token ("mm hm") at line 21. The doctor overlaps her continuation token and continues with his WTM formulation at line 22, continuing his turn. As he does so, he brings up two more potential topics, how Amy might feel and "what happen," both at line 23. While the end of the doctor’s turn does not have rising intonation, it seems to be inviting acceptance or acknowledgment. At the very least, Amy treats it as such by quickly latching to her doctor’s utterance and accepts the proposed action at line 27. Amy’s “right” (at line 27) can be treated as a continuation token or as acceptance. Dr. Blackwell elects to treat it (Amy’s “right”) as an opportunity to confirm that she is offering acceptance, by inserting the question component of a WTMI (“Is that what you want to talk about”). Amy again elects the same acceptance token, i.e., “right.”

Next, rather than fully launching into prognostic-talk we see Dr. Blackwell gather more information about Amy’s preferences. From lines 28 to 30, the doctor reviews how he might start his prognostic-talk, but also seems to organize the preview as another inquiry for Amy to accept or decline. After a pause of a little over half of a second (line 31), the doctor provides another preview of what he could discuss (“And >I guess, another question< is do you wanna talk about time too:?). Amy’s response (at line 34) shows signs of delay (e.g., tongue click, in breath, and uhm) that when done after a question or at the start of someone’s turn can indicate a dispreferred response—not aligning with the preferred affirmative response. The rest of Amy’s response at line 32 confirms the misalignment, “I'm no:t so: s:ure about talking about T:ime.” Notice, however, that she softens the voracity with which she declines the doctor’s question (lines 34-36). Rather than simply saying “no” or definitively rejecting his proposed action (to also discuss time), Amy tells her doctor that she is “not so sure about talking about time” (line34). She goes further and gives him an explanation for why she would prefer to skip the discussion of time (lines 35-36).

Like Bruce, Amy helps guide the doctor’s approach to prognostic-talk. While she initially fully accepts the discussion of prognosis as the next topic, she uses the space created by Dr.

Blackwell’s WTMI to shape the conversation by expressing her preference. In fact, she triggers the WTM formulation by indicating her preference to discuss issues related to prognosis back at line 14. WTM inquiries helped create this space, providing “auspicious” opportunities for the doctor and patient to collaborative feel their way through prognosis—that is, confirming that prognostic-talk is appropriate, confirming how that discussion might go, and providing space for patients to express their preferences.

Discussion

In terminal cancer care, discussing prognosis and building a clear understanding of disease progression are key components of patient-doctor interactions. This chapter examines the use of topic proffering sequences that ask patients and caregivers if they would like to discuss prognosis. My analysis of “what this means” inquiries identifies the specific practices that introduce prognostic-talk as an appropriate next action. I show that participants (patients and caregivers) recognize WTM formulations as invitations to either accept or decline (Bolinger 1978; Raymond 2003). I maintain that WTMIs can also help doctors confirm that patients want to discuss prognosis. Like yes/no interrogatives that have positive polarity (Raymond 2003), WTMIs also have a preferred affirmative response. Yet, even with a preferred positive response, WTMIs support patient agency as they provide an “auspicious” interactional environment (Luftey and Maynard 1998, p. 322) for patients and caregivers to decide whether to engage in and shape prognostic-talk.

My analysis demonstrates the importance that WTM inquiries have in terminal cancer care. I delineate the different interactional tasks WTMIs work to achieve. WTM formulations set the next topical agenda by naming prognosis as an appropriate topic. Even still, the explicitness with which the next topic is nominated varies. For example, after Dr. Blackwell forms an ambiguous WTM formulation, he uses an “I-mean” utterance as a repair, which helps Ester and Neil identify that the doctor nominates life expectancy as the proposed topic. My analysis supports previous work that establishes inquiries are powerful tools in medical encounters (Heritage 2009; Roter and Hall 2006).

Additionally, WTM inquiries convey a preference for patients and caregivers to accept the proposed topic. Like Boyd and Heritage (2006) and Raymond (2006), I show the influence that first position speakers have on how the second position speakers (participants listening) responds to topic proferring sequences. One way first position speakers work towards acceptance is by providing a pre-announcement, which builds to establish the prognosis as a necessary topic. Betty’s case is a good example. Dr. Blackwell’s pre-announcement (“did anyone talk about what this means, that the cancer came in the brain?”) is a common strategy used to elicit positive responses (Pomerantz and Heritage 2013; Schegloff 2007). Finally, we see WTM inquires organized in ways that signal the appropriateness or importance of discussing prognosis. By simply nominating the topic within the WTMI, we see the doctor lexically provide legitimacy to prognosis as the next topic (Raymond 2010). In fact, WTMIs establish and confirm the epistemic domain of the doctor and the next proposed social action (Seuren and Huiskes 2017).

Related to setting the topical agenda, WTMIs provide patients and caregivers a preview of the valence of the news. That is, oncologists can warn others in the room that “bad” news or difficult discussion is coming (Maynard 1996). Despite the quickness between the indication of the valence of the topic and the question component of WTM formulations, the listeners still have time to prepare for the discussion. As I will mention below, having this advanced warning that prognosis is coming, and that the discussion might be difficult, can help patients and caregivers collect themselves and provide responses that help shape prognostic-talk.

This chapter draws from previous research (Cortez et al. 2019; Maynard et al. 2016; Singh et al. 2017) that shows how difficult it is to discuss prognosis. I add to this work by focusing on *how* physicians prepare the interactional environment that supports prognostic-talk. Rather than disturbing the typical phase structure of oncological visits, I show how WTM formulations work within the phase structure. WTM inquiries come after discussions of scan results (scan-talk). The position of WTMIs within the phase structure of clinic visits is important for two reasons. First, if a WTM formulation comes right after scan-talk, then the question carries further context cues, implying that “what this means” is referring to the topic that was just discussed (scan news). Second, by formulation a WTM question right after scan-talk, oncologists and patients can work to establish a clearer understanding of the prognostic landscape, prior to discussing treatment options.

Considering that more aggressive treatment towards the end-of-life is associated with lower quality-of-life (Earle et al. 2004; Zhang et al. 2009) it is important that doctors, patients, and caregivers maximize every opportunity to engage in discussions that help patients receive the information they need to make informed decisions. In fact, Russ and Kaufman (2005) suggest that patients and their loved ones do not need more information, instead, they need more interpretation of the medical details and larger prognostic landscape that those details point towards. WTMIs help transition into a phase that contains a good deal of interpretation.

Discussing prognosis towards the end of someone’s life comes with a number of clinical and interactional challenges. How can oncologists provide the right amount of information and interpretation without crushing existential hope? How do doctors take patients’ preferences into account when they might not align with the disclosure of bad news? What can doctors do to ensure that their understandings of the prognostic landscape more closely align with their patients' understandings? The data throughout this chapter details the range of interactional work WTM formulations do to help strike a balance between patients' goals and interactional preferences and clinicians' duties. WTM inquiries give patients and caregivers opportunities to decline the proposed next topic. Yet, even when accepting the proposed topic, we see patients take their turn-at-talk to do more than just accept the next topic. Bruce, for example, expresses his interest in learning "as much as possible," displaying his preference for a complete breakdown of his prognosis. In the same turn, he further directs his doctor to "be as straight as you can be with me," which seems to indicate that he prefers his doctor not to speak in euphemisms, provide overly optimistic framings, or silver linings. Instead, Bruce advocates for directness and explicit talk. While Dr. Blackwell's WTM formulation provides space for Amy to agree to discuss prognosis, it also provides an opportunity for her to express her preference to *not* discuss time left to live.

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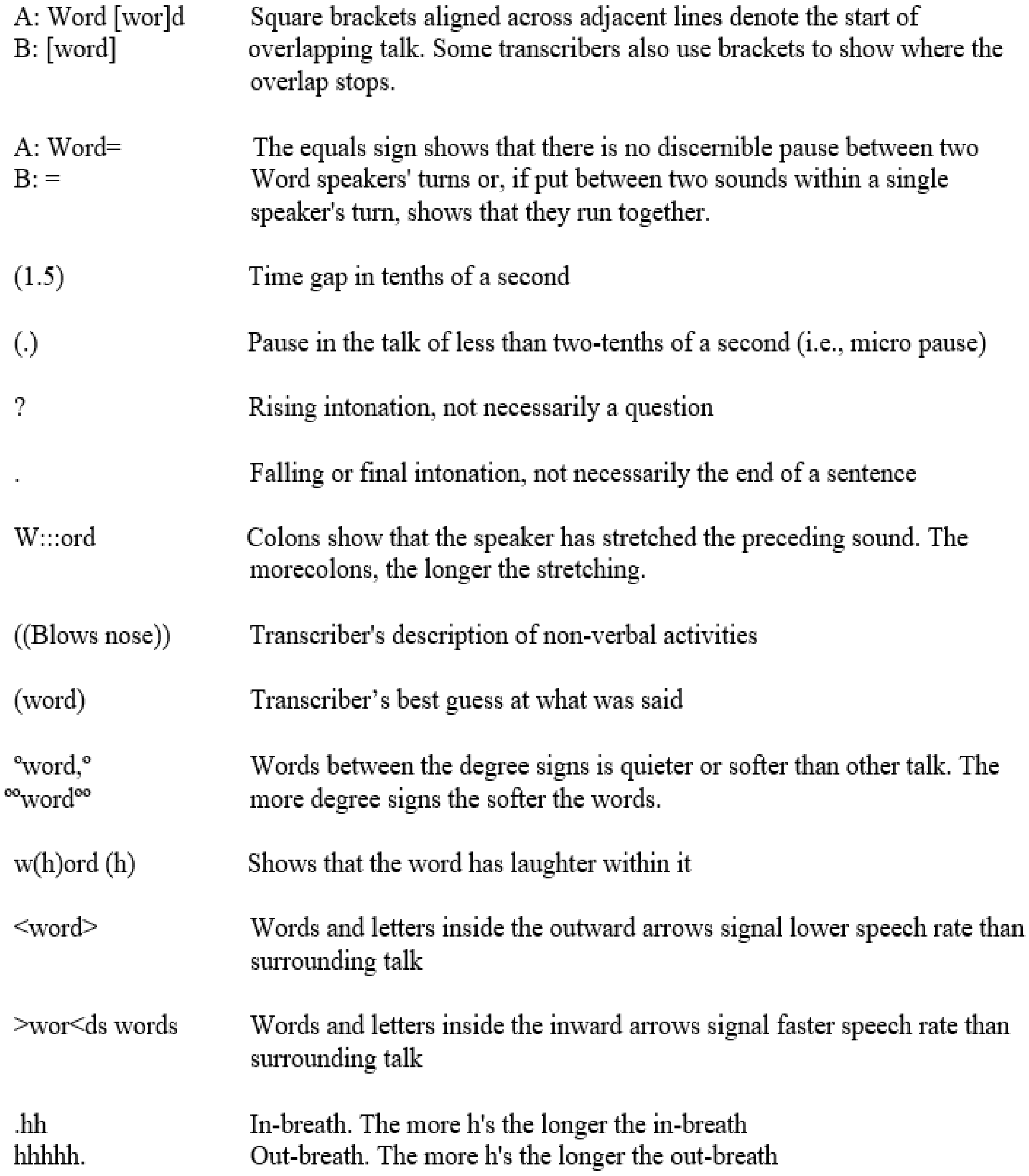
Appendix A, Transcribing Conventions in Conversation Analysis (adapted from, Jefferson 2004; Sacks, Schegloff, and Jefferson 1974)



A: Word [wor]d B: [word]	Square brackets aligned across adjacent lines denote the start of overlapping talk. Some transcribers also use brackets to show where the overlap stops.
A: Word= B: =	The equals sign shows that there is no discernible pause between two Word speakers' turns or, if put between two sounds within a single speaker's turn, shows that they run together.
(1.5)	Time gap in tenths of a second
(.)	Pause in the talk of less than two-tenths of a second (i.e., micro pause)
?	Rising intonation, not necessarily a question
.	Falling or final intonation, not necessarily the end of a sentence
W:::ord	Colons show that the speaker has stretched the preceding sound. The morecolons, the longer the stretching.
((Blows nose))	Transcriber's description of non-verbal activities
(word)	Transcriber's best guess at what was said
°word,° °°word°°	Words between the degree signs is quieter or softer than other talk. The more degree signs the softer the words.
w(h)ord (h)	Shows that the word has laughter within it
<word>	Words and letters inside the outward arrows signal lower speech rate than surrounding talk
>wor<ds words	Words and letters inside the inward arrows signal faster speech rate than surrounding talk
.hh hhhhh.	In-breath. The more h's the longer the in-breath Out-breath. The more h's the longer the out-breath

( )	Missing or inaudible sounds/words
word, WORD	Underlined words or letters are louder than surrounding talk, capitalized words are louder still
↑word ↓	Word Marked shift into higher or lower pitch
Wor-	A dash shows a sharp cut-off or self-interruption of the prior word or sound.
$	Dollar sign indicates smile voice, or suppressed laughter
→	Analyst's signal of a significant line

Appendix B, The Typical Phase Structure of Oncology Visits

I. Greetings / introductions

II. Symptom-talk

III. Scan-talk

IV. Treatment-talk

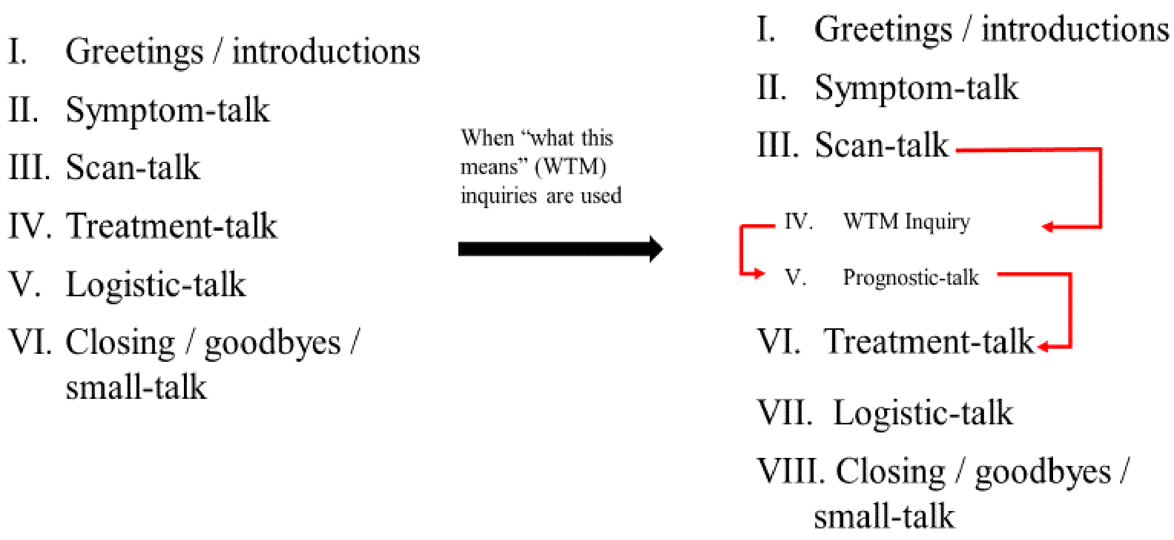
V. Logistic-talk

VI. Closing / goodbyes / small-talk

Appendix C, Transcforming the Typical Phase Structure with a WTM Inquiry

Typical Phase structure

Phase Structure with a WTM Inquiry



I. Greetings / introductions
II. Symptom-talk
III. Scan-talk
IV. Treatment-talk
V. Logistic-talk
VI. Closing / goodbyes / small-talk

When "what this means" (WTM) inquiries are used

I. Greetings / introductions
II. Symptom-talk
III. Scan-talk
IV. WTM Inquiry
V. Prognostic-talk
VI. Treatment-talk
VII. Logistic-talk
VIII. Closing / goodbyes / small-talk

CHAPTER 4 – Invoking Incurability to Discuss and Process Death

Abstract

Treating terminally-ill cancer patients involves biomedical challenges, and it is also fraught with interactional difficulties. Research suggests that end-of-life conversations are not common and that patients often believe their treatments are curative even though they have an incurable disease, which can lead to poor illness understanding and unrealistic views about treatment. There is a tension between patients' goals and the medical limits of treating incurable cancer. Drawing on two years of ethnographic research, I examine how oncologists balance patients' concerns, goals, and treatment preferences with open discussions about limited treatment options and death. I argue that oncologists "invoke incurability" to talk about death and dying and help patients process impending death. When oncologists invoke and establish the incurable nature of the disease, they attempt to accomplish three distinct, yet related, social actions: 1) update diagnosis and confirm the terminal prognosis; 2) temper unrealistic expectations about the overall efficacy of treatments; and, 3) improve prognostic awareness and knowledge. Doctors invoke incurability as a way of calibrating what "terminal" or "incurable" means for each patient at that particular time in their illness trajectory. I end with a discussion about the implications of my results for research on death and dying, emotional work, and patient-doctor communication.

Introduction

It is increasingly expensive to pay for the last year of someone's life. While there are many reasons why end-of-life care costs continue to rise, two of the biggest factors include the increase in medical advancement (technological and pharmaceutical) and the rising cost associated with that advancement. Paradoxically, less chemotherapy and radiation at the end of someone's life is associated with increased quality-of-life measures (Dalal and Bruera 2017; Zhang et al. 2009), yet treatment of terminal-patients has become more aggressive over time (Earle et al. 2004; Zhang et al. 2009). For example, researchers report improved physical and psychological outcomes for patients and their family members when hospice and palliative care services are introduced earlier into terminal-cancer patients' illness trajectory (Bakitas et al. 2009; Gade et al. 2008; Teno et al. 2004, 2013). Furthermore, it is widely established that earlier involvement in palliative care and hospice for seriously-ill patients tends to lower overall costs for health care facilities and patients alike (Ciemins et al. 2007; Dalal and Bruera 2017; May, Normand, and Morrison 2014; Morrison et al. 2008; Penrod et al. 2010). If less invasive and aggressive treatment at the end of someone's life is shown to result in less pain, fewer cognitive issues, a lower psychological burden on family caregivers, higher quality-of-life, and less financial cost, then why are patients and doctors opting to continue with standard care? Additionally, why do doctors and patients decide to continue with aggressive and costly curative treatments at the very end of patients' lives? My thesis is that important answers to these questions are embedded within patient-physician interactions.

I use cancer as my analytic case because of its prevalence. Cancer is the 2nd leading cause of death in the United States, with an estimated 1.68 million new cases identified each year (American Cancer Society 2016; Siegel, Miller, and Jemal 2016). I focus on terminal lung cancer because it comprises 27% of all cancer deaths (American Cancer Society 2016; Siegel et al. 2016). Although new therapies are starting to make a modest difference in the percentage of people alive five years after their initial diagnosis, especially in earlier stages (i.e., 0, I, II), the prognosis of patients with advanced disease (stages III and IV) remains dire. For instance, the median survival time for advanced lung cancer is 8–10 months (Abbasi and Badheeb 2011; Ali et al. 2013). Research shows that even after patients are told they have incurable cancer, they still believe their treatment is going to cure their cancer, illustrating a misunderstanding in prognostic outcomes related to their diagnosis (Pronzato et al. 1994; Rocque et al. 2015; Weeks et al. 1998, 2012). Misinterpreting the intent or purpose of treatments can lead to poor illness understanding, which can negatively impact decision-making and lead to unrealistic expectations about medical care and survival outcomes (Singh et al. 2017; Weeks et al. 2012). In the case of incurable lung cancer, chemotherapy and radiation can help alleviate or control pain and may extend life by weeks or months, but those treatments will not cure cancer.

In this chapter, I focus on clinical interactions among doctors, terminally-ill patients, and family members[12] to investigate how participants manage conversations about end-of-life issues, discuss impending death, and negotiate treatment decisions. Specifically, I analyze the conversational strategy that I term "invoking incurability," which oncologists use to open the discussion of impending death. This conversational strategy involves a range interactional tools, such as implicit and explicit references of the incurable nature of cancer, all of which attempt to acclimate patients and caregivers to news they have already been told in previous clinic visits—that their cancer is not curable, that treatment options are limited or no longer an option, and death is drawing closer. Here, I engage with and build on previous research that argues death is not explicitly discussed and that clinicians are gatekeepers of information who ultimately decide when patients and family members are ready for disclosure about impending death (Christakis 1999; Glaser and Strauss 1965; Hodkinson 2013; McIntosh 1977). I show that oncologists are in a position to decide *how* to carry out that conversation, rather than deciding *whether* they will disclose bad news.

Using ethnographic data collected at a large cancer clinic at a university hospital, I attend to three phenomena. First, I describe how invoking incurability reminds patients and caregivers that the cancer is incurable, which acclimates patients and caregivers to the notion that death may be close. Second, as patients progress in their illness trajectories, the treatment options designed to slow cancer growth become less viable. In some cases, patients or family members develop overly optimistic expectations about their future, which creates the interactional problem wherein

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[12] The terms "family member" and "caregiver" are used interchangeably throughout this paper. While caregivers can also be non-related paid helpers, all of the caregivers in this study were unpaid family members.

physicians must find ways to address the unrealistic goals of their patients. Invoking incurability helps oncologists temper unrealistic expectations about treatment efficacy and prognostic futures. Third, I analyze the ways in which invoking incurability helps oncologists lay the interactional groundwork needed to improve prognostic awareness[13] and knowledge. Drawing on an interaction order approach (Goffman 1983), I examine how discussions about death are introduced into clinic visits. Of specific importance is the manner in which clinical encounters are co-constructed such that patients and caregivers experience multiple occasions to wrestle with news of impending death.

Literature Review

Patient-Doctor Interactions

Research on patient-doctor communication and the patient-doctor relationship comprise a major feature of medical sociology (see Bloom 1963; Charmaz and Olesen 1997; Danziger 1978; Davis 1960; Hall et al. 1981; Haug and Lavin 1981; Heritage and Maynard 2006; Maynard and Heritage 2005; Parsons 1975, 1951, 1964; Roth 1963, 1972). Researchers document the influence that patient-doctor communication has on medical decisions and how patients view and understand their illness (Glaser and Strauss 1965; Koenig 2011; Koenig et al. 2015; Maynard 2003; The et al. 2000). Shaw, Dunn, and Heinrich (2012) argue that the manner in which news is delivered often influences the way people perceive the news. This suggests that the valence of news is not necessarily determined by whether it is categorically “good,” “bad,” or “neutral” (Maynard 1997) but instead may be a “conditional matter” that depends on the participants

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[13] By prognostic awareness, I mean the awareness patients have of their terminal prognosis and shortened life expectancy (Jackson et al. 2013). As such, when I write that doctors attend to improving prognostic awareness, I mean that they attempt to help patients and caregivers understand the patient’s prognosis and their likely illness trajectory (Applebaum et al. 2014).

involved in the interaction (p. 94). A considerable body of research forwards the idea that patient-doctor interactions are not only influenced by the doctor’s agenda, as had been previously thought but rather jointly constructed. As patients and caregivers are more than passive participants in clinical interactions, they actively influence these conversations.

Notwithstanding the co-constructed nature of patient-doctor interactions, the influence of each participant on any given interaction varies. For instance, analysis demonstrates that doctors tend to convey detailed information about a serious diagnosis only in response to direct inquiries from patients (Helft 2005; Schaepe 2013), surgeons frequently use 'evasion' as a method of coping with direct patient questions (Taylor 1988), and clinicians’ strategies of distancing themselves from a sensitive topic like death include using impersonal terms or simply avoiding difficult topics (Fagerlind et al. 2008; Sandén et al. 2001). Doctors can also influence the amount of time spent discussing non-curative treatments (Koenig et al. 2015). Other studies highlight the various ways that patients and caregivers influence clinical interactions and express agency. Gill (2005) demonstrates how patients were capable of exerting recurring pressure on clinicians for diagnostic tests. Koenig's work (2011) suggests that a patient’s silence can introduce resistance and agency into a medical encounter. Additionally, treatments, referrals, and tests are more likely to happen when patients directly request them, regardless of whether the patient needs what they ask for (Gill 2005; Kravitz et al. 2003; Mechanic and Mcalpine 2010).

And yet, despite literature that details the various ways clinicians, patients, and/or caregivers influence clinical interactions, communication difficulties that influence what and how patients understand medical information remain considerable. For example, Weeks and her colleagues show that 69% of patients with metastatic (late-stage) lung cancer and 81% of patients with metastatic colorectal cancer incorrectly believe that chemotherapy will cure their disease (2012). Compounding this problem, other work details how difficult it is to talk about death and dying (Glaser and Strauss 1965; Lutfey and Maynard 1998; Schaepe 2013), how end-of-life issues are not discussed (Schaepe and Maynard 2014), how doctors are reluctant to prognosticate even with terminally-ill patients (Christakis 1999), and how false optimism is *both* the result of doctors withholding information and patients' active role to ignore clear signs of impending death (The et al. 2000). This research points to the importance of patient-doctor interactions and the potential for these interactions to either muddle or potentially improve prognostic understanding and informed decision-making. It also suggests a need for additional research on how communication about death is structured and organized.

Patient-doctor interactions and relationships are a major focus of patient-centered care, the model of care that has come into prominence over the last three decades (Committee on Quality of Health Care in America 2001; Mead and Bower 2000). Patient-centered care stresses respect for and responsiveness to, "individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (Institute of Medicine 2001, p. 6). This is a dramatic pivot away from more paternalistic and biomedical models of care (Mead and Bower 2000). Pushing beyond the philosophical shift, Stewart et al. (1995) stressed the importance of research that influences the clinical application of patient-centered care. To aid in this endeavor, they propose a model designed to specify the various components of patient-centered care: (1) understanding both the physical characteristics of the disease and the patient's illness experience; (2) understanding the patient as a complete person, not just as someone who is ill; (3) finding common ground regarding illness management; (4) incorporating prevention and health promotion; (5) building up and supporting the patient-doctor relationship; and, (6) being realistic about resources, options, and the current state of illness. At the heart of this model and operational definition is patient-centered communication.

Death and Dying

Research in medical sociology, specifically work on death and dying, helps us understand the tension in patient-doctor interaction in the context of terminal cancer. I draw on Glaser and Strauss' (1965, 1968) idea that talking with dying patients is an important yet difficult activity for doctors. Specifically, I start with Glaser and Strauss' theory of awareness contexts (1965), which posits that patients are sometimes unaware of their impending death even though clinicians know that death is close. Glaser and Strauss contend that there are four types of death awareness: first, *closed-awareness* describes instances in which a patient does not recognize that they are close to dying, even though everyone else does; second, *suspected awareness* is where the patient suspects what others know (death is imminent) and attempts to confirm or overturn that suspicion; third, *mutual pretense-awareness* is said to exist when clinicians, caregivers, and patients all understand the patient is dying but pretend that the others' have not reached that understanding; and fourth, *open awareness* is said to be present when the clinicians, caregivers, and patients are aware that the patient is dying and explicitly say so and act accordingly.

I also draw on Timmermans' refinement of awareness contexts (1994). Timmermans' idea of "active open awareness context" (1994, p. 330) is useful for understanding why oncologists might invoke a patient's incurable diagnosis prior to recommending hospice or breaking the news that treatment options are limited. For example, Timmermans contends that "although patients or their family members possess medical knowledge, they may not really grasp the situation based on information alone" (1994, p. 329). Rather than tracking a psychological process, I show that death awareness can be interactionally assessed through an examination of how clinicians, patients, and caregivers discuss treatment options. In moments of bad news when a treatment stops working or the cancer is spreading, there is potential to gauge a patient's awareness context by paying attention to how they respond to the news in the situation of its delivery. In fact, invoking incurability is one way oncologists perform an interactional death awareness assessment to gauge whether patients and caregivers still remember the incurable diagnosis and make decisions with that in mind.

In the death and dying literature, scholars often analytically treat clinicians as gatekeepers of information who ultimately decide when patients and family members are ready for disclosure about impending death (Christakis 1999; Glaser and Strauss 1965; Hodkinson 2013; McIntosh 1977). I extend what we know about disclosure and argue that medical technology makes it easier to track tumor progression (Joyce 2008; Timmermans 1998) and provide clearer evidence for worsening disease. This creates the unique problem of forcing bad news (such as impending death) to come to the interactional surface of clinic visits. Roth (1963) and Davis (1963) promote the idea that doctors, patients, and family members enter into negotiations and compromises that take place within single interactions and also evolve over time, especially as the prognoses of patients change. Negotiations are not just seen in treatment decisions, they are also found in communication preferences. This is particularly true when deciding how explicit doctors, patients, and caregivers need to be when discussing death (Palmieri and Stern 2009). Communication styles are often implicitly negotiated (Botelho 1992); thus, clinicians communicating a dire prognosis to a patient may take a cautious approach, opting to talk to patients in a way that does not crush "existential hope" (Thulesius, Håkansson, and Petersson 2003, pg. 1361), while still sharing an accurate prognosis that points towards impending death. Shifting between early- and late-stage palliative care often coincides with the end of chemotherapy, which triggers the awareness of dying for both the patients and their caregivers (Thulesius et al. 2003). This shift accompanies compromises about the intent of treatment and negotiations over realistic goals. Furthermore, involving patients in the treatment decisions is a form of negotiation (Abraham and Alberts 2013) that is reconsidered and reestablished as patients get closer to death.

Methods

Data Collection

After obtaining IRB approval, I observed 108 clinical encounters, audio recording 85 clinic visits, including 65 lung cancer patients (35 female, 30 male), 48 family members (22 female, 26 male), 3 oncologists (2 female, 1 male), five nurses (all female), three medical assistants (1 female, 2 male), four medical residents (all female), and one clinical trial liaison (female)[14]. Patient ages ranged from late 50s to early 80s and all patients and caregivers are white. All patients were *previously* diagnosed with incurable lung cancer and were receiving treatment at a lung cancer clinic located in an academic hospital. Participants were recruited using a purposeful sampling design that later relied on theoretical sampling (Glaser and Strauss 1967), and data collection took place in The Lorne Cancer Center's (pseudonym) lung cancer clinic, which provides service for approximately 26 patients per clinic day. It has a total of four medical oncologists on staff who concentrate on lung cancer[15], three of whom participated in this study. Data collection primarily occurred in exam rooms and the clinicians' workroom—a large

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[14] The names of participants in this chapter are pseudonyms.

[15] The Lorne Cancer Center treats 25 different types of cancer.

room closed off to the public in the middle of the clinic that oncologists use to look at scans, review patient charts, and prepare for their clinic visits.

I audio recorded (and transcribed verbatim) clinic visits and supplemented those recordings with detailed ethnographic field notes. Following ethnographic conventions (Emerson, Fretz, and Shaw 1995), jottings and field notes include descriptions of each setting, the oncologists' preparations prior to meeting each patient, and the behavior of each participant during clinic visits—including non-verbal communication and the use of artifacts such as hand-drawn graphs and computers. Observations also include informal interviews and conversations with participants, caregivers, and oncologists. For example, after clinic visits ended, I regularly asked oncologists about the interaction that just took place or to reflect on different topics—e.g., conversational approach, medical decision-making, the difficulty of the conversation, treatment options discussed or avoided. Engaging in and observing "shop talk" with oncologists and nurses (Maynard and Clayman 1991) provided a deeper understanding of how clinicians accomplish cancer care. Audio transcripts and field observations of clinic visits were analyzed using MAXQDA-18, software designed for qualitative data analysis.

Data Analysis

I employed an inductive analytic approach (e.g., Charmaz 2006; Glaser and Strauss 1967) with analysis ensuing immediately after data collection started (Taylor, Bogdan, and DeVault 2015). Initial coding of transcripts and fieldnotes relied on line-by-line analysis (Charmaz 2006), with preliminary analyses leading to "focused coding" as initial codes collapsed into new codes and categories and themes emerge. This procedure was iterative, throughout the data collection process. In this process, the term code means a word or short collection of words that describe a segment of data. For example, I used the code “patient agency” to label all bits of data that show patients advocating for their needs or when they act in a manner that advances their agenda. Meanwhile, a category is a grouping of codes bound together. Categories are bundles of different segments of data that somehow relate to one another. For instance, “improving prognostic awareness” was a category I used to bundle together instances in which physicians “describe illness trajectory,” used “grounded language” to explain difficult information, or were “asking for meaning assessments” from patients. Finally, themes are broad concepts that house categories and codes, which give a broader sense of what might be happening in the data. Invoking incurability was one of these themes.

I also used a *constant comparative approach* (Glaser and Strauss 1967) to compare between—and within—segments of data, categories, and themes. I wrote memos to detail the features of the connections that develop between the constellations of codes and categories, and the relationships forged between (and among) categories and themes (Corbin and Strauss 2014). As an example, invoking incurability is the main phenomenon of this paper, but it started as 13 codes (e.g., “justifying scans,” “incurability,” “meaning making,” “processing” “extending prognosis-talk”) of 144 initial (or open) codes. As I compared segments of coded data and started organizing these codes into larger groupings, I noticed that in one of these bundles of codes, physicians were consistently mentioning the incurability of cancer. I called this category “establishing incurability;” however, I quickly realized that not all the codes under this new category neatly related to one another. For instance, when comparing “processing” and “justifying scans” I observed that these two codes were parts of two very different social actions. While “processing” is related to instances in which patients and caregivers take time to express what their thinking and feeling, “justifying scans” relates to instances in which doctors explain why they think their assessment of the scans accurately depict what is happening to a patient’s body. As such, I created new categories (e.g., “providing updated scan information”, “space to process,” “curbing expectations”). I noticed that these new categories all still related to “incurability” generally and so it became part of the larger theme (“invoking incurability”) and the main phenomenon of this paper.

Findings

Oncologists are particularly vigilant about tumor growth and metastasis (the spread of cancer from one part of the body to another) with terminal patients. When metastatic growth shows up in vulnerable areas (e.g., brain or liver) with limited treatment options for shrinking the associated tumors, oncologists find themselves in a difficult position. In these instances, they must inform patients that standard treatment options are no longer working and that death is getting closer, while simultaneously providing the patient with support. Relatedly, patients and caregivers have reciprocal difficulties: they must hear and process that treatments are no longer slowing down the disease and death is looming. Interactionally, doctors attempt to update the patient’s prognosis and provide support, as well as establish an open awareness of death (Timmermans 1994). Overwhelmingly, invoking incurability is the strategy they deploy.

Invoking Incurability

I developed the concept “invoking incurability” to describe how doctors segue into discussing death. Invoking incurability is a conversational strategy that consists of three social tasks: 1) update diagnosis and confirm the terminal prognosis; 2) temper unrealistic expectations about the overall efficacy of treatments; and, 3) improve prognostic awareness and knowledge.

In order to invoke incurability, and in turn accomplish these three tasks, oncologists rely on a number of conversational tools, such as emphasizing, establishing, re-establishing, and reminding patients and caregivers of the incurable nature of the cancer. Invoking incurability can start by using explicit language. Examples of this include: “we consider this incurable disease;” “so we know that when cancer cells are in the fluid that is not a curable cancer;” and “[this] is not curable.” However, invoking incurability can also start by using subtle language. Examples of this include: “we can't make the cancer go away;” “for people, like you, with your stage of disease, it's [the medication being discussed] FDA approved for people with advanced disease, stage 4;” “it’s possible that none of those [treatment] options are available to you.” The first example, while subtle, is straightforward—the medical team cannot make the cancer go away, meaning the cancer is not curable. The last two examples are more obscure. In the second example when the oncologist states, “people, like you, with your stage of disease,” the doctor is alluding to patients with highly advanced cancer. In fact, the doctor finally states this at the end, “…for people with advanced disease, stage 4.” Here, “stage 4” indicates incurability. In the third example, the indirect implication is that if there are no treatment options available, which means that the medical team can no longer treat the cancer with anti-cancer medications.

Overall, oncologists invoke incurability to communicate bad news and remind patients and caregivers of the terminal prognosis. Invoking incurability works towards one general interactional goal, which is to openly discuss death and dying. Next, I show how oncologists invoking incurability to restate diagnosis and move toward establishing a prognosis.

Updating Diagnosis and Establishing Prognosis

When terminal cancer spreads, physicians often invoke incurability by reminding patients that their cancer is not curable. Invoking incurability works towards updating a patient's diagnosis, which is seen when Bruce, his wife Julie, and Bruce's oncologist (Dr. Blackwell) discuss his most recent diagnostic scans on a warm June morning. Bruce, a 65-year-old man with stage IV cancer, starts the clinical visit by mentioning how he worked that morning "for a couple of hours." Bruce states that he is working full-time and that he is trying to "stockpile" his "time off" for when he gets "really sick." Bruce mentions that he does not want to keep working until "the 11th hour" because he would like to share some time with his wife. He states, "I've been a fool" my whole life," because he has given too much time to his work; he has been, "a company man." As Dr. Blackwell informs me, Bruce knows he has an incurable disease. During this clinic visit, Bruce indicates that he is hoping to hear that the radiotherapy did "something" and keep his cancer from growing. On this day, however, the scans show that the cancer has spread. After Dr. Blackwell presents the scan results, he invokes incurability by directly establishing the incurable nature of Bruce's disease:

> Dr. B: When a cancer spreads from one place to another place through the bloodstream, we might be able to control it, maybe help find more time, but not make it go away.
>
> Bruce: Right, I understand that.
>
> Dr. B: Okay. So it means that it's incurable, it means that- cause otherwise well-
>
> Bruce: Right.
>
> Dr. B: So. This is the thing that threatens your life.

Here, Dr. Blackwell tacitly implies that Bruce's cancer is not curable since it has spread from "one place to another place through the bloodstream" and that means they cannot make the cancer “go away.” And even after Bruce quickly indicates understanding (“Right, I understand”), his doctor upgrades to an explicit assessment by invoking the very word, “incurable.” Finally, he invokes a kind of meiosis, which is a form of understatement that lessens the severity of the prognosis. By proposing “this is the thing that threatens your life,” the doctor is telling Bruce how the spread of his cancer implicates his dying or eventual death, without using those more explicit words. In a mitigated way, this provides an opportunity for Bruce to grasp the seriousness of the news, that this progression is threatening his life.

Invoking incurability also creates possibilities for participants to discuss what the results mean for the rest of the patient’s life, which occurs right after the exchange above. Dr. Blackwell informs Bruce and Julie that life will get “murkier” because if they cannot immediately find a treatment that shows some signs of working, his life will be, “measured in months.” Bruce responds by telling Dr. Blackwell that he is being vague. Dr. Blackwell responds somewhat guardedly:

Dr. B: If I knew exactly how long for you, I- I would be honest with you

Bruce: Yeah

Dr. B: But I don’t

Bruce: I understand

Dr. B: It is ah, a life-threatening problem.

Bruce: Yes, I’m well aware of - I know my days are numbered, and I’d like to make the most out of ‘em.

Dr. Blackwell continues to discuss Bruce’s prognosis euphemistically, working to re-establish incurability by reverting to the phrase “life-threatening problem.” Nevertheless, this provides Bruce with an opportunity to reflect on how he is spending his time. At the beginning of this conversation, Bruce mentions that he wants to spend more time with his wife. That particular statement is further reflected in his final response to Dr. Blackwell, “my days are numbered, and I’d like to make the most out of ‘em.” We see that for the oncologist, invoking incurability starts by establishing that Bruce’s cancer is incurable, which helps convey difficult information and gauges whether Bruce understands the news. Dr. Blackwell re-establishes incurability later in the conversation in order to refine his initial assessment of Bruce’s diagnosis. Finally, bringing up incurability a third time helps everyone in the room transition beyond the diagnostic news and begin to explore what the news means for the rest of Bruce’s life.

Although they do not directly mention death, at least euphemistically Bruce and Dr. Blackwell interactionally establish an open awareness of death context (Timmermans 1994) which is the key purpose of invoking incurability. An open death awareness, in turn, presents Bruce and Julie time in the clinic visit to process what the news might mean for Bruce’s life, i.e., what is important to his life and how he might want to spend the time he has left. Bruce mentions that he will be taking the time off from work to stay home and be with his family.

While reminding patients that they have an incurable disease helps update diagnoses, it also carves out occasions in which participants build a working consensus about how close patients are to the end of their lives. Invoking incurability helps deliver an update on the diagnosis, which doctors use to forecast possible outcomes, like transitioning to hospice, palliative care, or both. Previewing death is a conversational tool used by medical professionals to ease patients into difficult news (Broom et al. 2013).

As an example, Marge knows she has a terminal illness. Her stage IV lung cancer had spread to various parts of her body and she had a baseball-sized tumor on her pelvic bone that was dissolving the bone. Her oncologist, Dr. Souza, describes her pelvic bone as looking like a "honeycomb." Marge is experiencing severe pain due to the cancer and her body is negatively reacting to her radiation treatment. On a cloudy March morning, Marge comes into the clinic with her three adult children and son-in-law. She is in a wheelchair because walking is difficult due to the bone damage. Three weeks earlier Marge spent time in the hospital due to severe pain and radiation poisoning. While Marge's children live near her, she needs an in-home nurse with her since she no longer manages on her own.

As Dr. Souza starts talking to Marge about her symptoms, she quickly reviews Marge's diagnosis and states that when Marge first came to the clinic, they started with the intention of curing the cancer; however, the cancer has spread through the bloodstream and shown up in multiple spots outside the lungs. "Unfortunately," Dr. Souza says, "what this cancer is showing us, is that it's staying." Here Dr. Souza is subtly establishing incurability. She gets more specific as she re-establishes incurability, "once it's spread through the bloodstream and goes to other organs, we can't cure it." By invoking incurability, Dr. Souza helps provide a clearer picture of why the cancer is incurable—because it has spread through the bloodstream. The doctor helps update Marge's prognostic understanding, while also segueing into the difficult topic of what to do next. This is seen when Dr. Souza laments the diagnosis and re-establishes incurability by forecasting how Marge will transition to end-of-life care:

> Dr. S: Well, sometimes the cancer doesn't allow you to get better even though you're trying your best, you may be working on physical therapy, but if there's no healing, or no response to the radiation, in the worst-case scenario, then that would be difficult if we're seeing that, you know, the cancer is just not allowing you to get better. And in that situation, then perhaps, managing symptoms and focusing on making sure the pain is well controlled.

Dr. Souza subtly invokes incurability by using a type of litotes, which is a figure of speech used to negate some subject (in this case getting "better") by expressing the opposite (Bergmann

1992; Maynard 2003, p. 84). Similar to someone saying that a sunny April day is “not bad” to mean the day was indeed very good, Dr. Souza establishes that Marge’s cancer “doesn’t allow” her to “get better” to establish that the cancer is making Marge worse. The same litotes device is used again, as Dr. Souza tells Marge, “the cancer is just no allowing you to get better,” right before she brings up a palliative care approach that focuses on managing her symptoms (i.e., stopping anti-cancer treatments). Marge simply nods her head.

Dr. Souza continues by telling Marge they have reached a point in which they need to, “do the right thing, and we do what's best for you, and what you feel is best for you, because sometimes it gets to the point where the course kind of declares itself, and we can't change the course without additional problems or complications.” Up to this point, Dr. Souza has been relatively subtle in her forecast. She is more explicit in her next turn-of-talk:

Dr. S: So it's not giving up, but sort of, accepting, in a way, but also focusing on different goals.

Marg: Mm hmm

Dr. S: And that would be going with hospice.

Marg: Right

Dr. S: And transitioning from home health care, to hospice.

We see here, Dr. Souza mentioning hospice with further accentuates the severity of the prognostic news. The doctor’s direct mention of hospice invokes a type of understanding of the severity of Marge’s situation (Luftey and Maynard 1998. p. 325). Dr. Souza then tells Marge they can try an immunotherapy treatment but that it comes with severe side effects and if it does not slow down the cancer, they would have to transfer her to hospice right after. Marge responds, “okay, that's kind of what we wanted to know,” as she looks at her family.

These examples display some of the ways physicians invoke incurability. Doctors often bring up incurability more than once and use that invocation for different reasons. Dr. Blackwell invokes incurability when he establishes that Bruce’s cancer is indeed incurable by initially telling him that they can try to control his cancer but cannot “make it go away.” However, Dr. Blackwell also continues to invoke incurability when he provides an assessment by positioning the updated diagnosis in the larger prognostic landscape (i.e., “this is the thing that threatens your life”). Similarly, Dr. Souza invokes incurability when she helps Marge better understand her disease (“this cancer is showing us, that it's staying”). She re-establishes incurability later in the conversation to give Marge the reason why her cancer cannot be cured—it has traveled through the bloodstream. Oncologists also routinely use subtle or euphemistic ways of invoking incurability to delicately ease patients into a new prognostic landscape. For example, Dr. Souza uses litotes to avoid telling Marge that her cancer is getting worse and is close to ending her life, and instead softens devastating news by telling her that her cancer is “not allowing” her to “get better.” By carefully building to a subtle open death awareness, oncologists look to treat the news with sensitivity, providing opportunities for patients and caregivers to acclimate to the news.

The continue invocation of incurability interactionally lays the diagnostic and immediate prognostic groundwork for the doctor’s transition to the next topic of conversation, which is what to do next, given that the cancer is getting worse and they cannot make it go away. Invoking incurability assists physicians in reminding patients of their diagnosis, while also updating them on the most recent scans and laboratory results. While doctors use different interactional tools to invoke incurability, each different instance that brings incurability to the interactional surface provides patients and caregivers chances to make sense of the latest news in relation to the diagnosis and the patient's illness trajectory. All this work is geared to start the process of interactionally co-constructing an open discussion of impending death.

Curbing Expectations

With each updated diagnosis that involves cancer growth, patients and caregivers face the difficult tasks of rationally understanding the information, emotionally processing the news, and then making informed decisions about what to do next. Often choices are limited to finding a clinical trial (if patients qualify) or transitioning to a palliative care plan that might also include hospice. As patients move closer to death the number of treatments that slow down tumor growth (i.e., anti-cancer options) significantly reduces. Yet, for some patients there comes a time when there are no more treatment options available. Even when facing these circumstances some patients and caregivers display optimism about continuing anti-cancer treatments. In these cases, oncologists attempt to curb unrealistic expectations. By invoking the incurable nature of the cancer, participants start to build an awareness about how close patients are to death.

When Ruth, a 64-year-old woman with stage IV disease, and her sister Linda come into the clinic, Dr. Abassi works to curb Ruth's optimism for continuing chemotherapy. Before the clinic visit starts, Molly, the nurse who works with Dr. Abassi, comes through one of the workroom doors and mentions that "Ruth's scans are in" and that there are signs of progression. The doctor stops typing and looks up at Molly and tells her that she already saw them, and they do look bad. Neither person speaks for a few seconds, then eventually Molly breaks eye contact with Dr. Abassi. Molly says, "It's just so sad" and goes on to tell the doctor that it's not fair because Ruth just received "full brain [radiation]." The doctor slowly nods her head and simply says "yes." Dr. Abassi then cites the patient's rapid progression and the fact that her full brain radiation failed as major reasons the patient should stop all treatment. What is not being explicitly said, but is clearly based on the medical evidence, is that Ruth's prognosis is critical. The fact that the cancer spread to the brain, that the tumors in the brain had grown, and that radiation failed to slow the growth of the tumors indicates that Ruth is close to death and treatment options have run out. While this is sad news, it should not come as new news to Ruth since she was previously told that her lung cancer showing up in the brain was life-threatening. Before we go into the visiting room, Dr. Abassi turns to me and says that the conversation, "is going to be difficult," because Ruth sometimes has a difficult time "accepting things." As we see next, Ruth is reminded that the cancer is not curable and that death is close, but she seems to have difficulty processing the news and wants to continue with her chemotherapy.

After a few minutes of "symptom-talk" (Maynard, Cortez, and Campbell 2016), Dr. Abassi starts to discuss scans and treatment options by saying, "the question now is whether or not we are going to continue with the current chemotherapy." Ruth asks what the chemo is treating and Dr. Abassi tells her that it is only treating the lung, but that the Paclitaxel (chemo) is not going to do anything for the five new brain tumors. Dr. Abassi continues:

> Dr. A: What will limit your survival is your brain disease. Not your other disease [tumors in lung]. And so doing the Paclitaxel at this point will just, I know you're not having any side effects from it but doing it will give you side effects, that might give you side effects that might not be worth the trouble.
>
> Ruth: Okay.
>
> Dr. A: I'm trying to phrase it in a good way.
>
> Ruth: Okay.
>
> Dr. A: I'm not sure if you're getting the picture.
>
> Ruth: Well no because, uhm, like what kind of side effects?

Like the other oncologists, Dr. Abassi euphemistically explains potentially troubling news, which is that Ruth's anti-cancer medication (Paclitaxel) is likely no longer working and should be stopped (i.e., "might not be worth the trouble"). Ruth simply acknowledges her doctor's attempt to establish incurability ("Okay"). Dr. Abassi then tells Ruth that she's, "trying to phrase it in a good way," the "it" here being both her updated diagnosis and the larger message that the lung cancer is no longer a concern. To this, Ruth again responds with "Okay," which prompts Dr. Abassi to suggest that Ruth is not "getting the picture." Ruth responds by asking about side effects, and thereby not addressing the tacit communications embedded in Dr. Abassi's talk, which is that she suggests that they should stop the Paclitaxel because the brain tumors are now the major concern.

In the next exchange, Dr. Abassi re-establishes Ruth's incurability, stressing the toxicity involved in continuing the current treatment that will not affect her overall survival, and implicitly suggests a palliative care plan. Dr. Abassi tells Ruth that continuing with any treatment, "will not influence how much you live." The physician asserts that they can "address the pain" or the bowel issues she is having. She reminds Ruth that nausea and vomiting is easily treated. Dr. Abassi then tells Ruth that continuing chemotherapy, "can cause neuropathy, can affect any nerves in the body and the nerves of the colon or the bowel." Ruth repeatedly mentions that she understands, yet still asks questions about other chemotherapies for her lung cancer.

While patients can develop overly optimistic expectations about treatment possibilities (Weeks et al. 1998, 2012), doctors try to find ways of grounding overly optimistic projections (cf. Cortez et al. 2019; Maynard et al. 2016). Dr. Abassi's exchanges with Ruth attempt to ease her into an active open awareness context (Timmermans 1994) by curbing her hope in chemotherapy and providing her with more opportunities to process and understand the news. Unfortunately, from a clinical perspective, Ruth's treatment decisions are limited to choosing a palliative treatment plan and deciding when hospice will play a part in the last weeks or months of life, as evidenced by Dr. Abassi's exchange with Molly (nurse) in the workroom right before the clinic visit and the exchanges above.

Knowing what the scans indicate, the doctor attempts to guide Ruth through the news by providing multiple opportunities for her to understand how the cancer progression is impacting her life, which includes helping Ruth accept a decision that she had a very little part in making (i.e., the transition to palliative care). The doctor suggests that Ruth start thinking about her last weeks of life. While Linda stays quiet, Ruth still does not explicitly indicate that she understands why it is necessary to stop chemotherapy. Towards the end of the conversation, Dr. Abassi once more re-establishes incurability and is more explicit ("frank," as she says below) about the severity of the news:

> Dr. A: With having a brain disease that is not controlled, I might be talking about more of weeks than months [left to live]. Just to be frank. Uh, but I want you to enjoy those weeks to be near your family, to not have, you know any uncontrolled symptoms and having to deal with all of those things, plus the chemo visits all of those things.

Dr. Abassi reiterates the toxicity of continuing treatment throughout the visit and in this exchange is more explicit about how much time Ruth has left, a detail physicians tend to avoid (Christakis 1999; Colleen Cartwright et al. 2007; White et al. 2007). It is interesting to note that even when Dr. Abassi is "frank," she is still careful to hedge her estimate of Ruth's life expectancy. The doctor's use of "might" mitigates the certainty of her estimate, providing room for prognostic error (Christakis 1999). Together, the doctor and patient build an understanding of the scan results from a medical perspective—chemotherapy will not help Ruth with the brain tumors, and this progression to the brain is what will end her life, so the brain tumors are what they should focus on.

Doctors in this study consistently focus on the life left to live, rather than the death that is coming, especially as patients are nearing the end of their lives (Broom et al. 2013; Henselmans et al. 2017). By the end of the conversation with Ruth, it seems that she processed and accepted the news:

> Dr. A: I know it's hard. *[Patient's eyes start watering and she looks visibly upset]*
>
> Ruth: It is, I mean I'm trying ta- I'm trying ta- be really rational about it and *[Ruth is avoiding eye contact with the doctor, she is crying, and tightly holding wadded up tissue]* it's hard to be- and I think I'm being rational about it and I think the rational thing would be to stop the chemo.

In the end, Ruth accepts the news and agrees that they should focus on alleviating symptoms, so she can enjoy her remaining life.

Dr. Abassi uses a range of tactics to invoke incurability. We see Dr. Abassi attempt to "phrase it in a good way" by using allusive language, stressing the toxicity of anti-cancer treatment a number of times, emphasizing the importance of Ruth's quality of life more than once, and pronouncing that Ruth likely only has weeks left to live. There is a progression here from the inexplicit versions to more explicit assertions about Ruth's health. It is only towards the end of the conversation that Ruth fully accepts the news and lets go of the idea that treatment options are still available, which suggests that such an approach works for the problem of "realization" (Heritage and Maynard 2006b; Maynard 1996). Fortunately, Ruth had time to recover from the severe side effects of her treatments before she dies five weeks later. She had a chance to create a palliative care plan and work with her medical team to help her transition into the last stage of her life relatively pain-free.

Curbing expectations is especially difficult when patients have further options for trying anti-cancer treatments. When treatment options are available, patients and caregivers sometimes display overly optimistic ideas of what treatment options might accomplish. However, even when treatment options are no longer available, patients and caregivers hold onto the possibilities for treating cancer. In Ruth's case, she is told multiple times, across visits (and during this visit), that her brain metastasis is life-threatening and that if the brain tumors continue to grow then that will severely reduce the number of treatment options. And yet despite the reminders, in this clinic visit, she still wants to continue the Paclitaxel. By invoking incurability throughout each clinic visit, oncologists carve out opportunities for their patients to process the seriousness of their diagnostic scans and temper their expectations. However, doing so can be a difficult process that develops over time. For example, Ruth's clinic visit is 69 minutes long with the bulk of the visit dedicated to discussing the scan results and what the results mean for her life.

Improving Prognostic Awareness and Knowledge

Invoking incurability increases and updates what patients and caregivers know about the patient's changing illness status. While improving prognostic awareness is also done when there is news of illness improvement and stability, it is considerably more difficult to do when bad news is presented. Establishing or re-establishing the incurable nature of a patient's lung cancer provides occasions to jointly construct (between doctors, patients, and caregivers) an updated understanding of where the patient currently stands in the dying process, while also providing the patient and caregivers space to emotionally grasp the changing situation and discuss their concerns.

When Dr. Blackwell steps into the clinic room to speak with Kat and her husband Ben on a cold April morning, Kat looks nervous. After exchanging brief greetings, the doctor asks if they would like to talk about the recent scans. Kat tells him that she would. Dr. Blackwell informs them that, “the overall picture is that things got a little worse,” and that there is a small increase across all the old tumors, but that there are now a few other tumors that have “popped up” that were not there before. Kat looks down at the floor and utters “crap” under her breath. Dr. Blackwell tells her that, “crap is right, I would use stronger words actually.” Dr. Blackwell then starts drawing a tree chart with three branches. He tells Kat and Ben that they seem to be “funneling back to this spot” and writes the words, “no treatment” at the end of one of the branches. Next, he writes, “chemotherapy,” and “clinical trials” on the other two branches. Dr. Blackwell then says:

> I always indicate that one option is to not use anti-cancer drugs. To focus on you and your symptoms. At some point when it is that we decide either you saying, ‘It's not for me anymore.’ Or I say, ‘I don't think there's any good options anymore. Here the door is open to bringing more resources to you at home like hospice for example.’

As he explains that one option is to not use “anti-cancer drugs,” Dr. Blackwell is pointing towards the branch that has “no treatment” written at the end of it. And while Dr. Blackwell goes on to discuss the two other treatment avenues—standard treatment options and clinical trials—it is important to note that he starts this exchange by explaining that they have the option to stop taking all anti-cancer medication. By discussing this avenue first, Dr. Blackwell implicitly legitimizes this option, while also previewing it as a real option and even a possibility in the future.

After discussing the two other treatment avenues, Dr. Blackwell asks Kat and Ben which option they would like to try. While Ben is silent, Kat starts to quietly cry. Kat tells Dr. Blackwell that she cannot make up her mind. It is at this point that the doctor tries another tactic, by asking Kat to tell him about what she is thinking. Kat starts breathing hard, and after a few long silences, she mentions that her last cycle of chemotherapy, “was definitely easier.” Kat continues to quietly sob between her words. Dr. Blackwell asks her if she is thinking about dying. Kat slowly nods her head. She goes on to say that she was hoping that her tumors had not grown and that she could avoid experiencing “really bad side effects” with treatment moving forward. Kat worries that the end of her life will be “really painful” and “awful.” Dr. Blackwell reassures her that, physically, patients’ deaths are “not usually awful” and that they (her healthcare team) will work really hard to make sure the end of her life will be relatively pain free. At this point, discussing incurability is blended into the diagnostic background, and the participants segue into an open discussion about what Kat’s potential death might be like. Dr. Blackwell guesses that Kat might be worried about dying. When she confirms that this is the case and expresses her worries, Dr. Blackwell displays empathetic concern (Finset and Ørnes 2017; Halpern 2003; Lief and Fox 1963) by addressing Kat’s fears and treating her emotions as a normal part of the clinic visit. In doing so, Kat and Ben also improve what they know about her eventual illness trajectory.

Recalibrating what patients know about their illness entails explaining devastating information in ways that resonate with patients and caregivers. While it is possible to narrow incurability’s meaning by using highly medicalized terms and technical information, such as response rates and showing tumor sizes on computer screens, this tactic may obscure the message (Sivell et al. 2008). Oncologists in this study regularly depend on medical jargon and probabilistic language to describe the implications of scan results, but when patients struggle to fully grasp diagnostic news, doctors attempt to discuss diagnostic and prognostic information using non-medical terms.

Dr. Blackwell uses this strategy when he tells Kat what the rest of her life might look like, given the new diagnostic landscape (i.e., more tumors showing up in the scans):

> Dr. B: Uhm, you know before you were sick you could go anywhere you wanted to go. Right? Hop on a plane go to a- you were limited by money and time. Now you got limits that are more physical. You're tied to this place, coming for labs and chemo and you can leave the house, you can- people can come, you can go. Essentially things just get smaller. You know, what happens when people are dying is that they are less able to do, and sometimes less interested in doing more.
>
> Kat: Yeah

Dr. Blackwell has his hands cupped and they are set approximately three feet apart. They start out wide and as he talks about the way Kat's life will be limited, his hands get closer together.

> Dr. B: And life physically gets narrower. Mostly in the house [*hands get closer together*]. Leaving the house for important stuff [*hands get closer*]. Pretty much just in the house [*hands get closer*]. But you can be all over the house. Pretty much in a few rooms of the house [*hands get closer*]. Pretty much in bed [*hands are touching each other*].

> Dr. B: At that point when your life is contracted enough that you're mostly in bed. That's when we're often talking about days.
>
> Kat: Yeah.
>
> Dr. B: Uhm, but as that happens, you know it happens slowly enough that, you know, you notice it but it's not sudden, usually. And there isn't usually, I mean while sometimes people have pain or cough, or shortness of breath, we try hard to manage those and often it means taking medicines to manage those symptoms, but usually we can keep a lid on things. So you're not miserable or suffering. That's kinda, that's kinda how it goes.

The doctor briefly mentions the most common symptoms patients experience towards the end of their life: shortness of breath, a cough, and some pain. He then invokes incurability for a second time, “in the worst case, if we see again that treatment isn’t working, I think that probably makes it clear that time is measured in months.” Earlier in the conversation the patient and caregiver were talking about how much they enjoyed spending time at their lake house. He goes on:

Dr. B: I would be very surprised if it was shorter than two months

Kat: Kay. Yeah. Okay. Good. I want to get to the lake.

Dr. B: I think you should. I think you should get to the lake.

Kat: I have a lake house, we have a lake house. That’s important to me.

Dr. B: The season is upon us.

Kat: *[Kat is laughing]* Okay, I think, I think I’d like to try the immunotherapy.

Dr. B: Okay.

Kat looks much more at ease after her doctor tells her that she should go to the lake; she stops crying and even lets out a faint laugh right before making her choice. When highly medical language seems to confuse Kat and she starts crying unable to decide between her options (just prior to all these exchanges), Dr. Blackwell invokes incurability and grounds his discussion of death in Kat’s daily life. Using the context cues Kat provides—her suspicion that the end of her life would be “awful” and “really painful”—the doctor frames his discussion of death in a way that connects to Kat’s concerns and explains the dying process in terms that relate to Kat’s life.

It is well-established that patients and family members routinely misunderstand diagnostic or prognostic information (Weeks et al. 1998, 2012). Yet, for some patients it is not that they misunderstand that they have a terminal illness, it is that they do not know how close they are to dying. They are unclear about where the cancer has spread or what the current state of their illness means for their lives. This extends to caregivers as well. As doctors establish incurability (or re-establish it), they also provide important diagnostic and prognostic information along the way before they segue into even more difficult conversations. In these instances, invoking incurability is the interactional byway used to start talking about prognosis and comfort care. And even when incurability is left behind and discussions of death start, the patients and caregivers go into those conversations with multiple opportunities to increase their prognostic knowledge. Starting discussions about death and dying with updated prognostic information seems particularly vital when participants are making decisions that can impact the rest of a patient's life.

Discussion

Openly discussing death is an important dimension of patient-doctor interactions involving terminally-ill patients. This paper demonstrates how participants consistently reinterpret what it means to have an incurable disease, especially when treatment options are limited (or exhausted) and death is looming. As such, being "terminal" or having an "incurable" disease is as much a socially mediated endeavor as it is a medically-tracked prognosis. The exact valence of terms like "incurable" and "terminal" is created through clinical interactions and consensus. Oncologists in this study invoke incurability in an attempt to carefully calibrate what "terminal" means for each patient. However, agreement is not always accomplished, and patients do not always orient to the bad news. Sometimes patients, or their caregivers, have a difficult time accepting that death is close, which can be seen in a single clinic visit or across multiple encounters. Despite oncologists invoking incurability, patients and caregivers showed signs of slipping out of death awareness (Glaser and Strauss 1965; Timmermans 1994) or displaying difficulty accepting evidence that pointed to impending death. In response, oncologists repeatedly established the incurable nature of the patient's cancer.

My findings detail how invoking incurability creates opportunities for participants to gain an updated prognosis. Invoking incurability is a general conversational strategy, but it is "done" in a variety of ways. Oncologists routinely use euphemistic language and litotes to soften harsh news that points to impending death. For example, using euphemistic language, such as "threatens your life" and "not allowing you to get better," gives prognostic information in a manner that can build up to more precise language if needed or asked for. It contains enough information that points to impending death, without harshly or explicitly declaring that death is coming soon. Yet, this euphemistic language can be further clarified if needed, so in a stepwise fashion, participants can build on this initial disclosure of bad news by getting more precise or technical (see Dr. Souza and Ruth). While oncologists use this conversational strategy to improve prognostic awareness, patients and caregivers did the difficult work of understanding the new prognostic information and accepting the updated consensus of what the scans meant for the patient's life. As such, when oncologists invoke incurability, patients and caregivers improve their diagnostic awareness and gain a deeper insight into the likely illness trajectory (Applebaum et al. 2014; Jackson et al. 2013). These findings build on past research that shows that clinicians do not openly talk about death or dying and sometimes even withhold information about a patient's impending death (Christakis 1999; Glaser and Strauss 1965; McIntosh 1977; The et al. 2000). This research contributes to the literature by showing how clear diagnostic signs of cancer progression forced participants to have frank discussions about death and the end-of-life. Physicians invoke incurability to segue into open discussions of difficult news (i.e., impending death) and create an understanding of the updated prognosis. Invoking incurability balances two interactional agenda—first, the conversational strategy generally provides important diagnostic information, and second, it creates opportunities to integrate what patients want to discuss in the visits.

How might engaging in end-of-life conversations earlier in the dying process affect the total cost of cancer care? A growing body of literature shows that patients who are told they are close to death prefer a treatment protocol that focuses on alleviating pain and discomfort over curative-based treatment (Barnato et al. 2007; Dalal and Bruera 2017; Gott et al. 2004; Pritchard et al. 1998; Rose et al. 2004; Townsend et al. 1990). Future research would benefit from focusing on how open discussions of death in terminal cancer care impacts medical decisions.

My findings also have policy implications. Patients with advanced cancer generally want to discuss end-of-life issues, including life expectancy (Enzinger et al. 2016), yet oncologists receive little training in how to have these discussions. In fact, Granek et al. (2013) show that despite the fact that talking about death and end-of-life issues is central to what oncologists have to do, they receive little to no training and often report having difficulty having these discussions. Informed decision-making is more than just a main tenet of patient-centered care, it also works to engender patient and caregiver agency. Discussions about patients' fears, goals, and concerns are identified as critical for shared decision making (Ford, Schofield, and Hope 2003). Furthermore, improved prognostic awareness facilitates end-of-life discussions and planning, which includes talking about the differences and the preferences between life-prolonging treatment versus treatment that improves quality-of-life only (Applebaum et al. 2014; Bradley et al. 2001; Mack et al. 2008). As such, research detailing how physicians can improve prognostic awareness and how that impacts decision-making may improve end-of-life care and patient-doctor communication more broadly.

Finally, this chapter also highlights how patients' emotions are integrated into the clinic visit. The association between doctors providing empathic responses and positive clinical outcomes, including reduced anxiety and distress (Zachariae et al. 2003), patient adherence to treatments(Davis 1968; Soo Kim, Kaplowitz, and Johnston 2004; Squier 1990), and patient satisfaction with medical care (DiMatteo and Hays 1980), are well-established. I show here how patients routinely reacted to difficult news by bringing up topics that were important to them as they emotionally processed news of impending death. Bruce, for example, did not want to work until "the 11th hour" and clearly stated that he wanted to make sure he spends quality time with his family before he died. For Kat, emotionally processing news of impending death instigates the conversation about the concerns she has about the dying process and then focuses on a trip to her lake house. For patients and caregivers, this emotional and cognitive work functions a conduit through which they come to terms with difficult news. Having the time to reflect on the updated diagnostic news also provides the opportunity to reevaluate what is important in their life and medical care. For oncologists, validating emotions helps them secure important information about how patients and caregivers are thinking about prognosis. Doctors display the kind of empathy work that is the cornerstone of patient-centered care by creating time for patients and caregivers to express their feelings during clinic visits. Their emotional reflection (Craciun 2018) and emotional talk are then used as a resource to provide authentic care (Bolton 2000).

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CHAPTER 5: CONCLUSION

Caring for terminal cancer patients is an important task that is replete with difficulties. There are calls for researchers to investigate ways clinicians and hospitals might provide better and more transparent care. Models of care often prioritize evidence-based practice but also suggest integrating patients' goals and preferences into patient-doctor interactions. Scholars recognize that improved patient-doctor communication is one avenue to address the changing landscape of medical care of dying patients. This point especially resonates in societies experiencing sharp increases in the aggressiveness of treatment without much evidence of the effectiveness of such aggressive treatment at the end of life. Generating new interventions and approaches to healthcare policies requires accounts of the interactional obstacles that inhibit discussions of end-of-life issues and dying. It also requires that we understand how patients prioritize goals at the end of their lives.

This dissertation reveals aspects of the difficult tasks participants face while receiving care for an incurable disease, especially when recent scans or laboratory results suggest worsening disease. For some patients in this study, there are still other options to try. For others, the only treatment option left is a clinical trial. And yet for others, anti-cancer drugs are no longer options as diagnostic technology indicates that death is imminent. Patients and caregivers are expected to process information that points to tumor growth, limited treatment options, or impending death, and then make consequential decisions based on that knowledge. Meanwhile, oncologists try to find ways to integrate their patents' goals and perspectives into clinical visits and help guide their patients through a medical decision-making process that becomes increasingly challenging as people get closer to death.

In this chapter, I provide a brief summary of each empirical chapter. In doing so, I note key findings, while also remarking on the contributions to the sociological study of prognosis, death and dying, and clinical practice. Next, I suggest future research that expands this study. Finally, I end with implications for future research that moves beyond the clinic to focus on the lives of patients outside of the formal healthcare setting.

Review of Findings

Chapter 2, *Uncertainty and Certain Death: Interactions Surrounding Clinical Trials in Terminal Cancer Care*, analyzes the phenomenon of uncertainty as it surrounds the consideration of clinical trials for terminal lung cancer patients. This chapter shows how terminally-ill patients experience tension due to the uncertainty they confront when faced with the choice of transitioning to palliative care or volunteering for experimental medications to postpone death. I detail how the consideration of clinical trials manifest the phenomenon of uncertainty through discussions about the trials' efficacy, descriptions of the physiological consequences of clinical trial medications, and exchanges surrounding prognoses. My analysis focuses on a central paradox—patients (and their family members) may have high prognostic certainty, i.e., they know that the disease is fatal, yet they experience elevated levels of uncertainty in relation to making the crucial choice about participation in clinical trials.

This chapter provides empirical evidence of the ways uncertainty and risk are introduced into patients' lives. Rather than presenting an abstracted or detached theoretical concept, I detail the specific social actions that cause uncertainty. For example, I show how physicians frequently employ probabilistic language and rely on highly technical jargon to discuss trial drugs and their effects. Far from clarifying how any particular trial works or how a patient's body might react with the trial medication, the use of quantitative and technical language to describe experimental drugs muddle explanations of potential outcomes and biophysical side-effects. In these cases, patients and caregivers must navigate a combination of interactional hedging (e.g., “if,” “might,” or “maybe”), a dizzying use of probabilities, and often abstruse medical language. The result is that patients experience a disruption in their lives and illness experiences (Bury 1982; Pietilä et al. 2018), with a once clear prognosis now made more ambiguous by interactionally generated uncertainty. In effect, discussions of clinical trials reintroduce “unorganized” illness (Balint 1957; Brown 1995; Mishler 1981) into a secure diagnosis and certain prognosis, i.e., death.

Chapter 2 enters a recent debate about the analytic utility of uncertainty (Brown 2013; Green 2009) by establishing uncertainty as a socially mediated phenomenon, which can be traced empirically through the analysis of clinical interactions surrounding clinical trials. Like previous studies (Littlejohn and Kimport 2017), this chapter advocates for the continued analysis of uncertainty. The ways patients understand uncertainty and risk have a major influence on medical decision-making. If we continue to track and analyze the various ways participants “manage” (Zinn 2008, 2009) and navigate uncertainty, we can provide both practical (or clinical) and theoretical insights into how patients, caregivers, and physicians make medical decisions in the circumstances. This is particularly important as recent research demonstrates that patients living with extended medical uncertainty experience increased anxiety, distress, and decreased life satisfaction (Pietilä et al. 2018). These empirical and theoretical contributions respond to Brown’s (2013) call to develop new “theoretical paths” (p. 624) and provide future researchers a primer for new analysis—such as a focus on clinical interactions.

While Chapter 2, focuses on interactions surrounding clinical trials, Chapters 3 and 4 attend to the discussions of prognosis. Together, these chapters contribute to the growing sociological literature on this topic (Timmermans and Stivers 2018) by showing *how* prognostic-talk is interactionally achieved. Chapter 3, *Do you want to talk about it?: Asking questions, supporting patient agency, and discussing death*, examines how oncologists initiate discussions of prognostic-talk. In order to understand prognostic-talk, I first focus on how these conversations start. I analyze the use of a *"what this means inquiry"* (WTMI) to suggest prognosis as the next topic of discussion. WTMIs work to set the topical agenda (prognosis), but also forecast the valence of the news, and work towards an acceptance of the nominated next action. While WTMIs are topic-proffering actions that present in a manner that transmit a preferred positive response, patients and caregivers still have opportunities to shape the proceeding talk. My analysis illustrates the collaboratively organized beginnings of prognostic-talk. I show how participants build an interactional environment that supports both the physician's agenda (to discuss prognosis) and the patient's preferences.

WTMIs provide oncologists a mechanism with which to carve out space within the typical phase structure common to oncology visits (see Singh et al. 2017 for a description of each phase) in order to discuss prognosis. This chapter builds on previous work by showing how prognostic-talk can occur in a manner that does not radically alter the sequential order of other components of the oncology visit (see Appendix C). This practical insight can inform future clinical practice in a manner of ways. First, discussing bad news is difficult. As established in social scientific research that is heavily cited throughout the preceding chapters, clinicians and patients alike avoid discussing issues that point to bad news or the suggestion of impending death (see Christakis 1999; Glaser and Strauss 1965; Luftey and Maynard 1998). The integration of WTMIs into clinical practice can help ease patients into the news, providing opportunities to warn and acclimate participants of the potentially difficult conversations to come (Maynard 1996).

Second, WTMIs initiate discussions of prognosis, which provide important information that can help patients and caregivers make treatment decisions. This point holds particular weight considering previous research that suggests prognostic clarity leads to higher satisfaction of medical care (Jackson, Chamberlin, and Kroenke 2001; Jackson and Kroenke 2001), lower reported stress and anxiety (Bakitas et al. 2009; Temel et al. 2010), and higher reported quality-of-life measures (Detering et al. 2010; Gade et al. 2008; Teno et al. 2004, 2013; Wright et al. 2008). Despite the importance of prognosis, patients and doctors dread discussions of prognosis that point to bad news. WTMIs provide physicians as well as patients and caregivers a distinct way of clearly marking the initiation of prognosis.

Finally, WTMIs align with the goals of patient-centered care. Seen as a paradigm with a set of core values that prioritize clinical practice that respects “individual patient preferences, needs, and values” (Institute of Medicine 2001, p. 6; Levit et al. 2013), patient-centered care promotes collaborative clinical interactions. WTMIs particularly respond to suggestions by Stewart and colleagues (2000) to build a supportive patient-doctor relationship and realistically discuss resources, options, and the current state of a patient’s illness. WTMIs can be the foundation and an ongoing interactional touchstone for conversations related to treatment planning and goal-setting (Paterniti et al. 2010). When all participants have a clear sense of prognosis, they can move forward with treatment planning by allowing the prognostic landscape to shape the appropriateness of one particular treatment over another. WTMIs help participants bring reported lived experiences (side-effects or physical issues patients report) and the newest available medical information (e.g., diagnostic scans and laboratory results) into the discussion of treatment options. In other words, WTMIs help initiate prognostic information discussions that can play a role in choosing appropriate treatment options (Paterniti et al. 2010), inclusive of stopping treatment altogether and starting palliative care or hospice.

Chapter 4, *Invoking Incurability to Socially Calibrate and Process Death*, builds on Chapter 3 by showing how prognostic-talk is “done” in clinical interactions. Whereas chapter 3 primarily focuses on the interactional mechanism that introduces prognosis as the next potential topic, chapter 4 shows how oncologists “invoke incurability” to talk about death and dying and help patients process impending death. Oncologists invoke the incurable nature of a patient’s disease in an attempt to provide an updated diagnosis and confirm the terminal prognosis. Marge’s visit with Dr. Souza provides a good example of the way doctors invoke incurability to update the patient’s diagnosis and establish that her disease is indeed terminal. When Marge initially came to the Lorne Cancer Clinic she had multiple treatment options and her disease had not spread to her hip. Over time, however, Marge’s cancer spread and started eating away at her bones and her radiation therapy made her so sick that she needed to spend time in the hospital. Yet, despite Marge’s physical symptoms pointing to the cancer spreading—e.g., limited mobility and extreme pain in her hip, her hospitalization, and her overall fatigue—she was unsure about her prognosis. By invoking incurability, Dr. Souza broaches the subject of worsening disease and confirms that Marge’s progression (the spread of her cancer to her hip) has worsened. Dr. Souza links diagnostic images to Marge’s physical symptoms, giving Marge a way of understanding highly medicalized evidence through her lived experience. The doctor also describes what is happening to Marge’s body in plain language, noting that her pelvic bone looks like a “honeycomb,” which provides another opportunity to understand diagnosis in a non-technical manner.

With the diagnostic news established, Dr. Souza and Marge could then discuss the prognostic landscape. Together they adjust and assess where Marge is on her illness trajectory. Marge's cancer is not going away—radiotherapy is not helping slow down the disease and Marge's cancer is not responding to any anti-cancer treatments. Yet, this conversation helps Marge recognize that she still has time to focus on managing her symptoms. By invoking incurability and updating diagnostic news, oncologists can improve prognostic awareness and knowledge. As such, oncologists invoke incurability as a way of calibrating what "terminal" or "incurable" means for each patient at that particular time in their illness trajectory.

A great deal of the sociological literature on prognosis details the various interactional difficulties preventing clear communication about prognosis (Christakis 1999; Cortez, Maynard, and Campbell 2019; Luftey and Maynard 1998; Singh et al. 2017; Thulesius, Håkansson, and Petersson 2003; Timmermans and Stivers 2018). This chapter contributes to this literature by focusing on how participants "accomplish" prognosis. While some turns-of-talk still include euphemistic language (see Dr. Souza and Ruth and Dr. Blackwell and Bruce in Chapter 2), participants build an understanding of prognosis that develops over multiple turns. Invoking incurability helps frame this multi-turn process.

Prognosis is as much a part of the "language of medicine" (Brown 1995, p. 39) as other clinical tasks. Yet this task, like others (e.g., diagnosis), takes place and is negotiated in a social (albeit institutional/clinical) realm, despite the fact that it is understood and measured using technical skills in a highly medical realm. On the one hand, oncologists attempt to provide an accurate prognosis based on medical evidence while patients and caregivers attempt to listen and understand the prognostic news that is based on medical science. And on the other hand, oncologists and patients also attempt to collectively make sense of the prognostic landscape, with its technical and highly medicalized features (Clarke et al. 2010; Conrad 2007), through social interaction. We see oncologists invoke incurability to translate medical understandings of "incurable" and "terminal" for patients, while also attempting to negotiate a social understanding of the illness. In essence, these two agendas operate in two language registers. The medical register provides the justification for framing diagnostic and prognostic insights, while the social (or interactional) register then endeavors to have patients see and process what the highly medical register means for their illnesses and the rest of their lives. While the clinical and interactional tasks of initial diagnosis and calibrating prognosis are distinctly different, there are similarities in the ways clinicians propose and assign a diagnosis and establish prognosis. Turowetz and Maynard (2017), for example, show how clinicians propose diagnostic categories and then interactionally negotiate and ultimately apply them to children. Chapter 4, details how participants come to discuss the incurable nature of a patient's disease and then participants negotiate what terminal or incurable truly means for patients and caregivers.

Directions for Future Research

My suggestions for future research are divided between those relevant within the clinic and those for outside of the clinic. I first turn my attention to research that continues to focus on clinical interactions.

Continued Focus on Clinical Interactions

First, future research can help explore the prevalence of the phenomena I explore in this dissertation. For example, future projects could ask if other oncologists bring up death in the same way the Lorne Center's physicians did. Are these interactional patterns specific to the Lorne Cancer Center? How does the clinical context—Lorne is in a teaching hospital and a major cancer center in its state—affect these phenomena? Would conversations in a clinic at a community hospital fundamentally change discussions of prognosis?

The patient participants in this study were all white and insured. Future research could examine how patients' backgrounds affect clinical interactions. These questions can be further extended by asking how language and culture might influence conversational practices used to initiate prognostic-talk and discuss death. Does the racial/ethnic makeup of the patients influence end-of-life conversations? If so, why? How might these factors influence and shape conversations about end-of-life decisions? Further, how does the match/mismatch between a doctor's and patient's racial/ethnic/linguistic identity influence these conversations?

Medical research establishes that Latino communities are "especially vulnerable to cancer inequalities," partly due to their inability to access quality healthcare (Miller et al. 2018, p. 2). This is particularly significant since cancer is the leading cause of death among Latinos in the United States (Miller et al. 2018). Additionally, members of non-white ethnic groups are also less likely to discuss end-of-life issues with their doctors or use hospice services (Gelfand et al. 2001; Kreling et al. 2010). Future research could ask, how do predominantly Spanish-speaking patients and predominantly English-speaking oncologists initiate discussions of prognostic news that point to impending death? Research focusing on this question could contribute to our understanding of the ways language, culture, health coverage, and socioeconomic status (SES) complicate terminal cancer care and end-of-life conversations. Currently, there are calls to focus on how health disparities influence clinical care and how Latinos navigate those inequalities (Edberg et al. 2015), which future research on clinical interactions between physicians and Latino patients could directly respond to.

This avenue of future research can extend empirical work that shows that racial and ethnic minorities receive less medication than whites (Bernabei et al. 1998; Juarez, Ferrell, and Borneman 1998), are less likely to receive standard end-of-life medications (Werth et al. 2002), and generally receive less care when dealing with cancer, with Latinos encountering a particularly elevated risk (Anderson, Green, and Payne 2009). Since there is less research that details how health inequalities influence care, conversation analytic studies that focus on interactions between Spanish-speaking patients and English-speaking doctors can help demonstrate how social processes either reinforce or attempt to interrupt inequalities.

New Avenues: Looking Beyond the Clinic

A number of patients in this study do not live in the city in which Lorne Cancer Center is located. In fact, many patients drive several hours to come to the clinic. When asked about why patients would travel for their care, they routinely cite access to treatments their local hospitals do not have, clinical trials only available in the general geographic region at the Lorne Cancer Center, and recommendations from their local primary care physicians. While patients did complain about the extra resource burden such travel imposes, not a single patient cited distance or travel as prohibitive. Even Ester (chapter 3), who lives in a remote area and has to take a small propeller plane to a major city, rent a car, and stay in a hotel every time she visits, does not let these impediments hinder her cancer care. In fact, she manages to frame her travel in a positive light, mentioning how "touched" she is that her community has supported her to help her make the travel happen. For example, Ester's neighbor is the pilot of the plane she takes and he lets her and her husband fly for free. Marge (Chapter 4) also travels a distance to access care. She lives approximately two hours away from the clinic by car. But since her cancer spread to her hip bones, she cannot drive, so she has to rely on her adult sons to drive her.

However, not all cancer patients in the United States are as fortunate as Ester and Marge with their levels of social (and financial) support. Research on health inequality documents persistent disparity in access to treatment. Literature analyzing various risk factors of late stage cancer concludes that spatial access to both cancer screening facilities and primary care physicians are among the biggest influences of health inequalities (Wang 2012; Wang and Luo 2005). Additionally, health disparities in the US among racial/ethnic minority groups are, in large part, attributed to unequal access to healthcare facilities (Blendon et al. 1989; Cornelius 1983, 1993). For example, Menck and Mills found that black and Latina women have less access to breast cancer screening and had higher rates of late-stage breast cancer (2001). Studies also show that longer travel time to treatment facilities and clinics increases risks of advanced cancer (Gumpertz et al. 2006), limits a patient's likelihood of enrolling in clinical trials (Avis et al. 2006), and reduces the utilization of certain therapy (Celaya et al. 2006). This type of geographic disparity increases patients' mortality rates (Onega et al. 2009; Shi et al. 2012; Wang and Onega 2015). Scholars find that "travel barriers," such as long distance, discourage people from seeking routine preventive care or screening (Dai 2010; Luo and Wang 2003). Other studies show better health outcomes are associated with easy access and increased use of healthcare facilities (Hillner, Smith, and Desch 2000; Wang and Onega 2015).

Future research could measure and map travel time and routes that low-income Latino patients take to access care. Using qualitative geographic information systems (QGIS), future researchers can use cartographic methods to map routes, while also accompanying participants on medical visits. Combining walking/driving interviews, also known as "go-alongs" (Anderson

2004; Carpiano 2009; Kinney 2017; Kusenbach 2003), with ethnographic observations, and cartographic data like GIS-based maps (Jung and Elwood 2010; Milton et al. 2015), future research can detail experience through the words and actions of participants. During a go-along, researchers can ask patients why and how they decided to attend one clinic or hospital over another, as well as what kind of care they think they are going to receive. These informal interviews will contextualize the cartographic data and parse out why participants decided to use their clinic over other options. Finally, this future work can analyze the resources (material and social) that participants use to get to their healthcare facilities, paying close attention to the strategies employed.

Final Remarks

Cancer care for patients with a terminal prognosis comes with a number of interactional challenges. This dissertation focuses on some of these challenges, such as how discussions of clinical trials introduce a good deal of uncertainty into patient-doctor interactions. Yet, this dissertation also analyzes the ways doctors and patients achieve prognostic clarity and effective patient-doctor communication. My findings suggest that patients routinely display agency during difficult conversations by introducing their preferences and emotions into clinical interactions. Meanwhile, physicians use a variety of interactional strategies and mechanisms to introduce bad news into clinical interactions in a manner that both informs patients of pertinent information, while also grounding such news in a manner that brings patients’ concerns and goals to the forefront of discussions. Through these complex interactions, there is a movement toward more clarity in discussions of death and dying and better patient-centered care.

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