# **UCLA**

# **UCLA Electronic Theses and Dissertations**

## **Title**

The Interactional Negotiation of Complex Treatment: Physician Authority and Patient Agency in Cancer Care

## **Permalink**

https://escholarship.org/uc/item/57w6p6zz

## **Author**

Tate, Alexandra

# **Publication Date**

2018

Peer reviewed|Thesis/dissertation

# UNIVERSITY OF CALIFORNIA

# Los Angeles

The Interactional Negotiation of Complex Treatment:

Physician Authority and Patient Agency
in Cancer Care

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of Philosophy in Sociology

by

Alexandra Lee Tate

© Copyright by

Alexandra Lee Tate

#### ABSTRACT OF THE DISSERTATION

The Interactional Negotiation of Complex Treatment:

Physician Authority and Patient Agency
in Cancer Care

by

Alexandra Lee Tate

Doctor of Philosophy in Sociology

University of California, Los Angeles, 2018

Professor Tanya Jean Stivers, Chair

Situated in the domain of the cancer clinic, this dissertation uses conversation analytic and ethnographic approaches to explore the ways in which patient involvement and physician expertise are negotiated in an age of evidence-based medicine, decreased medical authority, and increased patient agency and autonomy under the tenants of shared decision-making. Although cancer care is a major site for clinician-patient treatment negotiation requiring a careful balance of potentially competing viewpoints, little is known about how clinicians promote their treatment recommendations to patients, what the manner of promotion tells us about the oncologist-patient relationship, and how clinicians respond when patients resist their treatment recommendations.

Drawing on video-recorded encounters between oncologists and their patients, this analysis examines treatment decision-making in oncology and investigates how physicians balance asserting their authority while at the same time attending to patient agency and involvement in decision-

making. Taking this one step further, this work explores how physicians negotiate decision-making with patients given that they occupy a liminal state between obligations to policy imperatives and commitments to their professional knowledge and technical expertise. This dissertation first investigates the ways in which oncologists present treatment recommendations and the treatment contexts in which they are made. Subsequently, it identifies moments of patient resistance to those recommendations and how oncologists address patient resistance through modes of persuasion to secure treatment acceptance. Taken together, the following chapters establish that oncologists and their patients orient to cancer treatment as negotiable and that cancer treatment can—and *should*—be treated at all stages of disease. Investigating the interactional practices which contribute to these orientations uncovers physicians' and patients' collective sensemaking of how complex diagnoses get addressed in the structural environment of the cancer clinic.

This dissertation of Alexandra Lee Tate is approved.

Patricia A. Ganz

John Heritage

Stefan Timmermans

Tanya Jean Stivers, Committee Chair

University of California, Los Angeles

2018

For my family and friends....
...it takes a village.

# TABLE OF CONTENTS

CHAPTER 1	· FROM PATERNAL	LISTIC MEDICINE TO	SHARED DECISION-

MAKING: HISTORICAL AND METHODOLOGICAL CONSIDERATIONS 1		
1.1 Introduction	1	
1.2 PHYSICIAN AUTHORITY AND MEDICAL EXPERTISE	2	
1.2.1 Paternalism in Medicine	2	
1.2.2 Professional Decline of Physicians	3	
1.3 PATIENT INVOLVEMENT IN HEALTH CARE	6	
1.3.1 Patients' Rights and Informed Consent	6	
1.3.2 Patients as Consumers	8	
1.3.3 The Internet Health Consumer	9	
1.4 THE PARADIGM OF SHARED DECISION-MAKING	9	
1.4.1 Towards Collaborative Decision-Making	9	
1.4.2 The Components of Shared Decision-Making	10	
1.4.3 Patient Involvement and Health Outcomes	12	
1.4.4 The Enduring Power of Shared Decision-Making	13	
1.5 BARRIERS TO THE SHARED DECISION-MAKING MODEL	15	
1.5.1 Patient Participation	15	
1.5.2 Patient Participation	17	
1.5.3 Variations in Illness	18	
1.6 PHYSICIAN-PATIENT INTERACTION IN CANCER CARE	18	
1.6.1 Studying Physician-Patient Interaction	18	
1.6.2 The Conversation Analytic Approach to Physician-Patient Interaction	21	
1.6.3 Conversation Analysis in Cancer Care	24	
1.6.4 The Treatment Environment of Cancer Care	24	
1.7 Dama	2/	

1.8 METHOD	26
1.9 OVERVIEW OF DISSERTATION	28
REFERENCES	31
CHAPTER 2: TREATMENT RECOMMENDATIONS IN CANCER VISITS:	
IMPLICATIONS FOR PATIENT AGENCY AND PHYSICIAN AUTHORITY	46
2.1 BACKGROUND	46
2.2 ANALYSIS OF TREATMENT DECISION-MAKING IN CANCER CARE	52
2.3 INCLUSION CRITERIA	54
2.4 OPTION-LISTING IN CANCER CARE	55
2.4.1 Option-Listing in the Initial Treatment Context	56
2.4.2 Option-Listing in the Context of Ineffective Treatment	63
2.4.3 Providing the No-Treatment Option	68
2.5 SINGLE RECOMMENDATIONS FOR TREATMENT	70
2.6 SINGLE TREATMENT RECOMMENDATION ACTIONS	74
2.6.1 Pronouncements	74
2.6.2 Suggestions	77
2.6.3 Proposals	81
2.6.4 Offers	86
2.6.5 Assertions	89
2.7 TREATMENT RECOMMENDATION ACTIONS AND TREATMENT CONTEXTS	92
2.7.1 Recommendations for New Treatments	96
2.7.2 Recommendations for Mid-Course Treatment	102
2.7.3 A Deviant Case	107
2.7.4 Recommendations for Ancillary Treatments	108
2.8 DISCUSSION	115
Decementors	100

# CHAPTER 3: FOREGROUNDING MEDICAL CERTAINTY IN RESPONSE TO PATIENT RESISTANCE......129 CHAPTER 4: INVOKING AND AVOIDING DEATH: RESOURCES FOR SECURING TREATMENT ACQUIESCENCE ......180 4.4.1 What is an Invocation of Death?.....207 4.4.2 When Invocations of Death Occur 213 4.4.4 Invocations of Death to Advocate for Particular Treatment Outcomes.......231

4.5 DISCUSSION	236
REFERENCES	242
CHAPTER 5: CONCLUSION	250
5.1 TREATMENT RECOMMENDATIONS IN CANCER CARE VISITS	2 <b>5</b> 1
5.2 FOREGROUNDING MEDICAL (UN)CERTAINTY FOR TREATMENT ACCEPTANCE	254
5.3 INVOKING AND AVOIDING DEATH: RESOURCES FOR SECURING TREATMENT ACQUIES	CENCE
	255
5.4 LIMITATIONS	259
5.5. FUTURE RESEARCH DIRECTIONS	260
REFERENCES	262
APPENDIX I: CONVERSATION ANALYTIC TRANSCRIPTION CONVENTIONS	262

# TABLES

# Chapter 2

Table I	48
Table II	71
Table III	72
Table IV	93
Table V	96
Table VI	110
Chapter 3	
Table I	136
Table II	140
Table III	145
Table IV	147
Table V	150
Chapter 4	
Table I	208

# FIGURES

Figure 1	140
. 18410 1	. ı ı,

#### ACKNOWLEDGEMENTS

My gratitude for those who supported me throughout this project fills so much more than just these few pages. This work was very much a collective enterprise and I owe so very much to my family, friends, and mentors. I am especially indebted to the oncologists, patients, nurses, and families in the cancer clinics where I spent so much of my time.

This work spanned six years of my life and took an incredible amount of emotional and intellectual energy. Through the countless days in the field, deadlines, doubts, and triumphs, my friends and family in Providence, Chicago, Los Angeles, and Philadelphia offered the best support I could have asked for. They took me to dinner, encouraged me to travel, texted or called me with sage advice or hilarious messages when they were most needed, and most importantly, listened to me. My mom did these things especially well, and, as my eternal rock, provided invaluable advice, love, and inspiration. Without her support and grace, I quite literally would not have completed this project. My sister (Biffiel) grounded me always and made me laugh like no one else could. Her resilience is inspiring. I owe much of my intellectual and observational curiosity to my dad, who notices *everything* around him and asks questions like no one else can. My family did so much more for me than I can do justice here, but put simply, this PhD would not have happened without them.

I consider myself the luckiest person in the world for the friends I have. I'm so grateful to have had my childhood friends by my side, especially those from Wheeler. Aaron Spacone, Baker Coon, Martin Baginski and Woody Fazzano always made Providence the best place to come home to. Sonia Djordjevic, Sara Wasserman, and Sarah Semel were the best LA roommates Leroi and I could have asked for. I'm especially blessed to have lived with Paula Hislop for three years in Evanston and Chicago. Paula inspired me to pursue a PhD. I continue to admire her intellectualism, strength, and sense of humor. I'm deeply grateful for my friendship with Sarah Semel. We've known each other since 7th grade and she still sends me text messages that give me life. I'm indebted to her

and Sam Levine for hosting me at the Mayfield apartment as I traveled back and forth from LA.

Paula and Sarah are the kind of best friends every PhD student needs during this journey.

I'm also so thankful for the friendships I had back in Chicago, especially the friends who encouraged me to apply to graduate school and choose UCLA. Luke Stadel, Brad Matas, Nathan Looyenga, Anshuman Mukerji, Samantha Lipinsky, and the Rathinam family gave me a family away from my family. Speaking of, Joy Feinberg and Greg Brown, as my Chicago "parents", gave me a home away from home and no amount of thanks can do them justice. I am also deeply thankful for Anna Manda's friendship, from Northwestern, to Kappa Delta, to now. And I'm thankful for my friend Beth Semel, whose admiration for my work held me up as I wrote, and whose nerdiness about the social world is just like mine. I'm lucky to have you as a friend AND colleague.

During my time in Philadelphia, I also had a little village of friends who supported me through the ups and downs of writing the dissertation and the job market. Special thanks go out to Jess Corsaro, whose generosity and like-mindedness meant so much to me, and David Ain and Andrew Fish who offered me the best kind of distraction, their baby daughter Zoe. David and Andrew also kept me sane with their empathy and some really good takeout. UCLA colleagues and friends in Philadelphia at the time also deserve special thanks for being by my side through the job market and offering invaluable advice and therapy, especially Laura Orrico, Peter Catron, and Amada Armenta.

My mentors and colleagues shaped me in countless ways. I owe a huge debt of gratitude to my advisor and mentor Tanya Stivers, whose brilliance, patience, and wisdom made me into the scholar I am today. I am so thankful for her support of this project and her belief in me, even as I moved across the country during my last two years as her student. I also have her to thank for my iced tea addiction. I'm also incredibly grateful for John Heritage's guidance, support, and kindness. Every time I met with John I grew as a scholar, and I have him to thank for my first publication

while at UCLA. John's powerful intellectualism and very British sense of humor made him a meaningful mentor to me during this project. I would also like to thank Stefan Timmermans for crucial feedback on this work and ongoing encouragement of this project. Stefan has continued to inspire me not only as an expert in the field, but as a legendary medical sociologist. Last but certainty not least, Patricia Ganz was an extraordinary "external" committee member on this dissertation. I use quotes because Patti was not external to this project whatsoever. She kept my work honest, focused, and translatable to a medical audience. Having the support and mentorship of Patti has been invaluable to me and I owe much of my love of translational medicine to her. And a major thank you to administrators Wendy Fujinami and Irina Tauber who seamlessly guided me through the rules, regulations, and administrative tasks of the dissertation process from start to finish.

In addition to the members of my committee, I'm thankful to others at UCLA and beyond who offered guidance, support, and inspiration as I grew as a scholar. The Conversation Analysis Working Group, the EMCA Section of the ASA, and the LSI Section of the NCA provided me a space to share my early work and gave me important feedback. I've been lucky to interact with countless brilliant minds, especially Hannah Landecker, Steven Clayman (thank you for all of those LA walks!), Douglas Maynard, Jeffrey Robinson, Virginia Gill, Galina Bolden, Rebecca Barnes, Ruth Parry, Alexa Hepburn, Jonathan Potter, Jenny Madelbaum, Federico Rossano, Felicia Roberts, Gene Lerner, and Lisa Mikesell. Extra special thanks are due to Deborah Carr, who selflessly offered lots of her personal time and effort to my job market search and professional development.

My career as a sociologist began with my time at Northwestern and I owe much to the undergraduate mentors and sociologists who continue to inspire me, especially Monica Prasad, Wendy Espeland, Leslie McCall, and Karrie Ann Snyder, who offered incomparable advice as I applied to graduate school. I also owe a lot to the Department of Sociology at Temple University, who gave me an intellectual "home" away from UCLA during my time in Philadelphia. I especially

want to thank faculty members Judith Levine, Kimberley Goyette, Bob Wagmiller, Tania Jenkins, Bob Kaufman, Gretchen Condran, and Matt Wray for career advice, job talk feedback, and community. I'm grateful to Temple graduate students Ciauna Heard, Cody Spence, Keith McIntosh, David Schrieder, Molly Sapia, Rachel Wildfeuer and Brandon Fairchild, who let me crash their office space and embraced me as a friend while at Temple.

Finally, I chose UCLA Sociology because of its collegiality and graduate student culture. I will be forever grateful for the lovely human beings in the graduate program whom I am lucky enough to call colleagues. I will forever remember our holidayoffice crawls, hallway chats, iced tea runs, and theoretical debates. I am especially grateful for the support and friendship of Anne White, Chase Raymond, Clara Bergen, Caroline Tietbohl, Nan Wang, Zach Griffen, Kyle Nelson, Chris Rea, Rebecca DiBennardo, Eleni Skaperdas, Amelia Hill, Amanda MacArthur, Jessica Huerta, Leydy Diossa-Jimenez, Juan Delgado, and Saskia Maltz. I look forward to seeing where our career paths lead us, and I hope my path continues to cross yours as we work to better understand the social world.

# VITA

# **EDUCATION**

	LDCGMION		
2014	M.A. in Sociology University of California, Los Angeles		
2010	B.A in Sociology with Departmental Honors Northwestern University		
PUBLICATIONS			
Revise & resubmit	Tate, A. "Matter Over Mind: How mental health symptom presentations shape diagnostic outcomes."		
Revise & resubmit	Tate, A. "Treatment Recommendations in Oncology Visits: Implications for patient agency and physician authority."		
Frth.	Snyder K.A., A. Tate & E. Roubenoff. "Young Women with Breast Cancer and Treatment Decision-making: Rethinking patient involvement and empowerment." Research in the Sociology of Health Care. 36(1).		
2016	Robinson, J.D., A. Tate & J. Heritage. "Agenda-Setting Revisited: When and how to primary care physicians solicit patients' additional concerns" <i>Patient Education and Counseling.</i> 99(5): 718-723.		
2014	Snyder, K.A. & A. Tate. "Oncofertility and the Potential for Patient Navigators," in <i>Oncofertility Communication: Sharing Information and Building Relationships Across Disciplines</i> . Ed. Theresa Woodruff et al. New York: Springer Press. 49-60		
2013	Snyder, K.A. & A. Tate. "What To Do Now: How Women with Breast Cancer Make Fertility Preservation Decisions." <i>Journal of Family Planning and Reproductive Health Care.</i> 39(1): 172-178.		
EMPLOYMENT			
2017-2018	Instructor, Department of Sociology Instructor, Gender, Sexuality & Women's Studies Program Temple University		
2016-2017	Teaching Assistant, Department of Sociology University of California, Los Angeles		
2015	Graduate Student Researcher (PI: Hannah Landecker)		

University of California, Los Angeles

2013-2014 Teaching Assistant, Department of Sociology University of California, Los Angeles **SELECTED PRESENTATIONS** "Mobilizing Certainty in Medicine to Secure Treatment Acceptance." 2017 National Communication Association Annual Meeting, Dallas, TX. "Invocations of Death: A resource for negotiating treatment compliance in cancer care." American Sociological Association Annual Meeting, Montréal, Canada. 2016 Option-Listing and Physician Bias in Cancer Care. National Communication Association Annual Meeting, Philadelphia, PA. 2015 "The Role of Patient Symptom Presentation in Mental Health Diagnosis and Treatment in Primary Care." American Sociological Association Annual Meeting, Chicago, IL "Solidarity and Affiliative Disagreement in the Focus Group Setting: A case 2014 study of female cancer patients." International Conference of Conversation Analysis, Los Angeles, CA. SELECTED AWARDS AND FELLOWSHIPS 2017-18 Dorothy L. Meier Dissertation Fellowship 2017 Top Paper Panel, Language and Social Interaction Section of the National Communication Association 2014-2015 Graduate Research Mentorship Award 2014 Excellence in Teaching Award, Department of Sociology Graduate Summer Research Mentorship Award 2013 Graduate Summer Research Mentorship Award Honorable Mention, National Science Foundation Graduate Research Fellowship Program

# Chapter 1: From Paternalistic Medicine to Shared Decision-Making: Historical and methodological considerations

#### 1.1 Introduction

In a commencement address to the 2013 class of medical graduates at the University of Chicago, Dr. Joel Schwab encouraged the newly-minted physicians to go beyond simply treating their patients and encouraged them to foster relationships with their patients: "Be kind. Never forget this: the patient comes first and is always the most important person in the equation. Be compassionate; put yourself in their shoes. Learn something about them—where they went to school, what they do for a living, what they do for fun, what their kids do, what they like, what they don't like. Having them feel that you are rooting for them and that you're interested in them can make a tremendous amount of difference." This emphasis on treating patients not just medically well but *socially* well reflects how far the medical profession has come from the days where physicians had ultimate decision-making power. Nearly 150 years earlier, in an 1871 medical school graduation address, Oliver Wendell Holmes famously stated, "Your patient has no more right to all the truth than he has to all the medicine in your saddlebags...he should get only just so much as is good for him..." (Holmes, 1883).

Cancer care is a treatment domain in which the physician-patient relationship is critically important for treatment efficacy, adherence, and achieving a good quality of life for patients. This dissertation explores the ways in which this therapeutic relationship plays out in the decision-making process, zooming in on how patient involvement and physician expertise are negotiated in an age of decreased medical authority and increased patient agency and autonomy, partially implemented through health policies of shared decision-making (SDM) and increased patient involvement in medical care. In what follows, I argue that that physicians approach delivering treatment

recommendations in nuanced ways that work to secure the patient's acceptance of treatment – prioritizing medical authority in some cases and patient agency in other cases.

## 1.2 Physician Authority and Medical Expertise

#### 1.2.1 Paternalism in Medicine

To better situate the paradigm shift towards a shared model of decision-making, it is critical to understand the point at which the medical profession had the most professional power. As the medical profession consolidated authority by securing external legitimacy and internal consensus from the mid-19<sup>th</sup> century through the 1930s (see Starr, 1982), Holmes' paternalistic sentiments were synthesized into ideal type physician and patient roles by Talcott Parsons in 1951. The Parsonian logic placed patients in a sick role, exempt from normal activities and expectations until they became well. Patients were normatively obligated to want to become well and accordingly seek the proper help, trust the physician, and adhere to the physician's treatment plan. As such, the physician served as the gatekeeper of patients' reentrance into good health (Parsons, 1951b). Such a concept placed the patient in a vulnerable and passive role and the physician in an authoritative role. Freidson (1970) further emphasized this point in conceptualizing the patient at this time as "a ward of the system versus the patient as a well-paying customer in a buyer's market." Reeder (1972) noted one consequence of this power imbalance was a lack of patient bargaining power in medical decision-making. Patients had little leverage to negotiate medical decisions.

This paternalistic ideology was prevalent throughout the field of medicine at the time (Siegler, 1985), an era formally termed the "Golden Age of Doctoring" by McKinlay and Marceau (2002), to refer to a period following WWII through the 1980s. During this time, physicians had a substantial amount of moral authority and professional legitimacy. They were viewed by society as the only ones who had the expertise necessary to get patients well again (Light, 1979). The profession was internally regulated and largely evaded external checks on its power (Freidson, 1970;

Hafferty & Light, 1995; Parsons, 1951b). It enjoyed a strong hold on its own training, licensing, method of practice, and billing practices (Burrow, 1977; Freidson, 1970; Light & Levine, 1988; Rayack, 1967). Physicians joined the American Medical Association, had their own independent or small group medical practices, and set prices for services. At the same time, patients bought private health insurance so they could access the physician of their choice for care (Pescosolido, Tuch, & Martin, 2001) or—increasingly—were provided insurance through their employer (Mendel & Scott, 2010).

There was also rapid development in how the medical community managed and cured disease. Koch and Pasteur's "germ theory of disease" set a foundation on which several significant biomedical innovations were built (Bud, 2007; Conrad & Schneider, 2009). Physicians were accredited with successes in managing acute illness through substantial biomedical innovation, most notably life-saving vaccinations and antibiotics, new surgical techniques, and effective pain medicines (Starr, 1982). There was a focal shift from largely curative treatments to preventative care (Reeder, 1972). Concurrently, patients demonstrated high levels of trust towards and confidence in their physicians (McKinlay & Marceau, 2009).

## 1.2.2 Professional Decline of Physicians

The age of unchecked medical paternalism slowly faded from view in the late 1960's as structural changes to the medical institution came about. First and foremost, the medical profession was unable to maintain internal control with the rise of external regulation. The passage of Medicare & Medicaid legislation in 1965 activated a new age of federal involvement in healthcare and brought larger bodies of oversight into medical operations (Wear & Aultman, 2006). As a consumer of half of all health services, the federal government sought to regulate rapidly increasing medical costs. For the first time, the medical profession's governance had to share the financial playing field with federal agencies and work with them to negotiate prices for services (Mendel & Scott, 2010). The

1970's were also time of economic scarcity. Federal and state agencies adopted a new focus on economic efficiency, further policing physician decisions for particular treatment choices by holding physicians accountable for the reasoning behind their treatment decisions (Ubokudom, 2013).

These significant changes to the institution of medicine led to its eventual "corporatization" (Light, 2014; McKinlay & Marceau, 2002; Wear & Aultman, 2006) whereby the nature of physician employment transformed from economic and administrative autonomy to "bureaucratic encroachment". From 1983 to 1997, physicians' ownership interest in their own practices changed dramatically. During these years, the proportion of physicians involved in an employment-based arrangement (without ownership interest, in contrast to a solo or group practice model) nearly doubled, from 24 percent to 43 percent (Kletke, Emmons, & Gillis, 1996). Kletke et al. also noted that the proportion of self-employed solo practices fell from 40 to 26 percent. They further underscored that this trend was especially obvious among those who had been practicing for 0 to 5 years. The proportion of younger physicians employed without ownership interest rose from 37 percent in 1983 to 66 percent in 1997 (Kletke et al., 1996).

Throughout the corporatization of medicine, physicians were subjected to forms of external (largely corporate) control that they were not accustomed to, such as incentivized pay, practice restrictions, and quality control (Light & Levine, 1988). Even though these changes primarily occurred in larger healthcare systems, smaller medical practices were affected as well. Both large hospitals and small clinics were being externally restructured. Independent providers were forced into networks comprised of large, multi-level medical complexes (Light & Levine, 1988; Scovern, 1988; Stoeckle, 1988)

In addition to institutional restructuring, other structural factors like increasing education levels of Americans contributed to a declining confidence in physicians. As education levels of the general public increased, there was a steady erosion of the decision-making autonomy and

consequently the deontic authority (see Stevanovic & Peräkylä, 2012) of medical professionals. By 1972, the majority of Americans had finished 12 years of elementary and secondary schooling (U.S. Bureau of the Census, 1972) which implied a widespread basic understanding of hygiene and nutrition (Haug, 1976) and increased the likelihood of challenge to physician claims of knowledge (Haug, 1976; Wilensky, 1964). The popular membership group, AARP, reflected this new skepticism of authority in its magazine by urging its readers to assert their rights as patients and to be involved in their own medical decisions (Demkovich, 1987; Haug, 1973).

Haug (1973) hypothesized that the "deprofessionalization" of medical practice would take hold. She argued that physicians, who once enjoyed a near-total monopoly over the delivery of health care services after weeding out "quacks" and alternative practitioners through stricter licensing measures (Conrad & Schneider, 2009), found themselves sharing the practice arena with paraprofessionals like nurse practitioners in primary care and nurse midwives in obstetrics. Haug argued that this reconfiguration of medical work—coupled with patients' increasing educational attainment—would undermine the physicians' professional dominance. Freidson (1985) debated much of this theory, arguing instead that ever-changing medical technology and complex knowledge kept (and would continue to keep) physicians in a position of professional dominance.

In addition, many physicians were facing mounting legal pressures. As patients became more informed about their care, they took their physicians to task on medical decisions in the civil courts. This led to a "malpractice crisis" prompted by skyrocketing malpractice insurance premiums for physicians. Some areas experienced physician strikes and local hospitals were forced to limit the healthcare services they normally provided. An increase in patient litigiousness in addition to the thalidomide and DES scandals and reports of problematic patient experimentation further compounded a growing public attitude that physicians may not always act in patients' best interests (Reeder, 1972; Timmermans & Oh, 2010).

#### 1.3 Patient Involvement in Health Care

# 1.3.1 Patients' Rights and Informed Consent

Prior to the patient rights movement in the 1970s, it was believed that ethically practicing medicine meant physicians were to make decisions for their patients (Parsons, 1951b; Rodwin, 1994). However, in the 1960's and for two decades following, the contours of the traditional physician-patient relationship began to be reshaped by numerous lawsuits by patients and their advocates.

With an increasing number of medical advances and scientific innovations in the mid-20<sup>th</sup> century came some negative consequences for physicians. In particular, there were reported instances of patients being denied their basic human rights by their healthcare providers in the name of medical experimentation (Beecher, 1976). Among the most troubling instances of this were confirmed reports of medical experimentation on patients without their knowledge or consent.

George Annas famously described the typical hospital at this time as a "human wasteland" (Annas, 1988). It was still the case by the late 1950's that in the context of ordinary medical care, physicians did not typically discuss treatment options or treatment decisions with patients (Rodwin, 1994).

Such violations of basic human rights and asymmetrical decision-making created an impetus for change in the late 1950's, a time when the Parsonian logic that once advocated for absolute medical authority was taken to task by disillusioned patients with the help of legal professionals. After a law was introduced in a state decision in the late 1950's and then further fleshed out in a longer opinion in 1960, physicians became legally obligated to obtain informed consent from patients for treatment decisions (Katz, 1994; for further discussion see Salgo v. Leland Stanford Jr. University Board of Trustees, 154 Cal. App. 2d 560, 317 P.2d 170; Natanson v. Kline 350 P 2d 1093). Subsequently, three more famous appellate court cases on informed consent and patient

rights in decision making ended in decisions that crystallized the informed consent doctrine (Nelson-Marten & Rich, 1999a).

The notion that physicians were now under federal mandate to share decision making with their patients, relinquishing some of their medical authority, was a shock to the profession (Katz, 1994). Legally, patients became the ultimate decision-makers and had to sign off on all treatment decisions prior to any medical procedure (Rodwin, 1994). The doctrine of informed consent, more than any prior legal doctrine, encouraged patient autonomy and introduced the idea of both physician and patient sharing in medical decision making (Veatch, 2003). This marked a break from a long-standing medical tradition of unilateral medical judgment, for practicing medicine under the informed consent doctrine required some degree of collaboration between doctor and patient, however small and pro-forma, as a legal mandate. Published in 1972 by the American Hospital Association, the *Patient Bill of Rights* further affirmed that patients had authority in their own care. This document established that patients should participate in their own treatment decision-making and marked some degree of acceptance by the medical community in sharing responsibility for medical decision making with patients (Katz, 1994).

After the initial informed consent decision, other legal decisions contributed to still more patient autonomy in medical decisions. For instance, before the 1970s physicians were typically the ones to decide when to end treatment for terminally ill or dying patients (Faden, Beauchamp, & King, 1986a; Rodwin, 1994). After this longstanding belief was successfully challenged in the courts in 1976, patients were given the rights to decide when to stop or refuse treatment, even if the result meant death (Faden et al., 1986a). This decision confirmed that if patients established a power of attorney or an advanced directive in an instance of mental incapacity, they could set the terms for treatment or ending their life and the physician was legally obligated to abide by those wishes (for

further reading, see Superintendent of Belchertown State Sch. v Saikewicz, 370 N.E. 2d 417 Mass. 1977).

After many well-publicized unethical experimentations on human subjects, especially African Americans (Bhopal, 1998), the courts established that patients must be informed of participation in any medical experimentation, have an expectation of safety in the case of participation, and have the right to refuse participation at any time (Annas, 1975). Such experiments were required to disclose all potential risks to the patient (Faden et al., 1986a). The justice system allowed for an unprecedented expansion of patients' rights in response to these lawsuits and the medical profession was held to a new standard of accountability (Annas, 1993).

#### 1.3.2 Patients as Consumers

Timmermans and Oh argued that the erosion of trust in physicians, enabled largely by increasingly visible malpractice suits and increasing health care costs, is "both a consequence and accelerant of patient consumerism" (2010: S97). Prior to the 1970's, medicine was considered a "seller's market" where doctors knew best and patients were active and willing consumers. Reeder (1972) argued that because the main prerogative of the medical community was curing acute and infectious diseases, the patient did not need to be persuaded to understand the need to visit the doctor. They were sick and needed to get well. Yet, as medicine saw numerous successes in curing acute and infectious diseases and developed well-tested protocols for treatment, it shifted its attention towards preventing the onset of chronic disease and managing the progression of chronic disease (Beisecker, 1988; Reeder, 1972). Disease prevention and preventative medicine became a new priority in medical research and practice. Consequently, healthy people needed to be convinced of the need for regular medical check-ups and to visit the doctor even though they were not sick, transforming most medical care into a "buyer's market." (Reeder, 1972). This marked a shift in the economic conceptualization of patient care. Patients began to be treated as consumers of medicine,

thereby changing the ideal medical model to one that was more "responsive to patients' wants, needs, and desires" (Laine & Davidoff, 1996). Patients themselves began to demonstrate more cost sensitivity in selecting health care providers and were encouraged to shop around (Hibbard & Weeks, 1987; Timmermans & Oh, 2010).

#### 1.3.3 The Internet Health Consumer

The increasing availability of health information on the Internet over time has been found to facilitate patient involvement in decision-making (Akerkar & Bichile, 2004; Boyer & Lutfey, 2010; Wald, Dube, & Anthony, 2007) and has contributed to the concept of the "Internet health consumer" (Akerkar & Bichile, 2004; Frist, 2014). This has resulted in the "democratization" of health information through its accessibility to not just healthcare professionals but also to patients (Anspach, 2011). The Internet has created a space for a new and unprecedented amount of medical information to be consumed (Eysenbach, 2001) and is often cited as a reason for patients' desire to participate in their own care (Sainio, Lauri, & Eriksson, 2001; Xiang & Stanley, 2017). Patients have begun to join online social support groups for information about their healthcare in increasing numbers (Chung, 2014). Because the Internet transcends local boundaries, patients have been increasingly able to access information about their treatment their own physicians may not have endorsed (Frosch & Kaplan, 1999). Patients now have new leverage in decision-making through the ability to mobilize information about treatment options researched online as they make decisions with their healthcare provider (Wald et al., 2007).

# 1.4 The Paradigm of Shared Decision-Making

#### 1.4.1 Towards Collaborative Decision-Making

Shared decision-making (SDM), a process by which patients make decisions about their treatment in collaboration with their physicians (Briss et al., 2004), was first officially defined by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and

Behavioral Research in a 1982 report titled *Making Health Care Decisions* (Makoul & Clayman, 2006). SDM came about as a concept that sought to remedy the more controversial paternalistic model of practicing medicine, called for patient participation in their own treatment decisions, and encouraged patient expression of desired outcomes (Frosch & Kaplan, 1999). Further, the SDM model was an idealized solution to the need for patient adherence in the context of longer-term chronic illness management (Fraenkel & McGraw, 2007) as patients who were more informed about (and involved in) their care were more likely to adhere to treatment (Greenfield, Kaplan, & Ware, 1985). It has since been advocated for as an ideal way to involve patients in medical decisions (D. W. Brock & Wartman, 1990; Charles, Gafni, & Whelan, 1997, 1999; Emanuel & Emanuel, 1992). Following the accomplishments of informed consent litigation and the patient consumer movement, the physician was no longer seen as the absolute "guardian of the patient's best interests" (Charles et al., 1997) and a process of patient inclusion in the medical decision-making process was pushed as a new treatment paradigm (Emanuel & Emanuel, 1992). However, there still remains a continuum of patient participation in medical decisions (Chewning & Sleath, 1996), from the passive patient to the "active consumerist" who regularly challenges physician authority (Haug & Lavin, 1981).

### 1.4.2 The Components of Shared Decision-Making

SDM sits in the center of a spectrum of decision-making models, from the paternalistic model on one end to the informed choice model on the other (Emanuel & Emanuel, 1992). While in the paternalistic model the physician provides little to no information about treatment options and makes medical decisions unilaterally, in the informed choice model the decision-making onus is entirely on patients once they receive all possible treatment options from their physician (Emanuel & Emanuel, 1992). Advocates of SDM believe that empirical facts about a patient's condition ought to be contextualized in the patient's subjective and personal experience. At the same time, physicians

ought to provide guidance in treatment decisions (Charles et al., 1999; Eddy, 1990; Emanuel & Emanuel, 1992).

For treatment decision-making to be considered shared, it must meet certain conditions. The most self-evident component of SDM is that it must involve at least two people, one of those the patient and the other the physician (Charles et al., 1997). While many conceptions of shared decision-making involve just two participants, it is important to consider that many scenarios can involve more than a dyadic relationship. Sometimes, this is a triadic relationship if patients bring a companion to the clinic visit, or it can involve more participants if multiple clinicians participate in decision-making using a team-based approach during more complex treatment. For instance, in cancer care, the medical oncologist, surgeon, and radiation oncologist often all contribute to treatment decision-making (Charles et al., 1997).

SDM has been framed as a division of labor between physician and patient, where the physician supplies all relevant information, including alternative treatments, to the diagnosis and management of the patient's condition. It has been idealized as a cooperative process through which physician and patient work together to each communicate their preference with a joint investment in the treatment decision (Légaré & Thompson-Leduc, 2014). The physician is charged with providing information regarding all available treatment options, risks and benefits, and impacts on patients' well-being. Conversely, patients must offer their preferences, values, beliefs, and burden tolerances (Charles et al., 1997, 1999).

Advocates of SDM argue that the key to achieving patient desire to participate in decision-making is information (Sainio & Lauri, 2003). The delivery of sufficient and relevant information to patients up front is crucial to shared decision-making, for it would be impossible for patients to collaborate in the treatment process without it (Charles et al., 1997; Coulter, Entwistle, & Gilbert, 1999). Information must be clear and comprehensive so patients effectively understand what is

being communicated prior to participating in the decision (Davison, Kirk, Degner, & Hassard, 1999; Mackillop, Stewart, Ginsburg, & Stewart, 1988).

Mutual participation, respect, and power-sharing are also argued to be important components of SDM (Makoul & Clayman, 2006). In the SDM model, physician and patient both equitably share power over the treatment decision and thus both take responsibility for the decision (Charles et al., 1997). Katz, in his 2002 book *The Silent World of Doctor and Patient*, offered further detail to the SDM model and focused on the role of compassionate conversation in accomplishing SDM. He interpreted SDM from a Freudian perspective, where self-determination was constrained by underlying unconscious influences. He concluded that the core of successful decision-making was compassionate dialogue, where physicians spoke with patients in an empathic conversation and actively listened to patients so that their wants and needs were heard (Katz, 2002).

# 1.4.3 Patient Involvement and Health Outcomes

The SDM model came out of a need for patients to be involved in their own care, and it has often been cited as successful because it encourages patient adherence to physician treatment recommendations, especially in chronic care situations (Greenfield, Kaplan, Ware Jr, Yano, & Frank, 1988; Greenfield et al., 1985; Hamann et al., 2006). This is because the SDM model encourages patient involvement and therefore can engender patient self-advocacy in health care (Montgomery, Harding, & Fahey, 2001). This is often cited as positive for health outcomes (Corser, Holmes-Rovner, Lein, & Gossain, 2007a). However, more involved patients sharing in the treatment decision can lead to adverse health outcomes as well. In a study done by Stivers (2002a) parent/patient participation often went too far and led physicians to inappropriately prescribe antibiotics to their pediatric patients because they gave into parent/patient pressure. While SDM offers evidence for treatment adherence resulting from increasing patient involvement, it can also be disadvantageous.

Many argue that increased patient involvement and the simultaneous erosion of physician authority has even led to an interactional tension between physicians and patients (Maynard & Heritage, 2005; Stacey, Henderson, MacArthur, & Dohan, 2009; Waitzkin, 1991). In some cases, patient involvement in treatment decisions can be particularly tricky for physicians to manage because patients may actually advocate for their own preferred treatment or question the proposed treatment plan, in effect challenging the physician's professional expertise (Stivers, 2002a, 2007). Consequently, treatment recommendations have been found to be interactionally negotiable events whereby both physicians and patients each put their preferences for treatment on the table. This is argued to be the case because when patients resist treatment (see Stivers 2002a) it can trigger physician persuasion for treatment acceptance (Stivers, 2005b, 2007). Exploring the problem of parent pressure for antibiotics in a context of a child's upper respiratory infection, Stivers (2002a) looked at how physicians balanced of their own medical agenda-avoiding inappropriate antibiotic prescribing-and preserved patient (in this case, parent) participation in decision-making. Stivers found that parents used distinct tactics to pressure physicians for antibiotics to treat their child for the cold virus. This could come in the form of overt pressure or a communication of certain treatment expectations (Stivers, 2002c, 2002a) which ultimately shaped physicians' treatment recommendations.

## 1.4.4 The Enduring Power of Shared Decision-Making

When Congress crafted the Patient Protection and Affordable Care Act of 2010, the most significant change to the US healthcare system since Medicare and Medicaid, it integrated the main components of SDM into a sleeper provision (Frosch, May, Rendle, Tietbohl, & Elwyn, 2012). Many states have also endorsed collaborative decision-making practices and have put forth policies intended to encourage patient involvement in medical decisions (Frosch et al., 2012). Shared decision-making has been connected to better health outcomes. Patients who used shared decision-

making often chose less invasive surgical options (Oshima Lee & Emanuel, 2013). Specifically, a study conducted in 2012 by Group Health in Washington showed that implementing SDM reduced rates of surgery by 38% (Arterburn et al., 2012; Oshima Lee & Emanuel, 2013). SDM has also been shown to reduce healthcare costs. In the same 2012 study by Group Health, SDM implementation reduced healthcare costs up to 21% over a span of 6 months (Arterburn et al., 2012; Oshima Lee & Emanuel, 2013). It has also been estimated that if SDM was incorporated into the standard of care in just 11 medical procedures, the US would save \$9 billion on healthcare spending over 10 years.

Respecting patient autonomy and the desire for patients to be involved in their medical decisions is widely considered a primary ethical component of practicing medicine (Richards, 1998). In literature on the implementation of shared decision-making, SDM is inexorably linked to ethical medicine. Notably, SDM has been referred to as an "ethical imperative" of the medical community (Drake & Deegan, 2009) and an "ethical necessity" in critical care. The increasing attention on patient empowerment in the medical encounter in recent decades has contributed to the popularity of the SDM model (Roberts, 1999) The widespread call to empower patients in the medical counter is often connected to discussions on the redistribution of power in the physician-patient relationship. Patients are encouraged by the media and other mainstream organizations to "take charge" of their healthcare (Roberts, 1999), for example, by engaging in self-care (Lorig, Mazonson, & Holman, 1993). Empowerment in the medical visit has been shown to lead to successful treatment outcomes. For example, patients who demonstrated empowerment by asking more questions of their physician during their visit had an increased adherence to their follow-up care (Roter, 1977). Empowerment has also been shown to contribute to patient mastery of monitoring chronic illness (Funnell, 2004). In diabetes care, it was shown that patients who participated in an empowerment seminar had improved self-efficacy and lowered their hemoglobin A1C levels (M. S. Arnold, Butler, Anderson, Funnell, & Feste, 1995).

## 1.5 Barriers to the Shared Decision-Making Model

## 1.5.1 Patient Participation

For many patients, the concept of asking questions, expressing preferences, and even disagreeing with their physician is an entirely new one (Entwistle et al., 2010; Frosch et al., 2012). Many sociodemographic variables are believed to impact the degree to which the patient will participate in medical decision-making (Chewning & Sleath, 1996). Many studies have demonstrated that younger patients generally prefer more involvement in medical decision-making, while older patients prefer less (Haug & Lavin, 1981; Hibbard & Weeks, 1987; Stewart, Meredith, Brown, & Galajda, 2000). Many studies support the claim that patients with higher educational attainment and of higher socioeconomic status demonstrate a strong desire to be an active part of their treatment decisions (Ende et al., 1989; Haug & Lavin, 1981; Robinson & Thomson, 2001). Conversely, patients of low socioeconomic status and low educational attainment express a weaker preference for participation in their treatment decisions (Levinson, Kao, Kuby, & Thisted, 2005; Waterworth & Luker, 1990). This could potentially be explained by their low "cultural health capital" (Shim, 2010). Grounded in Bourdieu's work on cultural capital, cultural health capital is a "specialized form of cultural capital that can be leveraged in health care contexts to effectively engage with medical providers" (Shim, 2010). Similar to cultural capital, the attainment of cultural health capital is largely subject to the social inequalities found in most institutional settings. When a patient has low cultural health capital, s/he often struggles to communicate with the physician using a mutually understood vocabulary (Shim 2010). For instance, if a physician uses medical vocabulary to discuss treatment options with a patient and the patient does not possess the cultural health capital necessary to understand the options, the patient may feel less than willing to partake in the treatment decision making process and will likely defer to the physician (Baker et al., 2007).

Possessing medical vocabulary, often termed "health literacy," is crucial to patient participation a clinical setting (Baker et al., 2007). Low health literacy disproportionally affects low income patients and patients belonging to ethnic minorities (Sarkar, Fisher, & Schillinger, 2006; Shim, 2010). This discussion of cultural health capital in hindering the process of SDM runs parallel to arguments made by literature on "fundamental causes", where certain social conditions impact the causes of disease (Link & Phelan, 1995, 1996). The connection between fundamental causes of disease and participation in SDM could be made given the strong relationship between low health literacy and lack of desire to participate in medical decisions.

Insofar as patient participation in decision-making is encouraged, this scenario runs the risk that the physician provides too much information and leaves all of the choices to the patient, providing insufficient guidance. The "informed choice" model, where the physician provides all the necessary options to the patient but offers no direction, risks abandoning the patient entirely (Elwyn, Edwards, Kinnersley, & Grol, 2000; Quill & Cassel, 1995). Although this is a controversial practice, it has been reported by both physicians and patients that this model of little physician involvement and total patient involvement is widely used in medical decision-making (Elwyn et al., 2000). Yet, it is important to differentiate between a fully involved patient and a fully informed one in the SDM model. Blanchard and colleagues (1988) found that while an overwhelming majority of cancer patients surveyed (92%) wanted to be informed of all news about their condition whether good or bad, a substantially smaller number (69%) wanted to participate in treatment decisions. This finding was supported by an earlier study by Lidz et al. (1983), where patients with non-serious illnesses were surveyed about their preferences for involvement in decision-making. Again, the majority of patients expressed the desire to be informed but ultimately wanted their physician to make the treatment decisions. Beisecker and Beisecker (1990) had similar results when examining decisionmaking preferences in decisions about medications and dosing.

## 1.5.2 Patient Participation

There are still many barriers on the physician side of the coin that are cited as impeding physician implementation of shared decision-making (Frosch et al., 2012; Légaré, Ratté, Gravel, & Graham, 2008). In spite of SDM advocacy, some physicians are reported to still make many treatment decisions unilaterally (Gravel, Légaré, & Graham, 2006) and to be authoritarian in the medical encounter (Frosch et al., 2012). Even when physicians are not necessarily authoritarian, there is still evidence that underscores the lack of complete adoption of a shared decision-making practice (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999). In a systematic review of the literature, Gravel et al. (2006) found that studies on physician participation in SDM cited three key barriers to its implementation. Most often cited by physicians were constraints on time because SDM can potentially extend the duration of the visit as it involves more extensive deliberations which can discourage physician implementation as clinic schedules are busier than ever (Charles et al., 1999; Frosch et al., 2011).

The second and third most often cited impediments to physician participation in SDM both involve applicability. Gravel et al. (2006) found that many physicians believed certain patient sociodemographic characteristics were not applicable to SDM. This is worrisome, because this demonstrates that physicians were making assumptions about patients that no doubt derive from embedded discrimination about various social variables (Bruera, Willey, Lynn Palmer, & Rosales, 2002). The third most often cited barrier to SDM Gravel and colleagues found was the degree to which physicians believed SDM was applicable to the clinical situation at hand. Certain decisions were noted as more conducive to patient involvement than others. For instance, a course of action that involved multiple legitimate treatment options was cited by healthcare practitioners as one of the only proper instances to incorporate patient involvement (Elwyn et al., 2000).

#### 1.5.3 Variations in Illness

Patients with more acute conditions are less likely to participate in care (Butow, Maclean, Dunn, Tattersall, & Boyer, 1997). More serious conditions generally require more toxic and invasive treatment decisions that patients are often unwilling or not prepared to make (Redmond, 1998). For instance, those examining decision-making in high stakes treatment environments have argued that patients want a more paternalistic physician (Rosenbaum, 2015). Another study found that an increase in functional incapacity decreased patients' willingness to participate in their treatment decisions (Cole, Kiriaev, Malpas, & Cheung, 2017). It is also important to note that many treatments have only one realistic intervention and thus demonstrate the limitations of implementing shared decision-making (Whitney, 2003). For example, while a patient may be peripherally involved the decision to undergo to life-saving emergency surgery due to informed consent laws, s/he is not participating in shared decision-making as s/he is not given a choice in the matter. In less serious scenarios, for instance when a patient is deciding between treating hypertension and maintaining normal sexual function, the patient's perspective and therefore participation is more feasible (Whitney, 2003).

# 1.6 Physician-Patient Interaction in Cancer Care

# 1.6.1 Studying Physician-Patient Interaction

In the mid-20<sup>th</sup> century, theorists began to build off of Parson's 1951 theoretical analysis of the physician-patient relationship. Szaz and Hollender (1956) conceptualized three physician-patient relationship models representing a cline of physician authority and patient agency: activity-passivity, guidance-cooperation, and mutual participation. In the first, the patient is totally incapacitated, is unable to assert agency, thus the physician has complete control. They argued that this relationship was appropriate in an emergency setting where acute issues required immediate expert action. In the second, the patient is aware of his/her surroundings, may ask for the physician's help and

subsequently be expected cooperate under the guidance of the physician's care. In the final model, the authors argued that the mutually beneficial nature of a collaborative relationship could motivate both parties to work together. This more egalitarian concept would ultimately allow patients to care for themselves in a more chronic care environment.

Similar to Szaz and Hollender's theory of mutual participation, Balint's theory of the physician-patient relationship (1964) used a psychosocial lens to conceptualize a partnership between physician and patient. In this partnership, Balint argued that physicians were themselves therapeutic in their own right because their "self-as-expert" was the strongest treatment tool they had. Over time, Balint claimed, physicians became more effective and efficient practitioners because they gained their patients' trust, understood their values and preferences, and learned about their social and physical lives.

Taking this theory one step further, in *Doctors Talking to Patients* (1976), Byrne and Long isolated the medical visit into stages and characterized physician behaviors according to each stage. The analysis reported a preponderance of behaviors which facilitated the therapeutic partnership originally established by Balint (1964). The authors identified both cooperative features of physician-patient interaction, like questioning, reassuring, and encouraging, and also noted several dysfunctional features. This study, which largely focused on physician behaviors, was designed to be both an empirical contribution and a learning tool for practitioners in its own right (Heritage & Maynard, 2006).

These early investigations into the physician-patient relationship sharpened focus on the patient experience known as patient-centered care. This practice is widely taught from the perspective of the seminal three-function medical interview model (Cohen-Cole, 1991; Cohen-Cole & Bird, 1991). The model encourages diagnostic and treatment procedures to be carried out through considering the patient's psychosocial context (e.g., how the patient behaves as a patient and what

the illness means for him/her), developing of a therapeutic partnership whereby the physician works to build a relationship with the patient, and educating the patient about treatment and identifying potential barriers to treatment implementation (Cohen-Cole, 1991; Heritage & Maynard, 2006).

Patient-centered medicine takes a psychotherapeutic approach in prioritizing the relationship between physician and patient rather than the former approach which was concerned with how to manage and cure illness scientifically, ignoring the concerns of patients. Building on a new concern with the patient experience, Korsch and Negrete (1972) demonstrated in a groundbreaking study that systematically studying physician-patient interaction (in their study, pediatric acute care) was not only possible but its results could yield improved patient health outcomes. Their approach implemented Bales' (1950) Interaction Process Analysis (IPA), which offered a way to evaluate group behavior through classifying behavior (what they term an "act") into different categories of actions. While process analysis allowed researchers to study physician-patient interaction for the first time and in an orderly way, it has been argued that the coding categories of IPA were too general and did not offer the specificity needed to capture the fine-tuned gears of medical interaction (Heritage & Maynard, 2006).

To confront these shortcomings, Roter and colleagues tailored more a specific coding scheme, the Roter Interaction Analysis System (RIAS). RIAS broke down the broad categories from process analysis into more comprehensive categories. These included 15 socio-emotional categories and 24 task-focused categories (Roter & Larson, 2002). Using RIAS, coders are able to categorize interaction without transcribing the visit, allowing for the analysis of larger data sets at a cost-effective price. RIAS opened up the boundaries of coding physician-patient interaction to cover visits beyond primary care and allowed for studies of the relationship between social variables (e.g., gender) and patient satisfaction. Yet RIAS and other process-oriented models are not without criticisms. Charon et al. (1994) argued that RIAS overlooks the context of the medical visit and how

the interaction between one participant influences the other. Along these lines, Heritage and Maynard (2006) contend that simply focusing on outcomes can produce a study that overlooks patient preferences across a variety of illness contexts: "A consumerist patient in the context of upper respiratory infections may look for a more paternalist stance from a physician in the context of a cancer diagnosis" (p. 358).

Microanalytic approaches to studying interaction came about as more ethnographically focused and originated from the Chicago School of ethnography in sociology. Mishler, in his seminal work, *The Discourse of Medicine*, used microanalysis as a tool for understanding history taking. He concluded that physicians and patients pursued distinct medical agendas: while physicians were biomedically focused, patients were focused on their lifeworld concerns. Strong (1979), in studying pediatric encounters through microanalysis, found that bureaucratic medicine (politeness, emotional control) dominated the medical visit. Strong offered medical sociologists insight into how the medical authority many were preoccupied with at the time played out in interaction, in this case, through a "ceremonial order". As a symbolic interactionist, Emerson (1970) demonstrated that the traditional understanding of bureaucratic, authoritative medicine could be challenged through examining interaction in more sensitive, specialty contexts. Miscommunication has also been studied in this vein. Observing the frequency with which physicians interrupted patients, West (1984) concluded that physicians exerted this form of social dominance much more frequently than did patients, and gender—when the physician was male and the patient was female—was most predictive of interruptive behavior.

## 1.6.2 The Conversation Analytic Approach to Physician-Patient Interaction

Conversation analysis emerged as a way for researchers to systematically analyze distinct patterns in interaction and related outcomes. It connected traditions of symbolic interactionist approaches to ethnography and earlier methods of quantitatively coding interaction (Douglas W

Maynard & Heritage, 2005). Many conversation analysts have applied these strengths in studying the institution of medicine and their approaches have been driven by the logic that practicing medicine is inherently *social*, involves not just biomedicine but interaction, and thus is accountable to interactional norms of ordinary conversation. Over the past 30 years, conversation analysis have explored a multitude of therapeutic environments like adult primary care (Heritage & Maynard, 2006; Koenig, 2011; Robinson, 2006; Robinson, Tate, & Heritage, 2016), pediatric primary care (Stivers, 2002c, 2005b, 2007), and specialty contexts like surgery (Mondada, 2014), anesthesia (Hindmarsh & Pilnick, 2007), AIDS treatment (Peräkylä, 1995), pediatric genetics (Stivers & Timmermans, 2016), psychiatry (Quirk, Chaplin, Lelliott, & Seale, 2012), and neurology (Toerien, 2017), among others.

Conversation analytic approaches to studying medicine hinge on the idea that the medical encounter involves commonsense reasoning (Garfinkel, 1967) and a distinct interaction order (Goffman, 1983) present in ordinary conversation. That is, "interactional practices through which persons conduct themselves elsewhere are not abandoned at the threshold of the medical clinic" (Heritage & Maynard, 2006). Conversation analyses of medical interaction are inextricably linked to already-established conversational structures like the machinery of turn-taking (Sacks, Schegloff, & Jefferson, 1974) troubles telling (Jefferson, 1984), repair (Schegloff, Jefferson, & Sacks, Harvey, 1977) and are organized through ritualized cooperation between the self and the other (Goffman, 1955).

The proceedings of the medical encounter are subject to the same constructs as ordinary interaction (Heritage & Maynard, 2006). It has been found that participants treat these interactional projects within the medical visit (e.g., diagnosis, history-taking, treatment) in sequentially distinct ways (Heritage & Maynard, 2006; J. D. Robinson, 2003). Heritage and Sefi (1992) found that treatment recommendations required acknowledgement, most frequently in the form of acceptance.

Stivers (2005) uncovered that lack of this acceptance sequentially after a treatment recommendation was treated as problematic and lead to a negotiation between physician and patient about the recommendation that involved concessions, re-doing the recommendation, and providing accounts for the recommendation. In addition, the sequence of the medical visit can be altered by clinicians for particular interactional ends. Maynard (1996) established that, before delivering diagnoses, physicians used prospective display sequences as a pre-diagnosis to prepare patients for the receipt of bad news and "forecast" to them the impending delivery of bad news.

In particular, analyzing turn design in the medical visit has been an important means for uncovering critical findings. Medical questions are constructed on the theories of "optimization" (favoring a no- or minimal-problem response) and "recipient-design" (based on the patient's individual circumstances) (Boyd & Heritage, 2006). Heritage and Stivers (1999) discovered important ways physicians managed patient expectations of diagnostic outcomes in the ways they organized their talk during the physical examination. Turn design has also revealed important aspects of patient responses. Stivers (2002b) concluded that the way parents presented their child's symptoms had important implications for diagnosis and subsequent treatment of upper respiratory infections.

Bergen and Stivers (2013) uncovered ways in which patient disclosures of medical "misdeeds" (e.g., failures of treatment adherence, taking an OTC medication differently than indicated) were mobilized for particular interactional ends like an evaluation of their behavior or a particular treatment. The method of conversation analysis offers a novel and important lens through which Goffman's interaction order plays out in medicine and how the physicians and patients work to coconstruct a medical visit; patterns in clinical interactions are evaluated turn-by-turn, dysfunctions are identified, and cooperation between physician and patient is assessed.

## 1.6.3 Conversation Analysis in Cancer Care

A handful of conversation analysts have taken foundational studies of interaction in medical care settings to the domain of cancer care. Extending the examination of bad news delivery into the oncology space, Lutfey and Maynard (1998) analyzed how oncologists brought up death and dying with their patients near the end of life. The authors concluded that oncologists reflected a long-standing reticence towards directly talking about death with their patients. Instead, oncologists delivered an *implied* message to their patients signaling that they were near the end of their lives. Several years later, Beach and colleagues (2005) explored how patients demonstrated fears in cancer care and oncologists' subsequent responses to those fears. Beach and Dozier (2015) found that patients who demonstrated high levels of uncertainty in the visit also demonstrated the most proactivity. But the lack of conversation analytic research in the cancer care domain noted by Beach and Anderson (2003) remains true today.

# 1.6.4 The Treatment Environment of Cancer Care

A cancer diagnosis is a life-altering event. Fears of death and uncertainty are pervasive throughout diagnosis and treatment. After being diagnosed, patients need to make significant, time-sensitive decisions with a physician who is relatively new to them: their oncologist. Cancer patients are delicate patients and need to be watched closely throughout the treatment process, which could last from months to years. Cancer can progress slowly or rapidly, and no one can be fully certain whether it will respond to the standard treatments. Additionally, once treatment has begun, cancer patients often have compromised immune systems with high risk of infection, can be nutrient-deprived, and can have nervous system defects (American Cancer Society 2015). Patients require consistently close monitoring by their oncologist because of onerous nature of the treatments, the potentially harmful side effects, and the essential uncertainty of the disease itself. This necessitates a particularly close therapeutic partnership between patients and their oncologists.

When we think specifically about how patients and clinicians deal with treating cancer, many important problems come to mind. Cancer is malignant, difficult to treat, and carries with it substantial amounts of uncertainty about its prognosis (Avis et al., 2005; Garofalo et al., 2009; Mishel, 1990). Treatment decisions in the arena of cancer can be life altering, for instance, whether or not to have a hysterectomy, whether or not to undergo chemotherapy, or whether to continue a chemotherapy regimen that may no longer have utility in treating the disease. Conversely, other decisions can be less weighty, for instance, whether to use a cream to help with a healing wound, or whether to take certain supplemental vitamins to aid in symptom relief. Significantly, looming in the background of many decisions about cancer treatment is that the treatments can be burdensome insofar as they are long with substantial side effects, and that the disease can be deadly.

A primary function of clinical consultations with ill patients is to identify an appropriate treatment. Physicians hold most of the cards in this situation: they have the knowledge to diagnose and to understand what the diagnostic implications are for treatment, and they possess the legal and cultural authority to prescribe (Starr, 1982; Stivers, 2002a; Timmermans & Oh, 2010). Yet, the aforementioned shift in patient-provider dynamics since the 1960s has provided patients with increasing power. As was previously discussed, the rise of patient consumerism and informed consent has re-oriented the medical profession towards increased patient involvement (Jones, 2017). The increasing availability of health information on the internet has also facilitated increased patient involvement in their own health care (Akerkar & Bichile, 2004; Boyer & Lutfey, 2010; Wald et al., 2007). Some have pointed out that a consequence of this is the "democratization" of health information through its availability to *both* laypeople and healthcare professionals (Anspach, 2011). Moreover, patients are the practical gatekeepers of all actual treatment implementation insofar as they must ingest pills, show up for chemotherapy, etc. This yields an interdependent relationship between physician and patient, making treatment decision-making made an exceptionally rich

communicative environment. This is particularly the case in cancer care because treatments are complex and range from innocuous to toxic, from symptomatic to life-saving. A patient's refusal of treatment could lead to increased morbidity and mortality, but it also can represent an autonomous choice within their rights.

#### 1.7 Data

The data come from 90 video-recorded clinic visits between oncologists and their patients collected between 2014 and 2017 at two large academic health centers in the western United States. Ethnographic field notes were collected concurrently with video data collection in the hallways when the camera was on inside the room, in the clinic offices before and after clinics, and if a patient did not consent to be video-recorded but was comfortable with me in the room shadowing the oncologist. Research protocols were IRB-approved. All clinician participants (e.g., oncologist, residents, fellows, nurses) and patient participants (including any companions in the room at the time of recording) provided written informed consent.

Oncologist participants spanned two sub-specialties, gynecologic oncology and urologic oncology. Two participants were urologic oncologists, three were gynecologic oncologists. One participant, and gynecologic oncologist, was female and the rest were male. Of the 82 patient participants, 17 were male patients being treated for a urologic cancer or pre-cancer, and 65 were female patients being treated for a gynecologic cancer or pre-cancer. Visits involved patients actively being treated for cancer or pre-cancer or being monitored post-treatment. Visits were transcribed according to CA conventions (Hepburn & Bolden, 2012; Heritage, 1984b) and analyzed using CA methodology.

#### 1.8 Method

This dissertation uses primary conversation analytic (CA) methodology to analyze the data, and at times supplements the CA analysis with ethnographic analyses from an interactionist

approach. Conversation analytic approaches to medical interaction maintain the crucial stance that medical practice is inherently a social activity subject to the same conversational norms as ordinary interaction. Accordingly, through an understanding that interactants co-construct and collaborate to complete an interactional project, conversation analysts offer critical insight into the physician-patient relationship and the means through which that relationship achieves particular therapeutic outcomes (Maynard & Heritage, 2005). Those outcomes at times can be effective, and at others, demonstrate room for improvement. Therefore, approaching the medical visit using conversation analytic methodology is an important tool for measuring patient-centered care and SDM.

CA serves as an important methodology for analyzing patterns in interaction which can then be shown to be ordered and systematic in usage by co-participants as a practice. In order to uncover and label a way of communicating as a practice of interaction, it must be a repeated communication behavior for doing some action which has distinct and patterned consequences for subsequent turns at talk (Heritage, 2010). For instance, a certain action done by one interactant can be seen across multiple cases (e.g., an invitation, a request), but what makes it significant as a practice is that it is done in distinct and patterned ways (e.g., requesting with a directive form "Hand me the salt" is used in different contexts than requesting using an interrogative form "Could you hand me the salt?) (Heritage, 2010a; see also Curl & Drew, 2008; Heritage, 2010; Rossi, 2012). Such conversational practices are meaningful on an institutional level (Heritage, 2011) because interactions are couched in larger activities and end-goals to which the institutional figures are no doubt oriented (Drew & Heritage, 1992).

Conversational practices can provide robust evidence for the accomplishment of a social action in medicine (e.g., a diagnosis, physical exam, treatment recommendations). Medical CA scholars have found there to be recurrent and patterned ways in which patients account for seeking acute care (Heritage & Robinson, 2006), patients present symptoms (Stivers, 2002c), physicians

conduct physical exams (Heritage & Stivers, 1999b), and physicians recommend treatment (Stivers, 2005a). Drawing on foundational studies in treatment recommendations, most recently by Stivers and colleagues (Stivers et al., 2017), this work will likewise use CA as a primary methodology for identifying practices through which oncologists recommend treatment to their patients, practices in how patients respond, and how these practices can add to our understanding of the physician-patient relationship in cancer care. Accordingly, the following analyses use standard CA practices of transcription—including transcription symbols—to demonstrate beyond simply what was said, but *how* it was said (see Hepburn & Bolden, 2012; see also Appendix I)

### 1.9 Overview of Dissertation

In this dissertation, I will show how oncologists recommend treatment to patients, how patients respond to those recommendations, and to what degree physicians work to get patients on board with what they believe to be the best therapeutic path forward. In Chapter 2, I begin by providing a conceptual framework for understanding how decisions are made by examining the treatment context in which oncologists recommend: new treatment recommendations, mid-course treatment recommendations, and recommendations for treatment that are ancillary to the primary cancer treatment. I find that physicians demonstrate different orientations to patient participation and thus patient agency depending on the type of decision being made. Notably, physicians are aligned with where patients are in the process of their treatment. The results suggest that physicians reflect different norms for patients' rights and responsibilities to be involved in decision-making: they deploy more agency and are more authoritative in recommendations for changes to treatment and less so when making recommendations for new treatment. When recommending treatments ancillary to the primary cancer treatment, physicians deploy more authority when they index concern for patients' well-being and deploy less when patients ask for an ancillary remedy themselves. This analysis highlights that the consideration of the different types of decisions in the treatment process

and the therapeutic partnership between oncologist and patient matter significantly in understanding how treatment decisions play out in interaction.

Physicians of all sorts face patient resistance, and in Chapters 3 and 4 I observed that the key issues of uncertainty and death could be invoked to combat patient resistance in the cancer care consultation. Specifically, with regard to uncertainty, in Chapter 3 I build on extensive work in medical sociology with respect to professional socialization and the patient experience and argue that while physicians have more or less knowledge with respect to available evidence, they can *present* their degree of certainty about this knowledge differently. What do I mean by this? I argue that when we look at talk of what is certain (or uncertain) through a conversation analytic lens, certainty and uncertainty in medicine can be separable from available knowledge and also can be flexible depending on their interactional function. Notably, we can see physicians foregrounding their degree of medical certainty moment by moment. In the face of a resistant patient, a physician's recommendation of a particular treatment may become more certain to work, for instance. In particular, physicians at times highlight the inherent limits of medical knowledge, and at other times they underscore the certainty of particular outcomes, both as a way of mobilizing patient acceptance of a treatment recommendation.

In Chapter 4, I examine how end of life discussions are broached. Existing sociological research documents a deep-seated reticence to discuss death and dying in medical care, which can lead to poor prognostication, late palliative care or hospice referrals, overtreatment, and patients unaware about the terminality of their illness. I show that consistent with prior research, physicians rarely topicalize death or dying in the end of life context. Instead, physicians avoid discussions about end of life care in favor of recommending further treatment. This is particularly striking when patients are at an advanced disease stage with little chance of remission. I approach this from two angles.

The first part of the chapter zooms in on interactional practices that represent and reinforce larger concerns: suboptimal quality of life at the end of life, poorly prepared patients and families, and higher health care costs. In the second part of the chapter I discuss how although death and dying are not directly topicalized as an end of life discussion in most cases, death and dying are nonetheless invoked, but in a completely different way than prior sociological research found. I show that clinicians invoke dying to persuade patients towards a particular treatment. Like the Chapter 3, invoking death is another strategy oncologists use to lobby for treatment. When patients demonstrate resistance, or when resistance is anticipated, physicians invoke the possibility of the patient's death for treatment acquiescence. Ultimately, I conclude that there is a diametric nature to the way death gets broached in cancer treatment. On the one hand death inhabits encounters as a way to get patients to acquiesce to treatment. On the other hand, death and the terminality of illness get written out of these encounters when treatment cessation or end of life care are appropriate to broach. In spite of this, the overall functions of these opposing forces are the same: to get patients to accept more treatment.

#### References

- Akerkar, S. M., & Bichile, L. (2004). Doctor patient relationship: changing dynamics in the information age. *Journal of Postgraduate Medicine*, 50(2), 120.
- Annas, G. (1993). Experimentation and research. *The Journal of the California Alliance for the Mentally Ill*, 5(1), 9–11.
- Annas, G. J. (1975). The rights of hospital patients: the basic ACLU guide to a hospital patient's rights. Discus Books New York.
- Annas, G. J. (1988). Judging medicine. Humana Press.
- Anspach, R. R. (2011). Preface. In P. McGann & D. J. Hutson (Eds.), *Sociology of Diagnosis* (Vol. 12, pp. xiii–xxvii). Bingley, UK: Emerald Group Publishing.
- Arnold, M. S., Butler, P. M., Anderson, R. M., Funnell, M. M., & Feste, C. (1995). Guidelines for facilitating a patient empowerment program. *The Diabetes Educator*, 21(4), 308–312.
- Arterburn, D., Wellman, R., Westbrook, E., Rutter, C., Ross, T., McCulloch, D., ... Jung, C. (2012). Introducing decision aids at Group Health was linked to sharply lower hip and knee surgery rates and costs. *Health Affairs*, *31*(9), 2094–2104.
- Avis, N. E., Crawford, S., & Manuel, J. (2005). Quality of life among younger women with breast cancer. *Journal of Clinical Oncology*, *23*(15), 3322–3330.
- Baker, D. W., Wolf, M. S., Feinglass, J., Thompson, J. A., Gazmararian, J. A., & Huang, J. (2007).

  Health literacy and mortality among elderly persons. *Archives of Internal Medicine*, 167(14), 1503–1509.
- Bales, R. F. (1950). Interaction process analysis; a method for the study of small groups.
- Beach, W. A., & Anderson, J. K. (2003). Communication and cancer? Part I: The noticeable absence of interactional research. *Journal of Psychosocial Oncology*, 21(3), 1–23.

- Beach, W. A., & Dozier, D. M. (2015). Fears, uncertainties, and hopes: patient-initiated actions and doctors' responses during oncology interviews. *Journal of Health Communication*, 20(11), 1243–1254.
- Beach, W. A., Easter, D. W., Good, J. S., & Pigeron, E. (2005). Disclosing and responding to cancer "fears" during oncology interviews. *Social Science & Medicine*, 60(4), 893–910.
- Beecher, H. K. (1976). Ethics and clinical research. Springer.
- Beisecker, A. E. (1988). Aging and the desire for information and input in medical decisions: patient consumerism in medical encounters. *The Gerontologist*, 28(3), 330–335.
- Beisecker, A. E., & Beisecker, T. D. (1990). Patient information-seeking behaviors when communicating with doctors. *Medical Care*, 28(1), 19–28.
- Bergen, C., & Stivers, T. (2013). Patient Disclosure of Medical Misdeeds. *Journal of Health and Social Behavior*, 54(2), 221–240.
- Bhopal, R. (1998). Spectre of racism in health and health care: lessons from history and the United States. *BMJ: British Medical Journal*, *316*(7149), 1970.
- Blanchard, C. G., Labrecque, M. S., Ruckdeschel, J. C., & Blanchard, E. B. (1988). Information and decision-making preferences of hospitalized adult cancer patients. *Social Science & Medicine*, 27(11), 1139–1145.
- Boyd, E., & Heritage, J. (2006). Taking the history: questioning during comprehensive history-taking. STUDIES IN INTERACTIONAL SOCIOLINGUISTICS, 20, 151.
- Boyer, C. A., & Lutfey, K. E. (2010). Examining Critical Health Policy Issues within and beyond the Clinical Encounter Patient–Provider Relationships and Help-seeking Behaviors. *Journal of Health and Social Behavior*, *51*(1 suppl), S80–S93.
- Braddock III, C. H., Edwards, K. A., Hasenberg, N. M., Laidley, T. L., & Levinson, W. (1999).

  Informed decision making in outpatient practice: time to get back to basics. *Jama*, 282(24), 2313–

- Briss, P., Rimer, B., Reilley, B., Coates, R. C., Lee, N. C., Mullen, P., ... Kerner, J. (2004). Promoting informed decisions about cancer screening in communities and healthcare systems. *American Journal of Preventive Medicine*, 26(1), 67–80.
- Brock, D. W., & Wartman, S. A. (1990). When competent patients make irrational choices. *The New England Journal of Medicine*, 322(22), 1595–1599.
- Bruera, E., Willey, J. S., Lynn Palmer, J., & Rosales, M. (2002). Treatment decisions for breast carcinoma. *Cancer*, 94(7), 2076–2080.
- Bud, R. (2007). Antibiotics: the epitome of a wonder drug. Bmj, 334(suppl 1), s6–s6.
- Burrow, J. G. (1977). Organized medicine in the progressive era: The move toward monopoly. Johns Hopkins University Press Baltimore, MD.
- Butow, P., Maclean, M., Dunn, S., Tattersall, M., & Boyer, M. (1997). The dynamics of change: cancer patients' preferences for information, involvement and support. *Annals of Oncology*, 8(9), 857–863.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social Science & Medicine*, 44(5), 681–692.
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine*, 49(5), 651–661.
- Charon, R., Greene, M. G., & Adelman, R. D. (1994). Multi-dimensional interaction analysis: a collaborative approach to the study of medical discourse. *Social Science & Medicine*, *39*(7), 955–965.
- Chewning, B., & Sleath, B. (1996). Medication decision-making and management: a client-centered model. *Social Science & Medicine*, 42(3), 389–398.
- Chung, J. E. (2014). Social networking in online support groups for health: How online social

- networking benefits patients. Journal of Health Communication, 19(6), 639-659.
- Cohen-Cole, S. (1991). Why "three" functions. The Medical Interview: The Three-Function Approach. St Louis: Mosby, 4–10.
- Cohen-Cole, S., & Bird, J. (1991). Function 1: gathering data to understand the patient. *The Medical Interview: The Three-Function Approach. St Louis, MO: Mosby Year Book.*
- Cole, J., Kiriaev, O., Malpas, P., & Cheung, G. (2017). "Trust me, I"ma doctor': a qualitative study of the role of paternalism and older people in decision-making when they have lost their capacity. *Australasian Psychiatry*, *25*(6), 549–553.
- Conrad, P., & Schneider, J. W. (2009). Professionalization, monopoly, and the structure of medical practice. In P. Conrad (Ed.), *The Sociology of Health and Illness* (pp. 194–200). New York: Worth Publishers.
- Corser, W., Holmes-Rovner, M., Lein, C., & Gossain, V. (2007). A shared decision-making primary care intervention for type 2 diabetes. *The Diabetes Educator*, *33*(4), 700–708.
- Coulter, A., Entwistle, V., & Gilbert, D. (1999). Sharing decisions with patients: is the information good enough? *BMJ: British Medical Journal*, *318*(7179), 318.
- Curl, T. S., & Drew, P. (2008). Contingency and action: A comparison of two forms of requesting.

  Research on Language and Social Interaction, 41(2), 129–153.
- Davison, B. J., Kirk, P., Degner, L. F., & Hassard, T. H. (1999). Information and patient participation in screening for prostate cancer. *Patient Education and Counseling*, *37*(3), 255–263.
- Demkovich, L. (1987). Fight for your rights. *Modern Maturity*, 29(2), 33–41.
- Drake, R., & Deegan, P. (2009). Shared decision making is an ethical imperative. *Psychiatric Services*, 60(8), 1007–1007.
- Drew, P., & Heritage, J. (1992). *Talk at work: Interaction in institutional settings* (Vol. 8). Cambridge University Press.

- Eddy, D. M. (1990). Anatomy of a decision. *Jama*, 263(3), 441–443.
- Elwyn, G., Edwards, A., Kinnersley, P., & Grol, R. (2000). Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. *British Journal of General Practice*, 50(460), 892–899.
- Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *Jama*, 267(16), 2221–2226.
- Emerson, J. (1970). Behavior in private places: Sustaining definitions of reality in gynecological examinations. *The Production of Reality: Essays and Readings on Social Interaction*, 247–260.
- Ende, J., Kazis, L., Ash, A., & Moskowitz, M. A. (1989). Measuring patients' desire for autonomy. *Journal of General Internal Medicine*, 4(1), 23–30.
- Entwistle, V. A., McCaughan, D., Watt, I. S., Birks, Y., Hall, J., Peat, M., ... Wright, J. (2010). Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. *Quality and Safety in Health Care*, 19(6), e33–e33.
- Eysenbach, G. (2001). What is e-health? *Journal of Medical Internet Research*, 3(2).
- Faden, R. R., Beauchamp, T. L., & King, N. M. (1986). A history and theory of informed consent.
- Fraenkel, L., & McGraw, S. (2007). What are the essential elements to enable patient participation in medical decision making? *Journal of General Internal Medicine*, 22(5), 614–619.
- Freidson, E. (1970). *Professional dominance: The social structure of medical care.* New Brunswick, NJ: Transaction Publishers.
- Freidson, E. (1985). The reorganization of the medical profession. *Medical Care Review*, 42(1), 11–35.
- Frist, W. H. (2014). Connected health and the rise of the patient-consumer, 33(2), 191–193.
- Frosch, D. L., & Kaplan, R. M. (1999). Shared decision making in clinical medicine: past research and future directions. *American Journal of Preventive Medicine*, 17(4), 285–294.
- Frosch, D. L., May, S. G., Rendle, K. A., Tietbohl, C., & Elwyn, G. (2012). Authoritarian physicians

- and patients' fear of being labeled "difficult" among key obstacles to shared decision making. Health Affairs, 31(5), 1030–1038.
- Frosch, D. L., Singer, K. J., & Timmermans, S. (2011). Conducting implementation research in community-based primary care: a qualitative study on integrating patient decision support interventions for cancer screening into routine practice. *Health Expectations*, 14(s1), 73–84.
- Funnell, M. M. (2004). Patient empowerment. Critical Care Nursing Quarterly, 27(2), 201–204.
- Garfinkel, H. (1967). Studies in ethnomethodology. Englewood Cliffs NJ.
- Garofalo, J. P., Choppala, S., Hamann, H. A., & Gjerde, J. (2009). Uncertainty during the transition from cancer patient to survivor. *Cancer Nursing*, 32(4), E8.
- Goffman, E. (1955). On face-work: An analysis of ritual elements in social interaction. *Psychiatry*, 18(3), 213–231.
- Goffman, E. (1983). The interaction order: American Sociological Association, 1982 presidential address. *American Sociological Review*, 48(1), 1–17.
- Gravel, K., Légaré, F., & Graham, I. D. (2006). Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions.

  Implement Sci, 1(1), 16.
- Greenfield, S., Kaplan, S. H., Ware Jr, J. E., Yano, E. M., & Frank, H. J. (1988). Patients' participation in medical care. *Journal of General Internal Medicine*, *3*(5), 448–457.
- Greenfield, S., Kaplan, S., & Ware, J. E. (1985). Expanding patient involvement in care: effects on patient outcomes. *Annals of Internal Medicine*, 102(4), 520–528.
- Hafferty, F. W., & Light, D. W. (1995). Professional dynamics and the changing nature of medical work. *Journal of Health and Social Behavior*, 132–153.
- Hamann, J., Langer, B., Winkler, V., Busch, R., Cohen, R., Leucht, S., & Kissling, W. (2006). Shared decision making for in-patients with schizophrenia. *Acta Psychiatrica Scandinavica*, 114(4), 265–273.

- Haug, M. R. (1973). Deprofessionalization: An altherate hypothesis for the future. *Sociological Review Monograph*, 20, 195–211.
- Haug, M. R. (1976). The erosion of professional authority: A cross-cultural inquiry in the case of the physician. *The Milbank Memorial Fund Quarterly. Health and Society*, 83–106.
- Haug, M. R., & Lavin, B. (1981). Practitioner or patient-who's in charge? *Journal of Health and Social Behavior*, 212–229.
- Hepburn, A., & Bolden, G. B. (2012). The Conversation Analytic Approach to Transcription. In J. Sidnell & T. Stivers (Eds.), *The Handbook of Conversation Analysis* (pp. 57–76). Malden, MA: Wiley-Blackwell.
- Heritage, J. (1984). Garfinkel and ethnomethodology. Polity Press Cambridge.
- Heritage, J. (2010). Conversation analysis: Practices and methods. *Qualitative Sociology*, 208–230.
- Heritage, J. (2011). The interaction order and clinical practice: Some observations on dysfunctions and action steps. *Patient Education and Counseling*, 84(3), 338–343.
- Heritage, J., & Maynard, D. W. (2006). Communication in Medical Care: Interaction between Primary Care

  Physicians and Patients. Cambridge University Press.
- Heritage, J., & Maynard, D. W. (2006). Problems and prospects in the study of physician-patient interaction: 30 years of research. *Annual Review of Sociology*, 351–374.
- Heritage, J., & Robinson, J. D. (2006). Accounting for the visit: Giving reasons for seeking medical care. In *Communication in Medical Care: Interactions between Primary Care Physicians and Patients*. (Vol. 20, pp. 48–85). Cambridge: Cambridge University Press.
- Heritage, J., & Sefi, S. (1992). Dilemmas of advice: Aspects of the delivery and reception of advice in interactions between health visitors and first-time mothers. In P. Drew & J. Heritage (Eds.), *Talk at work: Interaction in Institutional Settings* (pp. 359–417). Cambridge: Cambridge University Press.
- Heritage, J., & Stivers, T. (1999a). Online commentary in acute medical visits: a method of shaping

- patient expectations. Social Science & Medicine, 49(11), 1501–1517.
- Heritage, J., & Stivers, T. (1999b). Online commentary in acute medical visits: A method of shaping patient expectations. *Social Science & Medicine*, 49(11), 1501–1517.
- Hibbard, J. H., & Weeks, E. C. (1987). Consumerism in health care: Prevalence and predictors. *Medical Care*, 1019–1032.
- Hindmarsh, J., & Pilnick, A. (2007). Knowing bodies at work: Embodiment and ephemeral teamwork in anaesthesia. *Organization Studies*, 28(9), 1395–1416.
- Holmes, O. W. (1883). The young practitioner. In *Medical Essays* (p. 338). Boston: Houghton Mifflin Co.
- Jefferson, G. (1984). On the organization of laughter in talk about troubles. *Structures of Social Action:*Studies in Conversation Analysis, 346, 369.
- Jones, D. S. (2017). Patients, Consumers, and the Enduring Challenge to Medical Authority. *Reviews* in American History, 45(1), 128–135.
- Katz, J. (1994). Informed consent-must it remain a fairy tale. J. Contemp. Health L. & Pol'y, 10, 69.
- Katz, J. (2002). The silent world of doctor and patient. JHU Press.
- Kletke, P. R., Emmons, D. W., & Gillis, K. D. (1996). Current trends in physicians' practice arrangements: from owners to employees. *JAMA*, *276*(7), 555–560.
- Koenig, C. J. (2011). Patient resistance as agency in treatment decisions. *Social Science & Medicine*, 72(7), 1105–1114.
- Korsch, B. M., & Negrete, V. F. (1972). Doctor-patient communication. *Scientific American*, 227(2), 66–75.
- Laine, C., & Davidoff, F. (1996). Patient-centered medicine: a professional evolution. *Jama*, 275(2), 152–156.
- Légaré, F., Ratté, S., Gravel, K., & Graham, I. D. (2008). Barriers and facilitators to implementing

- shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient Education and Counseling*, *73*(3), 526–535.
- Légaré, F., & Thompson-Leduc, P. (2014). Twelve myths about shared decision making. *Patient Education and Counseling*, *96*(3), 281–286.
- Levinson, W., Kao, A., Kuby, A., & Thisted, R. A. (2005). Not all patients want to participate in decision making. *Journal of General Internal Medicine*, 20(6), 531–535.
- Lidz, C. W., Meisel, A., Osterweis, M., Holden, J. L., Marx, J. H., & Munetz, M. R. (1983). Barriers to informed consent. *Annals of Internal Medicine*, *99*(4), 539–543.
- Light, D. (1979). Uncertainty and control in professional training. *Journal of Health and Social Behavior*, 310–322.
- Light, D., & Levine, S. (1988). The changing character of the medical profession: a theoretical overview. *The Milbank Quarterly*, 10–32.
- Light, D. W. (2014). Countervailing powers. In W. C. Cockerham, R. Dingwall, & S. R. Quah (Eds.), The Wiley Blackwell Encyclopedia of Health, Illness, Behavior, and Society (pp. 1–7). Hoboken, NJ: John Wiley & Sons.
- Link, B. G., & Phelan, J. (1995). Social conditions as fundamental causes of disease. *Journal of Health and Social Behavior*, 80–94.
- Link, B. G., & Phelan, J. C. (1996). Understanding sociodemographic differences in health–the role of fundamental social causes. *American Journal of Public Health*, 86(4), 471–473.
- Lorig, K. R., Mazonson, P. D., & Holman, H. R. (1993). Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. *Arthritis & Rheumatism*, 36(4), 439–446.
- Lutfey, K., & Maynard, D. W. (1998). Bad news in oncology: How physician and patient talk about death and dying without using those words. *Social Psychology Quarterly*, 61(4), 321–341.

- Mackillop, W., Stewart, W., Ginsburg, A., & Stewart, S. (1988). Cancer patients' perceptions of their disease and its treatment. *British Journal of Cancer*, 58(3), 355.
- Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*, 60(3), 301–312.
- Maynard, D. W. (1996). On" realization" in everyday life: The forecasting of bad news as a social relation. *American Sociological Review*, 109–131.
- Maynard, D. W., & Heritage, J. (2005). Conversation analysis, doctor–patient interaction and medical communication. *Medical Education*, *39*(4), 428–435.
- McKinlay, J. B., & Marceau, L. D. (2002). The end of the golden age of doctoring. *International Journal of Health Services*, 32(2), 379–416.
- McKinlay, J. B., & Marceau, L. D. (2009). The End of the Golden Age of Doctoring. In P. Conrad (Ed.), *The Sociology of Health and Illness* (pp. 213–238). New York: Worth Publishers.
- Mendel, P., & Scott, W. R. (2010). Institutional change and the organization of health care. *Handbook of Medical Sociology*, 249–269.
- Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: The Journal of Nursing Scholarship*, 22(4), 256–262.
- Mondada, L. (2014). Instructions in the operating room: How the surgeon directs their assistant's hands. *Discourse Studies*, *16*(2), 131–161.
- Montgomery, A. A., Harding, J., & Fahey, T. (2001). Shared decision making in hypertension: the impact of patient preferences on treatment choice. *Family Practice*, 18(3), 309–313.
- Nelson-Marten, P., & Rich, B. A. (1999). A historical perspective of informed consent in clinical practice and research (Vol. 15, pp. 81–88). Presented at the Seminars in oncology nursing, Elsevier.
- Oshima Lee, E., & Emanuel, E. J. (2013). Shared decision making to improve care and reduce costs.

- New England Journal of Medicine, 368(1), 6–8.
- Parsons, T. (1951). The Social System. Glencoe, Ill.: The Free Press.
- Pescosolido, B. A., Tuch, S. A., & Martin, J. K. (2001). The profession of medicine and the public: examining Americans' changing confidence in physician authority from the beginning of the'health care crisis' to the era of health care reform. *Journal of Health and Social Behavior*, 1–16.
- Quill, T. E., & Cassel, C. K. (1995). Nonabandonment: a central obligation for physicians. *Annals of Internal Medicine*, 122(5), 368–374.
- Quirk, A., Chaplin, R., Lelliott, P., & Seale, C. (2012). How pressure is applied in shared decisions about antipsychotic medication: a conversation analytic study of psychiatric outpatient consultations. *Sociology of Health & Illness*, *34*(1), 95–113.
- Rayack, E. (1967). Professional power and American medicine: The economics of the American Medical Association. World Publishing.
- Redmond, K. (1998). Assessing patients' needs and preferences in the management of advanced colorectal cancer. *British Journal of Cancer*, 77(Suppl 2), 5.
- Reeder, L. G. (1972). The patient-client as a consumer: some observations on the changing professional-client relationship. *Journal of Health and Social Behavior*, 406–412.
- Richards, T. (1998). Partnership with patients. Bmj, 316(7125), 85–86.
- Roberts, K. J. (1999). Patient empowerment in the United States: a critical commentary. *Health Expectations*, 2(2), 82–92.
- Robinson, A., & Thomson, R. (2001). Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. *Quality in Health Care*, 10(suppl 1), i34–i38.
- Robinson, J. D. (2003). An interactional structure of medical activities during acute visits and its implications for patients' participation. *Health Communication*, *15*(1), 27–59.

- Robinson, J. D. (2006). Soliciting patients' presenting concerns. *Studies in Interactional Sociolinguistics*, 20, 22.
- Robinson, J. D., Tate, A., & Heritage, J. (2016). Agenda-setting revisited: When and how do primary-care physicians solicit patients' additional concerns? *Patient Education and Counseling*, 99(5), 718–723.
- Rodwin, M. (1994). Patient accountability and quality of care: lessons from medical consumerism and the patients' rights, women's health and disability rights movements. *American Journal of Law and Medicine*, 20, 147–169.
- Rosenbaum, L. (2015). The paternalism preference—choosing unshared decision making. *New England Journal of Medicine*, *373*(7), 589–592.
- Rossi, G. (2012). Bilateral and unilateral requests: The use of imperatives and mi x? interrogatives in Italian. *Discourse Processes*, 49(5), 426–458.
- Roter, D. L. (1977). Patient participation in the patient-provider interaction: the effects of patient question asking on the quality of interaction, satisfaction and compliance. *Health Education & Behavior*, *5*(4), 281–315.
- Roter, D., & Larson, S. (2002). The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. *Patient Education and Counseling*, 46(4), 243–251.
- Sacks, H., Schegloff, E. A., & Jefferson, G. (1974). A simplest systematics for the organization of turn-taking for conversation. *Language*, 696–735.
- Sainio, C., & Lauri, S. (2003). Cancer patients' decision-making regarding treatment and nursing care. *Journal of Advanced Nursing*, 41(3), 250–260.
- Sainio, C., Lauri, S., & Eriksson, E. (2001). Cancer patients' views and experiences of participation in care and decision making. *Nursing Ethics*, 8(2), 97–113.
- Sarkar, U., Fisher, L., & Schillinger, D. (2006). Is self-efficacy associated with diabetes self-

- management across race/ethnicity and health literacy? Diabetes Care, 29(4), 823-829.
- Schegloff, E. A., Jefferson, G., & Sacks, Harvey. (1977). The preference for self-correction in the organization of repair in conversation. *Language*, *53*, 361–382.
- Scovern, H. (1988). A physician's experiences in a for-profit staff-model HMO. *The New England Journal of Medicine*, 319(12), 787–790.
- Shim, J. K. (2010). Cultural health capital a theoretical approach to understanding health care interactions and the dynamics of unequal treatment. *Journal of Health and Social Behavior*, *51*(1), 1–15.
- Siegler, M. (1985). The progression of medicine: from physician paternalism to patient autonomy to bureaucratic parsimony. *Archives of Internal Medicine*, *145*(4), 713–715.
- Stacey, C. L., Henderson, S., MacArthur, K. R., & Dohan, D. (2009). Demanding patient or demanding encounter?: A case study of a cancer clinic. *Social Science & Medicine*, 69(5), 729–737.
- Starr, P. (1982). The social transformation of American medicine: The rise of a sovereign profession and the making of a vast industry. New York: Basic books.
- Stevanovic, M., & Peräkylä, A. (2012). Deontic authority in interaction: The right to announce, propose, and decide. *Research on Language & Social Interaction*, 45(3), 297–321.
- Stewart, M., Meredith, L., Brown, J. B., & Galajda, J. (2000). The influence of older patient-physician communication on health and health-related outcomes. *Clinics in Geriatric Medicine*, *16*(1), 25–36.
- Stivers, T. (2002a). Participating in decisions about treatment: overt parent pressure for antibiotic medication in pediatric encounters. *Social Science & Medicine*, 54(7), 1111–1130.
- Stivers, T. (2002b). Presenting the problem in pediatric encounters: "Symptoms only" versus "candidate diagnosis" presentations. *Health Communication*, 14(3), 299–338.
- Stivers, T. (2005a). Non-antibiotic treatment recommendations: delivery formats and implications for parent resistance. *Social Science & Medicine*, 60(5), 949–964.

- Stivers, T. (2005b). Parent resistance to physicians' treatment recommendations: one resource for initiating a negotiation of the treatment decision. *Health Communication*, 18(1), 41–74.
- Stivers, T. (2007). Prescribing under pressure: Parent-physician conversations and antibiotics. New York: Oxford University Press.
- Stivers, T., Heritage, J., Barnes, R. K., McCabe, R., Thompson, L., & Toerien, M. (2017). Treatment recommendations as actions. *Health Communication*, 1–10.
- Stivers, T., & Timmermans, S. (2016). Negotiating the diagnostic uncertainty of genomic test results. Social Psychology Quarterly, 79(3), 199–221.
- Stoeckle, J. D. (1988). Reflections on Modern Doctoring:[Introduction]. *The Milbank Quarterly*, 76–91.
- Strong, P. M. (1979). The ceremonial order of the clinic: Patients, doctors and medical bureaucracies. Routledge & Kegan Paul.
- Timmermans, S., & Oh, H. (2010). The continued social transformation of the medical profession. *Journal of Health and Social Behavior*, *51*(1 suppl), S94–S106.
- Toerien, M. (2017). Deferring the decision point: Treatment assertions in neurology outpatient consultations. *Health Communication*, 1–11.
- Ubokudom, S. (2013). United States Health Care Policymaking: Ideological, Social, and Cultural Differences and Major Influences. New York: Springer.
- U.S. Bureau of the Census. (1972). Statistical Abstract of the United States (93<sup>rd</sup> ed.). Washington D.C.
- Veatch, R. M. (2003). The basics of bioethics. Prentice Hall Upper Saddle River, NJ.
- Waitzkin, H. (1991). The politics of medical encounters: how doctors and patients deal with social problems. *New Haven and London, Yale University*.
- Wald, H. S., Dube, C. E., & Anthony, D. C. (2007). Untangling the Web—the impact of Internet

- use on health care and the physician–patient relationship. *Patient Education and Counseling*, 68(3), 218–224.
- Waterworth, S., & Luker, K. A. (1990). Reluctant collaborators: do patients want to be involved in decisions concerning care? *Journal of Advanced Nursing*, 15(8), 971–976.
- Wear, D., & Aultman, J. M. (2006). Professionalism in medicine: Critical perspectives. Springer.
- West, C. (1984). When the doctor is a "lady": power, status and gender in physician-patient encounters. *Symbolic Interaction*, 7(1), 87–106.
- Whitney, S. N. (2003). A new model of medical decisions: exploring the limits of shared decision making. *Medical Decision Making*, 23(4), 275–280.
- Wilensky, H. L. (1964). The professionalization of everyone? American Journal of Sociology, 137–158.
- Xiang, J., & Stanley, S. J. (2017). From Online to Offline: Exploring the role of e-health consumption, patient involvement, and patient-centered communication on perceptions in health care quality. *Computers in Human Behavior*, 70, 446–452.

# Chapter 2: Treatment Recommendations in Cancer Visits: Implications for patient agency and physician authority

## 2.1 Background

Early advocates of the shared decision-making (SDM) paradigm idealize the decision-making process as collaborative: physician and patient are involved in the treatment decision through a twoway information exchange, communication of preferences, and joint investment in the treatment decision (Légaré & Thompson-Leduc, 2014). The physician is charged with providing information regarding all available treatment options, risks and benefits, and impacts on patients' well-being. Conversely, patients must offer their preferences, values, beliefs, and burden tolerances (Charles et al., 1997, 1999). While physicians are required to mobilize their expertise in SDM through communicating their treatment preferences, the model represents somewhat of an erosion of physician authority insofar as it runs counter to the model of paternalistic decision-making through promoting more patient autonomy and choice than in earlier years (Brown, Butow, Butt, Moore, & Tattersall, 2004). This model represents one of many structural changes to the institution of medicine that strips physicians of some of their once-total control of the medical institution (Starr, 1982). Of course, physicians continue to possess particular medical expertise and technical knowledge specific to their profession (Timmermans & Mauck, 2005) which they bring to the table when implementing SDM. Moreover, they too have preferences and beliefs about what is best for their patients, sometimes with significantly greater experience to draw on about the possible efficacy and side effects of a treatment. Given this, physicians arguably walk a tightrope between their obligations to facilitate patient choice and the mobilization of their medical expertise when making treatment decisions.

Yet how physicians navigate patient involvement in decision-making varies. In recent years, conversation analytic scholars have described the process of treatment decision-making adult

primary care (Koenig, 2011), pediatrics (Stivers, 2007), neurology (Toerien, Shaw, & Reuber, 2013) and psychiatry (Quirk, Chaplin, Lelliott, & Seale, 2012; Thompson & McCabe, 2017). Stivers (2007) has shown that treatment recommendations for upper respiratory infections in pediatric encounters are shaped by both physician and patient. When parents actively or passively resisted a treatment recommendation, physicians would work to gain acceptance of the recommendation prior to moving to the next activity. Stivers (2007) also found that in the context of parents' outright acceptance of the treatment recommendation, physicians would treat that activity as complete and move to close the encounter. Thus, Stivers (2007) concludes that treatment recommendations in primary care settings *are* inherently cooperative endeavors. Further, in both adult and pediatric primary care contexts, it has been shown that physician and patient jointly treat consensus of the treatment recommendation as required, hence the term "resistance" when patients display non-acceptance of the recommendation (Stivers 2007; Koenig 2011).

Other conversation analytic scholars have explored features of treatment recommendation design. For instance, it was found that when treatment recommendations were negatively designed (e.g., "She doesn't need any antibiotics), they were more likely to attract patient resistance in contrast to affirmatively designed recommendations (e.g., "I can give her cough medication") (Hamann et al., 2006). Further, Kushida and Yamakawa (2015) have observed that different proposal types are used in different contexts of medical decision-making. In their data, while the proposal type "Let's" or "How about" is used to make a treatment decision, the declarative evaluation proposal type, (e.g., "It may be better to switch to another drug") is used to cautiously propose a treatment option.

Additionally, how patients account for resistance to (and rejections of) treatment recommendations has been empirically studied (Lindström & Weatherall, 2015), as have physician accounts for treatment recommendations (Angell & Bolden, 2015).

Besides proposals, other actions are used to produce treatment recommendations. Investigating treatment recommendations in U.S. and U.K. primary care, Stivers, Heritage, Barnes, McCabe, Toerien and Thompson (2017) established a typology of five treatment recommendation actions drawn from their data: pronouncements, suggestions, proposals, offers, and assertions. The authors argue that each has features which communicate different degrees of physician authority and patient agency in the decision (see Table I). Additionally, Stivers et al. explored both the frequency of each treatment recommendation action.

Table I: Treatment recommendation actions from Stivers et al. (2017)

Coding	Options (if	Explanation	Example (if
Dimension	applicable)		applicable)
Social action			
	Pronouncement	Physician asserts recommendation as	"I'll start you
		instigator, decision maker and presents	on X"
		as already determined	
	Suggestion	Physician recommends as instigator but	"You could
		treats patient as decision maker and	try X"
		medication as optional	
	Proposal	Physician recommends as instigator but	"Let's try X
		decision making is treated as shared by	and see how
		doctor and patient. Proposals highlight	that goes"
		the recommendation as speculative	
	Offer	Physician treats patient as having	"Would you
		instigated recommendation and as the	like me to
		decision maker, thus treating medication	give you X"
		as having been occasioned.	
	Assertion	Physician's asserts a generalization about	"X is good
		a treatment's benefit implying a	for this"
		recommendation but not proffering an	
		overt directive.	

Pronouncements (e.g., "I will start you on X") assert full deontic authority (Stevanovic & Peräkylä, 2012) as they frame the treatment recommendation as already decided by the physician and *as if* the patient has no choice in the matter. These occurred 65% of the time in the U.S. data Suggestions (e.g., "You could try X") allow for the patient to ultimately decide whether or not s/he is going to

act on the recommendation while still establishing that the physician has agency in the decision insofar as it has originated with him/her. Proposals ("Let's try X and see") are like suggestions insofar as they originate with the physician and do not direct the patient (as pronouncements do). But, proposals uniquely treat the decision as shared between physician and patient. While suggestions occurred 21% of the time in the U.S. data, proposals occurred just 4% of the time. Offers (e.g., "Would you like me to give you X?") exert low physician authority over the decision treating the patient as instigator of the recommendation and frame the recommendation as something the physician is prepared to do for the patient as a response to a patient issue. Finally, assertions (e.g., "X is good for this") are statements of fact about a treatment's benefit that *imply* a recommendation without personalizing the recommendation for the patient. Both were infrequent and had a rare occurrence rate of 5% in the U.S. data.

When applying this schema to U.S and U.K. primary care, Stivers et al. ultimately found that U.S. physicians rely more heavily directive actions like pronouncements, while U.K physicians are more likely to use inclusive recommendations like proposals and offers. This suggests a greater willingness to exercise authority when recommending treatment and a reciprocal de-emphasis on patient agency in the U.S., with the inverse occurring in the U.K. In specialty contexts in the U.K., this trend was even stronger with a greater emphasis on forms that amplify patient agency in psychiatry (Thompson & McCabe, 2017) and neurology (Toerien, 2017)

In part of the same study, Stivers et al. (2017) explored subsequent patient response to treatment recommendations. They find that despite the differences in treatment recommendation formats, each was statistically equally likely to elicit patient response. This is in line with conclusions from prior research, which finds that there is a norm of patient response to treatment recommendations (Stivers, 2005b). Despite the nature of the pronouncement format, which frames the treatment recommendation as already decided by the physician and *as if* the patient has no choice

in the matter, patients were no less likely to respond to pronouncements than they were to suggestions, proposals, offers, or assertions. Given this, Stivers et al. (2017) ultimately conclude that securing patient response is not the main task of these different action types. The authors speculate that the different action types are instead reflective of the various treatment contexts in which they are produced.

Yet Stivers et al. (2017) *do* find that different action types elicit different levels of treatment resistance. Following pronouncements and suggestions, the authors observed a reduction in resistance. They hypothesize that this could be due to higher physician demonstration of epistemic and deontic authority associated with those action types (Stivers et al., 2017). The authors further speculate that pronouncements are resisted less often because their use may be associated with the anticipation of less resistance, or because they themselves condition less resistance (Stivers et al., 2017). In contrast, Stivers and colleagues (2017) find that proposals and offers elicit the most resistance as they are resisted 30% of the time. The authors explain this result by positing that offers represent a rescission of physicians' deontic authority over both the initiation of the recommendation and the treatment decision (Stivers et al., 2017). While in proposals physicians do claim deontic authority over initiating the recommendation, they-like offers- share the treatment decision with patients which could account for similarly high resistance rates (Stivers et al. 2017).

Similar systematic investigations of treatment recommendation actions have occurred in chronic and specialty care contexts. In the chronic care domain, Thompson and McCabe (2017) examined different recommendation formats in psychiatric encounters, both in the context of new medication prescriptions and the context of changes to medication prescriptions. The authors found that physicians deployed different treatment recommendation actions depending on the degree of patient resistance anticipated. In instances where resistance was anticipated, treatment recommendation actions which framed the decision as "shared", such as proposals and offers, were

the most common. In the realm of specialty care, (Toerien, 2017) investigated treatment recommendations neurology. The author finds that physicians typically deployed "forecasting," or preliminary assertions, prior to making the explicit recommendation to deal with the interactional delicacy of prescribing medication in a typically medication-resistant environment.

These endeavors have begun to fill gaps in our understanding of moment-to-moment decision-making in primary care contexts, specialty care contexts, and chronic care contexts.

Notably, treatment decision-making in more routine primary care contexts differs from specialty care contexts in general (see Barnes, 2017; see also Thompson & McCabe, 2017 & Toerien, 2017). Yet, only a few specialty care contexts have been explored in this particular domain. We might predict that in cancer care the way treatment decision-making happens between physician and patient may be different from other clinical contexts. But, to what degree may treatment decision-making in cancer care be different?

Cancer care *is* often considered a form of chronic care because the illness is expected to last for some time and therefore care and treatment is ongoing (Biegel et al., 1991; Fishman et al., 1997; McCorkle et al., 2011). Yet some aspects of cancer care more closely resemble acute care as quick decisions need to be made before the disease progresses. However, there are important differences between acute care, chronic care, and cancer care. Relative to most other chronic, acute, and specialty care settings, cancer care is a particularly high-stakes treatment environment. A cancer diagnosis is generally perceived as life-threatening. Soon after diagnosis, patients need to make timesensitive major decisions with a care provider with whom they do not yet have a relationship (Hillen et al., 2012). Further, cancer patients are vulnerable. Their disease could progress slowly or rapidly, and no one can be fully certain whether it will respond to the standard treatments. Additionally, once treatment has begun, cancer patients often have compromised immune systems with high risk of infection, can be nutrient-deprived, and can have nervous system defects (American Cancer

Society 2015). Because of the onerous nature of the treatments and the essential uncertainty of the disease itself (Avis et al., 2005; Garofalo et al., 2009; Mishel, 1990), patients require constant and close monitoring by their oncologist. This necessitates a particularly close partnership between both oncologist and patient. Because of this need, we might assume that physicians would recommend treatment in such a way that balances both their expert opinion and patient involvement in his/her own treatment. Based on the five action types, we can speculate that proposals and suggestions will dominate in this treatment environment.

# 2.2 Analysis of Treatment Decision-Making in Cancer Care

Some treatment decisions in the arena of cancer care can be life altering, for instance, whether to have a hysterectomy, whether to undergo chemotherapy, or whether to continue a treatment regimen that may have diminishing returns in treating the disease. Other treatment decisions can be less weighty, for instance, whether to get hydration during a particular chemotherapy infusion, or whether or not to take certain supplemental vitamins to aid in symptom relief. Significantly, looming in the background of many decisions about cancer treatment is that the treatments can be burdensome insofar as they are long with substantial side effects. Studies have shown that patients demonstrate substantial amounts of anxiety and fear about not just their diagnosis, but about the severe treatment side effects (see Levin et al., 1985; Passik et al., 2001). Rarely, patients can demonstrate anticipatory emesis *prior* to beginning chemotherapy treatment (Molassiotis et al., 2016).

Thus, in this area of highly consequential decision-making, it may seem to make sense for physicians to implement SDM based on its facilitation of treatment adherence (Hamann et al., 2006; Wilson et al., 2010), its relationship to better health outcomes (Corser et al., 2007; Elit et al., 2003), and the fact that patients prefer it (Charles et al, 1998). So what possible reason could there be for physicians not to engage in SDM, and thus to provide all viable options, letting the patient decide?

One reason could be that physicians may want to work to get patients to accept a regimen that may be problematic in terms of side effects and fear of those side effects (Levin et al., 1985), but that stands the best chance of successful treatment. If patients are resistant, this puts clinicians in a tricky position: having to balance their own medical agenda while still incorporating the patient into the decision.

Physicians already must exist in two worlds, on the one hand attending to policy pressures for SDM implementation and on the other focusing on their professional obligations. Given this, how do physicians balance asserting their medical authority and attending to patient involvement? Furthermore, what do they do this for? We might speculate that there is a policy imperative to involve patients in decision-making. For instance, physicians have been incentivized to implement SDM in clinical encounters by Medicare (see Landro, 2017). Furthermore, the Health and Human Services Secretary has been given the power to fund tools which help facilitate SDM, like decision aids (Lee & Emanuel, 2013). Furthermore, physicians may be motivated to involve patients from a moral standpoint. More specifically, physicians may believe in respecting patients' autonomy and self-determination in their own healthcare (Elwyn et al., 2012; Ryan & Deci, 2000). On the other side of the coin, physicians may believe they have a moral imperative to abandon SDM if a patient is indicating resistance to a potentially effective treatment, and instead make a unilateral decision for the best possible treatment course given their medical expertise and experience.

SDM involves a negotiation of decision-making between physicians and their patients. Importantly, any time physicians direct a patient through recommending treatment, they exercise a degree of deontic authority (see Stevanovic & Peräkylä, 2012). The question is, to what degree they assert this authority in cancer care? When patients are allowed to decide, how is "sharedness" (Landmark et al., 2015, p. 55) over the decision maintained between medical expert and patient in this particular specialty care context? Studies of secondary care consultations have found that

physicians assert epistemic and deontic rights from the biomedical domain of medical experience and expertise, while patients assert these rights from the standpoint of their own illness experience and personal preferences (see Landmark et al., 2015).

This study examines decision-making against this backdrop of policy imperatives, moral obligations, and deontic authority where the push and pull of physician and patient agency is apparent. This analysis seeks to explain how physicians balance mobilizing their medical expertise and authority while preserving patent agency in oncologic decision-making. I first ask, how do physicians do that? To answer this, I identify the different ways in which physicians present treatments to patients. Then I ask, to what degree do physicians involve patients? Further, under what circumstances would they do the opposite and only mobilize their professional authority? Thus, I subsequently examine whether different ways of recommending are associated with different types of treatment decisions. This allows us to assess whether there are meaningful patterns in the way physicians orient to patient involvement across different types of decisions and how physicians reflect different norms for patient rights and responsibilities in the treatment process.

# 2.3 Inclusion Criteria

The data set of 90 video-recorded cancer care encounters were coded for initial treatment recommendations. These included either recommendations for single treatments, or multiple options for a given treatment. Only initial treatment recommendations were included. Interactionally generated recommendations, for instance recommendations from second position in response to a patient request for a treatment, or re-done recommendations for the same treatment, were excluded. Recommendations for surgical interventions, prescription drugs including chemotherapy and radiation, and over-the-counter medications were included. Recommendations for treatment not central to the treatment of the cancer/pre-cancer yet resulting from a side effect of the cancer/pre-cancer or a side effect of the medication treating the cancer/pre-cancer were included.

Recommendations for testing were excluded. Recommendations for treatments outside of the cancer/pre-cancer were excluded.

# 2.4 Option-Listing in Cancer Care

Arguably, the most straightforward way to prioritize patient agency is to provide patients with an array of options and allow them to decide which to pursue. Toerien et al. (2011) refer to this as option-listing. They define option-listing as the physician providing a "menu of choice" to the patient which includes more than one course of action for a given treatment. Further, patients more effectively understand that they have a choice in treatment when physicians do option-listing (Reuber et al., 2015). Both ways of producing treatment recommendations—as single recommendations or as a list of options— are important to examine because both provide more nuanced insight into how physicians involve their patients in making treatment decisions (Toerien et al., 2013). Toerien et al. argue that in making one single treatment recommendation physicians display knowledge of both the possible course of treatment and what should be done, while in doing option-listing, physicians only explicitly show knowledge of the possible courses of treatment. Thus, it can be argued that option-listing treats patient involvement as more important than does single recommending because physicians reduce their own involvement in the decision-that is, including what should be done in a single recommendation- and in doing so rescind some of their medical authority over the decision (Heritage, 2012; Toerien et al., 2013). Effectively, when using optionlisting the physician abdicates deontic authority while retaining epistemic authority.

In the data set, option-listing occurs only 10% (n=7) of the time in the data, while making single treatment recommendations occurs 90% (n=61) of the time. This result may initially suggest that physicians prefer providing single treatment recommendations over multiple options. However, when each patient's diagnosis (type of cancer, stage, and grade) was cross-referenced via the American Cancer Society's treatment standards of care, it was found that in most cases physicians

only have one treatment plan available to them according to the standards of care for the diagnoses present in my data set. In just 3% (n=2) of recommendations, physicians provided a single treatment recommendation for a diagnosis which had multiple treatment options according to the standard of care. In general, physicians do not appear to withhold multiple treatment options in favor of providing one single treatment recommendation.

Given this, we may wonder: when are options given in a context dominated by single recommendations and how are they presented to patients? More specifically, are they presented as a true "menu of choice," where each option is presented without an indication for physician preference thus displaying maximal orientation to patient agency? Or, do physicians mobilize some of their medical authority by presenting options in such a way where their preference is revealed towards one option over the others? If so, to what degree do they orient to one treatment as more desirable?

In these data, option-listing is rarely used to present treatment as a menu of choice. Rather, it is used in the context of initial treatment presentations where the patient has a diagnosis but has not yet begun treatment. Physicians provide options but clearly reveal one treatment as more desirable in every case. Only rarely are options presented as choices, and this is in the context of an already-begun treatment that was found to be ineffective. In this context, each option given is minimized and the physician does not reveal a preference for one treatment over another.

## 2.4.1 Option-Listing in the Initial Treatment Context

An instance of the first context is shown in Extract 1. In this encounter, a gynecologic oncology patient, who has presented with pre-cancerous lesions on her labia, sits down with her oncologist in his office following a physical examination of the lesions. The option-listing begins in Extract 1a:

(1a)0206b

```
01
   DOC:
             Usually we like to get negative margins (.) meaning that we'd
02
             want to see healthy tissue beyond where the abnormal lesion was
03
             to ensure that we've removed the whole abnormal lesion. .hh the
04
             theory being that if you leave some of that behind it may grow
             over time and become a cancer.
05
06
   PAT:
             [Okay,
07
   DOC:
             [Mokay, .hh so with the goal of removing the whole abnormal
80
             lesion before it becomes a cancer .hh I would 57omething:d some
09
             type of treatment. .hh again the treatments would be:: um (.)
```

Here, the physician begins to discuss the goals of the treatment with the patient, which are to remove not only the abnormal lesion, but beyond it- into the "margins" (lines 01-02). He accounts for this in lines 03-05, where he states that if the margins are not also removed, the lesion could grow back and become cancer. He continues that removing the whole lesion is important to avoid cancer (line 07-08) and then recommends "some type of treatment" (lines 08-09) for the lesion. He next moves on to list three different treatment options by doing option-listing. He first provides the option of surgically removing the lesions, shown in Extract 1b:

## (1b)0206b

```
01 DOC: > type of treatment. .hh again the treatments would be:: um (.)

02 > doing a small procedure where you kind of come and go home the

03 > same day where we just excise those areas? [en put some sutures=

04 PAT:

[Mhm,

05 DOC: =in just to keep the area- h- to heal it well?
```

The first option is framed as one of a set when the physician prefaces it in line 01 with: ".hh again the treatments would be:: um (.)" before he produces the option itself, an outpatient surgical procedure: "doing a small procedure where you kind of come and go home the same day where we just excise those areas en put some sutures in" (lines 02-03). Note that the "just" in this line is used to minimize the excision (the procedure) itself. Then he moves on to discuss the healing: "en put some sutures in just to keep the area- h- to heal it well?" (lines 03 & 05). In this case, the "just" in line 05 downgrades the inclusion of the sutures and frames the sutures as only there to help "heal it well". Following this first option, the physician moves to the next two treatment options in Extract 1c:

(1c)0206b

```
01 DOC: > [.hh another option would be to use a <u>laser</u> and ab<u>late</u> meaning
02 > burn that area .hhh um: o:r to use some topical cream. .pt.hh I
03 don't necessarily recommend the topical cream for you because you
04 only have two little areas that look involved? en that's >kind of
05 > a< (.) quite a long process >that's twelve weeks of kinda (.)
06 > shmearing this cream over the (.) outside of your vagina: like
```

The next treatment option, offered immediately following the first, is to use a laser and burn the area of concern (lines 01-02). The use of "ablate" and "burn" as central to this treatment are both negative and medically weighty terms to use. In the next TCU, the physician produces the third treatment option, "to use some topical cream" (line 02), which, in the context of treating a precancer, may sound to the patient like it is inappropriately mild given that this is a pre-cancer. It is also inconvenient, as the physician states in lines 05-06, "en that's >kind of a< (.) quite a long process >that's twelve weeks of kinda (.) smearing this cream over the (.) outside of your vagina:". He also plainly frames the third option as undesirable in his medical opinion, when he states that he does not "necessarily recommend the topical cream" in lines 10-11. After more discussion of side effects of the topical cream, the physician includes which of these options he recommends in Example 1d:

## (1d)0206b

```
01 DOC: > U:m but I think (.) the: I think it'd be very reasonable just to
02 > do uh little wide local excision of those two areas? en just-
03 remove them and hopefully (.) be done with it.
04 PAT: That works,
```

While the physician has revealed a preference in favor of one option is apparent earlier, it becomes explicit when, lines 01-02, he states, "I think (.) the: I think it'd be very reasonable just to do uh little wide local excision of those two areas?" and this is partially accounted for by how the physician insinuates both the rapidity and the finality of the procedure, that the patient could just "hopefully (.) be done with it." (line 03) rather than having to undergo the previously mentioned twelve weeks of applying cream. Immediately following his revelation of preference towards the first

option, the patient shows acceptance of this treatment route in line 04: "that works,". Not only does the physician orient to a treatment as more desirable and the patient accepts, but the patient next asks the physician what she ought to do, as shown in Example 1e:

# (1e)0206b

```
DOC:
                            [.hhh um. (0.2) okay (.) if tha- if you're
01
02
             ame[nable
03
                [IF: (0.2) yeah [h h I mean what do you think is best?
   PAT:
04
   DOC:
                                [Yeah.
             .pt [I think- I think e I think the straightforward thing is just
05
   DOC:
06
   PAT:
                 [I-
07
             Tuh do the little excision of each .hh and then just be done with
   DOC:
80
```

The physician confirms the patient's acceptance of the treatment in lines 01-02. Yet, the patient explicitly requests the physician's advice, "I mean what do you think is best?" in line 03, to which the physician responds with the same desirable option, that the local excision is best (lines 07-08). Therefore, in this context of a set of options, the patient explicitly demonstrates the desire for her oncologist's medical advice. In sum, what is salient about this example of option-listing is that the patient has non-malignant, non-metastatic disease, standard options remain to treat her diagnosis, and options are presented in the context of pursuing some initial treatment. Further of note is how each option is framed in this case. In the context of the first option, the other two options are given less description and are presented as either maximally painful or extremely mild and quite inconvenient. The first option is presented as neither of these things: it is minimal and it is convenient. Further, the physician explicitly treats one option as more desirable, and the patient demonstrates a desire for his medical input. Both physician and patient look to medical authority as the arbiter. Thus, although three options are given, one is clearly presented as best. This case suggests that option-listing may function less as a way to provide the patient with real choice and more of a way to persuade a patient towards the best treatment given all of the possible treatments.

As we observed in Extract 1, patients can explicitly ask physicians what they think is best, suggesting a patient preference for demonstration of medical expertise. However, the following

excerpt shows that this is not always the case. In this encounter, the patient is a 29 year-old female recently diagnosed with high grade dysplasia on her cervix from a biopsy. She and her gynecologic oncologist are discussing a treatment plan. In Extract 2a, the oncologist presents two options to the patient for removing the pre-cancerous cells, either a LEEP procedure or a cone procedure:

### (2a)0120

```
So the part that they biopsied is out here. ((points to picture))
01
   DOC:
02
   PAT:
             Yeah.
             Okay, .hh so- (0.2) what we would recommend is (.) cutting this
03
   DOC:
04
             ((points to picture))off.=So you can do it in one way- (.) You
             can do a leep procedure? Which is with a:. electrified loop? .hh
05
06
             [and it literally just shaves it off like this.((moves pen))=
   DOC:
07
   PAT:
             [Yeah.
             =.tchhh or¿ you could do something called a con:e procedure .h
80
   DOC:
09
             which is where we use a scalpel and instead of shaving? .hh we:.
10
             cut. (.) Like this. ((moves pen))
11
   PAT:
             M[hm,
```

The oncologist enters into the treatment recommendation in line 03, where she invokes the institutional "we" to propose an excisional treatment plan, "what we would recommend is (.) cutting this off." She then, via an abrupt-join (see Local & Walker, 2004) moves straight through to the first option, a LEEP procedure (loop electrosurgical excision procedure), which she explains uses an "electrified loop". Following an in-breath, she expands on the details of this in line 06, where she demonstrates the procedure using a pen over an illustration of gynecologic organs while explaining "and it literally just shaves it off like this." The use of the word "just", similar to its use in Extract 1, serves to minimize the procedure, which initially was presented as using an electrified instrument which could be perceived as intense or severe. Further, the physician specifies that this procedure, originally framed as "cutting" in line 03, is in fact a procedure that "shaves it off" (line 06), which-relative to cutting- also serves to minimize the severity of this option. She then moves right to the next option in line 08, "ore you could do something called a conse procedure. In which is where we use a scalpel and instead of shaving? In the cut." The framing of this option relative to the first, that a scalpel is used and the procedure involves cutting rather than shaving, is presented as more of an

invasive surgery with the use of "scalpel" and "cut". Recall that the first option was presented as "just" shaving the area off, which is more mild in contrast. After a continuer by the patient in line 11, the physician continues with more details of each procedure in Extract 2b:

#### (2b)0120

```
DOC:
             scalpel and instead of shaving? .hh we:. cut. (.) Like this.
01
02
   PAT:
             M[hm,
              [.tchh okay, .hh there's advantages and disadvantages to both.
03
   DOC:
04
             For the type of l:e- (.) For the type of thing that you: .hh
05
             have based on your slides? .hh we would probably recommend doing
06
             this ((points to LEEP picture)) rather than this. (.) We save
07
             the cone for when we- when the (.) biopsy results are bad up in
80
   DOC:
             here? [and we need to get here? .hh when things are:. (.) .pt
09
10
             surfac:e? problems? We can actually, .hh take less cervix?
```

Here, the physician begins to discuss the "advantages and disadvantages to both." in line 03. Yet, rather than laying out the benefits and trade-offs of each procedure, she moves straight to reveal an explicit preference for one procedure over the other. In the next TCU she explains that based on the patient's slides, "we would probably recommend doing this ((points to LEEP picture)) rather than this." (line 05-06). While she overtly treats this option as more desirable, the physician does hedge and thus pull back on preference for this option slightly by invoking "probably" in making the recommendation. She next accounts for why she recommends the LEEP procedure in the subsequent TCU, that the cone procedure is better suited for instances where the biopsy results are "bad" further inside the cervix (lines 06-08). She then tells the patient that removing less cervix is appropriate when the issue involves "61omethic problems" (line 10). Her push for the LEEP procedure continues in Extract 2c:

### (2c)0120

```
01 DOC: actually, .hh take less cervix? (.) >you know< but get good
02 result.
03 PAT: Got[cha.
04 DOC: [The- (.) we don't wanna take a lot:
05 PAT: I un[derstand I've read everything o(h)n(h)lin(h)e hheh heh
06 DOC: [You need your cervix.
```

She explains that the LEEP procedure allows them to take less cervix but, in spite of this, still get a good result (lines 01-02). After her turn completion, the patient responds by registering this information in line 03, during which the physician comes in via overlap in line 04, further accounting for the first option, "we don't wanna take a lot;" The patient responds that she understands this, and provides an account for her understanding, that she has read everything online (line 05) and laughter also infiltrates the word "online", indexing a misdeed (Haakana, 2001; Jefferson, 1985). In overlap with the beginning of the patient's turn in line 05, the physician continues to reveal her preference towards taking less cervix with an assertion in line 06, that the patient needs her cervix, and then moves on to discuss the risks of surgery. In this instance of option-listing, two options are presented to the patient to treat her high-grade dysplasia. Both options are surgical excisional procedures: a LEEP procedure and a cone procedure. Initially, the physician frames the LEEP procedure as minimally invasive relative to the cone procedure by focusing on the instruments used to remove the area (a loop versus a scalpel) and the manner used to remove the area (shaving versus cutting). In the framing of each, the physician implicitly reveals a preference for the LEEP procedure because its severity is minimized. Next the physician moves to explicitly reveal a preference for the LEEP procedure over the cone procedure, and over the course of multiple turns continues to account for why the LEEP procedure is better, focusing specifically on evidence from patient's biopsy results, preference to remove less cervix, and the importance of an intact cervix. In these ways this encounter is similar to the first: that the physician first orients to one option as more desirable in the framing of the options and then explicitly recommends one option. However, this instance of option listing does not include the patient soliciting the physician for her opinion, as in the first, suggesting that patients do not always need the physicians to explicitly tell them which option to pursue for them to align with the physician's preferred treatment course.

Yet, what is similar across both cases is that persuasion takes a particular form: that discussion of the less desirable option works to bolster the reasonableness of the other, more desirable option.

In contexts where initial treatment is being discussed, physicians treat one option as more desirable than the others. This is apparent both in the framing of the treatment and subsequently made explicit by the physician. This result suggests that when initial treatment plans are discussed, multiple options for treatment can exist and when they do, each option gets presented. However, physicians appear to default to their medical expertise by advocating for one option which they believe to be best in this context. While there still may be an ethical imperative to lay out all of the options according to the standard of care, we see in this analysis physicians providing their clinical preference. This is not surprising given that physicians, over their years of practice, have developed clinical preferences for one treatment in a set of treatment options. Out of 8 total instances of option listing, 5 cases occurred in the context of initial treatment and 3 in the context of an ineffective treatment that is being revisited. Of the instances where option-listing occurred in the context of ineffective treatment, all involved the provision of options without any revelation of preference- implicit or explicit- for one treatment option over others. I now turn to an analysis of the results in this context.

## 2.4.2 Option-Listing in the Context of Ineffective Treatment

The context in which options are truly given is when the patient's current treatment has been found to be ineffective and the physician is revisiting the treatment plan with the patient. I suggest that, perhaps counterintuitively, giving the patient a "menu of choice" may suggest minimal hope for cure or maintenance of the disease, clinically bad news. Maynard (1996) argues that physicians use one of three interactional strategies for delivering bad news: forecasting, stalling, and being blunt. While Maynard argues that stalling avoids the delivery of bad news altogether and being blunt is a straightforward telling of the bad news, forecasting- in contrast- coaxes patients towards realizing

the bad news on their own (1996). This tactic, Maynard argues, "fosters realization through giving advance indications of bad news in a way that allows recipients an opportunity to estimate or calculate the news in advance" (1996: 116). It thus follows that doing option-listing in a context where standard treatments have failed could function to help trigger patients' awareness of the diminishing possibilities of disease remission. In the ensuing analysis, I explore this possibility

In the following encounter, a urologic oncologist has just finished telling the patient- who has prostate cancer- that while he clinically looks good, his scans are showing more bone metastasis of his cancer than the prior visit and that the current treatment is no longer effective in treating his cancer. In contrast to the previous patients' clinical circumstances, this patient has disease that is not currently under control. In Extract 3a, the physician enters the treatment recommendation via option-listing:

## (3a)0413

```
01 DOC:
.hhhh there are hh >whater-< what are the standard options that
02 > are left hhh=there's (0.2) kind of (0.8) .pt.hh there's kinda
03 > two: that one could consider:. ok,
```

The physician indicates that he is shifting into making some sort of treatment recommendation by beginning a discussion of the standard options that are "left" (lines 01-02). Here, the use of the word "left" is significant, because whatever options follow are options occasioned by the inefficacy of the current treatment. He then continues to say that "there's kinda two:" options (lines 02-03), the "kinda" showing that there are other options but they are either a variation of the standard treatment or less desirable treatments. Then, the physician moves to the first option as shown in Extract 3b:

#### (3b)0413

```
.hhhh there are hh >whater-< what are the standard options that are left hhh=there's (0.2) kind of (0.8) .pt.hh there's kinda

> two: that one could consider: ok, (.) .tch.hh one is Jevtana?

((PAT scrunches face, then leans in with one ear close to DOC))

DOC: > Jevtana?

((PAT glances up at DAU confused))
```

```
07 DOC: > Chemo.=
08 DAU: = <u>Jev</u>tana,
09 PAT: Oh Jevtana.
```

The first option, Jevtana, is portrayed as one of two "standard options" remaining (line 03). We learn that this is a chemotherapy drug from the physician's response to the patient's implied repair initiation via his facial movement and body movement, where he positions his ear closer to the physician (line 04). The physician treats this as other-initiated repair with his partial repeat, including just the drug's name again, with marked upward intonation (line 05) (Schegloff, 1997). The patient still displays confusion (line 06), and the physician understands this to be a problem of understanding, and not of hearing, as he entirely reformulates to include the more commonly understood word, "chemo" in line 07. Subsequently, this option gets major resistance (Stivers 2005a & 2005b; Stivers 2007) from the patient. He quickly gets emotional and begins crying when he reflects on his last experience with a chemotherapy drug similar to Jevtana, Taxotere and the inefficacy of these past treatments. Amidst this resistance, the physician offers the second option.

The second option, offered in Extract 3c, is presented to the patient after an extended discussion about the patient's demonstrated concern for the side effects and efficacy of the Jevtana:

(3c)0413

```
. hhh so >lemme say- if you said< .hh gimme another option besides
that chemotherapy. there is another one that's a little more

second it's an old dru:g, (.) ok but it's still chemo ok, (.) but that's
not the only option you can look it u:p it's the- one of the
first chemotherapies approved for prostate cancer.</pre>
```

While it may seem like this is the second of the two options initially presented in Extract 3a, this option is provided as a responsive alternate to the first option (lines 01-03). It is produced amidst massive resistance to the first option as the patient begins to cry after recalling his prior experience with chemotherapy and its inefficacy. This second option, the chemotherapy drug Midoxantrone, is framed as a gentler version of the Jevtana (line 03). The physician does remind the patient that this treatment is still chemo (line 04), therefore perhaps insinuating that the concerns the

patient had about the first chemo option could still be present here. He also frames the drug as "old" (line 04), which- in an area of constant treatment innovations and research- serves to minimize this option.

After no uptake, a third option is provided soon after to the patient- one that is *not* a chemotherapy drug- which is how the physician frames it as Example 2d demonstrates:

#### (3d)0413

```
one's gonna do that <u>test</u> anymore. (0.4) okay, .hhh >but if you said< ^well okay you're still talkin chemo gimme: gimme something else that's not chemo <u>wh</u>at haven't I tried yet (.) that is reasonable that I could—that I could still do, .hhh so one thing that we haven't—we haven't gone through yet, (0.4) u:m that's not experimental, (0.4) .pt is estrogen therapy?
```

This third option- for estrogen therapy- was likely the second of the two options initially presented in Extract 3a. In a preamble leading up to the presentation of the estrogen treatment itself, the physician indexes this option as "reasonable" (line 04) and "not experimental" (line 06). Once he offers this option, the patient asks about whether it will make his neuropathy worse. It is at this point that the physician includes an argument *against* going with the Jevtana option. This is shown in Extract 3e:

#### (3e)0413

```
01
   DOC:
             Yiknow your nerves are beat up,
02
             Uh huh,=
   PAT:
            En that would be a disincentive for the Jevtana, (.) cuz I think
03
   DOC: >
04
             that could actually (0.2) carry further with the numbness thing.
05
             Eh-the so the Jevtana a disincentive?
   PAT:
06
   DOC:
             Yeah, = it could actually make that worse.
07
             .hhhh wHHHHHH|HHH
   PAT:
80
                          [Neuropathy could get worse with the Jevtana.
   DAU:
```

In contrast to the first two instances of option-listing, the physician does not explicitly offer his opinion *for* or *against* this drug- he only offers its negative side effects as a "disincentive" (line 05). Subsequently, the physician does the same with the estrogen option. He just presents the positive and negative aspects of this treatment route in lieu of an explicit path forward, as shown in Extract

```
(3f)0413
   DOC:
01
             Yep. .h okay? .hhh so- >yiknow< estrogens especially if you have
02
             patch may actually be kind of an attractive option.=reduces hot
03
             flashes, .hh eh the-
04
   PAT:
             Well that'd be nice.
   DOC:
05
             Bu:t w:o w- side effect that- it can be a little troubling is
06
             breast growth.
```

07 PAT: .hh is what?
08 DOC: Breast growth. (0.2) they're estrogens, (0.2) they're feminizing hormones. °yi[know°

In light of the just sequentially prior side effect of the neuropathy worsening on Jevtana, the physician establishes that the estrogen may be a good treatment to pursue because it can reduce hot flashes (lines 01-03). Yet, in his next turn he moves right to a "troubling" side effect of this option in lines 05-06, breast growth, which he repeats in the first TCU of line 08 after the patient's repair initiation in line 07. After the repair, the physician includes that these drugs are "feminizing hormones" (lines 08-09), also likely a negative side effect for this male patient. He continues to discuss the negative effects of the estrogens in Extract 3g:

### (3g)0413

```
01
   DOC:
             testosterone but we add estrogen in the system. .hh I mean I've
02
         > had guys (.) develop- pretty good gynecomastia on these things.
03
   PAT:
             Develop what,
04
   DOC:
            Man boobs.
05
   PAT:
             Oh I've already got em.
             .hh t-they might get a little bigger if we put you on- [on
06
   DOC:
07
   PAT:
                                                                      [Wow.
80
   DOC:
             estrogen.
```

The physician expands on the feminizing side effect of the estrogen option, telling the patient that in his experience he has had patients develop "pretty good gynecomastia" (lines 01-02) for which he uses a more colloquial term, "man boobs" in line 04. When the patient tries to normalize this side effect, that he already has them (line 05) the physician persists with, "they might get a little bigger" (line 06), to which the patient registers surprise in line 07.

Up until this point, the patient has been told that his bone scans show the disease spreading, a sign of ineffective treatment. The physician follows up this clinically bad outcome with option-listing of the choices that are "left", and that there are "kinda" two options, signaling dwindling

treatment possibilities and hedging on the number of options which remain. Next the physician lays out three options, one occasioned by the patient's massive resistance in the form of crying. No indication is given to the patient of which option to pursue. The benefits of each option are minimized, while the "disincentives" for both chemotherapy and estrogen therapy are thoroughly laid out. Drawing on the earlier discussion of Maynard's work on bad news delivery, option-listing here could be functioning as a forecast to the patient in the form of "elaborate reports" (see Maynard, 1996). In laying out three options with no clear benefit in the context of the inefficacy of the current treatment could activate the patient's awareness of shrinking treatment possibilities.

# 2.4.3 Providing the No-Treatment Option

Notably, in the second case, an option that is not brought up- in light of the two other treatments provided- is the option to stop treatment. Given that the physician has framed the two options provided as the two that are "left," and given that the primary treatment to treat the patient's prostate cancer is not working and the scan is showing metastasis, it is salient that the physician does *not* include stopping treatment altogether. Yet, if a physician brings up stopping treatment later in the course of the patient's treatment, it becomes a harder recommendation to make. Theoretically, not having treatment is always on the table for a patient; not treating is an omnipresent option once a disease diagnosis has been made. But if a patient has been on one treatment for a while and the physician puts stopping treatment on the table, it means more than just selecting a no-treatment option at the beginning of treatment. There is a meaningful reason that the physician is bringing it up *at this point* in treatment even though it was always available to the patient. In these data, it is notable how rarely clinicians bring up the "no treatment" option. Of the 74 instances where some treatment recommendation is made, only once is a no-treatment option presented. So, if this is not an option that physicians make, what are they doing instead? In examining what happens in the case above (see Extract 3b), the physician highly minimizes the

options that remain. In stating that there are "kinda two:" (lines 02-03) options that remain, the physician sets up the two options to come as either a variation on the current treatment or less desirable in some way.

There is also evidence for the physician framing the options as a brainstorm rather than a dedicated treatment recommendation. Evidence for this is shown in the addition of an option occasioned by the patient's adverse reaction to the first option. This is also indicated by the physician not demonstrating preference for one option over another and downplaying each as having a host of undesirable side effects. Therefore, in an environment where the main treatments are found to be ineffective and stopping treatment is not brought up, there is suggestive evidence that physicians instead rely on option-listing and frame it as doing brainstorming, or to forecast bad news (Maynard, 1996).

To summarize, in this case the patient has malignant, metastatic disease and option-listing is occurring in the context of the main treatment no longer working. During the listing of these options, for two of them, the Jevtana and the estrogen, the physician includes both reasons for and against these treatment options. Yet, he does not explicitly do recommending, that is, he does not tell the patient what he *ought* to do, as is done in the initial treatment context. Further, the patient does not solicit the physician's preferred course of action. In contrast, in the first case discussed (as shown in Extract 1) the patient has non-malignant disease which requires treatment because if left untreated it is likely to develop into cancer. In this case, option-listing is done in the context of pursuing an initial treatment course. The patient ultimately decides to pursue the surgical option, the option the physician treated as more desirable. In contrast, in Extract 2 the patient does not solicit the physician's position on the treatment, yet similar to other instances in the initial treatment context, the physician treats one option as more desirable- both implicitly and explicitly- an option which the patient chooses to pursue.

In the third case, where the initial treatment is found to be ineffective and the cancer continues to grow, the option of no-treatment is notably left off the table in favor of option-listing. Yet, the physician frames option-listing in this instance as a foreshadowing of limited options because each option presented is heavily minimized and comes with no true benefit. Ultimately, the patient decides to think about the options and does not make a decision during this visit. In answering how option listing is being used by physicians, as this case suggests, option listing in the context of disease that is not under control is used as a forecasting tactic when a single treatment has failed and no other standard treatments are available. In sum, when physicians do option-listing in these data they are skewing more often towards one preferred treatment route and mobilizing their medical authority. Yet, the data suggest that when physicians have run out of options because the main treatment has been found to be ineffective, they do not orient to one treatment as more desirable and withhold their medical authority over the decision.

# 2.5 Single Recommendations for Treatment

The data in my sample show that physicians do lay out multiple treatment options when they are part of the standard of care, but that is relatively uncommon. When they do this, physicians generally treat one option over another as more desirable, showing that physicians are inclined toward providing a recommendation even when working to provide options. Even when physicians have run out of standard options, they *still* provide options yet withhold a preference for one particular route, in effect rescinding authority over the medical decision. But what happens when multiple treatment options do not exist and there is only one single treatment decision to make?

Taking this one step further, are all single treatment decisions the same? In order to tease this question apart, this analysis divides single treatment recommendations into three treatment recommendation types: (1) recommendations for new cancer treatments; (2) recommendations for

mid-course cancer treatments; and (3) recommendations for ancillary treatments, as these are different aspects of the cancer treatment process (see Table II).

In considering this, a question emerges: might we see different physician orientations to patient participation in different types of decisions in cancer care? Ultimately, cancer treatment decisions, unlike many primary care decisions, are generally based in a long-term treatment context, allowing multiple opportunities for patients to be involved in treatment decisions. Recall our earlier discussion that literature on SDM has suggested that physicians should incorporate patients into the treatment decision (Charles et al., 1997), and this can be motivated by moral and ethical obligations.

Table II: Treatment Context Definitions with Clinical Examples

Treatment context	New	Mid-course	Ancillary
Definition	Not yet begun	Already begun	remedies to a
	treatment for a	treatment for a	particular medical
	particular cancer-	cancer-related issue	complaint, and issue
	related issue		was ancillary but
			related to the primary
			treatment
Treatment	Surgery,	Switch from one	Treatment of nausea
	chemotherapy,	chemotherapy to	from chemotherapy;
Examples	radiation, hormone	another; change from	treatment of infection
_	therapy to control the	chemotherapy to	around incision area
	growth of new cancer	hormone therapy	after surgery

With this in mind, another question arises: what actions predominate physicians' treatment recommendations in cancer care? Do these actions afford physicians and patients an opportunity for shared decision-making? Will the distribution of these actions be different from primary care? Will they differ from chronic care?

To evaluate these questions, I first divide treatment recommendation actions into the five categories developed by Stivers, Heritage, Barnes, McCabe, Thompson & Toerien (2017). Using the

authors' parameters and applying their coding schema for treatment recommendation actions, 61 instances of treatment recommendations met the inclusion criteria. Examples of each action type from these oncology data and comparable primary care action types are detailed in Table III.

This categorical schema effectively captures the spectrum of physician authority and patient agency in the way single treatment recommendations are delivered in cancer care. (1)

Pronouncements, e.g., "I am going to start you on X" demonstrate significant physician agency over the recommendation, as they frame the treatment recommendation as already decided by the

Table III: Treatment Recommendation Action Examples in Cancer Care

TR action	TR action in primary care <sup>1</sup>	TR action in cancer care
Pronouncement	"I'll start you on iron tablets"	"You'll get both infusions today"
Suggestion	"You know you could try Claritin for that"	"We strongly recommend you consider using the birth control pill for prevention"
Proposal	"Why don't we put you on the plain Allegra"	"I still think we need to do chemotherapy"
Offer	"Would you like me to give you a stronger pain killer"	"We can give you some lidocaine jelly and see if that helps"
Assertion	"This medication that will take care of [it] is called Actifed"	"There's still utility in taking the ovaries out of people with BRCA2"

physician and as if the patient has no choice in the matter. (2) Suggestions, e.g., "I'd recommend that you try X, You could try X" allow for the patient to ultimately decide whether or not s/he is going to act on the recommendation while still establishing that the physician has agency in the decision insofar as it has originated with him/her. (3) Proposals, e.g., "How about we try X medication?" or "Why don't we start X and see" like suggestions, endorse the recommendation and do not direct the

\_

<sup>&</sup>lt;sup>1</sup> Examples taken from Stivers et al. (2017).

patient (as pronouncements do). But, proposals uniquely *imite* the patient to agree on the physician's idea, thus allowing for some patient agency in agreement prior to implementation. Yet, similar to suggestions, the idea inside the proposal has originated with the physician. Arguably, suggestions hold less endorsement of the recommendation than proposals, as suggestions frame the recommendation as entirely up to the patient to execute, while proposals *imite* acceptance of future, already-determined execution. (4) Assertions, e.g., "In general the first step is to begin X to treat this problem" are statements of fact about pursuing treatment that can still be heard as a recommendation, yet do not include any explicit endorsement. (5) Offers, e.g., "Do you want some X to help with the pain?" or "If you want, you can try X" are framed as something the physician is prepared to do for the patient as a response to some patient issue. As the authors of this framework argue, offers show the least amount of physician endorsement, as the patient's role in presenting the problem is framed as crucial before the recommendation is made.

This analysis seeks to help explain how physicians balance mobilizing their medical expertise and authority and preserve patent agency at the same time in oncologic decision-making. I first ask, how do physicians do that? In order to answer this, I identify the oncology treatment recommendation actions according to the schema established by Stivers et al. in the sample. Then, I ask, when would they involve patients, and when would they not? Thus I subsequently examine whether different treatment recommendation actions are associated with different types of treatment decisions. This allows us to assess whether there are meaningful patterns in the way physicians orient to patient involvement across different types of decisions and how physicians reflect different norms for patient rights and responsibilities in the treatment process.

# 2.6 Single Treatment Recommendation Actions

#### 2.6.1 Pronouncements

One way for physicians to recommend a course of treatment is to frame it in the form of a pronouncement action. As was mentioned earlier, this action asserts high physician authority, as the patient is presented as if s/he has no choice in the matter. Consequently, this action discourages resistance, although resistance is, of course, still possible (see Stivers, 2005). In the primary care context, resistance was found to be is negatively associated with pronouncements. (see Stivers et al., 2017). Per my earlier discussion, Stivers et al. speculate that this result is either because pronouncements themselves discourage resistance more than other action types or because pronouncements are used more often in instances where anticipated resistance is minimal. The following encounter, Extract 1, shows a pronouncement being made by a gynecologic oncologist to her patient who has recurrent ovarian cancer.

# (1)0121

```
01
   PAT:
            But I'm happy I'm here.
   DOC:
             I'm happy you're here too.=Hopefully we'll get you fixed right
02
03
             up okay?
04
   PAT:
             Ok[ay thank you.
05
   DOC:
               [.hh this is (.) the same chemo that you had before it worked
06
         > really well for you before and we're hopeful it will work again.
07
   PAT:
             Okay.
80
   DOC:
         > Okay? So we will- start it toda:y, you'll get the- e- both
          > infusions toda:y you've taken your medicines you'll get some
09
            more medicines you'll be kinda sleepy,
10
11
   PAT:
             Ok[ay,
12
   DOC:
               [Later today and that'll be good because you probably didn't
13
             sleep very well last night.=
14
             =No hh I didn't.
   PAT:
```

Leading up to the treatment recommendation, the patient announces that she is "happy" to be "here" (line 01) and the physician provides an affiliative response echoing the patient's sentiments (line 02). In stating in the immediate next TCU that she will "hopefully" get the patient "fixed up right away", (lines 02-03) the physician is providing an account for why she is glad to see the patient at the clinic- to begin to treat her disease. After the patient registers this (line 04), the

physician moves into her treatment recommendation in lines 05-06 by telling the patient which drug she has chosen for her treatment and offering an account for why she has chosen this drug- that it worked "really well" before and she is "hopeful it will work again." (line 06). There is initial evidence for a pronouncement action here, as the physician has communicated that she has already chosen the chemotherapy treatment and is thus framing the treatment to the patient as if she has no choice in the matter. After the patient provides acceptance for this in line 07, the physician continues the recommendation by using a pronouncement action: "So we will- start it toda:y, you'll get the- e-both infusions toda:y" (lines 08-09). In telling the patient that she "will" get both infusions today-infusion drugs that have already been chosen for her- the physician is handing down the treatment recommendation to the patient. This treatment decision, as is common with pronouncements, does not actively solicit patient agreement for the decision to be made, nor does it frame the decision as up to the patient in any way (though patients typically nonetheless accept, as she does here) (Stivers, 2005b). Notably the patient does not resist treatment in this instance. Of further note is that this recommendation is framed as a decision that has already been made, usurping the patient's agency in the decision. Therefore, the pronouncement action is treating patient involvement as unsought.

Another instance of a pronouncement is found in Extract 2. In contrast to Extract 1, where the physician has chosen to re-start the patient on a drug that she had already tried for her recurrent ovarian cancer, in this instance- also recurrent ovarian cancer- the physician is recommending a new drug to the patient to treat her cancer. This patient, a middle-aged female, has a tumor in her lower abdomen from her cancer metastasizing, which is causing her some discomfort. She has had two cycles of one type of chemotherapy drug already. The physician produces the treatment recommendation in lines 15-16 below:

(2)0127

01 DOC: .hhh so you're eating a little bit again?

02 PAT: Yes?

```
03
   DOC:
             Good good=
04
   PAT:
             =yes,=Ays u:h no more nauseous:?
05
    DOC:
             Goo[d.
06
   PAT:
                [No diarrhea,
   DOC:
07
             Great.
80
   PAT:
             No fever?
09
   DOC:
             No fever,
             Just ((PAT motions across abdomen)) the pain I still have it a
10
   PAT:
11
             [little bit,
   DOC:
             [Mhm (.) okay en it's not really any better since we started
12
13
             chemo.
14
   PAT:
             Yea:h no,
15
   DOC:
             .hhh hmm okay .pt .hh well we're gonna try this time we're gonna
16
             try: a-a new dru:g that you have not seen before=hopefully will
17
             not make you so nauseated,
18
   PAT:
             Okay.
19
   DOC:
             Um:. it'[s cal-
20
                      [by now I have a whole pharmacy in my house heh heh
   PAT:
((2 lines omitted about having lots of drugs at home))
             ((Smile voice)) .hh I know,=
24
   PAT:
              =Eh[eh
25
   DOC:
                  [but I don't wan:t to go::[backwards.>Maybe this will help=
26
   PAT:
                                             [Yeah.
27
             =you: feel better.
   DOC:
28
   PAT:
             ((head nod)) >Ok[ay.<
                              [.h So we're gonna try it out.>It's called Doxil
29
   DOC:
```

At the beginning of the visit, the physician inquires about the patient's eating habits, which we can assume the patient had not been doing well with before but is doing fine now, as is shown by the polar question in line 01: ".hhh so you're eating a little bit again?" to which the patient provides a preferred, yes-response (Heritage, 2010b) in line 02. The patient goes on to provide an account for why by continuing to list other improved gastrointestinal conditions which have allowed her to eat more. Once those symptoms have been listed and received by the physician (lines 01-09) the patient brings up the recurring pain she is having in her abdomen (line 10-11), which is one of her symptoms that is, unlike the ones she just listed, not improving. The physician takes this information and leverages it to discuss its relationship to the chemotherapy and draw a parallel between the chemotherapy regimen and the still present pain (lines 12-13). The physician next moves into a recommendation for a new drug (lines 15-16) in the context of the continued complaint of pain.

This treatment recommendation for a new chemotherapy drug is done via a pronouncement, "we're gonna try this time we're gonna try: a-a new drug that you have not seen before=hopefully will not

make you so nauseated," (lines 15-17). This pronouncement, in line with the earlier example, effectively presents the patient as having no choice or input in the matter, "we're gonna try: a-a new dru:g." and demonstrates maximal physician authority and mobilization of expertise over the decision. It is built to discourage patient resistance, even though the patient still may resist. In this extract, like the one prior, the patient does not demonstrate resistance following the pronouncement.

Note that in Extract 1, in making the treatment recommendation to re-start a chemotherapy regimen, the physician is not addressing a complaint from the patient. Conversely, in Extract 2, the physician is addressing a patient complaint- one of pain- in making the treatment recommendation to change chemotherapy drugs. In both cases, pronouncements are relied on. This suggests that the discussion of the complaint alone does not account for the action used. Yet, what accounts for pronouncements being used at all in cancer care when this treatment context is one of collaboration and partnership? In the primary care data, Stivers et al. (2017) found that the use of pronouncements resulted in a reduction of resistance. The authors speculate that one explanation for this was because pronouncements themselves discourage resistance. Given that the two examples shown demonstrate no patient resistance, this could similarly account for the use of pronouncements in cancer care, perhaps in particular when resistance is anticipated.

## 2.6.2 Suggestions

Another way physicians recommend treatment is via a suggestion. With this format, the physician endorses a particular treatment recommendation, but ultimately orients to the patient's role as the decision-maker. On the spectrum of physician authority and patient agency, it effectively balances both. While physicians using this format mobilize their expertise, they simultaneously allow for patient involvement in the decision. In Extract 3, a 29 year-old female patient is seeing the gynecologic oncologist for a medical consultation regarding her BRCA1 mutation, a genetic

mutation that pre-disposes her to developing breast and/or gynecologic cancers. She is discussing options to reduce her risk of developing gynecologic cancers in the future. After spending time discussing what her genetic mutation would predispose her to gynecologically and the related statistics, the physician enters into her treatment recommendation (lines 07-08):

#### (3)0112

```
01
   PAT:
             [Okay cool.
             [.hhh what can we do for prevention of ovarian cancer?
02
   DOC:
03 PAT:
04 DOC:
             [So if you're not tryina get pregnant currently, .hh oral
05
   PAT:
06
   DOC:
             contraceptives? the pill the birth control pill is s-associated
07
             with a fifty percent risk reduction [in ovary cancer.
08 PAT:
                                                 [OH REALLY,
09
   DOC:
         > So if you're not tryna get pregnant we strongly recommend that
10
            you consider: just using the pi:ll until you wa[nt to get
11
   PAT:
                                                             [Ri::ght,
12
   DOC:
             pregnant because it does reduce your risk of getting an ovary
13
             cancer.
14 PAT:
             Oh wow. (.) For some reason I thought it was the other way
15
             around.
((9 lines about the patient's account for the change of state token and DOC
clarifying breast and ovarian cancer risk differences eliminated))
25
   DOC:
             .hhh so- (0.4) for some reason, e- (.) not ovulating_
26
   PAT:
             Yeah.
27
             (0.8)
28 PAT:
             Oka:[y,
29
   DOC:
                 [Seems to help.
30
   PAT:
             [So- e- do you have a pill that you've used in the past?
31
   DOC:
32
   PAT:
             I do::.
```

After the change of state token (see Heritage, 1984) in line 07 which is later accounted for by the patient's confusion of ovarian cancer statistics with breast cancer statistics (lines 14-15), the treatment recommendation is produced at line 09-10, where the physician states, "So if you're not tryna get pregnant we strongly recommend that you consider: just using the pi:ll until you want to get pregnant". This treatment recommendation, to use the birth control pill as prophylaxis against cancer, is done using a suggestion as shown by the use of "we strongly recommend." Thus, at the core of this recommendation is that the decision lies with the patient, but the physician has provided strong endorsement. The patient responds to this recommendation first by aligning with the

physician's treatment recommendation in line 11 with a stretched "Ri::ght". While she does not initially accept because she first accounts for her confusion (lines 14-15) which is subsequently further clarified by the physician, the patient does not resist the treatment recommendation. Once the physician completes multiple turns accounting for the difference in treatment for breast and ovarian cancer prophylaxis, the patient shows acceptance in line 28, where she says "Oka:y," prior to the physician's completion of the account and then re-does this acceptance with a turn-final "Okay." in line 30.

Another suggestion is shown in Extract 4. In contrast to the prior extract which recommended a treatment that the physician herself could prescribe, in this example the physician's recommendation is for a treatment that she can recommend but not administer- radiation- as the administration of that drug is left to the radiation oncologist. At the beginning of the visit, the physician begins to look at the incision site from the patient's hysterectomy as she has a uterine cancer diagnosis and thus the first step- surgery- was already pursued. While no overt recommendation for treatment has been produced yet, the physician orients to the patient's resistance to pursue further treatment just after she greets the patient. This is shown in Extract 4a: (4a) 0108

```
01 DOC: > Have you given any more thought to getting treatment?
02 PAT: ((PAT shakes head)) I don't want to any[more.
03 DOC: [You don't want to. (.)
04 okay.>well how are you feeling. Any nausea?
```

The physician's initial question in line 01, "Have you given any more thought to getting treatment" displays a familiarity with the patient's position on treatment, that she has declined to pursue treatment already in a prior visit. The physician asks a cross-cutting, no-preferring question about whether the patient has given "any" more thought to treatment, which is tilted towards the possibility that the patient has not thought about pursuing treatment (Heritage, 2010b) yet looks for a change in her position towards treatment. After the patient's no-response (line 02), the physician

produces a full repeat of this position, then transitions quickly into history-taking (lines 03-04), and then conducts a pelvic exam. Following the pelvic exam, the physician makes a positive assessment about not seeing anything significant on exam (line 01):

```
(4b)0108
   DOC:
             Okay so I don't see anything, (0.6) And that's good.
01
02
   PAT:
             Tha::::nk y[o:::::u,
03
                         [Okay?
   DOC:
             Hheh heh hh
04
   NUR:
05
   PAT:
             Whhu:[:h
                  [But it doesn't- (0.8) Just cuz I can't see it doesn't mean
06
   DOC:
07
            there's not microscopic stuff there. Okay? I'm still
08
             recommending that you see the radiation doctor and talk to him.
09
             (.) Oka:y? And think about getting at least radiation.
10
   PAT:
             I:. recommend tre[atment. (.) Okay,
11
   DOC:
12
   PAT:
                               [Okay I'm gonna talk to him.
```

The patient next produces a stretched "tha::::nk you:::u" response, orienting to herself as the beneficiary of the physician's exam and positive assessment (Heritage, 2005) and perhaps beginning to close the sequence and activity- although this is not always evidence for sequence termination (Schegloff & Sacks, 1973). Instead of responding to this with a type matched "you're welcome", the physician reinforces her position in line 01 with a response-mobilizing "okay?" and then launches her next turn with a contrastive "but." (line 06). The treatment recommendation arrives in this turn, prefaced by an account: "But it doesn't- (0.8) Just cuz I can't see it doesn't mean there's not microscopic stuff there. Okay?" which reinforces that even though the exam does not show anything problematic, which is good, the possible existence of microscopic cells is still troubling. Next the physician moves to her treatment recommendation: "I'm still recommending that you see the radiation doctor and talk to him. (.) Okay? And think about getting at least radiation" (lines 07-09). The treatment recommendation, that she see the radiation doctor and think about getting at "least" radiation, is a suggestion for two reasons. While the physician is demonstrating clear endorsement for this treatment course "I'm still recommending that" (lines 07-

08) she is also orienting to the ultimate decision as in the patient's hands "you see the radiation doctor" and "think about getting at least radiation" (line 09). The implementation of both things is conditional on the patient's acceptance of this treatment course.

Notably, this treatment is also a compromise in the face of treatment resistant behavior carried over from a previous visit, as the standard treatment for uterine cancer is a combination of chemotherapy and radiation. Thus, the treatment type selected- only radiation- is conditioned by the patient's prior resistant behavior. Ultimately, the patient does decide to "talk" to the radiation oncologist (line 12), demonstrating a reduction in her prior resistant behavior by accepting the recommendation to talk to the radiation oncologist. In sum, this suggestion, like all suggestions, shows the physician's strong endorsement for this treatment course and an orientation to patient involvement as high, creating a balance of physician authority and patient agency. Like the pronouncement extracts shown prior, the patients in this section do not demonstrate resistant behavior following the suggestion and accept the treatment recommendations. In contrast to pronouncements, suggestions make more room for resistant behavior by explicitly leaving the decisions largely in the patients' hands. We could speculate that because of this, patients would be more likely to demonstrate initial resistance and then engage in a treatment negotiation. However, these examples suggest that this is not necessarily the case. So, to what effect may physicians use suggestions? Physicians may use suggestions as a demonstration of SDM. As was previously discussed, physicians might implement SDM in the context of increasing policy imperatives and incentives and/or to the effect of respecting patient self-determination in their own health care, thus allowing for patients to use their own deontic authority in the treatment decision.

#### 2.6.3 Proposals

A third way physicians recommend treatment is using a proposal. With proposals, physicians facilitate involvement in patients deciding whether to accept the recommendation. The most

significant aspect of this format is that patients are *invited* to endorse the physician's idea. In this recommendation format, patient involvement is specifically provided for, or sought, in the treatment decision. In contrast to a suggestion, the proposal does not frame the decision as entirely left up to the patient; rather the patient is being invited to approve or reject the physician's recommendation for a future plan. In considering the SDM literature, proposals are well-suited to providing opportunities for patient involvement in their own health care because their involvement is sought. Insofar as deontic authority is concerned, physicians preserve their biomedical authority over the decision and simultaneously allow for patients to preserve their personal preferences and subjective authority over the decision. In the following example, a middle-aged female patient has just undergone a hysterectomy to remove the uterus, ovary and fallopian tube because she had experienced abnormal bleeding following menopause. During this visit, the physician discusses the results of the pathology report, which shows a high-grade serous carcinoma that likely originated in the fallopian tube but has now spread to the uterus. He then tells her that those are often hard to find until they have spread to other places, but that she is only a stage 2a, which is an early stage of cancer. He then gives the pathology report to the patient's daughter (line 01) as he continues with his treatment recommendation (lines 01-02):

### (5a)0209

```
01
    DOC: >
             So that's for you guys. .hhh now moving forward? I still think
02
             we do need to:::.h do: chemotherapy.=and the reason I say that
03
             is th-is a fallopian tube cancer there is a much higher risk of
04
             this: .hhh potentially coming back compared to a uterine cancer.
05
             (.) now the fact that it's an \underline{e}arly fallopian tube cancer is
06
             excellent and that's really really good news .hh and I think if
07
             we do the chemotherapy (.) .hh u:m I think you're gonna have a
80
             good chance of this staying away for a long long time en
09
             hopefully if not forever. (0.2) okay,=
10
   PAT:
             =.pthhh well- okay so I had a couple of- (0.6) question[s er,
11
   DOC:
             (0.4) thoughts. .hh um:. (0.8) Number one is I'd like to see what
12
   PAT:
             the genetic testing comes back,
13
14
             (.)
15
             .pt[hhh- ((Nods head))
   DOC:
16
   PAT:
                [What- what kind of um:. (0.8) wonderful genes I have there.
17
   DOC:
             [Yes.
```

```
18 PAT: [.hh and then I'd also- um: u- they: were saying that I had lymph node, (0.8) l- uh- no um: .tchh th<u>yr</u>oid. (.) no- n<u>odu</u>les.

20 DOC: Mhm.
21 PAT: .hh so I'd like to get those checked.
```

The physician transitions right into his treatment recommendation (lines 01-02) from the discussion of the cancer staging: ".hhh now moving forward? I still think we need to::..h do: chemotherapy." He then immediately follows the treatment proposal with an account for why this is his preferred treatment option, working to discourage the patient from intervening with a position on the treatment recommendation (see Local & Walker, 2004), as evidenced by the abrupt-join "=and" following downward intonation and syntactical completion of the prior TCU in line 02. This treatment recommendation invites the patient to provide input on his initial idea rather than framing the decision as already decided like a pronouncement. Note that the "I think" frame of this recommendation (lines 01) is of what "we" should do (line 02). This inherently proposes an idea and frames its implementation as conditional on the patient's acceptance as evidenced by the collective "we" in the recommendation proper. Thus, patient involvement in the decision is specifically sought in the proposal recommendation format.

In this case, the patient resists the treatment recommendation, as is shown by her response in line 10: "=.pthhh well- okay so I had a couple of- (0.6) questions er, (0.4) thoughts." She then goes on to outline the nature of these "thoughts", that before beginning chemotherapy, she wants genetic testing and examination of her lymph nodes. She goes on to account for this by referencing a friend who had lymph node cancer after breast cancer, and needed a second course of chemotherapy after her first. This patient wants to avoid that. The physician makes several more attempts to persuade the patient to accept the treatment recommendation to no avail. His final attempt to persuade the patient is shown in the following extract, 5b:

(5b)0209

01 DOC: [And then: um:. (.) yiknow reach out

```
02
             when you see Doctor Brodski >I'll reach out to her too in the
03
             next week or two just to discuss th-yiknow wher:e and when if-
04
             if you decide to do the chemotherapy? .hhh u:m again if it were
05
             me or anyone else I would strongly 84omething:d it there are
side
             effects but (.) again eighteen weeks of your life .hhh u:m:.
06
07
   SIS:
             In comparis[on to what could happen.
                        [In comparison to the [rest of your life,
80
   DOC:
```

As we see in lines 04-06, the physician produces a suggestion to recommend chemotherapy again, "if it were me or anyone else I would strongly 84omething:d". While he does acknowledge a concern of the patient's- side effects- he puts the difficult treatment in perspective, that "eighteen weeks of your life" (line 06) is not worth "the rest of your life" (line 08). Despite these attempts at seeking the patient's buy-in for treatment, the physician is unsuccessful as the patient continues to resist treatment. The patient leaves the visit with a decision to get genetic and thyroid testing done-two of her own agenda items- but does not decide about the treatment recommendation for chemotherapy.

While the previous instance of a proposal treatment recommendation was to recommend a particular drug, as was the case with the majority of the treatment recommendations in the sample, the following treatment recommendation in Extract 6 is a recommendation for surgery. This patient, a 45 year-old woman, has had a long history of endometriosis and is at the clinic with her niece.

After complaining of increased pain and bleeding with her period, she saw a specialist and got a scan of her uterus, tubes and ovaries. It was found that she had multiple cystic structures on her ovaries causing these symptoms, so she was referred to a gynecologic oncologist for treatment. In the below extract, she and the physician are discussing a treatment plan:

```
(6)0103
```

```
01
    DOC:
              .hh so we will do that?
02
    PAT:
              Okay.
              So we'll put that aside for a minute, (.) What do we do about
03
    DOC:
04
              your ovaries.
05
              (.)
              °Mm, °
06
    PAT:
07
              I think that (0.8) we [need to- (.) look at them. (.) With (.) a
    DOC:
                                       ^{\circ}m^{\circ}
80
   PAT:
```

```
09
   DOC: >
             camera, (.) and a surgery.
10
   PAT:
             Ok[ay,
               [And take th- take a look? .hh and decide (.) whether they
11
    DOC:
12
             look scary like cancer? .h \underline{o}r they look like endometriomas and
             then make a decision about whether or not we should take the
13
             cysts (.) themselves? Or whether we should take the ovaries.
14
15
   PAT:
             Okay [Doctor Leonard (.) tch-
16
    NEI:
                   [Well Doctor Leonard said that y-you- that I guess the
17
             procedur:e (.) Is that you gotta take hh the ovaries.
```

The recommendation for treatment, to look at her ovaries more closely with a surgery, is found in lines 07 and 09, "I think that (0.8) we need to- (.) look at them. (.) With (.) a camera, (.) and a surgery" is classified as a proposal because it is framed as an idea, "I think that we need to", thus and invites patient endorsement. Like the previous case, the recommendation's implementation is framed as conditional on patient acceptance via the use of the collective "we" when the physician produces the recommendation: "I think that we need to look at them with a camera and a surgery." After the patient's continuer in the next turn "Okay," (line 10), the physician expands on the details of the surgery (lines 11-14). Interestingly, it is revealed that the surgery will not be to simply "look" at the cysts but may also be an excisional procedure, in which either the cysts themselves may be removed or both the ovaries and cysts may be removed. Thus, following the proposal to "look" with a camera via surgery at the outset of the treatment recommendation, the physician sequentially builds the details of the recommendation as more invasive than was initially proposed. The niece, whose response, that you "gotta take the ovaries" indexes some previous understanding of what may need to happen to treat her aunt's symptoms. In the next several turns, the patient eventually displays this understanding and a surgery is pursued, yet not without initial treatment resistance. The patient asks the physician several questions about the details of the surgery, and why the cyst cannot just be removed without touching other structures.

At the center of this recommendation is that the physician has provided an endorsement for a particular treatment insofar as she is proposing an idea. However, the orientation of proposals is towards patient endorsement via an invitation to weigh in. Notably, in both instances of proposals

shown, patients display resistance. However, while the first patient did not accept the treatment recommendation despite attempts at persuasion by the physician, the second patient did decide to accept the treatment recommendation. This finding is in line with what Stivers at al. found in the primary care data, where proposals were most likely to be resisted (30% of the time in their data) relative to suggestions and pronouncements (resisted 11-13% of the time). As was previously noted, the authors speculate that this is perhaps due to the context in which proposals are given-when physicians anticipate the most resistance. Yet that does not explain the findings in these data. Significantly, a suggestion was used in an already resistant treatment environment, as was shown in Extract 4. So perhaps there is something about proposals themselves that condition resistance, while in contrast suggestions do not? Stivers et al. (2017) posits that the unique nature of proposals-inviting the patient to weigh in and make the final decision- may condition more resistant behavior. In line with the implementation of SDM, proposals, like suggestions, both endorse the treatment recommendation but leave the decision to pursue treatment as in the patient's domain. Further, the affordances of proposals are like those of suggestions. The use of them satisfies policy imperatives and moral obligations to patient involvement.

### **2.6.4 Offers**

Another directive action physicians rely on in making their treatment recommendations is offers. At the core of an offer is the physician expressing a willingness to provide some medical action (e.g., prescribe, refer, etc.) for the patient's treatment. In Extract 7, the patient is an elderly female who has a tumor in her lower abdomen for which she is being treated by chemotherapy. During this check-in visit, she is complaining of some rectal bleeding during bowel movements, which the physician explains is due to the tumor pushing on the rectum:

(7)0104

O1 DOC: So the bleeding we learned from: your last visit and >from what we knew before< with- it's the tumor that's pushing on the

```
03
             rectum en some of it has eroded through the rectum. .hh so if
04
             your stools are very firm they may be harder to get out and
05
             cause a bit more bleeding.
06
             [Mhm,
   PAT:
07
    DOC:
             [.hhh um we can give you medicines to with the:. s- >you know
80
             to< make them SOFTER and see if that helps us.
09
             .pt well yeah, but then wouldn't it be like if I don't make it
    PAT:
10
             to the toilet in time I'd make more of a mess?
```

The physician first provides an account to explain why the patient is seeing blood in her stool (lines 01-05) which was the presenting concern of the patient during this visit. The physician works to somewhat normalize this bleeding, that is, that the bleeding is to be expected because of the presence of the tumor and not some additional abnormal medical problem. Next, in overlap with an acknowledgment token by the patient in line 06, the physician begins a treatment recommendation to try to help with the rectal bleeding in the form of an offer (lines 07-08): ".hhh um we can give you medicines to help with the:. s- >you know to < make them SOFTER and see if that helps us." Here, the physician indicates her willingness to aid the patient in her complaint of bleeding with an offer for a solution. The physician does not actively endorse the solution. Active endorsement would be, in the form of a suggestion: "I recommend that you take some stool softener" or in the form of a proposal: "How would you feel about trying a stool softener?" Instead, the physician supports the solution to the problem in a passive way in response to some initial request, often in the form of a presenting concern originating from a patient complaint. In this case, the patient demonstrates initial resistance to the treatment recommendation in line 09-10: "pt well yeah, but then wouldn't it be like if I don't make it to the toilet in time I'd make more of a mess?" despite eventually accepting the recommendation for a stool softener.

In this next instance of an offer, the patient shown in Extract 8 is following up with her gynecologic oncologist after having surgery to remove her uterus (a hysterectomy) and tubes and ovaries (a bilaterial salpingo-oophorectomy) after a tumor growth was found in her abdomen. She is seeing the physician to follow up with the surgery and a possible infection she may have at the

incision site. After the physician explains why they swabbed the wound to get more information about the bacterium infecting it, she complains of a possible yeast infection:

```
(8a)0214
01
   DOC:
             .hh it's not uncommon to have something grow out there but
02
             that's why we did it. To know about it.
03 PAT:
             Uh uh. .hh en then I've had a little bit- >like< it feels like I
04
             h- might have a little bit of a yeast infection too.
05
   DOC:
             .pt we can- I can call in a prescription for that just a one- a
06
             one time dose pill. (0.2) For you. ((Turns to computer to order
07
             the prescription))
             .hh well I bought some Monistat over [the:. I just didn't want
80
   PAT:
09
   DOC:
                                                   [Oh then-
10
   PAT:
             take it until I talked to you.
11
   DOC:
             Ye:ah Monistat's okay,
12
   PAT:
             Okay,
```

After the patient's complaint of a yeast infection, the physician produces his treatment recommendation in lines 05-07, an offer for a one-time dose pill. Similar to the previous treatment recommendation, an offer for stool softener, this recommendation is responsive to the patient's complaint and frames the recommendation as made in service to the patient's issue. Here, this is evident in the physician's offering the one-time pill as a remedy, "I can call in a prescription for that" (line 05). The responsive nature of this recommendation is further shown by an increment (Schegloff, 1996), "a one-time dose pill. (0.2) For you.", the "for you" added on after a possible turn completion in line 06. After the patient tells him that she has already bought Monistat (lines 08 & 10), which he confirms is "okay," (line 11) without follow up, the physician switches topics after the results from the bacterial swab appear on his screen, results which he shares with the patient. Following discussion of treating this infection, the physician circles back to his treatment recommendation for the yeast infection in Extract 8b:

```
(8b)0214
```

```
01
   DOC:
            Regardless what I'm gonna do is I'm gonna call in a prescription
          > for the yeast infection, (.) okay? If you want it- it's just a
02
03
          > pill. >Keep it? If the- [if the Monistat goes- does- does well
04
   PAT:
                                     [Okay,
05
   DOC:
             you don't need it?
             [Yeah,
06
   PAT:
```

07 DOC: [.hh if the Monistat doesn't clear up take the pill.

Despite telling the patient earlier that the Monistat is ok, the physician reaffirms that he is going to follow through on his initial offer, to call in the prescription for the yeast infection (lines 01-02). He then tells her to "keep it" (line 03) and use it if the Monistat does not treat the infection (line 07). Like the prior example, this patient does demonstrate resistance. She does this here by including the possibility of taking Monistat, which she already purchased (lines 8 & 10 of Extract 9a). Despite this, and the weak endorsement of Monistat (line 11), the physician indexes that he is going to call in a prescription for the recommended treatment (lines 01-03). He then re-frames his recommended treatment as a "backup plan" to the Monistat (lines 03, 05, 07). Central to this treatment recommendation is that it is produced as responsive to a complaint made at the patient's initiative and is framed as a willingness to do something in service to the patient's needs.

Consequently, physician authority is treated as low in offers and patient initiative is treated as high.

The presence of resistance in these two instances of offers demonstrates evidence for patient orientation towards offers being a product of their own initiative. This finding is also in line with the primary care data, where offers were resisted as often as proposals (see Stivers et al., 2017). But what might account for offers being used in a cancer care setting, where treatments are generally higher stakes and treatment is time-sensitive, where there is no time for resistance? Would not physicians want to persuade patients to pursue treatment via endorsement, non-existent in offers? Perhaps offers are used when the treatment is lower stakes and thus persuasion unnecessary, even when patients resist, which they appear to do often after offers.

# 2.6.5 Assertions

Although rare in the data, another way treatment recommendations are produced is with the use of assertions. Assertions are hearable as treatment recommendations because they imply a recommendation for treatment without explicitly endorsing one (Heritage & Sefi, 1992; Stivers et al.,

2017). Oftentimes, assertions take the form of general statements about treatment for the patient's problem and can be heard as informing the patient about a problem. Stivers et al. (2017) argue that assertions are right at the edge of statements providing information and actual treatment recommendations. Yet, the authors argue that what tips the scales is that assertions "leverage the epistemic authority of the physician into the deontic force of a recommendation through a stepwise process of inference" (Stivers et al., 2017: 25). For instance, "Studies show that this drug is effective in treating your type of cancer" where there is no explicit endorsement from the physician is both informing the patient about a treatment and is hearable as a recommendation to the patient. Because the assertion about the treatment remedy has originated from the physician there is a small degree of implicit preference displayed for that treatment regimen as a remedy for the patient's problem. An instance of an assertion is found in Extract 9. In this encounter, the patient, a 61 year-old who has found out that she has a BRCA2 mutation, is discussing the next steps for treatment gynecologically once she finishes getting a double mastectomy. The physician begins by explaining to the patient the difference between the BRCA1 and BRCA2 genetic mutations (lines 01-03). This patient, who is past the recommended age (50) for removal of her ovaries, is told that despite this it is still desirable to remove her ovaries to reduce her risk:

# (9)0124

```
01
   DOC:
             .hhh B R C A two thankfully tends to:. if it's- e-when people
02
             have ovary cancer in general? (.) Tends to be ew- (.) ten years
03
             later than B R C A one.
04
   PAT:
05
   DOC:
             So there's still utility in taking ovaries out of people that we
06
            would think of o::h if I was gonna get it I would have gotten it
07
          > before.
80
   PAT:
09
   DOC:
            [.hh because e-with people have a B R C A (.) two mutation we
10
          > know that in general .hh their- the timin:g that they- °u°
            usually get an ovary cancer somewhere between their fi:fties and
11
12
            seventies.
13
   PAT:
             Mhm.
14
   DOC:
             Okay. .pthhh so we're in that window of time.
             ((nods head))
15
   PAT:
   DOC:
             .pt so how do we take ovaries out because it's really the only
16
17
             way to prevent this ^cancer. We: take them out like this
```

The physician begins by explaining to the patient that her genetic mutation "thankfully" tends to occur ten years later than the BRCA1 mutation (at age 50 versus at age 40), orienting to a potential concern that she has missed an opportunity to reduce her risk for ovarian cancer because of her age. Following registration of this information with a minimal response token "Mhm," in line 04, the physician continues by entering into the treatment recommendation in lines 05-07: "So there's still utility in taking ovaries out of people that we would think of o::h if I was gonna get it I would have gotten it out before." Inside the beginning of this treatment recommendation the physician makes a general statement, that it is still useful to remove the ovaries in patients who are beyond the recommended age for removal. This provides the patient an opportunity to get her ovaries removed despite a perceived assumption that there would no longer be utility in ovary removal given the standard protocols.

Further evidence for the physician's orientation to the current relevancy of removing the ovaries now is the emphasis on the word "still" in this TCU. The physician continues with her treatment recommendation in lines 09-12 with an account for why it is desirable to remove the ovaries, making it specifically relevant to this patient's situation by explaining the crucial window of time for removal of the ovaries to avoid cancer is between the ages of 50 and 70. After another minimal response token from the patient in line 13, "mhm.", the physician indicates a pursuit of response "Okay." in the first TCU of her next turn (line 14) and then further pushes the relevancy of removing the ovaries in the next TCU of this turn by explaining to the patient "so we're in that window of time." After the patient nods her head- another minimal response- the physician transitions to discussing how the ovaries are removed (lines 16-18). She pushes the point further that the removal of the ovaries is "really the only way to prevent this 'cancer' (line 16) via the emphasis on the word "really", indexing that there is one single way forward for this patient to prevent

ovarian cancer. The physician then discusses more details of the surgery which the patient accepts after demonstration of this passive resistance. Notably absent from the treatment recommendation is the physician's overt recommendation in the form of a suggestion or proposal format. However, the generalized statement to the patient is made to inform her that there is "still utility in taking ovaries out of people" (lines 05-06), even at a later age than the standard recommendation. That there is further emphasis to the patient that she is in that window of time where surgery is important (line 14), and the only way to prevent the cancer (line 16-17), makes this generalized statement hearable as a treatment recommendation.

Physician authority is less high in assertions than in suggestions and proposals because there is no explicit endorsement. Instead, endorsement is implicit insofar as the recommendation has originated with the physician as a remedy to the patient's complaint, but it is a weak form of endorsement. An assertion's orientation to patient's involvement is high because, like suggestions, the decision to accept the treatment is left in the hands of the patient. To what effect might physicians use assertions in a cancer setting, where physician ownership over the decision has been rescinded relative to suggestions, proposals, and pronouncements? What accounts for physicians' weak endorsements of a treatment course in such a consequential environment such as cancer treatment? We could speculate that physicians may rely on assertions in a more delicate treatment environment where resistance is anticipated and thus may want to more delicately lay the treatment recommendation on the table via a generalized statement rather than telling the patient directly what s/he ought to do.

# 2.7 Treatment Recommendation Actions and Treatment Contexts

These five treatment recommendation actions can be conceptualized as sitting on a cline of physician authority and patient agency, with a pronouncement asserting the most physician authority, and offers displaying the most deference to the patient. The question I ask now is whether

most treatment recommendations in cancer care use a proposal, as would be suggested to be "ideal" by the SDM literature, because this format demonstrates the most collaboration between physician and patient (see Charles et al., 1997, 1999; Towle & Godolphin, 1999). Of the 61 treatment recommendations analyzed in the data, 39% (24/61) were recommendations made via a pronouncement, 30% (18/61) were made via an offer, 21% (13/61) via a proposal action, 7% (4/61) via a suggestion, and finally 3% (2/61) via an assertion. The frequencies of these results, compared to those found in the US primary care data (see Stivers et al., 2017), are summarized in Table IV.

Table IV: Frequency of Treatment Recommendations in Cancer Care and Primary Care

Action type	U.S. cancer care	U.S. primary care
Pronouncements	39%	65%
Offers	30%	5%
Proposals	21%	4%
Suggestions	7%	21%
Assertions	3%	5%
Total	100%	100%

Total cancer care single recommendations: n=61; Total US primary care single recommendations: n=393

In answering my earlier question of what actions are used to make treatment recommendations in cancer care, the data show that pronouncements are most frequently used, followed by offers. Proposals occurred half as often as pronouncements in the data, suggestions one-third as often as proposals, and assertions were rare. When compared to the findings by Stivers et al. in Table IV, pronouncements similarly predominated in the context of cancer treatment, although to a lesser extent in cancer care. Recall that pronouncements treat patient involvement in the decision as non-existent and physician authority as high because the decision has been framed as

already made and is handed down to the patient. Significantly, this runs counter to the literature's recommendations, which advocates for a collaboration between physician and patient.

Now that it is clear which actions are used in cancer care, I next ask, what is each action used for? Perhaps certain physicians have a personal preference for using one action type when they make a treatment recommendation. Yet, my data show that is not the case. Recall Extract 2 (0127), Extract 3 (0112), and Extract 7 (0104). All of these treatment recommendations were made by the same gynecologic oncologist, identified as "01". Yet, this oncologist used a pronouncement in Extract 2, a suggestion in Extract 3 and an offer in Extract 8. Similarly, recall Extract 5 (0209) Extract 8 (0214). This gynecologic oncologist, identified as "02", used a proposal in Extract 5 and an offer in Extract 8. So, the variation in these data argues against the personal preference argument.

We also might wonder whether patient gender is an explanatory variable in these data. Of the 61 initial treatment recommendations, 17 were made to male patients and 44 to female patients. Given this information, there is a clear asymmetry in numbers which is problematic for any broad conclusion. But, these data offer preliminary evidence for physicians being more authoritarian with their male patients. Of 17 treatment recommendations made to male patients, 59% (n=10) were pronouncements. Of 44 treatment recommendations made to female patients, 32% (n=14) were pronouncements. This suggests that physicians are more authoritarian in delivering recommendations to male patients than they are to female patients. Yet it is unclear if this is a feature of gender, or a feature of the disease being treated. All male patients in the data set were being treated for urologic cancers, while all female patients in the data set were being treated for gynecologic cancers. Nonetheless, the preliminary evidence here shows that gender may have an effect on the degree to which physicians direct patients or collaborate with them, but the sample's gender breakdown does not offer us a solid foundation for conclusions. This result indeed

underscores the need for further research in this area. An idea future cite to explore would be an oncology treatment environment where oncologists treat *both* men and women for the same disease.

Maybe the severity of the patient's diagnosis explains why certain actions are used. Perhaps if the patient has been diagnosed with cancer, physicians will exert more authority over their treatment decisions because of the high stakes of treatment and thus use pronouncements. Yet this also does not explain the use of actions. Recall the diagnoses for Extract 5 (0209) and Extract 9 (0214). Both patients have been newly diagnosed with cancerous tumors that have not yet metastasized. Yet in Extract 5, a proposal is used to recommend treatment and in Extract 9 an offer is used to recommend treatment.

It is also possible that the treatment itself can explain the use of certain actions, and certain treatments- like chemotherapy- only get one kind of treatment recommendation action. Again, perhaps because of the high stakes of treatment, only pronouncements will be used to recommend chemotherapy because physicians want to exert maximal authority and professional expertise over this decision to get the patient to do what is best for their own survival. However, this does not account for the use of certain actions over others. Recall the treatment recommendations in Extract 1 (0121) and Extract 5 (0209), where chemotherapy is recommended in both. Yet Extract 1 uses a pronouncement for chemotherapy while Extract 5 uses a proposal. Furthermore, recall two recommendations for surgery in Extract 6 (0103) and Extract 7 (0124). In the former case a proposal was used and in the latter an assertion was used. Thus, the treatment type does not explain why particular actions are used either.

Pronouncements dominate in my data, which runs against the recommendations for patient involvement in cancer care. What could account for this counter-intuitive finding? One possibility is that treatment recommendation actions are shaped by the stage the patient is in the treatment process. Current SDM literature does not differentiate between different types of recommendations

by stage in the treatment process, yet doing underscores important nuances about decision-making, patient involvement, physician authority, and the relationship to treatment context. As discussed earlier, I conceptualize that where the patient is in the process of treatment matters. Thus, as mentioned earlier, I divide the data into three distinct treatment contexts: the new treatment context, the mid-course treatment context, and the ancillary treatment context. I find that there is a clear relationship between the treatment recommendation action and the context in which the treatment recommendation is being made. Significantly, pronouncements are not made in the new treatment context. They exist only in the mid-course treatment context, where they overwhelmingly dominate, and ancillary treatment contexts, where they are used when the complaint is brought up at the physician's initiative (see Table V). This observed relationship speaks to how physicians orient to patient agency in different types of decisions based on the type of recommendation action they use.

Table V: Treatment Recommendation Actions by Context

	New	Mid-course	Ancillary
Action			
Pronouncements	0% (n=0)	75% (n=6)	51% (n=18)
Suggestions	22% (n=4)	0% (n=0)	0% (n=0)
Proposals	61% (n=11)	12.5% (n=1)	3% (n=1)
Assertions	11% (n=2)	0% (n=0)	0% (n=0)
Offers	6% (n=1)	12.5% (n=1)	46% (n=16)
Total (n)	100% (n=18)	100% (n=8)	100% (n=35)

Total single treatment recommendations: n=61

### 2.7.1 Recommendations for New Treatments

Any time a patient has not yet begun treatment for a particular cancer-related issue, the clinician's recommendation is for a new cancer treatment. Most of these visits include: post-surgical visits to discuss pathology and next steps in disease management, initial visits where a

mass or pre-cancerous area had been suspected or found, and post-genetic consultation visits where prophylactic surgery had been recommended for carriers of genetic mutations that pre-disposed them to cancer. Of the total single treatment recommendations, 30% (n=18) involve recommendations for new treatments. In every case either a proposal action (n=11), suggestion action (n=4), assertion action (n=2), or offer action (n=1) is used by the physician. Strikingly, no pronouncements are used in this context. In the first example, Extract 10a, an instance of a proposal action occurring in a new treatment context is offered. This case was discussed earlier as Extract 5. As was mentioned earlier, this patient has just been diagnosed with a high-grade serous carcinoma in her fallopian tube and is staged with 2a fallopian cancer. Notably, this diagnosis is made just following a surgery that happened only a week before to remove the patient's uterus, tubes and ovaries. In addition to talking about the next treatment steps, the patient is also due to get the staples in her incision removed. The recommendation to treat her fallopian tube cancer occurs in lines 01-02:

# (10a)0209

```
DOC: >
            So that's for you guys. .hhh now moving forward? I still think
            we do need to:::.h do: chemotherapy.=and the reason I say that
02
03
             is th-is a fallopian tube cancer there is a much higher risk of
04
             this: .hhh potentially coming back compared to a uterine cancer.
             (.) now the fact that it's an early fallopian tube cancer is
05
             excellent and that's really really good news .hh and I think if
06
             we do the chemotherapy (.) .hh u:m I think you're gonna have a
07
80
             good chance of this staying away for a long long time en
09
             hopefully if not forever. (0.2) okay,
```

As was analyzed in the prior section, the treatment recommendation is characterized as a proposal because the "I think" invites the patient to collaborate with the physician on this treatment and the "we" frames the pursuit of chemotherapy as conditional on the patient's acceptance. An orientation to the context in which this recommendation is made- to pursue future treatment after surgery- is shown by the physician in the first few utterances of his recommendation: ".hhh now moving forward?" (line 01), which sets in motion a next step for treatment. Notably, in the next

TCU, the utterances "I <u>still</u> think" show evidence for the physician having already taken a position on the issue (though not in this visit) and maintaining that position now. Thus, patient involvement in this initial decision via the proposal recommendation action is pursued here. Insofar as physician endorsement in this recommendation is concerned, it is implied because the idea has originated with him. This recommendation is categorized as occurring in a new treatment context because it presents an initial pursuit of a not-yet-begun treatment therapy in a post-surgical consultation.

While the prior treatment recommendation was in a post-surgical context where cancer was found, Extract 11 (shown earlier as Extract 3) occurs in the context of preventative cancer care. Recall that this young female patient is seeing the gynecologic oncologist to discuss a recently diagnosed BRCA1 mutation. She has previously undergone a double mastectomy to reduce her breast cancer risk and is now discussing how to minimize the likelihood of developing gynecologic cancers. The physician enters into her treatment recommendation (lines 07-08) after discussing the standard screening protocols (lines 01-04):

# (11)0112

```
What I would recommend is first doing a normal gynecological
   DOC:
             exam. (.) .hhh from a cancer perspective we would get a baseline
02
03
             CA125 reading and then we'd >sort of< see each other every 6
             months or so for a routine exam..hhh what can we do for
04
             prevention of ovarian cancer. .hh oral contraceptives? are
05
             associated with a 50% reduction of ovarian cancers so: if you're
06
07
             not trying to get pregnant we strongly recommend that you
80
             consider just using the pi:ll (.) until you want to get pregnant
09
   PAT:
             [Ri::ght,
   DOC:
10
             [Because it does reduce your risk of getting an ovary cancer,
```

In lines 04-05, the physician begins to build the treatment recommendation as a way for the patient to prevent ovarian cancer and provides statistical evidence bolstering this claim. The core recommendation occurs in the next TCU (lines 06-08): "so: if you're <u>not</u> trying to get pregnant we strongly recommend that you consider just using the pi:ll.". This course of treatment, to take the birth control pill for a reduction in ovarian cancer risk, is framed as a new course of action that the patient has not pursued before. This recommendation in this new treatment context is done as a

suggestion action, "we strongly recommend that you consider just using the pi:ll" as is shown by both the strong physician endorsement "we strongly recommend" and the ultimate decision being left up to the patient "that you consider just using the pi:ll". In this new treatment context both orientation to patient agency and assertion of physician authority are high.

While the first two recommendations were for the pursuit of a single new medication, the recommendation shown in Extract 12 is a recommendation for new multiple therapies at the same time and additional therapy after that. Like Extract 10, the treatment recommendation here is occurring during a post-surgical consultation after cancer was removed. The patient is a 38 year-old female who has recently undergone surgery to remove her uterus, tubes and ovaries as she had shown high-grade dysplasia on her most recent pap smear. At the time of surgery, as is the protocol when cancer is suspected, the samples were sent to pathology for testing. The results came back as cancerous, which is why the patient is seeing the oncologist for this visit: to discuss the next steps of treatment. Prior to line 01, the physician discusses with the patient that she presented her pathology results (positive for cancer) to the others in her oncology group, also known as "tumor board." In line 01, the physician begins to discuss the results of the meeting. This is discussed in the below excerpt:

```
(12)0128
```

```
01
   DOC:
             fresh .hhhh (.) we talked about (.) your s::. your type of
02
             cancer:? (.) what the:. best treatment should be: and the: team
03
          > agreed that the best treatment would be a combination of
04
         > chemotherapy and radiation at the same time an[d then followed
05
   PAT:
                                                           [really?
06
   DOC: > with chemotherapy.
07
             .pthhhh because the: overall:.m (.) this is very rare (.) this
80
             clear cell: cancer of the cervix is a very
```

The physician states in lines 01-05 the treatment recommendation that the team came up with, which she also frames as her treatment recommendation: "the: team agreed that the best treatment would be a combination of chemotherapy and radiation at the same time an [d then followed with chemotherapy." Note that by invoking the team's consensus on treatment, the

physician is providing evidence that this is not only her recommendation for a future course of treatment, but that of her colleagues as well. This treatment recommendation action is a proposal because she states that the "best treatment would be a combination of chemotherapy and radiation", thus she is endorsing the decision but the decision is not purely on the patient's shoulders. Central to the proposal categorization of this recommendation are the words "would be" in the physician's recommendation proper. This indexes the need for patient agreement in the treatment decision, in other words, that implementation of this protocol is conditional on the patient's acceptance. This recommendation is inherently an idea posed by the physician and is framed as such when she invokes her colleagues' consensus, which implies that this recommendation is an idea invited to be agreed upon by the patient. What is notably not present is an explicit recommendation (e.g., "We recommend that the best treatment is X") as would be the case with a suggestion action. As with the first extract in this section, this case is also categorized under the new treatment context, as the patient has had surgery but has not yet pursued treatment for her diagnosis.

Once again, what is striking about the 18 new treatment recommendations in the sample is that no pronouncements are used and only action types which maximize patient agency are used in this context. Sharing in the decision with patients is demonstrated as a clear priority from this result. The majority (n=15) is either a made as a proposal or suggestion. Rarely, offers and assertions-which orient to patient involvement as higher than in suggestions or proposals- were used. The preponderance of suggestions and proposals provides strong evidence for physician orientation to the patient's ultimate decision-making capacities and physician willingness to collaborate with the patient even though a physician's tilt towards one course of action oftentimes implicit as in the proposal, or explicit in the suggestion. Further, in this context, there is a need to get patient acceptance of treatment and secure it quickly, as patients could potentially resist this initial treatment due to the burdensome nature of many of them. As was discussed earlier, beginning cancer

treatment following diagnosis is time-sensitive (Hillen et al., 2012). At the same time, physicians have to contend with patient fears of treatments themselves (Levin et al., 1985; Passik et al., 2001), making patient persuasion, and securing buy-in, especially pertinent.

If we conceptualize all action types in terms of patient agency and physician epistemic and deontic authority, we see that each action sits on a continuum from greatest to least demonstration of physician authority: pronouncements, suggestions, proposals, assertions, and offers. While offers demonstrate no physician authority over the decision because the recommendation is being framed as made at the patient's initiative, assertions demonstrate slightly more physician authority over the decision insofar the generalized statement about the treatment's benefit has been produced as a remedy to the patient's issue. Thus, in assertions endorsement is implicit because it has originated from the physician as a solution, yet endorsement is weak. In proposals and suggestions, physicians demonstrate significant authority by endorsing the decision (e.g., "I recommend X" or "I think that X"). Yet these actions continue to preserve patient involvement in the decision by leaving the decision in the patient's hands, as in a suggestion, or asking the patient to weigh in on the idea, as in a proposal. When pronouncements are made, patient involvement is inhibited as the recommendation is handed down to the patient with full physician authority behind it.

At a more basic level, we can see that there is a distinct dichotomy between pronouncements and all other action types. This is because pronouncements are the only action type that do not orient to patient involvement as relevant. Even though pronouncements inside a treatment recommendation still make relevant acceptance, the way they are delivered discourages negative patient uptake and they are notably absent in the new treatment context. Further, they privilege physicians' deontic authority insofar as biomedical expertise is concerned and discount patients' deontic authority in the context of their own subjective illness experience and personal preferences. Yet, the absence of pronouncements in this context shows an orientation by physicians to preserve

patients' deontic authority over the decision. Further, it shows that physicians are working to build a therapeutic partnership with these new patients orienting to their involvement as necessary for initial decision-making. Overall, in this context we see a tension between the attempt to preserve patient agency while at the same time maintaining physician authority. While physicians are asserting their authority by recommending a single treatment course, they are still looking for buy-in from the patient.

We might predict that the use of proposals and suggestions is an oncology effect and that we will see this in the other treatment contexts as well. If these two action types are used across all contexts, then physicians in these data are acting in line with the policy literature and implementing SDM. Yet this result would be out of line with what Stivers et al. (2017) find in the primary care data. It instead would be closer to the results found in the psychiatry data (see Thompson & McCabe, 2017), where the authors found that the majority use of proposals and suggestions signaled to patients that their experiential authority took precedence over medical authority. This would explain the result in the new treatment context, that physicians' treatment recommendations are motivated by patient involvement and seeking patient alignment with their position prior to making a decision. Yet, if proposals and suggestions dominate in the mid-course context that may be problematic interactionally, as Thompson and McCabe (2017) found that the use of majority proposals and suggestions communicated to patients that treatment was optional. Patients in a higher stakes environment like cancer care—where life or death is at stake—may find the framing of treatment as "optional" as abandonment while they are in the middle of their treatment. It therefore follows that we may see other types of actions predominate in the mid-course context.

# 2.7.2 Recommendations for Mid-Course Treatment

Of the total sample analyzed (n=61), 13% of instances (n=8) involved a recommendation for some intervention to an already begun cancer treatment course. As previously mentioned, these

already-begun treatments included chemotherapy treatments, testosterone suppression therapy, and steroid therapy to treat a tumor, to name a few. Notably, nearly all (n=6) of the treatment interventions in these contexts involved a pronouncement treatment recommendation action. This same action was entirely absent in the new treatment context. This finding represents a shift as it indicates more of a parallel to the findings in primary care (see Stivers et al., 2017) where majority pronouncements were used to recommend treatment. This is interesting because the medical issues present in this context are of an entirely different nature than those seen in primary care settings. Strikingly, the treatments recommended in this context are the same types of treatments recommended in the new treatment context and yet the actions used to recommend are completely different. For instance, in the following extract, chemotherapy is recommended. Chemotherapy is also recommended in Extract 12 in the new treatment context. However, proposals are used to recommend treatment to both of those patients. Here a pronouncement action is used despite the recommendation being for the same medication. In this encounter, shown earlier as Extract 2, a middle-aged female patient is currently being treated for metastatic ovarian cancer. She has complained of pain in her abdomen, which her oncologist believes is due to continued growth of the tumor. Before this visit, she has undergone two cycles of chemotherapy which has been shown to be ineffective in treating her tumor. In lines 15-16, the physician pronounces the treatment recommendation:

### (13)0127

```
DOC:
             .hhh so you're eating a little bit again?
             Yes,
02
   PAT:
03 DOC:
             Good good=
04 PAT:
             =yes? =Ays u:h no more nauseous:?
05 DOC:
06 PAT:
                [No diarrhea,
07 DOC:
             Great.
08 PAT:
             No fever?
09 DOC:
             No fever,
10 PAT:
             Just ((PAT motions across abdomen)) the pain I still have it a
11
             [little bit,
             [Mhm (.) okay en it's not really any better since we started
12 DOC:
```

```
13
             chemo.
14 PAT:
             Yea:h no,
15
   DOC:
             .hhh hmm okay .pt .hh well we're gonna try this time we're gonna
            try: a-a new dru:g that you have not seen before=hopefully will
16
17
             not make you so nauseated,
18
             Okay?
   PAT:
19
   DOC:
             Um:. it'[s cal-
                     [by now I have a whole pharmacy in my house heh heh
20
   PAT:
```

The physician takes the patient's complaint of pain (line 10-11) and uses it as leverage to connect the pain to the inefficacy of the chemotherapy she is receiving (lines 12-13). The patient confirms that the pain is still not improved since chemotherapy has been started (line 14). In the next turn, the physician provides a recommendation to change the treatment (lines 15-16) in the context of this continued complaint of pain. This mid-course treatment recommendation, from the existing chemotherapy drug to a new chemotherapy drug (which we later learn is Doxil), is made via a pronouncement: "this time we're gonna try: a-a new dru:g that you have not seen before=hopefully will not make you so nauseated," (lines 15-17). Due to the existing drug's inefficacy, a change to the treatment mid-course is pronounced, framing the decision as already determined and treating this patient as if she has no say in the matter. Recall that in addition to these key features, pronouncements also display high physician agency and patient acceptance is unsought.

A third example of a treatment recommendation that occurs in a mid-course treatment context is shown in Extract 14. Most of the recommendations in this context are responsive to a drug inefficacy problem, like pain or bleeding from continued tumor growth. However, in this case the physician is responding to the worrisome side effects of the drug treating this patient's cancer instead of the drug's inefficacy or cancer growth. The patient, a 48-year-old male, is dealing with recurrent prostate cancer and is being treated for it with both chemotherapy and steroid treatment at the same time. Earlier in the visit, the patient had complained of some nerve pain, which his physician associated with his taking of Ozurdex, a strong steroid used to treat some forms of

prostate cancer. In the below excerpt, we see the patient complaining of an "electrical charge" sensation in lines 03-04:

#### 

The physician's subsequent treatment recommendation in Extract 14b – to wean the patient off the strong steroid and replace it with a weaker one- is motivated by the patient's complaint of this uncomfortable sensation. The core treatment recommendation of the change to treatment midcourse is made in lines 06-08:

### (14b)0403

```
01
   PAT:
             So you're gonna wean me off [(0.2) completely?
02
   DOC:
                                          [I'm- com- ing you:. I'm gonna wean
03
             you off.
04 PAT:
             And then on the third round of chemo I won't be taking any of
05
             the stuff.
06
   DOC: >
             .hhhhh yeah.=WELL: you know what we're gonna do:. as you're
07
             coming off of this? we're gonna- (.) we're gonna switch you over
80
             to prednisone?
09
             (0.4)
10
   PAT:
             ((Y[uh:.))
11
   DOC:
                [It's a baby steroid ok,
12
   PAT:
13
   DOC:
             .hhhh u::m. (0.8) we're gonna do:. prednisone five milligram
14
             tablets.hhh um::. (1.0) we're gonna do::.. I'm gonna keep you a
15
             little on the low side David cuz I think this stuff messes ya up
16
             a little bit .hhh I'm gonna do five milligrams a day. (0.2) ok?
17
   PAT:
```

After the patient's question regarding complete dosage reduction in line 01, the physician comes in via overlap to confirm the patient's question, that he is weaning the patient off the original steroid treatment. The patient re-confirms the timeline of this in lines 04-05, verifying that by the third round of chemo he will be completely off this medication. The physician confirms this at the outset of his turn in line 06 using the downward intonation "yeah.". Yet, the physician quickly indicates a possible revision to this by using the latched and stretched "=WELL:" with increased

amplitude. Following this, the physician completes the turn by revising the treatment plan using a pronouncement action for the treatment recommendation (lines 06-08): "as you're coming off of this we're gonna- (.) we're gonna switch you over to prednisone?" This recommendation, for a change to steroid treatment from the Ozurdex to prednisone, is categorized as a pronouncement action because the physician frames the recommendation as if it has already been decided and as though the patient has no choice in the decision. Note that even when the dosage of the prednisone is discussed just after in lines 13-16, the physician continues to use a pronouncement action in determining the dosage: "we're gonna do: prednisone five milligram tablets" (lines 13-14). He also provides an account for doing so, that the steroids give him unpleasant side effects: "I'm gonna keep you a little on the low side David cuz I think this stuff messes ya up a little bit" (lines 14-16). The physician is therefore oriented to both the change to prednisone and its dosage as already determined and as if the patient has no choice in the matter.

Rarely in this context actions other than pronouncements, such as proposals, were used to recommend treatment. This is puzzling because the same treatments are being prescribed in both contexts and yet the actions used are completely different. This result shows that once patients have signed on to being treated for this cancer, and have forged a relationship with their physician, physicians do not require their involvement in the same way that they do in the new treatment context. Instead, they privilege their deontic authority in this context, demonstrating a position that their medical expertise comes before a patient's right to decide. These data suggest that, once patients sign onto treatment, their agency has been effectively transferred to physicians. Why are pronouncements relied on overwhelmingly in this context? Perhaps it is because the patient's treatment has been found to be ineffective and thus the stakes are higher in deciding about the next treatment course. It is possible that physicians do not look for patient buy-in in this mid-course context because that opens up the possibility of treatment resistance. Further, if they were to use

primarily suggestions and proposals in this context, it could communicate that, similar to the findings in psychiatry, the treatment is optional. In psychiatry, the use of proposals and suggestions did get resisted more often (see Thompson and McCabe, 2017). Using a suggestion or proposal in this context may be resisted because patients are pushing back on decisional responsibility and not just the treatment itself, as Thompson and McCabe found in their data. So perhaps pronouncements are relied on in this context to minimize resistance not just to treatment, but to having too great a burden at this stage of treatment.

### 2.7.3 A Deviant Case

Recall that proposals, while asserting physician authority, also work to preserve patient autonomy and role in the decision. While a proposal in this context may initially seem to depart from what we typically see in this context, Extract 15 underscores not only that the treatment context matters, but so too does the relationship between the physician and patient. In this encounter, the patient has been undergoing maintenance therapy for ovarian cancer, taking an oral multikinase inhibitor. But her CA-125 level has recently risen dramatically, evidence of further cancer growth. She has sought treatment for this with the physician in the below encounter, who is new to treating this patient. Prior to this, she was being treated by another oncologist and it is unclear why she has switched to this oncologist- whom she saw in a prior visit before this visit. In the following extract, after discussing the records from the patient's previous doctor, the physician enters into her treatment recommendation (lines 07-09):

(15)0123

```
DOC:
             Okay great. (.) So I do have those records. [Okay.
01
02
   PAT:
                                                           [Yeah >yeah< I mean
             he was on vacation fer .hh (.) Ith- uh bout a month, (.) en (.)
03
             en a lotta times on vacation. .hh [a:n-
04
05
   DOC:
                                                [^Okay,
06
   PAT:
             (.) so.
         > Okay so I think carboplatinum will be fine for you like we
07
   DOC:
80
          > talked last time. .hhh carboplatinum <u>is</u> a c- chemotherapy
09
          > drug.[=It does not make you lose your hair, .hh but it=uh is a
```

10 PAT: [Yeah.
11 DOC: real drug. It (.) can cause (.) bone marrow side effects? like
12 low blood counts?
13 PAT: Yes.

The treatment recommendation, "so I think carboplatinum will be fine for you like we talked last time." (lines 07-08) is categorized as a proposal as it is framed as an idea originating from the oncologist, "I think that". It is also looking for approval from the patient. It is also framed as something they had discussed before but because it is being brought up now we can deduce that a course had not been formally decided yet. However, this is a proposal given in a mid-course treatment context, which deviates from the common pattern. This physician is seeking the patient's buy-in in the recommendation, which does not fit with most of the recommendations in this context- pronouncements. Recommendations mid-course are typically handed down to the patient and presuppose patient agreement. In contrast, this recommendation *invites* patient agreement. Why might that be? When we look at what is new about this treatment encounter, it is not the context in which the recommendation is being made, rather it is the relationship between the physician and patient. This supports the idea that when a new physician-patient relationship begins, as in the new treatment context, the physician orients to the need to get the patient on board with treatment. While this encounter seems to deviate from what is usually done in this context, it in fact helps clarify what is salient about the different contexts: It is not just about whether or not the treatment is familiar or unfamiliar; it is also about the degree of familiarity in the physician-patient relationship. Here, because the physician and patient are relatively unfamiliar to each other, the physician orients to the need to get this patient's buy-in before changing the drug treating her cancer.

# 2.7.4 Recommendations for Ancillary Treatments

Ancillary treatment recommendations were the third type of recommendation observed in these data. These treatments were remedies to a medical complaint, but that medical issue was ancillary to the primary treatment. For instance, the complaint could be a direct side effect of

chemotherapy, like nausea or neuropathy, or a more indirect side effect of having cancer, like depression. It could also be a complaint associated with the surgery, for instance, an infection around the incision area or a urinary tract infection because of the catheter. In these data, 57% of the recommendations were for ancillary treatments (n=35). The salient aspect of an ancillary treatment context is that the treatment is not explicitly treating the existence of the disease itself but treats a side effect of the disease or a side effect stemming from treatment of the disease. Because many of the issues treated in this context are side effects, like nausea or pain, we might expect the results to pattern like primary care as the presenting complaints are similar to primary care. So, we might assume that physicians will rely primarily on pronouncements in this context.

Based on the data, ancillary complaints can come at the initiative of the patient or at the initiative of the physician, and this matters for the way the problem is addressed. Thus, these ancillary treatment contexts were further divided into categories separating whether the recommendation related to the ancillary treatment was 1) made at the physician's initiative or 2) in response to a complaint presented by the patient. When these were divided, 43% of ancillary treatment cases (n=15) were made at the physician's initiative, and 57% were made at the patient's initiative (n=20). Notably, all treatment recommendations given by the physician preemptively were done via the pronouncement recommendation action. However, those given in response to complaints were majority offers (16)², with few pronouncements (3) and one proposal (shown in Table VI). I propose that the action type indexes this relationship.

The first example of a recommendation done in the context of an ancillary complaint made at the physician's initiative is shown in Excerpt 16. In this example, the problem is brought to the fore at the physician's initiative. At the outset of the visit she registers that the patient does

=

<sup>&</sup>lt;sup>2</sup> Curl (2006) similarly found in her examination that offers were interactionally generated and sequentially relevant to prior talk when an *overt* problem was discussed. The speaker of the problem thus becomes the recipient of the offer.

Table VI: Ancillary Treatment Recommendation Action Frequency by Initiative

Ancillary Treatment Recommendation Action	Physician Initiative	Response to complaint
Pronouncements	100% (n=15)	15% (n=3)
Proposals	0% (n=0)	5% (n=1)
Offers	0% (n=0)	80% (n=16)
Total (n)	100% (n=15)	100% (n=20)

Total ancillary treatment recommendations, n=35

not look good and may need to be admitted. Further, she claims concern for the patient's immediate well-being. The patient, in the middle of chemotherapy treatment for ovarian cancer, has presented with dizziness, fever, and bloating. The discussion of the concern begins in lines 03-04 of Extract 16:

```
(16)0110
01
   DOC:
             So: we're gonna repeat some laboratory studie:s,
   PAT:
             O[k hh
03
           > [I:. er:. um looking at you: my gut says ^you might spend the
   DOC:
04
           > night with us^ .hhh becau[s:e
05
   PAT:
                                       [I actually packed a bag. hh [heh yeah.
06
   DOC:
                                                                    [Good,
             good. (0.2) 'you're gonna spend the night with us' no[w I'm just
07
80
                                                                   [Okey hhh
09
             gonna say it [because ya look a little dry: you're warm to the
10 PAT:
                          [okay.
11
  DOC:
             touch,
((34 lines omitted about more questions and discussion of symptoms))
46
   PAT:
             I am a little dizzy,
47
   DOC:
             You look dizzy,=
48 PAT:
             =yeah,
             ok. .hhh I'm pretty worried about you. I mean I'm glad- I'm glad
49
   DOC:
50
             you packed a bag so you can stay:. let's get s- things sorted
51
            out we'll getchya some IV fluids we'll get some things underway:
52
             you're gonna need a scan,
```

The pronouncement for an ancillary treatment (IV fluids) comes at line 51, "we'll getchya some IV fluids". The recommendation is ancillary because it is a treatment meant to deal with a

concern secondary to her cancer treatment, a concern that includes looking a little "dry" and being "warm to the touch" (lines 9 & 11). After the patient offers another symptom in line 46, "I am a little dizzy." the physician aligns with the patient in her turn (line 47). Following this, the physician tells the patient that she is "pretty worried" about her (line 49), which serves to partially account for the treatment recommendation for IV fluids even though it comes sequentially prior. Notably here the physician takes initiative to treat the ancillary problem by bringing up the concern herself. It then follows that this initiative is demonstrated via the pronouncement action as the physician was the one to bring the problem to the surface of the visit. In this case in particular there is an acute nature to the patient's symptoms, as evidenced by the fact that the physician wants to admit the patient to the hospital right then. It thus logically follows for the physician to assert full medical authority and hand down a treatment recommendation rather than collaborate with the patient in instances where the physician is the one to bring up the medical concern.

Another instance of a pronouncement recommendation action produced at the physician's initiative is shown in Extract 17. The patient is to begin her first chemotherapy treatment during this visit for recurrent ovarian cancer, and the physician is reviewing the process of the chemotherapy infusion, for instance, that she will be given some medicines to help her rest during the infusion today. She also reviews which chemotherapy drugs are to be administered during the infusion. She then asks the patient whether she filled her prescription for the anti-nausea pills, and then enters into a treatment recommendation for the patient to take those pills:

```
(17)0121
```

```
Do you have medicines?=I gave you some prescriptions before for
01
   DOC:
             anti-nausea pills?=
02
03
   PAT:
             =D-ye[s
                  [Do you have those filled [and at home?
04
   DOC:
                                             [yes I already: got everyt[hing.
05
   PAT:
   DOC:
06
             good good.=so when you go home today you'll be okay but tomorrow
07
   DOC:
           > when you wake up make sure you take .hh (.) one of those nausea
80
              (.) pills for the next couple of days to make sure that you're
09
10
              ok.
```

```
11 PAT: Oka[y.
12 DOC: [Okay we wanna prevent it,
13 PAT: Okay.
14 DOC: We don't want it to start.
```

Once the physician has confirmed that the patient did fill the prescription already given to her for anti-nausea pills and they are readily available to her (lines 01-05), she does a positive assessment (lines 06-07). Notably, the first two questions about the nausea pills (lines 01-02 & line 04) demonstrate a preliminary sequence (Schegloff, 2007; Terasaki, 2004), which Barnes (2017) argues can be used to "test the waters" in a potentially resistant environment prior to making the recommendation. In this case, the patient does *not* show resistance when asked about the medicines in the preliminary sequence, as is shown by her use of preferred, yes-responses (Heritage, 2010b). Thus, one could argue that the physician is cleared to make her treatment recommendation in favor of using those medications (Barnes 2017). This case is categorized as treatment recommendation made at the physician's initiative because the physician enters into her treatment recommendation to take the anti-nausea pills (lines 07-10) before any complaint or discussion about nausea has been made. Further, this case is classified as an ancillary treatment context because the anti-nausea pills are ancillary and indirectly related to the primary disease, which is ovarian cancer in this case. The anti-nausea pills are only treating a side effect of chemotherapy, the primary treatment for the patient's disease, thus categorizing this instance as an ancillary treatment context. Notably-like all other ancillary treatment types in which the physician preempts the medical complaint- the treatment recommendation is done as a pronouncement, that is, the physician telling the patient what s/he ought to do and thus discouraging resistance to treatment. Furthermore, these pronouncements treat the recommendation as not optional. It therefore follows that the preponderance of pronouncements in this ancillary treatment context suggest that physicians are strongly privileging their medical authority and experience, have a clear stance on what the patient ought to do, and therefore demonstrate more deontic authority in making these types of

recommendations. This could be motivated by the need to prevent risk. In the first extract, the physician wanted to prevent further risk to the patient's health as she appeared clinically weak, while in the second, the physician wanted to prevent the risk of nausea because of the chemotherapy drug.

The next instance is also an instance of a recommendation made in an ancillary treatment context, however this time the treatment recommendation action is an offer, as shown in lines 31-33. This patient has recently had surgery to remove her uterus, tubes and ovaries, as cancer was found in her cervix. She is back in the clinic to discuss the pathology results with the physician.

Before this happens she presents with some pain around the incision area:

```
(18)0128
```

```
01
             .hh en you know I have like som::e like (.) pinches er sti:ngs
   PAT:
02
             like really sharp stings. ((PAT points to incision area))
03
   DOC:
             Around the incision?
04
   PAT:
             Yeah sometimes they are short? (.) but- hhhh
             ((DOC begins to examine incision area 0.4)) kay. .hh so this hurts
05
   DOC:
06
             even just touching it.
07
   PAT:
             Mhm, yeah.=
80
             =Okay. (.) it looks perfectly normal.
   DOC:
09
             (0.8)
10
   PAT:
            Mkay,
11
   DOC:
             Oka:y it's not infected, ((continues to examine 2.2)) yeah it looks
12
             (0.6) perfect. (0.2) actually.
((19 lines omitted about details of pain in the area & more examining))
31 DOC: > I don't have a good explanation for why you're having so much
32
            discomfort (.) we can give you some lidocaine jelly and see if that
33
          > helps with it,
```

The patient first establishes in lines 01-02 that she is feeling sharp discomfort around the incision area in her initial presentation of the problem. Next, the physician begins to physically examine her (line 05) and then counters the patients concern by stating that the incision area looks normal (line 08) and that it is not infected (line 11). She re-confirms this by doing more of an exam and then, in more online commentary (Heritage & Stivers, 1999b), states that the incision area looks perfect (line 12), giving the patient a "no problem" response to her initial complaint of pain (Heritage & Stivers, 1999b). This sets the stage for an offer for treatment with a numbing topical cream (lines 32-33): "We can give you some lidocaine jelly and see if that helps with it", which

comes after more discussion of the nature of the patient's pain. Note that the physician has not registered any concern for the issue and is unable to explain why the pain is there (lines 11-12; 31-32). Then the treatment recommendation is built as something that is being constructed *in response* to an issue presented- this time, at the patient's initiative. Thus, in offers, even though the treatment recommendation is verbally launched by the physician, it is constructed as a remedy in service to needs originating from the patient.

Another instance of this is shown in Extract 19, Extract 8 shown earlier. As was already laid out, the patient is an elderly female who has a tumor in her lower abdomen for which she is being treated with chemotherapy. Recall that her primary complaint is of rectal bleeding during bowel movements, which we learn is the tumor pushing on her rectum:

### (19)0104

```
So the bleeding we learned from: your last visit and >from what
01
   DOC:
             we knew before< with- it's the tumor that's pushing on the
02
03
             rectum en some of it has eroded through the rectum. .hh so if
             your stools are very firm they may be harder to get out and
04
05
             cause a bit more bleeding.
06
   PAT:
             [Mhm,
07
   DOC: > [.hhh um we can give you medicines to with the:. s- >you know
          > to< make them SOFTER and see if that helps us.
80
             .pt well yeah, but then wouldn't it be like if I don't make it
09
   PAT:
10
             to the toilet in time I'd make more of a mess?
```

After the physician explains and subsequently normalizes the rectal bleeding (lines 01-05) she begins a treatment recommendation that is framed as helping with this complaint of bleeding (lines 07-08): ".hhh um we can give you medicines to help with the:. s- >you know to < make them SOFTER and see if that helps us." This recommendation, given in the form of "I can give you X to help" is clearly made an offer responsive to the patient's complaint. The key is, however, that the physician does not endorse the solution. Instead, she supports the solution to the problem in response to a complaint made at the patient's initiative. Notably, in the majority of ancillary context cases where the complaint was made at the patient's initiative, the physician recommended the treatment in the form of an offer, or something s/he would be doing *in service to* the patient. Why are

offers relied on so heavily when the patient brings up an ancillary issue at his/her initiative? Most importantly, physicians are not indexing worry or concern for the patient's actual disease in these contexts. Rather, they are attending do something else- the patient's discomfort. The stakes are lower in this environment, because while nausea is a nuisance or incision pain is uncomfortable, it is not typically indicative of a problem with the disease progressing. If it were, physicians monitor patients so closely with constant blood tests to measure tumor markets and scans that look at metastasis that they would nearly always have the support of this information in advance of the encounter. In instances where physicians are the ones to bring up the ancillary concern, occasionally they do index concern for the patient's overall well-being and act in response to those issues, sometimes ordering a test or scan to ensure that the disease has not spread. In general, when patients discuss a complaint ancillary to the primary disease treatment, offers are used likely because they treat the patient's deontic authority as the motivating factor behind the medical issue. More specifically, patient's experiential problems are not necessarily in the domain of the physician's authority. Therefore physicians do not orient to sharing in the decision, rather they orient to their role as gatekeeper to the remedy of the complaint.

# 2.8 Discussion

This chapter sought to examine what treatment decision-making looks like in cancer care visits and contribute to our understanding of the actions physicians interactionally deploy to accomplish treatment decisions in complex clinical care settings. By examining how physicians orient to balancing physician authority and patient agency we see how they walk a tightrope between obligations to policy imperatives to collaborate with patients and commitments to advocating for what they think is best based on their professional knowledge and technical expertise. How do they do this, and what accounts for this? To answer these questions, this chapter explored the ways in which physicians presented treatment recommendations. When multiple options were available

according to the standard of care for a given diagnosis, these were presented to patients via option-listing. When multiple options were not available, single treatment recommendations were used and these actions were coded according to the schema established by Stivers et al. (2017).

When option-listing was done, it was found that physicians overwhelmingly implicitly and explicitly treated one option as more desirable over the others in the context of initial treatment when standard options remained. Of the 8 cases in which option-listing was done, 63% (n=5) of the time orientation to one option as more desirable was present. In the context of the initial treatment no longer working and standard options no longer existing, physicians did not treat one option as more desirable and instead arrayed each option out equally, notably highlighting the negatives of each. These accounted for 37% (n=3) of the option-listing cases. The results from this analysis demonstrate that physicians reveal a preference for one decision in making a recommendation despite arraying multiple options. Only when no standard options remain do physicians rescind their deontic and epistemic authority over the decision and truly provide an equal framing of the remaining options. This could indicate a forecasting strategy by coaxing the patient towards realizing that the remaining treatments offer diminishing returns. We could speculate that an affordance of this is the avoidance of bringing up something more problematic that signals the end of life: palliative care or hospice care.

When single treatment recommendations were made for treatments that most often did not have multiple options (97% of cases), it was found that of the 61 treatment recommendations analyzed, 39% used a pronouncement action, 21% used a proposal action, 30% used an offer action, 7% used a suggestion action, and 3% used an assertion action. In considering other work done on treatment recommendation actions, it appears that the cancer care data in this sample patterns most similarly to the primary care data analyzed by Stivers et al. (2017) where pronouncements were used most often. This is interesting given that cancer care is often considered secondary or chronic care

(Biegel et al., 1991; Fishman et al., 1997; McCorkle et al., 2011) yet the findings here are—on their face—dissimilar to treatment decision secondary care contexts more generally (Thompson & McCabe, 2017; Toerien, 2017)

When an additional layer of analysis was undertaken to consider the context of the decision (e.g., new, mid-course, or ancillary), a salient finding emerged that allows accounts for this difference. When stage in treatment process was considered and the data were divided into three recommendation contexts (new, mid-course, and ancillary treatments), it was clear that oncologists differentiated between recommendation actions depending on the context. In this way, physicians demonstrated different orientations to patient participation and thus patient agency depending on the type of decision. Specifically, physicians considered where patients were in the process of their treatment and what the type of recommendation was (i.e., whether it was related to the cancer itself or the result of a side effect). The results suggest that physicians reflect different norms for patients' rights and responsibilities to be involved in decision-making depending on these variables. In the data, oncologists deployed more agency and were more authoritative in recommendations for changes to treatment and less so when making recommendations for new treatment. Significantly, the deviant case shown, a proposal made mid-course, points to evidence that the relationship between physician and patient and not just the treatment stage— is also at play in analyzing orientations to patient involvement across contexts. This case is evidence for the relationship between physician and patient superseding the context in which the treatment is given.

In looking at the 18 new treatment recommendations, most were made using a suggestion or proposal action. This result indicates that before patients sign on to being treated for a cancer-related issue, physicians orient to patient participation in the decision as necessary in order to move forward with implementing the treatment. They thus frame their decision as contingent on patient

acceptance with the use of suggestion and proposal actions. We can speculate that this need to seek patient buy-in could be due to the onerous nature of the recommended treatments and to combat patient fears of these treatments. The patient does not just have to take an antibiotic with minimal side effects for ten days- as in a typical primary care context- but s/he must undergo months of infusions or radiation and may experience hair loss, extreme nausea, nutrient deficiency, and intense fatigue. Many patients who undergo cancer treatment become work-disabled, most go on some kind of disability, and some even face job loss (Tiedtke et al., 2010). Given this, a physician who were to pronounce the treatment recommendation to the patient may run into trouble because s/he would be presuming that these sacrifices for treatment were unexceptional and thus would be minimizing the patient's difficult journey ahead.

Furthermore, does handing down a treatment recommendation ex-cathedra truly secure patient buy in like a proposal or suggestion would? Proposals and suggestions involve patients explicitly in the final decision, and thus involvement in decision-making is linked to buy-in. If patients explicitly get on board with these oftentimes burdensome treatments, they could be more likely to adhere to the treatment regimen then those who are simply told what is going to be done. While proposals could allow for more resistance to the treatment, as was found in primary care, suggestions do not see similar rates of resistance. Perhaps physicians are willing to open up the possibility for a treatment negotiation if it means ultimately securing buy-in up front.

At the same time, offering a patient chemotherapy, e.g, "If you want I can begin you on chemotherapy" treats patient initiative as the motivation behind the treatment and thus undermines the epistemic commitment and deontic force of the recommendation. This may put too much on the shoulders of patients as the decision to pursue such burdensome treatments is already weighty enough. Offers in this context could communicate the rescission of physician authority at a time when the patient is reliant on- and likely expects- expertise and guidance. The predominant actions

in this context, proposals and suggestions, therefore suggest a necessary duality between physicians mobilizing their authority via explicitly pushing for one type of treatment and an orientation to patient involvement in the decision to secure explicit buy-in before embarking on a likely difficult treatment course.

Upon examination of the 8 mid-course treatment recommendations, the majority of these were made using a pronouncement action. This result shows that once patients get on board with the initial treatment and are in the middle of being treated, physicians do not orient to their participation in the same way as with new treatment recommendations. In this treatment context, physicians assert full authority in the treatment recommendations they provide because these decisions are framed as having already been made with the use of pronouncements. These data suggest that, once the patient signs onto and begins the cancer treatment, his/her agency has been, in effect, transferred to the physician.

Why do physicians rely on pronouncements frequently in this context? One could speculate that here the stakes are higher because the patient is in the middle of treatment and his/her existing treatment has been found to be problematic in some way, either because of its efficacy or its side effects. If physicians were to look for patient buy-in this context, it would make relevant the patient's need to accept (or reject) before moving forward. As Stivers et al. (2017) found, resistance was minimized with the use of pronouncements, so they could be used to that effect in this context. In contrast, the suggestion or proposal action in this higher-stakes context could provide too much of an opportunity for discussion, and in that discussion the treatment runs the risk of getting rejected. Pronouncements are potentially used a resource for minimizing rejection, especially when the patient has already experienced the difficult burden of treatment and may want to back out given that the current treatment has been found to be problematic. Using a suggestion or proposal in this

context may be an indirect way of suggesting that stopping treatment is a possibility. That may be heard by the patient who wants to "fight on" as problematic.

Significantly, the deviant case shown in this context- a proposal made mid-course- points to evidence that the relationship between physician and patient is also at play in analyzing orientations to patient involvement across contexts. This case is evidence for the relationship between physician and patient superseding the context in which the treatment is given.

Finally, the 35 ancillary treatment recommendations in the data were split into two groups: patient-initiated complaints or preemptive, physician-initiated recommendations. Once divided, it was found that all ancillary treatments given preemptively by oncologists were made using a pronouncement action. Yet, when patients initiated the complaint for an ancillary treatment, most of the related treatment recommendations were made with an offer. These results highlight that initiative matters: when patients initiate a complaint not central to the treatment of their cancer, the physician will frame their recommendation as having originated with the patient, in service to the patient's needs, and thus rely on an offer to make the recommendation. Patients orient to their own initiative in offers as well, as is shown by the higher frequency of resistance relative to suggestions and pronouncements (see Stivers et al., 2017). Taking that a step further, pronouncements intrinsically orient to the treatment recommendation as not optional, while offers orient to the treatment as entirely optional. In each instance where pronouncements were used, physicians were heading off risk by lowering the likelihood of resistance to the recommendation (see Stivers et al., 2017). That could take the form of preventing nausea before it started resulting from chemotherapy, or admitting the patient to the hospital before her clinical condition got worse. We might then speculate that giving the patient no option and pronouncing the treatment recommendation is motivated by the avoidance of risk.

In the realm of empirical investigations of physician-patient interaction, this chapter uniquely focuses on physician orientation to patient involvement in decisions about cancer treatment and how this reflects medical norms in the preservation of patient rights in a domain of complex decision-making. This analysis also suggests that treatment context in decision-making is important. More importantly, these data highlight that the consideration of the different types of decisions in the treatment process matters significantly in understanding how decisions are made. At a fundamental level, physicians' behaviors appear to be shaped by their understandings of the physician-patient relationship at different stages of the treatment process. This chapter builds on foundational studies of how treatment recommendations are actually produced across different clinical contexts and implications for facilitating SDM (see Barnes, 2017; Bergen et al., 2017; Stivers et al., 2017; Thompson & McCabe, 2017; Toerien, 2017). This analysis of oncologic decision-making contributes to the next line of future research on the production of treatment recommendations. In analyzing cancer care, we have preliminary grounds for understanding the additional impact of treatment context in how decisions get made between physician and patient.

# References

- Akerkar, S. M., & Bichile, L. (2004). Doctor patient relationship: changing dynamics in the information age. *Journal of Postgraduate Medicine*, 50(2), 120.
- Angell, B., & Bolden, G. B. (2015). Justifying Medication Decisions in Mental Health Care:

  Psychiatrists' Accounts for Treatment Recommendations. *Social Science & Medicine*.
- Anspach, R. R. (2011). Preface. In P. McGann & D. J. Hutson (Eds.), *Sociology of diagnosis* (Vol. 12). Emerald Group Publishing.
- Avis, N. E., Crawford, S., & Manuel, J. (2005). Quality of life among younger women with breast cancer. *Journal of Clinical Oncology*, *23*(15), 3322–3330.
- Barnes, R. (2017). Preliminaries to treatment recommendation sequences in UK primary care: A Vehicle for Shared Decision-Making? *Health Communication*.
- Biegel, D. E., Sales, E., & Schulz, R. (1991). Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness, and stroke. Sage Publications, Inc.
- Boyer, C. A., & Lutfey, K. E. (2010). Examining Critical Health Policy Issues within and beyond the Clinical Encounter Patient–Provider Relationships and Help-seeking Behaviors. *Journal of Health and Social Behavior*, *51*(1 suppl), S80–S93.
- Brown, R., Butow, P., Butt, D., Moore, A., & Tattersall, M. (2004). Developing ethical strategies to assist oncologists in seeking informed consent to cancer clinical trials. *Social Science & Medicine*, *58*(2), 379–390.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social Science & Medicine*, 44(5), 681–692.
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine*, 49(5), 651–661.

- Charles, C., Whelan, T., Gafni, A., Reyno, L., & Redko, C. (1998). Doing Nothing Is No Choice:

  Lay Constructions of Treatment Decision-Making among Women with Early-Stage Breast

  Cancer. Sociology of Health & Illness, 20(1), 71–95.
- Corser, W., Holmes-Rovner, M., Lein, C., & Gossain, V. (2007). A shared decision-making primary care intervention for type 2 diabetes. *The Diabetes Educator*, *33*(4), 700–708.
- Curl, T. S. (2006). Offers of assistance: Constraints on syntactic design. *Journal of Pragmatics*, 38(8), 1257–1280.
- Elit, L., Charles, C., Gold, I., Gafni, A., Farrell, S., Tedford, S., ... Whelan, T. (2003). Women's perceptions about treatment decision making for ovarian cancer. *Gynecologic Oncology*, 88(2), 89–95.
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., ... Rollnick, S. (2012). Shared decision making: a model for clinical practice. *Journal of General Internal Medicine*, 27(10), 1361–1367.
- Fishman, P., Von Korff, M., Lozano, P., & Hecht, J. (1997). Chronic care costs in managed care.

  Health Affairs, 16(3), 239–247.
- Garofalo, J. P., Choppala, S., Hamann, H. A., & Gjerde, J. (2009). Uncertainty during the transition from cancer patient to survivor. *Cancer Nursing*, *32*(4), E8.
- Haakana, M. (2001). Laughter as a patient's resource: Dealing with delicate aspects of medical interaction. *Text–Interdisciplinary Journal for the Study of Discourse*, 21(1–2), 187–219.
- Hamann, J., Langer, B., Winkler, V., Busch, R., Cohen, R., Leucht, S., & Kissling, W. (2006). Shared decision making for in-patients with schizophrenia. *Acta Psychiatrica Scandinavica*, 114(4), 265–273.
- Heritage, J. (1984). A change-of state token and asqects of its sequential piacement. *Structure of Social Action: Studies in Conversation Analysis*, 299–345.

- Heritage, J. (2005). Conversation analysis and institutional talk. *Handbook of Language and Social Interaction*, 103–147.
- Heritage, J. (2010). Questioning in Medicine. In A. F. Freed & S. Ehrlich (Eds.), "Why Do You Ask?": The Function of Questions in Institutional Discourse (pp. 42–68). New York: Oxford University Press.
- Heritage, J. (2012). Epistemics in action: Action formation and territories of knowledge. Research on Language & Social Interaction, 45(1), 1–29.
- Heritage, J., & Sefi, S. (1992). Dilemmas of advice: Aspects of the delivery and reception of advice in interactions between health visitors and first-time mothers. *Talk at Work: Interaction in Institutional Settings*, 359, 417.
- Heritage, J., & Stivers, T. (1999). Online commentary in acute medical visits: A method of shaping patient expectations. *Social Science & Medicine*, 49(11), 1501–1517.
- Hillen, M. A., Onderwater, A. T., van Zwieten, M. C., de Haes, H. C., & Smets, E. (2012).

  Disentangling cancer patients' trust in their oncologist: A qualitative study. *Psycho-Oncology*, 21(4), 392–399.
- Jefferson, G. (1985). An I in the transcription and analysis of laughter. In T. A. Dijk (Ed.), *Handbook of Discourse Analysis* (Vol. 3, pp. 22–34). New York: Academic Press.
- Jones, D. S. (2017). Patients, Consumers, and the Enduring Challenge to Medical Authority. *Reviews* in American History, 45(1), 128–135.
- Koenig, C. J. (2011). Patient resistance as agency in treatment decisions. *Social Science & Medicine*, 72(7), 1105–1114.
- Kushida, S., & Yamakawa, Y. (2015). Fitting proposals to their sequential environment: a comparison of turn designs for proposing treatment in ongoing outpatient psychiatric consultations in Japan. *Sociology of Health & Illness*.

- Landmark, A. M. D., Gulbrandsen, P., & Svennevig, J. (2015). Whose decision? Negotiating epistemic and deontic rights in medical treatment decisions. *Journal of Pragmatics*, 78, 54–69.
- Landro, L. (2017, 28). How to Get Patients to Take More Control of Their Medical Decisions. *The Wall Street Journal*.
- Légaré, F., & Thompson-Leduc, P. (2014). Twelve myths about shared decision making. *Patient Education and Counseling*, 96(3), 281–286.
- Levin, D. N., Cleeland, C. S., & Dar, R. (1985). Public attitudes toward cancer pain. *Cancer*, 56(9), 2337–2339.
- Lindström, A., & Weatherall, A. (2015). Orientations to epistemics and deontics in treatment discussions. *Journal of Pragmatics*, 78, 39–53.
- Local, J., & Walker, G. (2004). Abrupt-joins as a resource for the production of multi-unit, multi-action turns. *Journal of Pragmatics*, *36*(8), 1375–1403.
- Maynard, D. W. (1996). On" realization" in everyday life: The forecasting of bad news as a social relation. *American Sociological Review*, 109–131.
- McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L. S., Lorig, K., & Wagner, E. H. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians*, *61*(1), 50–62.
- Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: The Journal of Nursing Scholarship*, 22(4), 256–262.
- Molassiotis, A., Lee, P. H., Burke, T. A., Dicato, M., Gascon, P., Roila, F., & Aapro, M. (2016).

  Anticipatory Nausea, Risk Factors, and Its Impact on Chemotherapy-Induced Nausea and Vomiting: Results From the Pan European Emesis Registry Study. *Journal of Pain and Symptom Management*, 51(6), 987–993.
- Oshima Lee, E., & Emanuel, E. J. (2013). Shared decision making to improve care and reduce costs.

- New England Journal of Medicine, 368(1), 6–8.
- Passik, S. D., Kirsh, K. L., Rosenfeld, B., McDonald, M. V., & Theobald, D. E. (2001). The changeable nature of patients' fears regarding chemotherapy: implications for palliative care. *Journal of Pain and Symptom Management*, 21(2), 113–120.
- Quirk, A., Chaplin, R., Lelliott, P., & Seale, C. (2012). How pressure is applied in shared decisions about antipsychotic medication: a conversation analytic study of psychiatric outpatient consultations. *Sociology of Health & Illness*, *34*(1), 95–113.
- Reuber, M., Toerien, M., Shaw, R., & Duncan, R. (2015). Delivering patient choice in clinical practice: a conversation analytic study of communication practices used in neurology clinics to involve patients in decision-making. *Health Services and Delivery Research*, 37.
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, *55*(1), 68.
- Schegloff, E. A. (1996). Turn organization: One intersection of grammar and interaction. *Studies in Interactional Sociolinguistics*, 13, 52–133.
- Schegloff, E. A. (1997). Practices and actions: Boundary cases of other-initiated repair. *Discourse Processes*, 23(3), 499–545.
- Schegloff, E. A. (2007). Sequence organization in interaction: Volume 1: A primer in conversation analysis (Vol. 1). Cambridge University Press.
- Schegloff, E. A., & Sacks, H. (1973). Opening up closings. Semiotica, 8(4), 289–327.
- Starr, P. (1982). The social transformation of American medicine: The rise of a sovereign profession and the making of a vast industry. New York: Basic books.
- Stevanovic, M., & Peräkylä, A. (2012). Deontic authority in interaction: The right to announce, propose, and decide. Research on Language & Social Interaction, 45(3), 297–321.
- Stivers, T. (2002). Participating in decisions about treatment: overt parent pressure for antibiotic

- medication in pediatric encounters. *Social Science & Medicine*, 54(7), 1111–1130.
- Stivers, T. (2005). Parent resistance to physicians' treatment recommendations: one resource for initiating a negotiation of the treatment decision. *Health Communication*, 18(1), 41–74.
- Stivers, T. (2007). Prescribing under pressure: Parent-physician conversations and antibiotics. New York:

  Oxford University Press.
- Stivers, T., Heritage, J., Barnes, R. K., McCabe, R., Thompson, L., & Toerien, M. (2017). Treatment recommendations as actions. *Health Communication*, 1–10.
- Terasaki, A. (2004). Pre-announcement sequences in conversation (pp. 171–223). Amsterdam: John Benjamins.
- Thompson, L., & McCabe, R. (2017). How psychiatrists recommend treatment and its relationship with patient uptake. *Health Communication*, 1–10.
- Tiedtke, C., de Rijk, A., Dierckx de Casterlé, B., Christiaens, M.-R., & Donceel, P. (2010).

  Experiences and concerns about'returning to work'for women breast cancer survivors: a literature review. *Psycho-Oncology*, 19(7), 677.
- Timmermans, S., & Oh, H. (2010). The continued social transformation of the medical profession. *Journal of Health and Social Behavior*, *51*(1 suppl), S94–S106.
- Toerien, M. (2017). Deferring the decision point: Treatment assertions in neurology outpatient consultations. *Health Communication*, 1–11.
- Toerien, M., Shaw, R., Duncan, R., & Reuber, M. (2011). Offering patients choices: A pilot study of interactions in the seizure clinic. *Epilepsy & Behavior*, 20(2), 312–320.
- Toerien, M., Shaw, R., & Reuber, M. (2013). Initiating decision-making in neurology consultations: "recommending" versus "option-listing" and the implications for medical authority. *Sociology of Health & Illness*, 35(6), 873–890.
- Towle, A., & Godolphin, W. (1999). Framework for teaching and learning informed shared decision

- making. BMJ: British Medical Journal, 319(7212), 766.
- Wald, H. S., Dube, C. E., & Anthony, D. C. (2007). Untangling the Web—the impact of Internet use on health care and the physician–patient relationship. *Patient Education and Counseling*, 68(3), 218–224.
- Wilson, S. R., Strub, P., Buist, A. S., Knowles, S. B., Lavori, P. W., Lapidus, J., & Vollmer, W. M. (2010). Shared treatment decision making improves adherence and outcomes in poorly controlled asthma. *American Journal of Respiratory and Critical Care Medicine*, 181(6), 566–577.

# Chapter 3: Foregrounding Medical Certainty in Response to Patient Resistance 3.1 Background

Parsons (1951) was one of the first to introduce the concept of medical uncertainty into the sociological domain. He established that uncertainty was inherent to medicine, and "loom[ed] so large in medical practice." Out of this he noted the "limits of control" which physicians regularly confronted (428-70). Parsons also argued that the advent of modern medicine brought higher stakes: physicians had the added task of providing a complete diagnosis and effective treatment plan. As such, responses to treating illness included "medically ritualized optimism" and "bias in favor of active intervention" (427-70). Yet, Parsons also noted an important consequence of this scientific progress: a heightened awareness of what is still not known by healthcare practitioners. He argued that this fundamental medical ignorance, coupled with the new burdens of diagnosis and treatment, put strain on the physician-patient relationship.

This fundamental uncertainty is still a driving force behind many different parts of medicine today including medical research, empirically-based decision-making, and patient involvement. For instance, the lack of medical knowledge about illness can actually promote medical research and innovation. This, at times, leads to a better grasp of illness, and at others, produces still more questions about illness by opening a so-called medical Pandora's box (Fox, 2000). The medical community's quest to assuage uncertainty when diagnosing and treating illness has led to the paradigm of evidence-based medicine (EBM) (Rosenberg & Donald, 1995; Timmermans & Berg, 2010) in which clinical questions are answered by external knowledge and best evidence (Sackett, 1997) rather than institutional commonsense or physicians' medical hunches. Patients diagnosed with medical issues also seek certainty in understanding their condition. After being diagnosed with a chronic or acute condition, it has been argued that patients routinely seek out information in order

to manage uncertainty about their health to better grasp the diagnosis, get prognostic information, and make informed decisions about treatment (Brashers, Goldsmith, & Hsieh, 2002).

Uncertainty, defined as awareness of one's own ignorance (Han, Klein, & Arora, 2011), is a particular source of unease for patients and can carry serious psychological and social consequences. Individuals confronted with uncertainty in illness experience anxiety that can affect social relationships, physical health, and mental health (Mishel & Braden, 1988). Prognostic unpredictability can impact a patient's own awareness of the terminality of their illness. Glaser and Strauss' seminal work on the stages of awareness in patients with terminal illness (1965) found that clinicians' prognostic uncertainty left patients uninformed about the terminality of their illness. More recent studies on patients with terminal illness continue to support the idea that prognostic uncertainty maintains patients' unawareness about their own death (see Christakis & Iwashyna, 1998; see also Timmermans, 1994).

In particular, patients with an ambiguous diagnosis face a difficult kind of uncertainty. The diagnosis of a medical problem, an interactional event (Peräkylä, 1998), allows both physician and patient to jointly enter into a project that makes relevant a solution to the problem (see Robinson, 2003). Thus, the inability to make a proper diagnosis violates the normative expectation that a diagnosis will be delivered in a given clinical encounter and a plan of action determined (Charmaz, 1991; Timmermans & Buchbinder, 2010). This diagnostic ambiguity can be distressing for patients and difficult for healthcare practitioners to manage (Feder, 2009). Diagnostic uncertainty can also create social isolation in patients (Barker, 2009; Mishel, 1984), whether the diagnosis is contingent on pending test results (Liao, Chen, Chen, & Chen, 2008) or a medically contested diagnosis altogether (Barker, 2008; Zavestoski et al., 2004)

How is this problem of medical uncertainty mitigated? Based on ethnographic observations, Fox (1957) established that uncertainty could result from a limited understanding of available

medical knowledge, a limit to what is known in the medical field, or a combination of both. During the process of professional socialization, Light —in reviewing Fox's analysis—put forth "medical students discover that medicine is not a 'science' but a series of observed relationships and probabilities with a few laws". Fox concluded that physicians attempted to remedy these knowledge shortcomings in the processes of socialization into the medical profession. Light (1979) theorized that this information control was grounded in the understanding that, as members of a profession, physicians had an expertise that outsiders did not. Therefore, physicians needed to maintain this control because they were regarded by the public as masters of their field; their help was sought precisely because they knew and practiced medicine to solve problems that *others* have (Light 1979).

Because the culture of medicine has been found to have an inherent preference for certainty (Atkinson, 1984) studies have concluded that medical professionals work to resolve uncertainty in their everyday professional practice. In a recent investigation of pediatric genetics, Stivers and Timmermans (2016) concluded that diagnostic uncertainty could be re-formulated in interaction into a more certain, and thus productive, concept in order to mitigate parents' feelings of anxiety and helplessness. They found that physicians deployed this interactional practice despite the persistent reality of diagnostic uncertainty in pediatric genetics testing.

Yet, the attempt to resolve uncertainty with medical information can also create more uncertainty as medical professionals continue to seek out greater medical knowledge. For instance, Timmermans and Buchbinder (2010) investigated the social effects of new infant screening for the genetic abnormality phenylketonuria (PKU), a poorly understood genetic test. After observing and interviewing families whose newborns had already been screened and received a suspicious—but inconclusive—test result, the authors concluded that further testing of patients with a suspicion of PKU counterintuitively kept families in a persistent state of illness ambiguity rather than providing them with the information they desired from the tests. As a result, parents would straddle a

diagnostic tightrope: while on the one hand their child was not conclusively ill, their child was not conclusively well, either.

Physicians can also, motivated by their professional obligations, invoke certainty for particular end goals. Davis (1960), in studying clinicians of polio patients, contended that physicians became deliberately more certain over time with the use of what he termed "functional certainty". This certainty could be real or fabricated and was deployed in instances where physicians needed to advocate for treatment or manage illness in patients.

Other studies have similarly found that medical certainty can be deployed for particular interactional functions, for instance, to manage the delivery of bad prognostic news. In an ethnographic study of how patients die in the hospital, Sudnow (1967) found that physicians kept patients and families in a state of uncertainty about the terminality of illness. Bad news delivery, he observed, was avoided and/or approached with hesitancy to control information about patients' prognoses. More recently, Sarangi and Clarke (2002) observed that genetics counselors also interactionally deployed uncertainty in delivering bad diagnostic news. The counselors, they noted, drew on both their limited expertise in adjacent medical areas and particular linguistic tools (e.g., hedging and contrast) to the effect of deflecting expertise onto other medical specialists, maintaining neutrality, and avoiding an advisory role when patients searched for further facts about their diagnosis. While Sarangi and Clarke studied genetic counselors adjacent to other medical specialties, Pilnick and Zayts (2014) studied experts in their own specialty: obstetricians who provided antenatal screening for genetic abnormalities. Because these were experts who could not deflect diagnostic uncertainty onto anyone else in the decision-making process, the authors concluded that the uncertainty prevalent in the world of antenatal screening had to be actively addressed. Yet, when patients were deciding whether to terminate a pregnancy with positive results for genetic abnormalities, the analysis concluded that actively addressing uncertainty in this context resulted in

obstetricians underscoring the fundamental limits of knowledge inherent to the field of obstetrics.

The authors suggested that this behavior in effect transferred the locus of decision-making responsibility onto patients.

#### 3.1.1 Uncertainty in Cancer & Contemporary Medical Paradigms

According to two key paradigms guiding decision-making, SDM and EBM, mobilizing information and citing scientific facts are integral to medical practice. The practice of EBM calls for the use of "current best evidence" in making decisions about patient care evidence which is typically based on statistical data, randomized clinical trials, and uniform outcomes reporting (Timmermans & Berg, 2010). In the realm of SDM, effective implementation calls for an increase in patient awareness and an increase in physicians' certainty (Han et al., 2011). Indeed, a publication from the National Cancer Institute targets uncertainty management as a facilitator of SDM (Epstein & Street, 2007). However, there is an inherent tension between the underlying logic of these paradigms, which emphasize being informed and using knowledge to make decisions, and the uncertainty that underlies the foundation of medical knowledge and practice.

Cancer in particular is a disease that is rife with uncertainty. Physicians can be mostly certain that the cancer exists through pathological and surgical findings, yet central to the uncertainty of cancer is that it is difficult for physicians to provide a patient's true prognosis (Smith et al., 2013; Yourman et al., 2012). A cancer diagnosis not only carries uncertainty for healthcare practitioners but also for patients. Once patients have been diagnosed with cancer, they commonly experience feelings of uncertainty (Karlsson, Friberg, Wallengren, & Öhlén, 2014; Mishel, 1984; Penrod, 2002). Particularly, patients face the realities of uncertain outcomes that pervade both how to treat the disease and the chances of treatment success (Shaha, Cox, Talman, & Kelly, 2008). Uncertainty notably prevails in the prediction of long-term outcomes of the disease, of central concern to cancer patients (Mishel et al., 2002). These experiences of uncertainty can lead to a lower quality of life

(Parker et al., 2016) through feelings of distress, fear, and social isolation (Husson et al., 2011; Zebrack & Isaacson, 2012). This is also true for patients who are in remission but have a fear of recurrence (Koch et al., 2014). As such, information-seeking is a primary way that patients cope with their cancer diagnosis (Valero-Aguilera et al., 2014). It has been reported that patients try to remedy uncertainty themselves by seeking out information on the Internet, where they frequently find gaps in consensus amongst medical professionals. This is argued to potentially undermine their confidence in, and relationship with, their physician(s) (Shaha et al., 2008).

The context of cancer care possesses a significant amount of uncertainty which is upsetting for patients who already have many consequential choices to make, like whether to undergo major surgery to remove reproductive organs, proceed with toxic treatments that can impact healthy organs, risk burning skin with radiation, or reduce hormone levels so dramatically it mimics those of a small child. Significantly, how this uncertainty gets realized and managed through interaction in cancer care has yet to be explored. This chapter explores how medical certainty in this particularly *uncertain* medical domain is addressed and how talk of different degrees of certainty gets put to work in interaction.

As we have seen, prior research underscores that uncertainty is fundamental to nearly every aspect of medicine and that physicians' social behavior reflects a preference for mobilizing certainty in their practice of medicine. Importantly, the literature conceptualizes medical certainty as a matter of degree but also one that is static and suggests that physicians generally favor increasing their degree of medial certainty which is upheld for the sake of bolstering medical authority and credibility. And yet, as discussed, it is also clear that *un*certainty sits at the core of scientific knowledge.

What the literature has yet to examine interactionally is the difference between the knowledge physicians have access to given available information and the knowledge physicians *claim* 

to know during medical encounters with patients. The primary concern of this analysis is just this, that medical knowledge given available evidence can be separated from the *presentation* of that medical knowledge in the clinical encounter. I will examine how different degrees of medical knowledge get foregrounded over the course of the visit as cancer treatment is discussed with patients. Subsequently, I will explore how physicians' claims to medical knowledge presented as certain at the outset of the treatment discussion can actually change to *uncertain* later on in the discussion, or vice versa. This flexibility of medical certainty leads me to next ask: what is its interactional function? What are physicians doing when they present themselves as more certain one moment, and less certain the next? I argue that one way physicians use talk of certainty is to the effect of advocating for treatment in the face of patient resistance. I also show that, as patients continue to resist treatment, physicians manipulate their presentations of certainty to lobby for treatment acceptance rather than acquiescing to patients' treatment resistant positions.

## 3.2 Operationalizing Certainty in Cancer Care

#### 3.2.1 The Presentation of Knowledge

In cancer care, some topics are more certain than others. For instance, pathology findings that diagnose whether cells are cancerous are—on the certainty continuum—relatively more certain medical knowledge. Tissue slides can be viewed under a microscope, and using established medical parameters for what cancerous cells look like, a cancer diagnosis can be made or ruled out fairly definitively. The type of cancer cells on a tissue slide can also be confirmed with relative certainty (Connolly, Schnitt, Wang, Dvorak, & Dvorak, 2000; National Cancer Institute, 2010). Similarly, staging cancer (i.e., whether or not it has spread and how far) is also done with relative certainty. Overall, diagnosing whether an individual has cancer falls in the domain of relative certain knowledge.

Yet, there are things that oncologists are less certain about. Even though we are beginning to understand factors which put patients at risk for cancer, like diet, weight, smoking, lack of exercise, and genetic and environmental factors, it is still unclear what leads to its cause or how to definitively prevent it (Danaei et al., 2005). Along these lines, a cure for cancer continues to elude researchers. In addition, although there are percentages to support prognostic information and survival rates based on population data, the certainty of prognostic information is relatively low. This is in part because it is impossible to tell whether an individual patient will respond to a given treatment (Mullins, Montgomery, & Tunis, 2010). While the medical community can know how likely particular treatments are likely to work for different cancer types at the population level, they have relatively less certainty about how any individual patient will respond to treatment. Further complicating this issue, specific cancer types can have more individual level variation leading to unpredictable responses to treatment; moreover, some individuals have risk factors that further complicate a treatment's efficacy (e.g., obesity, diabetes, autoimmune disorders, genetics). Similarly, how a patient's individual immune system (along with medical treatment) will fight or facilitate further growth of existing cancer cells is not well known (Mukherjee, 2017).

Table I: Certainty in Oncologic Medical Knowledge

Level of certainty	Types of medical knowledge			
More certain	Existence of visible cancer cells	Grade of cancer	Location of visible cancer cells	Degree of spread/stage
Less certain	Cause of cancer/prevention of cancer/curing cancer	Prognostic information	Body's response	Treatment efficacy

Despite the continuum of knowledge that is more certain or less certain, there remains a separate issue of how the certainty level of this knowledge is presented to patients in the clinical encounter. Consider Extract 1 in which a morbidly obese woman with diabetes and heart disease is undergoing treatment for metastatic uterine cancer. In discussing her new diet with the physician, which helps minimize nausea from chemotherapy, the physician uses the opportunity to bring up the importance of her eating habits:

```
(1)0208
```

```
01
   DOC:
             .hh uhm I n- >yiknow< eating is really the: the na- the thing
02
             you should worry about [I know the nausea impacts you, .hh
03 PAT:
                                     [Okay,
             yiknow weight loss is gonna be important for you? .h
04
   DOC:
05
   PAT:
                                        [Yes:
06
   DOC:
             [En so we- I do want ya to[:. at least when this is all said and
07
             done w- focus on that to.=because we know with your heart issues
             .hh an:d um: your overall health tha- that's probly: .hh to be
80
09
             perfectly frank the more likely thing you'll die from.
10
   PAT:
             [Okay,
11
   DOC:
             [.hh en so I think it's important that we focus on that too?
12
             .hh bu:t I think- en that's why I'm: I'm really encouraged by
13
             the fact that I heard you say that you're gonna k-find healthy
14
             things to eat [and juices en- en that's really good.
15
   PAT:
                           [Yes:.
```

The physician starts off by explaining to the patient that she should "really" worry about her eating and weight loss (lines 01-02, 04). After acknowledging that the nausea is impacting her at the present moment, the physician goes on to explain that the patient should make weight loss her primary focus when her treatment is "all said and done" (line 06-07). He accounts for this recommendation by invoking her future health outlook (lines 07-09): "at least when this is all said and done q- focus on that too.=because we know with your heart issues .hh an:d um: your overall health tha- that's probly: .hh to be perfectly frank **the more likely thing you'll** die from." By stating that the patient is "more likely" to die from her heart issues and "overall health" problems, the physician presents his knowledge as more certain than not that her death will be caused by these medical conditions rather than her cancer (or something else entirely). Yet, the physician does not

actually have access to knowledge about how *this patient* will die. Already, she is dealing with metastatic uterine cancer and undergoing chemotherapy and radiation therapy to treat it. However, the physician *claims* to have reasonable certainty (presented as likelihood) that her future death will instead result from her heart and overall health issues rather than her cancer. Thus, this case illustrates that an inherently uncertain event (cause of death) can be separated from the presentation of certainty about the event. In this case certainty is presented at a higher level than the knowledge would seem to warrant.

While Extract 1 is an instance of a physician treating an inherently uncertain outcome as more certain, Extract 2 illustrates the reverse. In this case, something that is inherently fairly certain is presented as uncertain. In this encounter, the patient has been diagnosed with a rare, metastatic clear cell cervical cancer after having surgery to remove her cervix, uterus, fallopian tubes and ovaries. After the patient shows preliminary resistance to the oncologist's recommendation to pursue chemotherapy and radiation followed with still more chemotherapy, the physician re-does her recommendation (line 01):

```
(2)0128
             .pt so our best goal? is [to get rid of it now.
01
    DOC:
02
                                       [.hh so right now right? now I: um:.
    PAT:
03
             (0.2) I don't have cancer or I do have cancer.
04
   DOC:
             We don't know if there's anything left so I took out everything
05
             that could be taken out? but [i-
06
   PAT:
                                           [>yeah< but you see me inside and
07
             [everything was,
             [ Teah but I can't see everything right I'm not a microscope
80
   DOC:
             there m:ight be microscopic even the lymph node I tooked out
09
10
             looked normal to me .hh but it wasn't it was full of cancer on
11
             the inside.
12
    PAT:
             Mm::.
13
    DOC:
             So- I can't kno- and your CT scan was normal (0.6) but clearly
             there's something there (.) so- I can't know for certain:? that
14
15
             we got it all even though: the margins were negative and the we
16
             took the lymph node.
```

After the physician explains to the patient that the best path forward is to treat the cancer now (line 01) the patient reveals the grounds of her resistance to be rooted in a lack of

understanding about whether or not she has cancer left in her body (lines 02-03). The physician responds that she does not know if there is any cancer remaining despite removing "everything that could be taken out?" (lines 04-05). The patient counters in overlap by pointing out that the physician saw her "inside", in effect questioning the grounds for the physician's lack of knowledge *after* a surgery where she was able to see the patient in more detail surgically. The physician pushes back on the presupposition that "seeing" is knowing, emphasizing the limits of the naked eye, that she cannot see "everything", is "not a microscope" (line 08), and that the cancer had spread to a normal-appearing lymph node, which she removed (line 09-11). Yet she also offers evidence for the cancer's removal during surgery. She puts forth that the patients scans were normal (line 13), the margins were negative (line 15), and the cancerous lymph node was removed (lines 15-16). Despite evidence that suggests a fairly solid degree of certainty that the cancer has been removed, the physician foregrounds that she "can't know for certain:? that we got it all" (lines 13-14). In this case, again we see that the degree of knowledge a physician has can be separated from the certainty with which a physician presents that knowledge.

## 3.2.2 Presenting Certainty Through Talk

Given the separation that is possible between the degree of certainty a physician has and the level of certainty a physician presents, the next question is how do physicians present knowledge certainty?

In the examples above, "the more likely thing you'll die from" or "We can't know for certain" are statements that specifically foreground knowledge certainty though they do it in different ways. In (1), the physician presents what I term "aggregate certainty": likelihood, risk, guarantee, ratios, and probabilities that apply to the patient (see Table II). In these cases, the application to the patient may be relatively direct (as in Extract 1) or may involve a "stepwise

process of inference" to apply an aggregate statement about likelihood or probability to the patient (Stivers et al., 2017, p. 8) (see Extract 6 below).

In contrast, in (2) the physician presents what I term "targeted certainty" in which the verb, modal, or modifier marks the certainty as focal and foregrounds the certainty (or uncertainty). Either certainty or uncertainty can be foregrounded in these ways (see Table II). Thus, in (1) certainty is accentuated whereas in (2) uncertainty is accentuated.

I now demonstrate how physicians foreground their knowledge in their lexical choices through targeted certainty. Targeted certainty occurred far more frequently than aggregate certainty in these data, 85% of the time (n= 28) across 33 cases. In Extract 3, the physician is

Table II: Targeted and Aggregate Certainty

Targeted certainty			Aggregate certainty	
Verb choice	Modals	Modifiers	Aggregate	
<ul> <li>Know/don't know</li> <li>Think/don't think</li> </ul>	<ul><li>Might/might not</li><li>May/may not</li><li>Will/will not</li></ul>	<ul> <li>Sure/unsure</li> <li>Possible/not possible</li> <li>Chance</li> <li>Probability</li> <li>Likelihood</li> </ul>	<ul> <li>Risk</li> <li>Ratio</li> <li>Percentage</li> <li>Guarantee</li> <li>Probability</li> <li>Likelihood</li> </ul>	

responding to a question from the patient about whether cancerous cells remain after surgery. She puts forth that she is unable to "know for certain" whether the surgical team was able to get all of the cancer during the procedure (lines 02-03):

(3)0128

<sup>01</sup> DOC: So- I can't kno- and your CT scan was <u>normal</u> (0.6) but clearly there's something there (.) So- I can't <u>know</u> for certain:? that we got it all even though: the margins were negative and the we

## 04 took the lymph node,

In this case, the physician presents herself as less certain through verb choice, "can't know", and targets this uncertainty as relevant for this individual patient through recalling the details of the patient's surgery. As part of the same visit, Extract 4 shows the physician presenting a definitively certain stance that the patient's cancer will return and be deadly:

(4)0128

(5)0505

```
01 DOC: .hhh (0.2) If we don't do it (.) we:: it will come back
02 (.)
03 And if it comes back it will be deadly.
```

By mobilizing the modal "will" in both line 01 and line 03, the physician is presenting her knowledge about the cancer's recurrence as certain and as immediately relevant to this patient through targeting her certainty at this patient's cancer recurrence specifically (rather than broadening her certainty to include patients *like* this one). A less certain, but still targeted, presentation of certainty is shown in Extract 5 through the use of lexical choice "not sure" (line 01):

```
01 DOC: Right. (.) isn't working now. .h en I'm- I'm not sure that there
02 is an oral pill that's gonna work you may need intravenous
03 antibiotics to help (0.6) beat the bug.
```

Once the physician establishes that the patient's current antibiotic is not working to fight the bladder infection (in this case presenting his medical knowledge as certain), in the next TCU he chooses the modifier "not sure" to present his medical knowledge about the efficacy of oral pills as less certain. By explaining to the patient that he may need intravenous antibiotics to help "beat the bug" (lines 02-03), the physician's uncertain knowledge presentation is targeted to this patient's experience in the here-and-now.

Now I turn to how physicians present medical certainty through the use of "aggregates". I define aggregate certainty as more abstract ways to present degrees of certainty through the use of data about a broad group of patients demonstrated through percentages, ratios, discussion of

guarantee, likelihoods, or discussion of risk. As I mentioned earlier, these can be relatively direct or can involve a stepwise process of inference. Of 33 instances of certainty talk, talk of aggregate certainty occurred just 15% of the time (n=5). Extract 6 offers an instance of presenting certainty through use of aggregates of risk. In this case, we meet this patient after having been diagnosed with a BRCA2 mutation, increasing her risk of breast and gynecologic cancers. After the patient asks about going back on a low-dose birth control pill or if she should "just let it be" (line 04), the physician provides a recommendation for birth control pills and accounts for this as prophylaxis against her increased risk for ovarian cancer (lines 02-03):

#### (6)0207

```
I'm kinda wondering if I should like (0.4) try: I- like
01
   PAT:
02
             just try a pill like try something [that's like pretty low dose?
03
                                                 [Yeah.
             [.hhh or just let it be? >I don't know.
04
05
   DOC:
             [.hhh-
   DOC:
             Yeah I think it's up to you guys.>Uh what I would recommend (.)
06
07
             and again this is my bias but we know that birth control pills
80
             are associated with reducing the risk of ovarian cancer?
```

In this case, the physician is presenting himself as more certain about the efficacy of the recommendation and does so by providing an aggregate about the patient's ability to reduce her risk of ovarian cancer should she take birth control pills. His recommendation for her is founded on information about patients like her for which this information about risk reduction is applicable, rather than directly relevant to her experience as a BRCA2 carrier.

While Extract 6 presents an aggregate of risk inside a recommendation for birth control pills, Extract 7 illustrates a presentation of aggregate uncertainty regarding the ability to guarantee. We meet this patient during a visit where she and her physician are making a decision about how to treat her metastatic uterine cancer which has spread to her lung (categorized as Stage IV cancer). After recommending surgery to address the spread of cancer, the patient provides challenges to the cancer's potential spread using the imaging results, which did not show metastasis (line 01): (7)0301c

```
01
   PAT:
             Why- doesn't it show .hh on the: nuclear pet scan.
02
   DOC:
             Cause scans are not a hundred percent- (0.2) accurate. (.) It's-
03
             it's probably accurate but no guarantee. (.) So while we're
04
             there why not take a few samples. .hh [and make sh-
05
                                                    [Of what.
   PAT:
06
   DOC:
             Of tissue.
```

In response to the patient's question (line 01) the physician provides a type-conforming response that presents uncertainty about the imaging results, "Cause scans are **not a hundred percent-** (0.2) accurate. It's- it's **probably** accurate but **no guarantee**." (lines 02-03). Here the physician presents himself as mostly uncertain by accentuating the small chance that scans *generally* are inaccurate, aggregating uncertainty through percentages and lack of guarantee.

As I previously noted, presenting knowledge in the aggregate occurs less frequently than does presenting knowledge as targeted to the patient's direct experience. What could account for physicians' infrequent use of aggregate certainty? Looking more closely at the infrequency of aggregate certainty, I observed that presentations of aggregate certainty were only produced in second position, in response to a patient question. This result suggests that physicians are less inclined to mobilize these broader, more general facts involving risk, percentages, etc. that only indirectly apply to the patient unless they are prompted to do so. In Extract 8 (shown earlier as Extracts 3 & 4), the patient has delayed acceptance of a recommendation for chemotherapy and radiation to treat her cervical cancer. In the following excerpt, the patients asks whether it is normal for there to be lymph node involvement given her diagnosis (lines 01-02):

## (8)0128

```
Mkay .hh u:m and it's normal from: (.) yiknow the stage that I
01
   PAT:
02
             was that now it's in the lymph node? is that no[rmal?
03
   DOC:
                                                              [So it's uh- (.)
04
             it's about fifty percent. (0.2) of people at the stage that you
05
             were. will have lymph node involvement with thi- with the clear
             cell cancer.
06
07
             (.)
80
   PAT:
             Mm::[:.
09
   DOC:
                 [With classic cervix cancer it's probably only about ten
10
             percent. .hh but with this kinda cancer it's about fifty
11
             percent.
```

12 PAT: Mm:.. >so like< this is more aggressive?
13 DOC: Very.

In response, the physician presents herself as more certain about the aggressive nature of this clear cell cancer by mobilizing percentages. In this case, the physician underscores that about half of those with this cancer have lymph node involvement (lines 03-06). She further situates the severity of this cancer by going on to note that "classic" cervix cancer has about a ten percent likelihood of involvement (lines 09-11). After the patient does a stepwise shift towards awareness that this cancer is more aggressive *in her situation* (line 12), the physician confirms this position (line 13).

Examples 6 and 7 likewise included presentations of varying degrees of aggregate certainty in response to a patient question. In the former, recall that the patient asked about whether she should go back on birth control. In response, the physician talked more generally about the association of birth control and risk reduction, hearable itself as a recommendation. In the latter, after the recommendation was produced and the patient pushed back with a question about why the cancer's spread did not appear on the scan, in response the physician offered an account which included general uncertainty about the accuracy of scans. Notably, this practice is not unique to one clinician; three of five clinicians mobilized aggregate certainty in these data. This practice also does not appear to mobilize response more or less relative to presentations of targeted certainty. What is evident is its lack of use in first position and its sole use in second position, as responsive to a patient query. This offers suggestive evidence that physicians in these data more readily present themselves as certain or uncertain in a targeted way that is specific to the individual patient in their unique therapeutic situation. However, while targeted certainty is more common, both modes of foregrounding certainty are used in similar ways. In the next section, we turn to the function of this foregrounding.

#### 3.2.3 Medical Certainty in the Background, Medical Certainty in the Foreground

At this moment it is important to address whether an endorsement of treatment can be considered a presentation of certainty since the physician is *implying* a degree of certainty about the recommendation being a solution to the patient's problem. As was analyzed in Chapter 2, these data contain five different kinds of treatment recommendations which communicate varying degrees of physician endorsement. Recall that pronouncements include a greater degree of endorsement through handing down the recommendation "ex cathedra" (Stivers et al., 2017). In contrast, suggestions and proposals offer variable levels of endorsement. While proposals communicate the physician's preference and request buy-in from the patients, suggestions mobilize the physician's preference while leaving it up for the patient to ultimately decide. On the other hand, offers provide little endorsement because the physician is acting in service to a patient need, and assertions simply imply a recommendation by making a general statement about a treatment's benefit (see Table III).

Table III: Treatment Recommendations and Degree of Endorsement

TR action	TR action example	Degree of endorsement
Pronouncement	"You'll get both infusions today"	High endorsement through directing the patient
Proposal	"I still think we need to do chemotherapy"	Varying levels of endorsement: seeks buy-in from patient
Suggestion	"We strongly recommend you consider using the birth control pill for prevention"	Varying levels of endorsement: up to patient to ultimately decide
Offer	"We can give you some lidocaine jelly and see if that helps"	Low endorsement: in service to a patient-originated complaint
Assertion	"There's still utility in taking the ovaries out of people with BRCA2"	Low endorsement: implies a recommendation

The examples in the rightmost column of Table III show high, variable, and low levels of endorsement depending on the recommendation action used. Yet, it is critical to note the knowledge the physician is drawing on to make these recommendations is not marked as more or less certain. In these cases, the physician's certainty is implied and left in the *background*. If the physician proposes a treatment (e.g., "I think it's best that we do X"), or pronounces a treatment (e.g. "We are going to switch you to X") the patient is given no access to the knowledge driving this recommendation. Accordingly, stand-alone treatment recommendations with only endorsement were not coded for certainty because medical certainty was similarly not foregrounded in these cases.

However, treatment recommendations like those in Table III, preceded or followed by a TCU involving a presentation of certainty, were included in the analysis. In these cases, certainty was foregrounded while recommending treatment. The patient was given some access to the physician's medical knowledge in accounting for the recommendation. For instance, "I think it's best that we do X because it is likely to work" endorses and provides the patient with access to the physician's knowledge through an account, here foregrounding the physician's certainty about the treatment's efficacy. Certainty could also be foregrounded in stand-alone statements produced while recommending treatment that presented the physician as more or less certain. These were similarly included in the analysis. Also included were statements in which certainty was foregrounded and were themselves hearable as treatment recommendations. Examples of these three types of statements coded in the analysis, along with excluded single treatment recommendations for contrast, are shown in Table IV.

Extract 9 offers an instance of a treatment recommendation followed by a presentation of certainty in the next TCU. In this encounter, the physician proposes a treatment of chemotherapy (line 01):

(9)0209

01 DOC:	I still think we do need to:::.h do: chemotherapy.=and the
02	reason I say that is th- i- a fallopian tube cancer there is a
03	much higher risk of this: .hhh potentially coming back compared
04	to a <u>uter</u> ine cancer.

After the proposal for chemotherapy, the physician moves to account for his recommendation by providing information about this cancer's higher risk of recurrence relative to a uterine cancer. The provision of "high risk" in discussing the probability of recurrence for

Table IV: Foregrounding Certainty/Uncertainty in Treatment Recommendations

TR with certainty before or after	Stand-alone certainty	Both recommending and certainty	TR with no foregrounding of certainty
• I recommend chemotherapy because it has a good chance of preventing a recurrence	Chemotherapy is likely to work	Weight loss is going to be important for you	I recommend we start you on chemotherapy
I still think we should do chemotherapy because I don't know if there's any cancer left	Scans are not one hundred percent accurate	You may need intravenous antibiotics to help beat the bug	This time we're going to try a new chemotherapy
• I don't know why the antibiotic is not responding which is why we should treat you	It's not a guarantee but it works pretty well		• If you want you can see if a stool softener will help.

this cancer foregrounds the physician's knowledge just after an endorsement for treating it with chemotherapy. In Extract 10, we see an inverse structure. Before the recommendation is produced, the physician responds to a question from the patient about why her CT scan did not show the definitive degree of her cancer's spread.

#### (10)0301c

01	DOC:	Cause scans are not a hundred percent- (0.2) accurate. (.) It's-
02		it's probably accurate but no guarantee. (.) So while we're
03		there why not take a few samples.

In his response, the physician initially presents what *appears* to be a greater degree of certainty through his use of lexical items "not a hundred percent" (line 01) and "probably" (line 02) in discussing the accuracy of her scans. Yet, what he actually foregrounds is the *lack* of certainty associated with the patient's scans. This lack of certainty is presented at the end of the TCU in line 02 where the physician puts forth that there is "no guarantee" of the accuracy of the scans. In the next TCU, the physician proposes that "a few samples" (line 03) be taken during the procedure in addition to the standard surgery. The sequential placement of the treatment recommendation just after the physician accentuates his presentation of uncertainty works to offer a solution to the lack of knowledge he has about the severity of the cancer's spread.

Extract 11 (shown earlier as Extract 1) offers a TCU that presents certainty and is also hearable as a treatment recommendation. Because no other treatment recommendations exist in the encounter, what appears to be a statement of fact is hearable as a treatment recommendation. This is also evident in what sequentially follows the recommendation. In this case, a morbidly obese patient is told to lose weight by her physician:

## (11)0208

```
01 DOC: Yiknow weight loss <u>is</u> gonna be important for you? .h
02 PAT: [Mhm, [Yes:
03 DOC: [En so we- I do want ya to[:. at least when this is all said and
04 done w- focus on that to.=because we know with your heart issues
05 .hh an:d um: your overall health tha- that's probly: .hh to be
06 perfectly frank the more likely thing you'll die from.
```

His presentation of certainty in line 01 is both a statement of certainty insofar as the physician is presenting his knowledge as unequivocally certain that weight loss will be important to the patient, and hearable as a treatment recommendation because what sequentially follows is the patient being told to focus on her weight loss after her current treatment is over (lines 03-04) due to her heart and overall health issues (lines 04-06).

Presentations of certainty can also appear as a TCU sequentially apart from the treatment recommendation proper but still during a treatment discussion. Extract 12 shows just this. After recommending chemotherapy and radiation to this cervical cancer patient, the physician works to manage the patient's resistance. Much of this resistance is in the form of questions about the severity of the cancer itself because the patient is unconvinced that there could be microscopic and aggressive cancer left after the surgery she just had to remove the cancer. In the following excerpt, the physician foregrounds aggregate certainty in discussing percentages with the patient:

(12)0128

```
O1 DOC: So it's uh- (.) it's about fifty percent. (0.2) of people at the stage that you were. Will have lymph node involvement with <a href="thi-">thi-</a> with the clear cell cancer.
```

In explaining to the patient that "about fifty percent" of patients at her stage will have cancer that also spread to the lymph node (a problematic course for the disease) the physician is presenting herself as more certain that this cancer has the potential to spread to areas beyond the cervix than if she did not have lymph node involvement.

To summarize, the structure of certainty talk within the treatment recommendation can include a TCU that indexes varying degrees of certainty immediately preceding or proceeding the recommendation, a statement of varying degrees of certainty that is also hearable as a treatment recommendation, or a stand-alone statement that indexes more or less certainty occurring during the treatment discussion.

Figure I provides a schema of how these four types observed in the data are structured.

Figure I: Structure of certainty talk in the treatment recommendation

- 1: [Treatment recommendation] + [TCU ↑↓certainty]
- 2: [TCU ↑↓certainty] + [Treatment recommendation]
- **3:** [Treatment recommendation + ↑↓certainty]

In thinking about these types, we might wonder which occurred most frequently in the data. When frequencies were calculated for these four structures (Table V), stand-alone statements of certainty dominated the data, occurring 67% of the time. TCUs indexing more or less certainty just before or just after a recommendation occurred 15% and 9% of the time, respectively. Statements of certainty hearable treatment recommendation also occurred 9% of the time.<sup>3</sup>

This result demonstrates that physicians most often do not preface, complete, or include certainty inside their recommendation for treatment. Rather, statements of certainty are produced on their own, somewhat distant from the recommendation itself. This shows infrequent prefacing of the recommendation with a presentation of certainty, infrequent expansion of the recommendation to include statements of certainty, and infrequent statements of certainty in the same TCU as the recommendation itself. This result provides evidence that recommendations in these data more often include only endorsement of treatment and that statements of certainty about treatment are made apart from the recommendation itself but during the treatment discussion. This points to a more frequent foregrounding of certainty during the treatment *negotiation* rather than proximate to the recommendation.

Table V: Frequency of Certainty Talk in Treatment Recommendations

	TR + certainty	Certainty TCU + TR	TR & Certainty	Stand-alone
	TCU			certainty
Frequency	15% (5)	9% (3)	9% (3)	67% (22)
			Total cas	es: 33

150

<sup>&</sup>lt;sup>3</sup> A TCU during the treatment recommendation indexing certainty was coded once, and certainty indexed twice in one TCU was also counted as a single instance of indexing certainty. Yet, two TCUs indexing certainty in the locations specified in Figure I were counted twice.

## 3.3 The Function of Physicians' Presentations of Medical Certainty

## 3.3.1 Foregrounding Medical Certainty in Cancer Treatment

Foregrounding certainty is most common in the context of patient resistance, suggesting that it is a resource that physicians use to combat resistance. This, in turn, suggests that foregrounding certainty is an interactional resource for persuading patients to accept treatment. One way that physicians foreground certainty is in advocating for treatment by indexing the treatment recommendation's likelihood to work. An instance of this is offered in Extract 13. We meet this patient just after being diagnosed with Stage 2a fallopian tube cancer. After handing her the results from her post-surgical pathology report, the physician recommends that the patient pursue chemotherapy (lines 02-03):

#### (13a)0209

```
01
   DOC:
             So that's for you guys. .hhh now moving forward? I still think
02
             we do need to:::.h do: chemotherapy.=and the reason I say that
03
             is th- i- a fallopian tube cancer there is a much higher risk of
04
             this: .hhh potentially coming back compared to a uterine cancer.
05
             (.) now the fact that it's an early fallopian tube cancer is
06
             \underline{e}xcellent and that's really really \underline{go}od news .hh and I think if
07
             we do the chemotherapy? (.) .hh u:m I think you're gonna have a
80
             good chance of this staying away for a long long time en
09
             hopefully if not forever. (0.2) okay,=
10
   PAT:
             =.pthhh well- okay so I had a couple of- (0.6) question[s er,
11
   DOC:
                                                                        [Mhm,
12
   PAT:
             (0.4) Thoughts.
```

After the recommendation, the physician presents himself as more certain in several ways. For instance, his account for the treatment is that that this cancer, relative to a uterine cancer, has a high likelihood of recurrence (lines 02-04). Next, he tells the patient that the early stage of this cancer is "really really good news" (line 06) and connects this with the pursuit of chemotherapy as likely successful: ".hh u:m I think you're gonna have a good chance of this staying away for a long long time en hopefully if not forever." (lines 06-09). This offers the patient even further certain knowledge that the treatment is likely to be effective and has the effect of advocating for treatment. Up until now, the patient has only demonstrated passive resistance by withholding acceptance or

acknowledgement. The patient establishes an actively resistant stance just after the physician puts forth a response-mobilizing "okay," in line 09 by putting forth in a well-prefaced turn (see Heritage, 2015) that she has "a couple of- (0.6) questions er, (0.4) Thoughts." In the context of a treatment recommendation, this suggests resistance because she has failed to accept the recommendation (Stivers, 2005b) which is discussed further in Chapters 1 and 4.

After asking about getting her thyroid nodules checked before making a decision, and accounting for this by citing a friend who had cancer that was treated but it just came back in another place, the patient becomes more concrete in her stance against treatment:

#### (13b)0209

```
01
            Yiknow I'm not completely opposed to doing the- (.) the: um:.
   PAT:
02
             (0.2)
02
   SIS:
            Ch[emotherapy,
04
   PAT:
              [.h chemotherapy?
05
   DOC:
            Mhm,
   PAT: > I'm tending toward not doing it.
06
07
   DOC:
            Mm:. (.) .tchhh eh=
80
   PAT: > =Because, (0.6) well (.) I- I guess m- I'm tending toward because
         > like (.) yiknow I'm looking at this lady and she (.) had cancer:
09
10
         > and she had chemo: and then she had cancer again, (.) yiknow (.)
11
            different place.
```

In line 01, the patient expands her resistance, first rephrasing from a negative position, "not completely opposed" to chemotherapy (line 01) to "tending toward not doing it" (line 06).

Following the physician's minimal response and attempt to launch his turn (line 07), the patient accounts for this is in lines 08-11, referencing her friend who had a recurrence in another place despite initial chemotherapy treatment. Following further discussion about the friend's experience with chemotherapy and how the genetic testing results might inform the patient's decision, the physician offers further account for his recommendation which addresses the patient's resistance:

(13c) 0209

```
01 DOC: Um the reason is that this cancer .hh without chemotherapy:

> there's likely microscopic cells the naked eye cannot see, .hh

and there's a chance those microscopic cells will become active

at some point, (.) en: grow an- and recur.=

05 COM: =a[nd we don't want that.
```

06 PAT: [Even though you took it- you don't think it was: like [u:m:. 07 DOC: 80 don't think it had spread but but hh we always assume there's microscopic cells there.=we have to assume. (.) u:m so: that's 09 the much safer side of valor? .hh u:m if it were me I would do 10 11 the- I would without a doubt in my mind do the chemotherapy? 12 .hh I'm gonna play devil's advocate here and say eighteen weeks 13 of your lif:e (.) one day a week i:s much less than:. dying from 14 a recurrence in >three or four< years.

As the patient reveals more resistance in line 01, the physician pushes back with a statement that foregrounds his certainty about the disease threat and treatment outcomes: "without chemotherapy, there's likely microscopic cells the naked eye cannot see, .hh and there's a chance those microscopic cells will become active at some point, (.) en: grow an- and recur." (lines 01-04). Certainty is presented in this turn, where the physician first establishes that it is "likely" that microscopic cancer cells still exist in her body and then backs off on this certainty slightly by putting forth that "there's a chance" that these microscopic cells will come back without chemotherapy. After the patient launches a question that addresses the existence of these cells in spite of the removal of the cancer (line 06) in overlap, the physician counters this concern.

After re-launching the treatment recommendation in lines 10-11, which is "without a doubt" in his mind treatment the physician would pursue personally, he provides further certainty in the form of a trade-off: "I'm gonna play devil's advocate here and say eighteen weeks of your life (.) one day a week i:s much less than:. dying from a recurrence in >three or four < years." Certainty is presented in this scenario by specifically revealing the outcomes in an either/or framework: either the patient pursues the treatment or does not pursue the treatment and die from a recurrence in three to four years.

Similarly, Extract 14 illustrates a physician not simply presenting a high degree of certainty as responsive to resistance, but also foregrounding his degree of certainty as the patient continues to hold a line of treatment resistance. While the previous case demonstrated certainty about a treatment's likelihood to work, this case demonstrates certainty about a current treatment's

inefficacy and advocacy for changing to a different treatment. This elderly male patient has prostate cancer that has spread to his bones. A few days earlier, he visited the hospital's emergency room because he had a high fever. Before the ER visit, he was put on an antibiotic (Bactrim) to treat an earlier diagnosed UTI. He is visiting his oncologist to follow up on that ER visit. Just prior to this excerpt, the patient put forth that he feels worse again. Suspecting that the UTI is still not being treated, the physician suggests that the patient has the option to be admitted to the hospital so that he can quickly see an infectious disease specialist. The physician first accounts for this by telling the patient that his worsening symptoms could be because the infection is not being treated with the Bactrim he is on:

#### (14)0505

```
DOC:
            The ur- I think you might have an infection that we're not
01
02
          > treating en that might be why your m- you're feeling worse.
             Yeah but why would I- (.) they checked it over the weekend why
03 PAT:
04
             would I need to go in the hospital,
05 DOC:
             .hhhh[h- ((Doc nods))
06
   PAT:
                  [.h when they- when I was [just in the emergency with
07
             Doctor O'Shea?
80
   DOC:
             Yeah so wh[en they
                       [They- they went through all that en he took- he took
09
   PAT:
10
             the: um .pt (0.2) culture?
11
             (.)
12
             Right [the problem is- (1.0)] it's back en en en the [anti-
   DOC:
13
    PAT:
                   [En he's running it now]
                                                                    [Well that
14
             was jus- that was jus Sunday.
15
   DOC:
             Yeah. (.) I see it. .hh en the problem is that the antibiotic
16
             you're o:n isn't treating (.) wh[at's-
17
    PAT:
                                             [So the Bactrim.
            Right. (.) isn't working now. .h en I'm- I'm not sure that there
18
   DOC: >
19
          > is an oral pill that's gonna work you may need intravenous
20
             antibiotics to help (0.6) beat the bug.
21
             (0.8)
             E:n if we were to admit you we could have infectious disease
22
   DOC:
23
             doctors see you while you're in the hospital? en we could get
             you on the right antibiotic.
24
```

In accounting for his concern about the poorly treated infection, the physician presents uncertainty about whether patient's worsening symptoms can be explained by the existence of a still-untreated UTI despite the current medication he is on: "I think you might have an infection that we're not treating en that might be why you're m- you're feeling worse." This turn functions as the

beginning of a recommendation because the physician shows that he is taking a position on the current treatment's inefficacy and establishes the potential to treat it in the hospital. The existence of an untreated UTI as the cause of these symptoms is presented as an inference by the physician and demonstrates uncertainty.

Once the physician's position on pursuing a different treatment by a hospital admission to address the patient's symptoms is made clear, the patient demonstrates up front resistance. He does this by providing more evidence that the ER physicians already did all of the necessary tests. After this resistance, which lasts several turns, the physician reveals to the patient that the tests are back from the ER. He mobilizes these data to foreground his certainty about the ineffective treatment through an account for why the patient should be treated: ".hh en the problem is that the antibiotic you're o:n isn't treating (.) whats-" (lines 15-16).

When the patient seeks further clarification in overlap with this turn in line 17 about whether the Bactrim is indeed not working, the physician further foregrounds his certainty about the problem with a yes-response: "Right. (.) isn't working now" (line 18). Recall that the physician's earlier position, in lines 01-02, presented uncertainty about this situation, that the patient "might have an infection that we're not treating" and framed this as a proposal to treat it more effectively through a hospital admission. But in light of the patient's resistant behavior, the physician's position changes: he foregrounds that he is, in fact, *certain* that the patient has an untreated infection to account for his earlier proposal. Certainty is further foregrounded in the discussion of admitting the patient to the hospital in lines 22-24: "E:n if we were to admit you we could have infectious disease doctors see you while you're in the hospital? en we could get you on the right antibiotic." By using a conditional, the physician foregrounds certainty in outcomes: that if the patient agreed to be admitted he could be properly treated with "the right antibiotic." Here, the physician revisits the

initial source of resistance from the patient–that he does not want to be admitted to the hospital–by countering that hospital admission will ensure correct treatment to cure his worsening symptoms.

In this encounter, it is notable that after the patient resists being admitted to the hospital for care, the physician pivots from an uncertain position towards treatment to a certain one. He moves from presenting the patient's worsening symptoms as *potentially* due to an untreated infection to *certainly* providing test results that show an untreated infection and *certainly* blaming the antibiotic for the worsening symptoms of that infection. Like Extract 13, patient resistance occasions the sequential foregrounding of physician certainty as acceptance continues to be withheld. Thus, there is suggestive evidence that leveraging certainty is motivated by getting resistant patients to comply with treatment.

While the first two extracts in this section demonstrated foregrounding certainty occasioned by overt patient resistance, like leaning towards refusal or questioning the warrant for the recommendation, this next case (Extract 15, shown earlier as Extract 2) shows the physician foregrounding her certainty even in the context of seemingly innocuous resistant behavior. Similar to Extract 13, certainty is first presented in terms of the likelihood of treatment efficacy should the patient accept the medical advice. As was discussed earlier, this patient has already had surgery to remove her uterus, fallopian tubes, ovaries and cervix and a post-surgical pathology report confirms the existence of malignant cells not just on her cervix but also on a nearby lymph node. In turn, the physician explains her team's consensus on the recommendation for chemotherapy and radiation combined followed by more chemotherapy (lines 06-07 & 09):

#### (15a)0128

01	DOC:	.hh <u>ye</u> sterday we had our big conference? member I said I was
02		gonna present your case at the big conference and I did? .hh and
03		I'm glad you:re >sort of< here so we can talk about it very
04		fresh .hhhh (.) we talked about (.) your s::. your type of
05		cancer:? (.) what the:. best treatment should be: and the: team
06		agreed that the best treatment would be a combination of
07		chemotherapy and radiation at the same time an[d then followed

```
80
   PAT:
                                                            [really?
09
   DOC:
             with chemotherapy. .pthhhh because the: overall:.m (.) this is
10
   DOC:
            very rare (.) this clear cell: cancer of the cervix is a very
             rare kind..hhh your clear cell cancer >member I said< oh
11
12
             it's not related to HPV? (0.6) .pt your clear cell cancer
13
             unlike most of these? actually: .hh when we st- did some
14
             special: stains on it? (.) actually looks like it is result from
15
             HPV. .hhh and it is caused by HPV:- but most of them are no:t
16
             (0.8) Why yours is special and different I: cant- I don't know:
             but we did a bunch of other testi:ng some DNA testi:ng and some
17
18
   PAT:
                                                                  [°Mhm,°
             protein testing and found that out. (0.5) so that gives us an
19
20
             idea that when: we treat it .hh it should respo:nd hopefully:
            the same way HPV related cancers would respond.
21
```

After the physician provides the recommendation, the patient registers surprise in overlap following the recommendation for chemotherapy and radiation first (line 08), initial resistance. Yet, this type of resistance is relatively mild; the patient is not revealing an explicit position against the recommendation nor is she pushing back on the recommendation with challenge questions. But, when we look at the physician's subsequent response once she completes the recommendation, she offers a justification for the treatment (line 09) which indicates that she is treating the patient as indeed resistant (see Stivers 2007). In this justification, the physician presents her certainty as even stronger by mobilizing scientific evidence to foreground the "very rare" type of cancer this patient has: ".pt your clear cell cancer unlike most of these? actually: .hh when we st- did some special: stains on it? (.) actually looks like it is result from HPV. .hhh and it is caused by HPV:- but most of them are no:t" (lines 12-15). The emphasis on the rarity of this type of cancer has the effect of foregrounding its severity and instantiates a need to treat.

The patient provides minimal acknowledgement by nodding and a small acknowledgement token (line 18) but nothing more. Evidence that this is heard as continued passive resistance is shown in the physician's circling back to the original recommendation by providing further evidence for its efficacy: "so that gives us an idea that when: we treat it .hh it should respond hopefully: the same way HPV related cancers would respond." Here, the physician foregrounds certainty through mobilizing her experience in the form of a generalization: the proposed treatment will probably

work, emphasizing the normative "should" in speaking to the outcome of treatment: "it should respo:nd" hopefully:" (line 20). Despite the effect of "hopefully" which simultaneously pulls back on the physician's certainty and introduces a more personal emotional element to the recommendation, the certainty of treatment efficacy is still presented as likely. Notably, the end of this TCU provides an opportunity for the patient to accept the recommendation, which she continues to withhold despite the physician putting forth the likely certainty of the treatment's efficacy. In light of this, the physician further foregrounds her certainty in Extract 15b:

#### (15b)0128

```
Which means that radiation and chemotherapy is likely to \textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textstyre{\textsty}
01
                  DOC: >
02
03
                                                             Which is ↑good
                  DOC:
04
                                                               (0.4)
                                                             Um (.) if we don't do: the radiation and chemotherapy:
05
                  DOC:
06
                                                               (0.8) it's (0.4) °w-° (0.4) we may end up with e- a lot of
                                                > problems:. Okay, it's a very serious diagnosis to have anyway?
07
80
                                                             and because there was some cancer already in the lymph node?
09
                                                           .hhh (0.2) if we don't do it (.) we:: it will come back
10
                                                               (.)
                                                            And if it comes back it will be deadly.
11
12
                  ???:
                                                               [.pt so our best goal? is [to get rid of it now.
13
                  DOC:
```

The physician continues to foreground her certainty, as the patient continues to withhold acceptance, in justifying the treatment: "Which means that radiation and chemotherapy is likely to \tau\work" (line 01). After a micropause (line 02) where the patient still does not come in to acknowledge or accept the recommendation despite the continued evidence for treatment success, the physician further advocates for the treatment: "Which is \tag{2}good" (line 03). After still no uptake and a longer period of silence (line 04), the physician treats the patient as passively resisting by continuing to advocate for treatment. Here she provides an alternate reality should the patient not accept the treatment: "Um (.) if we don't do: the radiation and chemotherapy: (0.8) it's (0.4) "w-" (0.4) we may end up with e- a lot of problems:. Okay, it's a very serious diagnosis to have anyway? and because there was some cancer already in the lymph node?" Despite beginning this response to

resistance with some uncertainty "We **may** end up with e- a lot of problems:.", the physician strengthens her certainty when she tells the patient that she *does* have a serious diagnosis and that here *was* cancer already in her lymph node (evidence of spread).

Finally, the physician makes an extremely strong statement that presents an unequivocal certain stance towards what will happen should the patient not pursue treatment: .hhh (0.2) if we don't do it (.) we:: it will come back (.) And if it comes back it will be deadly." (lines 09-11). Not only does the physician go to an extreme reality, that the cancer will kill the patient if it comes back, but she foregrounds certainty about this potential reality. Next, she circles back once again to the treatment recommendation: ".pt so our best goal? is to get rid of it now." (line 13). After this, the patient ends up revealing the grounds for her resistance, that she is not sure whether she has cancer or not, orienting to the surgery as curative rather than one step in broader treatment for her cancer.

## 3.3.2 Foregrounding Certainty Outside of Cancer Treatment

These three extracts demonstrate varying degrees of patient resistance to treatment, all of which are responded to with physicians foregrounding their certainty as patients continue to resist treatment. This provides evidence that physicians present themselves as more certain in persuasive environments and leverage certainty for treatment acceptance. Further evidence that presentations of certainty function as persuasive is found in examining this next case, Extract 16 (shown earlier as Extract 1), in which certainty is mobilized even in medical treatment environment outside of the patient's cancer treatment. Earlier we met this patient in the middle of treatment for uterine cancer, for which she is receiving chemotherapy and radiation. She is also morbidly obese and is suffering from heart disease. We could make the argument that her visible morbid obesity, which has been the source of a multitude of health issues including heart disease, instantiates resistant behavior to medically preferable healthier habits. After the patient emphasizes to the physician that because of

her nausea she has made healthier eating choices like vegetable shakes, the physician responds by emphasizing that "eating is really the: the na- the thing you should worry about" (line 01):

```
(16)0208
   DOC:
             .hh uhm I n- >yiknow< eating is really the: the na- the thing
01
02
             you should worry about [I know the nausea impacts you, .hh
03
   PAT:
                                     [Okay,
04
   DOC:
             yiknow weight loss is gonna be important for you? .h
05
   PAT:
             [Mhm,
                                        [Yes:
06
   DOC:
             [En so we- I do want ya to[:. at least when this is all said and
             done w- focus on that to.=because we know with your heart issues
07
08
             .hh an:d um: your overall health tha- that's probly: .hh to be
09
             perfectly frank the more likely thing you'll die from.
10
   PAT:
             [Okay,
             [.hh en so I think it's important that we focus on that too?
11
   DOC:
             .hh bu:t I think- en that's why I'm: I'm really encouraged by
12
             the fact that I heard you say that you're gonna k-find healthy
13
14
             things to eat [and juices en- en that's really good.
15
   PAT:
                           [Yes:.
```

In line 01-02, the physician responds the patient's complaint of nausea and her eating adjustments by making her eating also a central health concern in the context of her cancer treatment and orients to this as normative: "eating is really the: the na- the thing you should worry about" (line 01). In overlap, the patient does align with this position in line 03. The physician continues to push this point, that "weight loss is gonna be important for you?" (line 04). The emphasis on the word "is" in this turn contrasts with a tacit position that weight loss has not been a concern for the patient before this. Notably, the physician foregrounds certainty in this turn by affirming the importance of weight loss for this patient.

The physician becomes more concrete in lines 07-09, where he speaks to when the patient should worry about her weight loss and why: "at least when this is all said and done q- focus on that to.=because we know with your heart issues .hh an:d um: your overall health tha- that's probly: .hh to be perfectly frank the more likely thing you'll die from." While the physician grants the patient some time to focus on her cancer treatment before worrying about weight loss, he becomes extreme in his presentation of certainty. Should she not follow medical advice and make changes to her diet,

she will likely die. In claiming that the patient is "more likely" to die from her heart issues and "overall health" problems, the physician is orienting to the patient's current resistance as more certainly linked to her potential death. Foregrounding certainty about an extreme outcome of the patient's future health should she not follow medical advice has the effect of instilling urgency in the patient.

Further, foregrounding certainty in this case is responsive to the patient's embodied resistance as it effectively takes a strong position in favor of pursuing a different—healthier—lifestyle in light of some evidence that the patient is pursuing that now because of nausea. Like the other cases analyzed, the physician is presenting his knowledge as mostly certain and foregrounds this to combat treatment resistance. Yet here, the resistance is embodied rather than active through the patient's visible obesity. Furthermore, the treatment recommendation in this case is unrelated to the patient's current treatment for cancer. This case, an instance of recommended treatment unrelated to the patient's cancer, provides further suggestive evidence that certainty is foregrounded to counter treatment resistance.

#### 3.3.3 Foregrounding Uncertainty (and Certainty) for the Same Ends

However, physicians demonstrate both certainty and uncertainty to combat patient resistance. While in the previous section we saw physicians presenting certainty in response to patient resistance for treatment advocacy, these data also show that physicians present *uncertainty*—in a similarly persuasive practice. Notably, presenting both medical certainty and uncertainty can be done in the same visit. An instance of this, Extract 17, is analyzed first. This patient has been diagnosed with Stage IV uterine cancer which has spread to her lung. The physician first provides a recommendation for surgery to remove her reproductive organs:

(17)0301c

01 DOC: We should take out the uterus and the cervix? .hh the tubes and the ovaries? .hhh through an incision that'll come down like

```
03
             this ((points downward from belly button))(.) Fix your hernia at
04
             the same time, (0.2) Why not. (.) Fix it at the same time.=.hh
05
             and then look around everywhere else and do biopsies, .hh and see
06
             if it's anywhere else. (.) At the same time.
             .pthh where else for example.
07
   PAT: >
80
   DOC:
             In the belly.
             ((Cocks head and raises eyebrows)) (0.4)
09
   PAT: >
10
   DOC:
             Anywhere in the belly.
11
             (0.2)
   DOC:
             Possible.
12
13
   PAT:
             Why- doesn't it show .hh on the: nuclear pet scan.
14
   DOC:
             Cause scans are not a hundred percent- (0.2) accurate. (.) It's-
15
             it's probably accurate but no quarantee. (.) So while we're
16
             there why not take a few samples. .hh [and make sh-
17
   PAT:
                                                    [Of what.
18
   DOC:
             Of tissue.
```

After the physician recommends surgery as the first step to treat this cancer (lines 01-06), the patient initiates treatment resistance by taking issue with the suggestion of the cancer's spread through recommending biopsies of surrounding areas and mobilizes a challenge question: ".pthh where else for example." (line 07). In doubting the spread of the cancer, this question has the effect of questioning the severity of the cancer itself and challenging the underlying logic of part of the proposed treatment for biopsies. In response, the physician pushes back on this challenge by foregrounding medical certainty. He puts forth—unequivocally—a place where the cancer could have spread: "In the belly. (0.4) Anywhere in the belly" (lines 08-10).

The patient continues to resist by embodying surprise in raising her eyebrows and cocking her head. Next, the physician slightly pulls back on his certainty by alluding instead to the cancer's *possible* spread to her belly (line 13). The patient maintains an actively resistant line to treatment by asking another question, this time challenging more concrete evidence for the cancer's spread: "Why-doesn't it show .hh on the: nuclear pet scan." (line 13).

In response to an accumulation of resistance, here in a series of questions challenging the cancer's severity, the physician pushes back by changing tack and foregrounding uncertainty: "Cause scans are not a hundred percent- (0.2) accurate." (line 14). Notably, he backs off this uncertain position by next foregrounding certainty: "It's- it's probably accurate" only to foreground

uncertainty again: "but no guarantee." (lines 15-16). After putting forth medical uncertainty in whether or not there is a spread of cancer in her abdomen, the physician circles back to the part of the treatment recommendation that was challenged: "So while we're there why not take a few samples." This second recommendation is produced after the physician presents medical uncertainty about the degree of the cancer's spread. This provides further support for the physician's orientation to the patient's behavior as resistant and that his foregrounding uncertainty functions as persuasive towards treatment.

Similarly, Extract 18 (shown earlier in this section as Extract 13) offers an instance of foregrounding uncertainty, this time about the cancer's spread, functioning as a warrant for pursuing further treatment. In this encounter, as was noted in the prior section, the patient is confronting a decision about pursuing post-surgical treatment for her stage 2a fallopian tube cancer, which the physician recommends. Subsequently, she resists the recommendation which the physician initially pushes back on by foregrounding certainty. First, the physician recommends chemotherapy as treatment:

#### (18a)0209

```
DOC: >
             So that's for you guys. .hhh now moving forward? I still think
02
             we do need to:::.h do: chemotherapy.=and the reason I say that
             is th- i- a fallopian tube cancer there is a much higher risk of
03
04
             this: .hhh potentially coming back compared to a uterine cancer.
             (.) now the fact that it's an \underline{e}arly fallopian tube cancer is
05
06
             excellent and that's really really good news .hh and I think if
07
             we do the chemotherapy? (.) .hh u:m I think you're gonna have a
80
             good chance of this staying away for a long long time en
09
             hopefully if not forever. (0.2) okay,=
10 PAT:
             =.pthhh well- okay so I had a couple of- (0.6) question[s er,
11
   DOC:
                                                                       [Mhm,
             (0.4) thoughts. .hh um:. (0.8) Number one is I'd like to see
12
   PAT:
13
             what the genetic testing comes back,
```

After the physician puts forth that chemotherapy following surgery is "still" what he recommends, which he endorses with certainty, the patient begins to push back on this recommendation by asking

for genetic test results first (lines 12-13). She continues to root her resistance in the desire to get more information from other medical tests before making a decision:

#### (18b)0209

```
PAT: > (0.4) thoughts. .hh um: (0.8) Number one is I'd like to see what
01
02
          > the genetic testing comes back,
03
             (.)
04 DOC:
             .pt[hhh- ((Nods head))
05
   PAT:
                [What- what kind of um:. (0.8) wonderful genes I have there.
06
   DOC:
   PAT:
07
             [.hh and then I'd also- um: u- they: were saying that I had lymph
80
             node, (0.8) 1- uh- no um: .tchh thyroid. (.) no- nodules.
09
   DOC:
10
   PAT:
             .hh so I'd like to get those checked.
```

The patient puts forth that she "Number one" wants to get information from her genetic test (lines 01-02, 05) "and then" get existing nodules on her thyroid checked (lines 08, 10). She reveals this as information she requires before making a decision about the treatment, delaying treatment acceptance. She becomes more overt in her resistance after some discussion about a friend who had cancer:

## (18c)0209

```
01
   PAT:
             Yiknow I'm not completely opposed to doing the- (.) the: um:.
02
             (0.2)
02
   SIS:
             Ch [emotherapy,
04
   PAT:
               [.h chemotherapy?
05
   DOC:
             Mhm,
06
   PAT: >
             I'm tending toward not doing it.
07
   DOC:
             Mm:. (.) .tchhh eh=
80
   PAT:
             =Because, (0.6) well (.) I- I guess m- I'm tending toward because
09
             like (.) yiknow I'm looking at this lady and she (.) had cancer:
10
             and she had chemo: and then she had cancer again, (.) yiknow (.)
11
             different place.
```

The patient specifies that her position on the recommendation for chemotherapy is that she is "tending toward not doing it." (line 06), and accounts for this in explaining a friend's experience with chemotherapy that was ineffective because it came back elsewhere (lines 08-11). The physician counters this resistance by providing more concrete reasoning behind his recommendation for chemotherapy:

#### (18d)0209

```
01
   DOC:
             Um the reason is that this cancer .hh without chemotherapy:
02
            there's likely microscopic cells the naked eye cannot see, .hh
03
             and there's a chance those microscopic cells will become active
04
          > at some point, (.) en: grow an- and recur.=
05
   SIS:
             =a[nd we don't want that.
               [Even though you took it- you don't think it was: like [u:m:.
06
   PAT:
07
   DOC:
08
            don't think it had spread but- but .hh we always assume there's
            microscopic cells there.=we have to assume.
09
```

The physician first accounts for his recommendation by addressing the patient's potential source of resistance grounded in the assumption that all the cancer was removed during surgery: "Um the reason is that this cancer .hh without chemotherapy: there's likely microscopic cells the naked eye cannot see, .hh and there's a chance those microscopic cells will become active at some point, (.) en: grow an- and recur." (lines 01-04). The physician first foregrounds certainty in establishing the likelihood that there are microscopic cancer cells left in her body after surgery and then backs off that certainty slightly by putting forth that there is "a chance" that those cells could come back and grow.

The patient, in overlap with her sister, reveals one source her resistance to be about the existence of these cells "Even though you took it- you don't think it was: like u:m:." (line 06). She does not finish her turn when the physician comes in in overlap, but we can assume she is pursuing additional questioning about the remnants of the microscopic cells in her body relative to the surgery she just had. The physician treats the patient as challenging the idea of chemotherapy and addresses this by foregrounding uncertainty. While he does not "think" the cancer had spread, he has to "assume" that microscopic cells exist because it is the more cautious route (lines 07-09). This is in contrast to his earlier position that there were "likely" microscopic cells remaining. The physician next re-does the recommendation, and in the face of continued resistance, accommodates one aspect of the patient's resistance by setting her up for thyroid testing. After the physician re-does the recommendation yet again, the patient responds by accounting for her resistance regarding the existence of microscopic cells in her body:

```
(18e)0209
01
    PAT:
             .pt well I was just- I mean I was [like questionin:q (.) if
02
    DOC:
                                                 [Yeah.
03
   PAT:
             everything's gone=
04
   DOC:
05
             =I know- [.hh >well< w- °r:.°
   DOC:
06
   PAT:
                      [If you took everything out it's like what's gonna get
07
             canc[er in that point. (0.2) In that case.
08
   DOC:
                 [.hh wer-
09
    DOC:
             There are these microscopic cells that may or may not always be
10
             there. (.) [No matter what.
          >
                         [But (0.4) what would it attack?
11
    PAT:
12
    DOC:
             Your pelvis it'd be: there'd be cells sittin there somewhere in
13
             your pelvis en probably something w- ^And sometimes it spreads
14
             elsewhere we don't know (.) we- we don't have- .hh I wish we had
15
             better ways of managing this but we don't.
```

In lines 06-07, the patient concretely accounts for her continued resistance, "If you took everything out it's like what's gonna get cancer in that point. (0.2) In that case." In response, the physician foregrounds uncertainty, that "There are microscopic cells that may or may not always be there." (lines 09-10). He next presents certainty by adding on in an increment (Walker, 2004) "No matter what." (line 10). After the patient asks what those cells would attack (line 11), the physician goes back to foregrounding uncertainty, "It'd be: there'd be cells sittin there somewhere in your pelvis en probably something w- 'And sometimes it spreads elsewhere we don't know (.) we- we don't have- .hh I wish we had better ways of managing this but we don't" (lines 12-15). Here, the physician postulates that the cells would attack her pelvis, but presents himself as uncertain about the behavior of these cells. In the next TCU, he more concretely admits that there are limits to medical knowledge that prevent him from knowing more. Foregrounding uncertainty in this encounter responds to the patient's resistant behavior. Additionally, invoking medical uncertainty here has the effect of advocating for treatment because it intimates that the general medical uncertainty of not knowing whether cells exist—and how they will behave—motivates the need to assume they exist and to play it safe by treating.

Likewise, the following case illustrates an instance of an oncologist presenting medical uncertainty with regards to the degree of the cancer's spread after a patient has demonstrated

treatment resistance. In putting forth that there are limits to what physicians can know from concrete medical evidence (what is visible to a surgeon's eye during surgery) this oncologist also foregrounds medical uncertainty to the effect of advocating for further treatment. This is shown in Extract 19 (shown earlier in this section as Extract 15). Recall that following a diagnosis of a rare cervical cancer that has spread to a lymph node, the physician recommends chemotherapy and radiation with follow-up chemotherapy as the best treatment plan moving forward. The patient enacts a mild form of resistance by indexing surprise and then withholding acceptance during times where it is actively sought. Earlier, I demonstrated that in response to the patient's resistance, the physician first presents medical certainty to combat her resistant stance:

#### (19a)0128

```
DOC:
             .hh yesterday we had our big conference? member I said I was
01
02
             gonna present your case at the big conference and I d\underline{i}d? .hh and
03
             I'm glad you:re >sort of< here so we can talk about it very
04
             fresh .hhhh (.) we talked about (.) your s::. your type of
05
             cancer:? (.) what the:. best treatment should be: and the: team
06
             agreed that the best treatment would be a combination of
07
             chemotherapy and radiation at the same time an[d then followed
80
   PAT:
                                                            [Really?
   DOC:
             with chemotherapy. .pthhhh because the: overall:.m (.) this is
09
            very rare (.) this clear cell: cancer of the cervix is a very
10
   DOC:
11
             rare kind..hhh your clear cell cancer >member I said< oh
12
             it's not related to HPV? (0.6) .pt your clear cell cancer
13
             unlike most of these? actually: .hh when we st- did some
14
             special: stains on it? (.) actually looks like it is result from
15
             HPV. .hhh and it is caused by HPV:- but most of them are no:t
16
          > (0.8) Why yours is special and different I: cant- I don't know:
17
             but we did a bunch of other testi:ng some DNA testi:ng and some
18
                                                                   [°Mhm,°
   PAT:
19
             protein testing and found that out. (0.5) So that gives us an
20
             idea that when: we treat it .hh it should respo:nd hopefully:
21
             the same way HPV related cancers would respond. Which means
22
             that radiation and chemotherapy is likely to \tag{work}
23
             (.)
             Which is Tgood.
24 DOC:
```

After most of the recommendation is produced (lines 05-07), the patient indexes a mild form of resistance in her response of surprise, "Really?" (line 08). The physician orients to this as resistant behavior, seen through her subsequent justifications for the treatment which highlight the rarity of

this cancer (lines 09-15). She then foregrounds medical uncertainty about *why* this patient's cancer is so rare "Why yours is special and different I: cant- I don't know:" underscoring the limits of her knowledge as a physician. This has the effect of heightening the serious nature of this cancer: when an expert in cancer does not know why the cancer is so rare, this casts the situation as more serious.

In the subsequent TCU, the physician contrasts this position with a more certain one, that they do know that the cancer is related to HPV through "a bunch of other testi:ng some DNA testi:ng and some protein testing and found that out" (lines 17, 19). She leverages this more certain knowledge to circle back to the original recommendation: "So that gives us an idea that when: we treat it .hh it should respoind hopefully: the same way HPV related cancers would respond. Which means that radiation and chemotherapy is likely to \tangle work (.) Which is \tangle good." (lines 19-22). In this turn, the physician is actively seeking acceptance. This is shown not only in her circling back to the recommendation, but in her presenting with certainty its likelihood to work, "Which means that radiation and chemotherapy is likely to \tangle work". After a micropause where the patient withholds response, the physician further pushes that the near certainty of treatment success "is \tangle good." After more patient resistance through the withholding of acceptance, the physician circles back to the recommendation again:

#### (19b)0128

```
01
   DOC:
             .pt so our best goal? Is [to get rid of it now.
02
   PAT:
                                       [.hh so right now right? now I: um:.
03
             (0.2) I don't have cancer or I do have cancer.
             We don't know if there's anything left so I took out everything
04
   DOC:
05
             that could be taken out? but [i-
06
   PAT:
                                           [>Yeah< but you see me inside and
07
             [everything was,
             [^Yeah but I can't see everything right I'm not a microscope
80
   DOC:
09
             there m:ight be microscopic- even the lymph node I tooked out
             looked normal to me .hh but it wasn't it was full of cancer on
10
11
             the inside.
12
   PAT:
             Mm::.
             So- I can't kno- and your CT scan was normal (0.6) but clearly
13
   DOC:
14
             there's something there (.) So- I can't know for certain:? that
15
             we got it all even though: the margins were negative and the we
16
             took the lymph node,
```

In line 01, the physician revisits the recommendation once more: ".pt so our best goal? Is to get rid of it now." In response, the patient reveals the source of her resistance. Her withholding of acceptance actually belied a different issue: the assumption that the surgery was curative and her lack of understanding about the need for further treatment: ".hh so right now right? now I: um:. (0.2) I don't have cancer or I do have cancer." In response the physician pursues a familiar persuasive tactic by foregrounding uncertainty about whether there is any cancer remaining: "We don't know if there's anything left so I took out everything that could be taken out? but i-" (lines 04-05).

In overlap, the patient launches her turn and continues to resist by doubting the existence of more cancer and thus the warrant for further treatment. She does this by citing the physician's ability to see inside her body firsthand as the surgeon: ">Yeah< but you see me inside and everything was," (line 06-07). The physician comes in via overlap with a counter that continues to foreground medical uncertainty: "Yeah but I can't see everything right I'm not a microscope there m:ight be microscopic- even the lymph node I tooked out looked normal to me .hh but it wasn't it was full of cancer on the inside." Like the physician in Extract 18, this physician puts forth the possibility of microscopic cancer cells remaining and mobilizes supportive evidence by citing the removed lymph node's deceptively normal appearance which surprisingly tested positive for cancer in pathology. Further, the physician cites the inherent imprecision of the human eye as limiting her ability to be able to know whether or not microscopic cells remain. In so doing, she emphasizes the limits of medical knowledge, like the previous cases in this section.

After the patient offers minimal acknowledgement (line 12), the physician continues by further foregrounding uncertainty: "So- I can't kno- and your CT scan was <u>normal</u> (0.6) but clearly there's something there (.) So- I can't <u>know</u> for certain:? that we got it all even though: the margins were negative and the we took the lymph node," (lines 13-16). Here, the physician underscores that

in spite of the normal imaging results, surgery showed signs of spread to the lymph node. Highlighting the mismatch of information further underscores the uncertainty inherent to this diagnosis. As such, the physician makes concrete that she "can't know for certain:? that we got it all", maintaining the possibility that further cells remain and addressing the core of the patient's resistance rooted in the belief that surgery was curative. Foregrounding uncertainty functions here, as in the other two cases shown, as a persuasive tactic in the context of the patient's challenges to the warrant for surgery. Also like the other two cases, uncertainty mobilizes the possibility of cancer being in places that medical technologies are unable to detect, despite patients basing a large part of their resistant behavior on the efficacy of these diagnostic tools.

# 3.3.4 Foregrounding Uncertainty for an Ancillary Issue

The previous extracts analyzed for presentations clinical uncertainty functioning as a persuasive tactic for treatment involved uncertainty about the behavior of the patients' cancer. In these cases, *both* clinical uncertainty and certainty were foregrounded to encourage patients to accept cancer treatment. While this next encounter (Extract 20, shown earlier in this section as Extract 14) involves a patient with Stage IV prostate cancer, the treatment being proposed is to address an issue ancillary to the patient's cancer: a urinary tract infection that is unresponsive to the current antibiotic treatment Bacrim. Recall from the earlier extract analyzed that the physician proposes a more effective treatment for the UTI—being admitted to the hospital for better treatment. The patient subsequently pushes back on this recommendation by citing that he had just had tests run over the weekend (lines 03-04):

#### (20a)0505

```
01 DOC:
             The ur- I think you might have an infection that we're not
02
             treating en that might be why your m- you're feeling worse.
03 PAT:
             Yeah but why would I- (.) they checked it over the weekend why
04
             would I need to go in the hospital,
05 DOC:
             .hhhh[h- ((Doc nods))
                                            [yeah.
                  [.h when they- when I was [just in the emergency with
06
   PAT:
             Doctor O'Shea?
07
```

```
08 DOC: Yeah so wh[en they
09 PAT: [They- they went through all that en he took- he took
10 the: um .pt (0.2) culture?
11 (.)
```

The patient continues to resist the proposal to change the treatment through a hospital admission in lines 06-07, citing his recent trip to the emergency room where they took these tests. The physician attempts to launch his turn, which he relinquishes (line 08) when the patient comes in via overlap. In his turn, the patient provides further supportive evidence that a lot of testing was already pursued when he was in the ER, "They- they went through all that en he took- he took the: um .pt (0.2) culture?" (lines 09-10). After a micropause, the physician attempts to respond to the patient's resistant position:

#### (20b)0505

```
Right [the problem is- (1.0)] It's back en en en the [anti-
01
   DOC:
                   [En he's running it now]
02
   PAT:
03
             was jus- that was jus Sunday.
04
   DOC:
             Yeah. (.) I see it. .hh en the problem is that the antibiotic
05
             you're o:n isn't treating (.) wh[at's-
06
   PAT:
                                             [So the Bactrim.
             Right. (.) Isn't working now. .h en I'm- I'm not sure that there
07
   DOC:
80
          > is an oral pill that's gonna work you may need intravenous
09
          > antibiotics to help (0.6) Beat the bug.
10
             (0.8)
11
             E:n if we were to admit you we could have infectious disease
   DOC:
12
             doctors see you while you're in the hospital? en we could get
13
             you on the right antibiotic.
```

During the physician's attempt at response (line 01), the patient produces overlapping talk, providing further evidence that these tests were done very recently, "Well that was jus-that was jus-Sunday." (lines 02-03). The physician responds to this resistant line by first foregrounding certainty: "Yeah. (.) I see it. .hh en the problem is that the antibiotic you're o:n **isn't treating** (.) what's-" (lines 04-05). After the patient clarifies that the antibiotic to blame is Bactrim, the physician confirms with further certainty that Bactrim "Isn't working now." (line 07). In the same turn, he then foregrounds medical uncertainty in producing a more concrete recommendation for treatment: ".h en I'm I'm not sure that there is an oral pull that's gonna work you may need intravenous antibiotics to help

(0.6) Beat the bug." (lines 07-09). Here, uncertainty is put forth during a recommendation for intravenous antibiotics, which can only be administered in the hospital. The physician becomes more firm in this position by continuing that "E:n if we were to admit you we could have infectious disease doctors see you while you're in the hospital? en we could get you on the right antibiotic." (lines 11-13). This provides a conditional situation, that if the patient acquiesced and agreed to be admitted to the hospital, there is a possibility that he could be treated more effectively. Throughout this recommendation, the physician presents a less-than-certain stance towards treatment efficacy. Yet, because of its sequential position as responsive to resistance and its invocation during a treatment recommendation (lines 07-09; 11-13) it functions as an endorsement for a new proposed treatment plan.

# 3.4 Discussion

Managing certainty is a pervasive reality of medical work. In an environment particularly plagued by uncertainty in diagnosis, treatment, and survivorship rates, cancer care offers a critical site to explore how certainty gets managed by physicians. While previous studies have found that certainty gets mobilized for the preservation of professional expertise, this analysis zooms in to the interactional practices that occasion certainty talk.

This analysis first established the difference between the knowledge physicians have more or less access to given available information and the knowledge physicians *claim* to know during medical encounters with patients. Medical knowledge given available evidence can be separable from how it gets presented to patients. With this I mind, this chapter's primary focus was how presentations of medical knowledge can be foregrounded as more or less certain as cancer treatment gets discussed with patients over the course of the visit.

To further specify what constitutes foregrounding certainty talk compared to talk that *implies* certainty but does not foreground it, I first described in the lexical boundaries of marked certainty

talk by identifying verbs, modals, modifiers, and aggregates that capture a presentation of certainty. Verbs, modals, and some modifiers in these data were used to present what I termed "targeted" certainty, or certainty that is presented to the patient as directly relevant to their experience as patients being treated in the here-and-now. In contrast, percentages, risk, guarantee, ratios, and probabilities were used to present what I termed "aggregate" certainty. I characterized aggregate certainty as certainty that mobilized aggregate information in an abstract presentation of knowledge, like percentages, risks, ratios, and probabilities. Aggregate certainty in these data could be presented to patients directly or in such a way that involved a stepwise process of inference. Upon analysis, I found that physicians only presented aggregate certainty in second position as responsive to a question from the patient. This result suggested physician reticence to cite broader data like percentages, probabilities, and ratios unless asked a question about the disease by the patient.

This chapter also found that physicians' claims to medical knowledge, presented as more certain at the outset of the treatment discussion, could actually change to less certain later on in the discussion, or vice versa. The ability of clinicians to manipulate their levels of certainty moment-by-moment necessarily led us to ask, what are physicians doing when they present foreground certainty one moment, and uncertainty the next?

Once certainty talk during treatment recommendations was identified, the analysis next sought to parse out its interactional function. Ultimately, its sequential placement was found to be following treatment resistant behavior. When patients demonstrated either active or passive resistance to the recommendation, one way physicians advocated for the recommendation was to foreground certainty or uncertainty depending on the nature of the patient's resistance. When certainty was foregrounded, it was typically when communicating the warrant for treatment, treatment efficacy, or the outcome of recurrence or even death should the patient refuse treatment. When uncertainty was foregrounded, it was typically when communicating about the precision of

diagnostic tools to rule out a No Evidence of Disease (NED) status, the reason for the disease's severity, or the reason for a treatment's inefficacy. Critically, foregrounding certainty and uncertainty served the same interactional purpose: to advocate for new treatment or justify further treatment. Accordingly, this analysis argues for a re-conceptualization of clinical certainty as a flexible, rather than static, concept. Interactional evidence suggests physicians can shift from more certain to less (or vice versa) as they respond to different aspects of patients' resistant behavior.

Both passive and active patient resistance to physicians' recommendations can be a way for patients to exercise agency over the treatment decision (Koenig, 2011; Stivers, 2007). The inherent power strain between physician and patient is attributed to both a the rise of patient consumerism and the medical community's commitment to acting in patients' best interests (Timmermans & Oh, 2010). As patient involvement is encouraged from a policy perspective for its benefits, it also represents an erosion of physician authority insofar as it runs counter to the model of paternalistic decision-making through promoting patient autonomy and choice. Yet, physicians have preferences and beliefs about what is best for their patients, sometimes with significantly greater experience to draw on about the possible efficacy and side effects of a treatment. One way they do this is by making use of an interactional tactic—foregrounding certainty or uncertainty— as they respond to patient pushback on their recommendation. In an era where patient agency is likely to be exercised and treatment buy-in is sought (see Chapter 2), leveraging medical certainty can serve as a useful tool for clinicians in responding to patient resistance, addressing patient concerns, and securing treatment acceptance.

## References

- Atkinson, P. (1984). Training for certainty. Social Science & Medicine, 19(9), 949–956.
- Barker, K. (2009). The fibromyalgia story: Medical authority and women's worlds of pain. Temple University Press.
- Barker, K. K. (2008). Electronic support groups, patient-consumers, and medicalization: The case of contested illness. *Journal of Health and Social Behavior*, 49(1), 20–36.
- Brashers, D. E., Goldsmith, D. J., & Hsieh, E. (2002). Information seeking and avoiding in health contexts. *Human Communication Research*, 28(2), 258–271.
- Charmaz, K. (1991). Good days, bad days: The self in chronic illness and time. Rutgers University Press.
- Christakis, N. A., & Iwashyna, T. J. (1998). Attitude and self-reported practice regarding prognostication in a national sample of internists. *Archives of Internal Medicine*, 158(21), 2389–2395.
- Connolly, J. L., Schnitt, S. J., Wang, H. H., Dvorak, A. M., & Dvorak, H. F. (2000). Principles of cancer pathology.
- Danaei, G., Vander Hoorn, S., Lopez, A. D., Murray, C. J., Ezzati, M., & Comparative Risk Assessment collaborating group (Cancers. (2005). Causes of cancer in the world: comparative risk assessment of nine behavioural and environmental risk factors. *The Lancet*, 366(9499), 1784–1793.
- Davis, F. (1960). Uncertainty in medical prognosis clinical and functional. *American Journal of Sociology*, 66(1), 41–47.
- Epstein, R., & Street, R. L. (2007). Patient-centered communication in cancer care: promoting healing and reducing suffering. National Cancer Institute, US Department of Health and Human Services, National Institutes of Health Bethesda, MD.
- Feder, E. K. (2009). IMPERATIVES OF NORMALITY From "Intersex" to "Disorders of Sex

- Development." GLQ: A Journal of Lesbian and Gay Studies, 15(2), 225–247.
- Fox, R. C. (1957). Training for uncertainty. In Robert K Merton, George G Reader, & Patricia Kendall (Eds.), *The Student-Physician: Introductory Studies in the Sociology of Medical Education* (pp. 207–241). Cambridge, Mass: Harvard University Press.
- Fox, R. C. (2000). Medical uncertainty revisited. *Handbook of Social Studies in Health and Medicine*, 409–425.
- Glaser, B. G., & Strauss, A. L. (1965). Awareness of dying. New Brunswick, NJ: Transaction Publishers.
- Han, P. K., Klein, W. M., & Arora, N. K. (2011). Varieties of uncertainty in health care: a conceptual taxonomy. *Medical Decision Making*, *31*(6), 828–838.
- Heritage, J. (2015). Well-prefaced turns in English conversation: A conversation analytic perspective.

  \*Journal of Pragmatics, 88, 88–104.
- Husson, O., Haak, H. R., Oranje, W. A., Mols, F., Reemst, P. H., & van de Poll-Franse, L. V. (2011).
  Health-related quality of life among thyroid cancer survivors: a systematic review. *Clinical Endocrinology*, 75(4), 544–554.
- Karlsson, M., Friberg, F., Wallengren, C., & Öhlén, J. (2014). Meanings of existential uncertainty and certainty for people diagnosed with cancer and receiving palliative treatment: a life-world phenomenological study. *BMC Palliative Care*, *13*(1), 28.
- Koch, L., Bertram, H., Eberle, A., Holleczek, B., Schmid-Höpfner, S., Waldmann, A., ... Arndt, V. (2014). Fear of recurrence in long-term breast cancer survivors—still an issue. Results on prevalence, determinants, and the association with quality of life and depression from the Cancer Survivorship—a multi-regional population-based study. *Psycho-Oncology*, *23*(5), 547–554.
- Koenig, C. J. (2011). Patient resistance as agency in treatment decisions. *Social Science & Medicine*, 72(7), 1105–1114.

- Liao, M.-N., Chen, M.-F., Chen, S.-C., & Chen, P.-L. (2008). Uncertainty and anxiety during the diagnostic period for women with suspected breast cancer. *Cancer Nursing*, *31*(4), 274–283.
- Light, D. (1979). Uncertainty and control in professional training. *Journal of Health and Social Behavior*, 310–322.
- Mishel, M. H. (1984). Perceived uncertainty and stress in illness. Research in Nursing & Health, 7(3), 163–171.
- Mishel, M. H., Belyea, M., Germino, B. B., Stewart, J. L., Bailey, D. E., Robertson, C., & Mohler, J. (2002). Helping patients with localized prostate carcinoma manage uncertainty and treatment side effects. *Cancer*, *94*(6), 1854–1866.
- Mishel, M. H., & Braden, C. J. (1988). Finding meaning: Antecedents of uncertainty in illness.

  Nursing Research.
- Mukherjee, S. (2017). Cancer's Invasion Equation. The New Yorker, 40–49.
- Mullins, C. D., Montgomery, R., & Tunis, S. (2010). Uncertainty in assessing value of oncology treatments. *The Oncologist*, 15(Supplement 1), 58–64.
- National Cancer Institute. (2010). NCI: Pathology Reports. Retrieved November 21, 2017, from
- Parker, P. A., Davis, J. W., Latini, D. M., Baum, G., Wang, X., Ward, J. F., ... Logothetis, C. J. (2016). Relationship between illness uncertainty, anxiety, fear of progression and quality of life in men with favourable-risk prostate cancer undergoing active surveillance. *BJU International*, 117(3), 469–477.
- Parsons, T. (1951). Illness and the role of the physician: A sociological perspective\*. *American Journal of Orthopsychiatry*, 21(3), 452–460.
- Penrod, J. (2002). Advancing uncertainty: untangling and discerning related concepts. *International Journal of Qualitative Methods*, 1(4), 54–61.
- Perakyla, A. (1998). Authority and accountability: The delivery of diagnosis in primary health care.

- Social Psychology Quarterly, 301–320.
- Pilnick, A., & Zayts, O. (2014). "It's just a likelihood": uncertainty as topic and resource in conveying "positive" results in an antenatal screening clinic. *Symbolic Interaction*, *37*(2), 187–208.
- Robinson, J. D. (2003). An interactional structure of medical activities during acute visits and its implications for patients' participation. *Health Communication*, 15(1), 27–59.
- Rosenberg, W., & Donald, A. (1995). Evidence based medicine: an approach to clinical problem-solving. *Bmj*, *310*(6987), 1122–1126.
- Sackett, D. L. (1997). Evidence-based medicine (Vol. 21, pp. 3–5). Presented at the Seminars in perinatology, Elsevier.
- Sarangi, S., & Clarke, A. (2002). Zones of expertise and the management of uncertainty in genetics risk communication. *Research on Language and Social Interaction*, *35*(2), 139–171.
- Shaha, M., Cox, C. L., Talman, K., & Kelly, D. (2008). Uncertainty in breast, prostate, and colorectal cancer: implications for supportive care. *Journal of Nursing Scholarship*, 40(1), 60–67.
- Smith, A., White, D., & Arnold, R. (2013). Uncertainty—the other side of prognosis. *The New England Journal of Medicine*, 368(26), 2448.
- Stivers, T. (2005). Parent resistance to physicians' treatment recommendations: one resource for initiating a negotiation of the treatment decision. *Health Communication*, 18(1), 41–74.
- Stivers, T. (2007). Prescribing under pressure: Parent-physician conversations and antibiotics. New York:

  Oxford University Press.
- Stivers, T., Heritage, J., Barnes, R. K., McCabe, R., Thompson, L., & Toerien, M. (2017). Treatment recommendations as actions. *Health Communication*, 1–10.
- Stivers, T., & Timmermans, S. (2016). Negotiating the diagnostic uncertainty of genomic test results. Social Psychology Quarterly, 79(3), 199–221.

- Sudnow, D. (1967). Passing on. Prentice-Hall.
- Timmermans, S. (1994). Dying of awareness: the theory of awareness contexts revisited. *Sociology of Health & Illness*, 16(3), 322–339.
- Timmermans, S., & Berg, M. (2010). The Gold Standard: The Challenge of Evidence-based Medicine and Standardization in Health Care. Philadelphia: Temple University Press.
- Timmermans, S., & Buchbinder, M. (2010). Patients-in-waiting: living between sickness and health in the genomics era. *Journal of Health and Social Behavior*, 51(4), 408–423.
- Timmermans, S., & Oh, H. (2010). The continued social transformation of the medical profession. *Journal of Health and Social Behavior*, *51*(1 suppl), S94–S106.
- Valero-Aguilera, B., Bermúdez-Tamayo, C., García-Gutiérrez, J. F., Jiménez-Pernett, J., Cózar-Olmo, J. M., Guerrero-Tejada, R., & Alba-Ruiz, R. (2014). Information needs and Internet use in urological and breast cancer patients. *Supportive Care in Cancer*, 22(2), 545–552.
- Walker, G. (2004). On some interactional and phonetic properties of increments to turns in talk-in-interaction. In E. Couper-Kuhlen & C. E. Ford (Eds.), *Sound Patterns in Interaction: Cross-linguistic studies from conversation.* (pp. 147–169). Amsterdam.
- Yourman, L. C., Lee, S. J., Schonberg, M. A., Widera, E. W., & Smith, A. K. (2012). Prognostic indices for older adults: a systematic review. *Jama*, 307(2), 182–192.
- Zavestoski, S., Brown, P., McCormick, S., Mayer, B., D'Ottavi, M., & Lucove, J. C. (2004). Patient activism and the struggle for diagnosis: Gulf War illnesses and other medically unexplained physical symptoms in the US. *Social Science & Medicine*, 58(1), 161–175.
- Zebrack, B., & Isaacson, S. (2012). Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology*, *30*(11), 1221–1226.

# Chapter 4: Invoking and Avoiding Death: Resources for securing treatment acquiescence

# 4.1 Background

Cancer is second only to heart disease as the most common cause of death in the world (CDC.gov Health Statistics, 2016; Shaha et al., 2008). While there have been many advances in treatment, fear of death inhabits the world of cancer care (Schulte 2002). For over fifty years, social scientists have been studying the experiences of terminally ill patients and how death and dying are discussed in clinical contexts. A primary finding is that dying is a process which neither the dying individual nor those around him/her find easy to deal with. In this way, significant psychological and sociological work is done to stave off talk related to (1) an awareness of dying, (2) confronting choices that dying makes relevant or (3) discussing the likelihood of dying from a given illness.

Among the first to investigate how individuals became aware of their own impending death, Kübler-Ross approached the topic using a social-psychological lens, examining 180omething180apy sessions (1969). Ultimately, Kübler-Ross concluded that once the sick became aware that they were terminally ill, they did not initially accept this news. Instead, they processed their own demise through "five stages of grief." These stages, she argued, were a series of emotions that individuals moved through before coming to eventually accept death (the fifth stage).

Other social scientists went beyond the individual experience of death and dying to explore death as a social experience: for instance, how individuals die in the hospital. The catalyst for this preoccupation was an increasing number of patients dying in hospitals rather than their homes (Glaser & Strauss, 1965). In 1949, 51% of Americans died in their homes; by 1980, only 16% did (D. B. Brock, Foley, & Salive, 1996). Much of this research studied dying as a process that was collaboratively managed between doctor and patient, finding that both patients and physicians approach discussions of death and dying with hesitancy. Glaser and Strauss (1965) explored how

hospital staff managed information about a patient's impending death within the confines of the social structural environment of the hospital. Physicians and nurses often tightly controlled and did not disclose to patients that they were terminally ill. Given this, the authors proposed that patients moved through four contexts of awareness based on how much information was shared with them about their illness. Related to each type of awareness was the calculated control of communication about the patient's condition.

Also exploring experiences of clinicians and the terminally ill dealing with death discussions, Sudnow (1967) primarily concluded that death and dying were made up of systematic processes organized by collaborative social interaction. He found that both physicians and nurses not only controlled information about patients' prognoses – as Glaser and Strauss found – but they structured their daily activities around avoiding the delivery of bad news until it was absolutely necessary. Clinicians would prepare in advance for death discussions by structuring the activities of unknowing relatives prior to the arrival of the doctor, typically escorting the relatives to a private room to await the impending news. Isolating the unknowing bereaved also served to protect the family from "indirect discoveries" and to control the way the bad news was delivered. Further, when news of a death was to be shared with unknowing relatives, Sudnow found that physicians worked to display a certain posture to signal bad news: "Should the surgery's outcome be poor, surgeons, as they appear from behind the doors to the operating suites, often assume a decidedly solemn appearance, giving indication to awaiting relatives that they news they bring is unfavorable" (Sudnow, 1967: 123).

Echoing these findings but using retrospective interviews of a variety of professionals who deliver bad news, including those in medicine, Clark and LaBeff (1982) found that those who undertook death notifications prepared for and consciously managed bad news deliveries by only indirectly approaching it. Drawing on five primary death telling strategies found in their data, the

authors concluded that those in hospital settings preferred to use more oblique ways of death telling rather than directly delivering the bad news. This culture of opacity around delivering bad news at the time went beyond just prognostic discussions, it even infiltrated delivering bad diagnostic news. The practice of diagnostic nondisclosure was even written into training guides about how to deliver diagnostic news (Fitts & Ravdin, 1953; Oken, 1961).

All of this early work points to an individual and institutional preference for avoiding confronting death and dying, as the bearer and even receiver of the news. Yet today, in the age of informed consent legislation (Katz, 1994; Nelson-Marten & Rich, 1999b), increasing patient's rights (G. J. Annas, 1998; Faden, Beauchamp, & King, 1986b), and calls for increased patient involvement across different types of decisions through the SDM paradigm (Barry & Edgman-Levitan, 2012)--- especially in end-of-life (EOL) (Periyakoil, Neri, & Kraemer, 2015; Rietjens, van der Heide, Onwuteaka-Philipsen, van der Maas, & van der Wal, 2006)-clinicians, families and patients are increasingly mandated to address these topics more and more directly.

Over the past two decades, access to EOL care has improved (Dumanovsky et al., 2016). There is some geographic variation to this improvement, however. EOL care is available to the vast majority of people in urban and suburban areas, while those in rural areas still face difficulty in availability and access (Virnig, Kind, McBean, & Fisher, 2000; Virnig, Moscovice, Durham, & Casey, 2004). From an economic perspective, hospice and many palliative care services are covered by Medicare through the Medicare Hospice Benefit, by Medicaid in most states, and the Veterans Administration. Overall hospice usage among cancer patients has increased over time (Aldridge, Canavan, Cherlin, & Bradley, 2015). Additionally, changing hospital infrastructures have allowed for more palliative care teams across the U.S. (Kelley & Morrison, 2015). Sixty-seven percent of hospitals with 50 or more beds reported having palliative care programs, with public and not-for-

profit hospitals 7.1 and 4.8 times (respectively) more likely to have a palliative care program than for-profit hospitals (Dumanovsky et al., 2016)

The preference for a hospice death rather than a hospital death is apparent not only in how healthcare markets and medical institutions are changing but is also reflected in studies of physicians and patients. A majority of cancer patients have expressed a preference for hospice care, at-home palliation, and the desire to die at home (E. Arnold, Finucane, & Oxenham, 2015; Finestone & Inderwies, 2008). Moreover, it appears that oncologists are more frequently referring patients to specialized palliative care (Wentlandt et al., 2012) and to hospice (Bergman et al., 2011), albeit quite late in the disease course.

The overall shift to specialty EOL care suggests that death is increasingly acknowledged and thus there is both greater license for clinicians and patients to discuss dying and some pressure to do so. However, there remain significant overtones of avoidance. First, referrals to EOL care are done very late. The Medicare hospice benefit covers hospice referrals at least six months before death. Yet, National Hospice and Palliative Care Organization (NHPCO) reports that in 2013 the median length of stay for Medicare beneficiaries in a hospice program was 18.5 days before death (NHPCO, 2014). Second, patients nearing EOL report unmet psychosocial needs through a lack of proper communication from care providers (Stephen, Skirton, Woodward, Prigmore, & Endacott, 2013; Ventura, Burney, Brooker, Fletcher, & Ricciardelli, 2014). Third, actual discussions of death remain fraught. For instance, breaking bad news is something that physicians still approach with hesitancy. Lutfey and Maynard (1998) took a more modern approach to studying death discussions, employing an analysis paralleling Sudnow's (1967) perspective. Using conversation analysis of three instances of bad news conversations with cancer patients, Lutfey and Maynard found that doctors still demonstrated "interactional caution" in discussing a patient's impending death. In two of the cases in their sample, the authors found that prospective display sequences – asking the patient his/her

own opinion about his/her own current health status first (Maynard, 1997) – were used to more gently break news about a patient's death.

Along similar lines, a recent ethnography of dying patients in the ICU uncovered a hospital staff who, even in recent times, worked to maintain knowledge opacity (Kaufman, 2005). In this study, Kaufman found that doctors and nurses possessed an expertise about the routine procedures of care for dying patients that they held close to their vests and did not share with patients' families. Kaufman further found that patients and families often had expectations for the dying process that sat in direct contrast to that of the hospital staff. In spite of this, clinicians did little to remedy this disparity in understanding (Kaufman, 2005).

One reason that clinicians may remain reticent to talk directly with patients about death is because they find prognoses difficult, both to make in the cognitive sense, and to deliver interactionally. Measuring physicians' self-reported attitudes on prognosticating death, Christakis & Iwashyna (1998) concluded that physicians did not feel comfortable estimating prognosis near death. The authors found that nearly 60% of respondents felt that it was stressful or difficult to make death predictions, and 44% waited to be asked by a patient before offering predictions. Further, 90% of respondents believed that they should avoid being too specific and surprisingly, 57% reported inadequate training in prognostication. Echoing these findings, prognosticating is not something that physicians are good at. Lamont and Christakis (2001), drawing on interview and hospice data, found that physicians tended to overestimate how long patients had to live. Further, when physicians were asked about giving patients in hospice a prognosis, just 37% said that they would provide an honest estimate (Lamont & Christakis, 2001). The authors speculate that these issues could be in part because medical training and published medical textbooks do not treat prognosticating as important (Christakis, 1997, 2001). Reflecting this issue, Atul Gawande (2014), drawing on his own experience

as a physician and surgeon, argued that physicians too often shy away from confronting the realities of death and therefore do not advise patients properly on various aspects of their healthcare.

Like physicians, patients and their relatives have a hard time coming to understand the terminality of illness. Concluding that patients could disbelieve or ignore bad prognostic news before fully understanding it, Timmermans (1994) provided an update to Glaser & Strauss' (1965) theory by focusing instead on the levels of awareness once patients and relatives *received* bad prognostic news. Timmermans proposed three more nuanced levels of awareness which patients and relatives could shift back and forth between once physicians provide bad prognostic news directly. While patients and families who came to be aware of bad prognostic news would have been considered inside the open awareness context in the Glaser & Strauss model, Timmermans argued that once information was provided, patients could exist in different levels of open awareness. Patients could disbelieve and deny the bad news altogether, termed "suspended open awareness", or hear the bad news but maintain a positive outlook by focusing on prognostic uncertainty, termed "uncertain open awareness". Only if patients fully came to realize and understand the terminality of their disease, were they in the state of "active open awareness" (Timmermans, 1994).

These more recent works on death discussions all point to physicians' sustained discomfort in discussing death with patients, and patients' own difficulty in hearing about their impending death. Despite policies advocating more explicit discussions of death and dying and ideological shifts toward patient involvement in EOL decision making, death remains a subject that healthcare practitioners broach with hesitancy (Gawande, 2014; Lutfey & Maynard, 1998). For physicians, death is a "dreaded" topic (Christakis, 2001) and something for which they need advance preparation for (Back et al., 2005). From the earliest studies of death discussions in the mid-20<sup>th</sup> century through today, physicians struggle with confronting their terminally ill patients with the topic of death. Activities are structured around avoidance of and advance preparation for having

these discussions. Further, when these conversations do happen, death itself is often still not directly confronted. The literature points to a deep and longstanding cultural orientation to death as a thorny topic of discussion within the structural environment of medical practice.

Perhaps one explanation for more recent findings about clinician reticence to discuss death is the context of these discussions. I look to my cross-section of cancer care visits to see whether there is evidence that hospice, palliative care, or death itself is being invoked. I then ask, to what degree is it being invoked? Further, to what end is it being invoked?

Up until now, research on death discussions has taken a decidedly straightforward approach to studying the relationship between death and dying and the medical institution: using ethnographically and theoretically motivated inquiry to study patients at the EOL and the discussions and behaviors that inhabit such experiences. Overall, these theories and data show that death and dying – then and now – are challenging and problematic to discuss for both physicians and their patients. Despite years of sociological research establishing and confirming this reality, my data show that physicians will discuss death, but not in the EOL context that sociologists up until now have anticipated.

In this chapter I will show that, consistent with prior research, physicians and patients rarely discuss death or dying in an EOL context, even though this is a pervasive fear in cancer care visits. Yet, I will also show that bringing up death does happen, albeit rarely. In one instance, the topic of death is broached in an EOL context. In thirteen other instances, the topic of death is left off the table despite patients having Stage IV cancer. In contrast, and somewhat surprisingly, I found that although death and dying are not directly discussed as an EOL discussion in most cases, death and dying are actually invoked, but in a way that is very different from what prior sociological research would have suggested. I will argue that clinicians invoke dying to persuade patients towards a

particular treatment regimen rather than invoking death in a context where the patient is near the EOL. In what follows, I will offer support for these claims.

## 4.2 Palliative Care Discussions in the Context of Advanced Disease

The first question I answer in this chapter is, to what extent is the reticence to discuss death documented in the literature exhibited in the context of cancer care? To answer this question, I identify a subset of cases where we would most expect the patient's EOL to be addressed: patients who have Stage IV cancer with whom treatment is being discussed. Cancer at Stage IV has spread to distant areas from where it originated (metastasis). Survival rates for Stage IV cancers are relatively low. The primary Stage IV cancers in my data- prostate, uterine, and ovarian- have five-year survival rates of 29%, 17%, and 17%, respectively (American Cancer Society, 2017a). These parameters are relatively conservative. One could argue that patients with earlier stages of cancer should also address the possibility of palliative care. For the purposes of this analysis, I maintain conservative boundaries and only focus on those patients with Stage IV cancer discussing treatment. In total, there are fourteen cases in my data set where the patient has Stage IV cancer and treatment is being discussed with him/her.

Of these, there is just one encounter which involves any discussion EOL care. Specifically, the topic is broached in the context of treatment cessation and a transition to hospice. In this encounter, an eighty-two-year-old man with metastatic prostate cancer and his urologic oncologist are at a treatment crossroads and are discussing how to proceed. Having already unsuccessfully tried all standard of care options for his cancer, the patient went on a clinical trial for treatment. He has been on a clinical trial drug for several months, which was initially showing some efficacy in keeping his prostate cancer from growing. However, his physician has just told him that the shoulder pain that he was experiencing from his last visit is abnormal. It is not arthritis as the patient had assumed; it is because his cancer has further metastasized. The physician establishes that the clinical trial drug

is no longer effective and the patient must stop it. He next summarizes the treatments the patient has undergone thus far, in Extract 1a:

```
(1a)0416
01
   DOC:
             You've been through a lotta treatments Phil.
02
   PAT:
               [°Okay° you've gone through: through the textbook. (.)you've
03
   DOC:
             ha:d you've had a-all kinds of hormonal 188omethin:rs, .hh
04
05
             you've ha:d (.) some chemotherapy you've had radiu:m .hh I mean
             we'v- we've do:ne (0.2) we've done- (0.4) >kind of< all the
06
07
             textbook stuff, (0.2) Okay?
80
   PAT:
             .pt.hhhh >if you said< what's left that I haven't tried yet,=now
09
   DOC:
10
             we talked a little bout the chemotherapy type thing kinda wa:y
             back when but here's the p- here's the problem with chemo,
11
```

In the first line, the physician establishes that the patient has been through "a <u>lot</u>ta treatments". In overlap with the patient in line 02, who offers minimal acknowledgement, the physician continues that the patient has "gone through: through the textbook."—treatments which he goes on to detail in lines 03-05. In the next TCU (line 05), the physician re-iterates that all textbook maneuvers have been attempted, "I mean we'v- we've <u>do:ne</u> (0.2) we've done- (0.4) >kind of< all the text book stuff, (0.2) Okay?". Doing this by listing all failed treatment maneuvers could be an attempt at forecasting (see Maynard, 1996), signaling to the patient that his options are dwindling. Further, the use of an address term in the first line could signal to the recipient a transition to serious talk (see Clayman, 2010).

In turn, this could allow for the patient to come to the realization that he is at the end of treatment this on his own (Maynard, 1996). Evidence for promoting the patient's acceptance of this realization can also be found in the upwardly-intoned, turn-final "Okay?", which, particularly positioned after no uptake and a silence, pursues response (Pomerantz, 1984; Stivers & Rossano, 2010). In response, the patient offers minimal acknowledgement "Mhm." in line 08. The physician next proposes a treatment option, chemotherapy, in line 09, but although he initially frames as one of the remaining options: ">if you said< what's left that I haven't tried yet,=now we talked a little

bout the chemotherapy type thing kinda wa:y back when". However, just after in line 11 -with no evidence for giving up the floor- the physician moves to detail "the problem with chemo." as shown in Extract 1b:

#### (1b)0416

```
01 DOC:
             back when but here's the p- here's the problem with chemo.
           > chemo is a loaded proposition. .hh you're bone marrow (.) right
02
03
             now is weak \underline{from} the \underline{can}cer, (0.6) if: (.) you \underline{go}t the chemo >en
             it< cleared out the marrow- your counts might come ba:ck, .hhhh
04
05
           > .pt but we gotta somehow make sure that we don't lose yo:u (0.4)
06
           > in the midst of giving the chemotherapy, =it's hard chemotherapy.
07
    PAT:
             Mhm.
80
    DOC:
              Okay? .hhhh (.) I think it's more dangerous:: u:m (0.2) now than
09
              it would have been: yiknow back when- back when you were- (.)
10
             when you were stronger.
```

The physician orients to chemotherapy as problematic because it is a "loaded proposition" (line 02), signaling that while more treatment may appear to sound helpful, it is not that simple. He then moves to account for why this is, that the patient's bone marrow is "weak from the cancer," (line 03) putting emphasis on the causal connection between the patient's current weak state and the cancer's spread. In the next TCU, the physician provides an upshot to chemotherapy, that the patient's marrow may be "cleared out" by chemo, which would improve his white and red blood cell counts (line 04). Yet he quickly follows this by alluding to the possibility of the chemotherapy itself killing the patient because of its strength: ".pt but we gotta somehow make sure that we don't lose yo:u (0.6) in the midst of giving the chemotherapy=it's hard chemotherapy," (lines 05-06). Overall, while this option is offered, the risks laid out- including death- serve to undermine its viability. Notably, while the physician uses the possibility of the patient's death from chemotherapy as a reason against this option, he does not use those words (lines 05-06). This is in line with other empirical findings of death discussions in cancer care (see Lutfey & Maynard, 1998).

After the option of chemotherapy is established as a "loaded proposition" and the patient offers minimal uptake, the physician provides another option, framed as outside of the standard of care, in Extract 1c:

```
(1c)0416
             .pthhh or hhh yiknow (1.2) .hhh you could tell me well we don't
01
  DOC:
             wanna do chemo what else is out there. = anything else that's out
02
03
             there would be kind of hh .hhh e- (.) off the textbook hh (.) at
04
             this point kind of: yiknow older treatments that we've
05
             trie:d en one could argue maybe using ster- uh hormones and
06
             steroids .hh estrogens en steroids. (0.2) [Okay,
07
   PAT:
                                                        ſ°Mm°
```

The physician explains that, should the patient be wondering "what else is out there" other than chemotherapy (line 02), "anything else that's out there would be kind of hh.hhh e- (.) off the textbook" (lines 02-03). This has the effect of undermining the safety of whatever option comes next and may also undermine it as having proven efficacy. Instead of offering another option outright, the physician distances his own endorsement of the treatment in recommending it through "one could argue maybe using stero— uh hormones and steroids .hh estrogens en steroids" in lines 05-06. Following some hedging in line 05 "maybe using", and two instances of self-repair, the option of a combination of estrogens and steroids is proposed (line 06).

After further explanation of oral estrogen therapy versus the patch, the physician explains another downside of the estrogen therapy as shown in Extract 1d:

```
(1d)0416
```

```
01 DOC: But- >yiknow< if you ask me is that gonna cu:re my situation is
02 that gonna reverse this. I don't kno:w, um I- it might stabilize
03 things, .hhh (.) Might. hh for a bit,
04 (0.6)
05 PAT: M[hm,
```

Arguably the most important goal of any cancer treatment is to cure the patient of cancer. The physician undermines this possibility in Extract 1d by establishing uncertainty in outcomes, "if you ask me is that gonna cu:re my situation is that gonna reverse this I don't kn:ow, um I- it might stabilize things, .hhh (.) might. hh for a bit," (lines 01-03). The physician first declines to answer the question in his own reported speech: "if you ask me is that gonna cu:re my situation is that gonna reverse this I don't kn:ow (lines 01-02). He then only intimates a no-response with a transformative

type of answer to his own question: "it might stabilize things, hhh (.) might. hh for a bit," (lines 02-03). He builds more uncertainty in the next TCU, focusing on the next best outcome other than disease reversal, by addressing whether the drug will stabilize things (lines 02-03). Yet, he downgrades this outcome as well "it might stabilize things," and then stresses the uncertainty of this by repeating "might" following the clause, after micropause and in-breath in line 03. The temporality of the cancer's stabilization is brought to the fore in the next TCU, where the physician states "for a bit," in an increment (Ford & Fox, 2002; Walker, 2004). Evidence for the uncertain nature of reversing or stabilizing this patient's disease is made apparent and stressed. So is the fact that, should the treatment stabilize things, it will probably be short-lived. Overall, stability is suggested as the best possible outcome and will be only temporary. This lays the groundwork for a decision that could reasonably reject these treatment options, even though they have been offered.

At this treatment juncture, two options are laid out. One option has the possibility of killing the patient given his weak state. The other, indexed as "off textbook", is hedged while being described as an option and could potentially stabilize things- but only temporarily. Both are framed as suboptimal options and are produced in the context of the patient having already exhausted all other textbook options as shown in Extract 1a. Just after the estrogen option is established as shown in Extract 1d, a third option is offered:

#### (1e)0416

```
01
   DOC:
              [.hhh or if you said listen yiknow, (0.6) .hh en- I'm not-
02
             trying to make this decision for you guys but (like a) this is a
             family decision, (.) you tell me- .hhh yikno:w listen I'm eighty
03
04
             two: (0.2) I've been haulin my butt out here all the way from
05
             Arizona. .hhh a:nd .h I'm tired now. (.) En I don't wanna do this
06
             anymore.
07
   PAT:
             [Mhm,
80
   DOC:
             [.hhhh yiknow .hh is it possible for me to get (.) yiknow kind of
09
             care at home that'[s: that's directed towards my comfort en let=
10
   ???:
                                [Mm,
             =this thing kind of .hh ride ou:t.
11
   DOC:
12
   PAT:
             Mhm,
13
   DOC:
             The answer's yes that's- that's- .hhh that's not an=unre:asonable
14
             option. (.) At this point either.
```

In line 01, the physician launches the third option as standing in contrast to the other two via the use of "or" following an in-breath. He prefaces this next treatment option by explicitly rescinding deontic authority (see Stevanovic & Peräkylä, 2012) in lines 02-03: "I'm not- trying to make this decision for you guys but (like a) this is a family decision (.) you tell me". In the next TCU the physician continues to preface the third option by privileging the patient's advanced age, the inconvenience of getting to the cancer clinic, and the patient's fatigue as reasons for why the patient might not want to continue with treatment (lines 03-06).

The possibility of stopping treatment is further expanded in the next TCU. In overlap with minimal acknowledgement from the patient in line 07, the physician continues by providing a treatment option of being cared for at home that is directed towards the patient's comfort (lines 08-09). He expands on this further by presenting a more concrete picture of what it would mean to stop treatment in lines 09 & 11: "en let this thing kind of .hh ride ou:t", a euphemism for letting the cancer grow until the patient eventually dies. After another "Mhm." from the patient in line 12, the physician confirms that it is indeed possible for him to get comfortable care at home and that this option is "not unreasonable" (lines 13-14). It can be deduced from this sequence that the option to which the physician is referring is hospice, one that is only eligible for Medicare coverage when the patient has six months or less to live (Harris et al., 2014). After several more minutes of discussion and question answering from the patient's family, the physician more explicitly references hospice care as the third option.

Interestingly, in other conversations in my data set when patients were in the middle of treatment, their discomfort and fatigue were minimized by healthcare providers. Yet, here the patient's fatigue and comfort are elevated as primary considerations in this treatment decision. It is notable that these experiences are made salient in this particular context, whereas in other instances of difficult treatment, they are not. What is also significant is the use of euphemism in this extract. In

lieu of saying "stop treatment", the physician talks about "care...directed at my comfort" and characterizes the dying process as "ride this thing out". This use of euphemism echoes findings from the literature on EOL discussions: not only do physicians dislike talking about ending treatment and bad prognoses, but when they do break bad news to patients, they do so with hesitancy (Glaser & Strauss, 1965; Lutfey & Maynard, 1998; Sudnow, 1967).

This encounter is the only encounter in my data where the possibility of the patient shifting to EOL care is put on the table by his physician. Although there are cases in the data set where patients have advanced disease, talking about EOL care simply does not happen in those encounters. In this case, addressing the patient's impending death is done by signaling dwindling treatment options, minimizing other possible treatments, and putting hospice on the table- something that is only done when the patient is believed to be within six months of death. This case underscores that physicians can, and do, break bad news, discuss how to manage treatment in light of a bad prognosis, and put EOL care on the table. Yet in doing this, my data also show that physicians continue to demonstrate reticence in breaking bad news and discussing a patient's EOL.

At this point, we might wonder whether the third option for palliative care was an interactionally-generated option or designed to be put on the table at the outset of the encounter. There is some evidence that this discussion was designed at the outset to have, at the very least, the palliative care option put on the table. Drawing on ethnographic notes from this case, the physician prepared in advance to have a difficult discussion with the patient. The patient and his wife arrived first with one of his sons but his daughter was stuck in traffic and, according to a phone call she made to the physician's assistant, she would be about an hour. The patient and his family were placed in an exam room. The physician, despite this being the last appointment of the clinic, decided to wait and had his assistant move his other meetings that day. While the physician waited, I observed him pacing back and forth along the mostly empty clinic hallway, sighing periodically and cracking his

knuckles. This was outside of his normal routine when waiting for patients. When I asked him why he opted to wait so long for this patient's daughter- something I had never seen him do before- he said that he "didn't want anyone to miss this discussion" and that it was an "important" conversation. Typically, this physician kept to a rigid schedule.

He also disclosed that it would be a good case for me to capture if everyone ended up consenting to be recorded because cases like this one were rare. At the time, I did not ask him to clarify what he meant by this. As he continued to wait in the clinic hallway, I noted that his arms were crossed and he did not talk with colleagues as he usually did while waiting for late patients. Instead, he fidgeted around the nurses' station and stayed quiet. At one point he went to his office in another section of the clinic to make a call. I did not follow him. He returned once his nurse paged him because the daughter had arrived, and I had completed consenting the patient and his family. The marked difference in the physician's typically jovial manner during down time in clinic; his willingness to clear the rest of the day's events to have this discussion with the entire family present; and his comments to me about the nature of this discussion all suggest that he was prepared to, at the very least, broach a difficult discussion during this visit. But it also attests to the rarity of this kind of discussion in his practice despite the fact that with the trends in health care to have EOL specialty care, we might have expected this to happen at least in the majority of the 14 cases of Stage 4 cancers.

## 4.3 When Palliative Care is Left Off the Table

In the other thirteen cases, although patients were at a very advanced stage of disease<sup>4</sup>, death and EOL care were not topics during the treatment discussion. In the following encounter, a urologic oncologist has just delivered some bad news to his patient. Specifically, he had explained that the patient's scans were showing more bone metastasis than the prior visit and thus that the

<sup>4</sup> Recall that I define advanced stage cancer as any Stage IV cancer, which is cancer that has spread beyond the area in which the primary cancer has been found to distant organs.

current treatment is no longer working. Similar to the case discussed in Extract 1, this patient's cancer is not under control with his current treatment regimen and decisions need to be made about what to do now. After explaining to the patient that his cancer is growing, the physician moves to detail different treatment options available to him:

## (2a)0413

```
.hhhh there are hh >whater-< what are the standard options that
01
   DOC:
02
             are left hhh=there's (0.2) kind of (0.8) .pt.hh there's kinda
03
             two: that one could consider:. ok, (.) .tch.hh one is Jevtana?
04
             ((PAT scrunches face, then leans in with one ear close to DOC))
   PAT:
05
   DOC:
06
   PAT:
             ((PAT glances up at DAU confused))
07
   DOC:
             Chemo.=
80
             =Jevtana,
   DAU:
09
   PAT:
             Oh Jevtana.
```

In laying out what options remain, the physician hedges in putting forth that there are "kinda two:" (lines 02-03). The "kinda" also indexes that options exist but they are either outside the standard treatment or less desirable. Jevtana, the first option, is framed as the first of these. This is a chemotherapy drug as the physician explains to the patient's implied repair initiation, where he positions his ear closer to the physician and pauses<sup>5</sup> (line 04). The physician treats this as other-initiated repair, specifically as a hearing problem, and produces drug's name again<sup>6</sup>. The patient continues to demonstrate confusion (line 06), which the physician understands to be a problem not of hearing but of understanding, as he reformulates to include a more commonly understood word, "chemo" in line 07 (for further discussion, see Kitzinger & Mandelbaum, 2013).

Subsequently, the patient strongly resists this option (Stivers 2005a & 2005b; Stivers 2007).

Not only is he concerned about losing his hair and other chemotherapy-related side effects like

-

<sup>&</sup>lt;sup>5</sup> Non-verbal other-initiated repair has been analyzed by Manrique & Enfield (2015). Investigating other-initiated repair in Argentine sign language, the authors find that a similar embodied action, termed "freeze-look", is a practice for initiating repair from second position.

<sup>&</sup>lt;sup>6</sup> Svennevig (2008) found that because addressees have a preference for trying the least complicated route for other-initiated repair, they treat issues of understanding as problems of hearing first then subsequently treat the trouble source as a problem of understanding.

fatigue and nausea, but the chemotherapy option triggers frustration in the patient about the overall treatment for his disease. He gets emotional and begins crying when he reflects on his last experience going back and forth from watchful waiting to treatments that are only temporarily effective:

```
(2b)0413
           > Yiknow it- it really it really does bother me, .hh that I go
01
   PAT:
02
           > through all these protocols en I- I do what you wanna do,
03
   DOC:
           > .hhh a:n u:m ((voice quivering; looks up)) .hh hh .pthh yiknow
04
   PAT:
05
           > hh I- I- I- (.) Between watchful waiting and buying time, (.)
06
           > yiknow, .hh u:::m ((motions with both hands up and forward))
07
           > (0.8).pthhhh HHHHHHH hhh I don't know. ((Begins crying)) (0.4)
08 DOC:
             .pthhh
09
   PAT:
           > I don't know.
10
   DOC:
             'Well it's a hard' e- th- this is a har- En this is why (.) I
             didn't come in here and say this is what we're gonna d[o. (.)
11
12
   PAT:
                                                                    [.hhh
13
   DOC:
             Okay, (.) [I-
14
   PAT:
                       [I don't know.
15
   DOC:
             We've been through this_ (.) [We've had this discussion::.
16
   PAT:
                                          [.hhh hhhhhh
17
   DOC:
             before.
18
   PAT:
             IT's like a kabuki dance yiknow [I call it a kabuki dance but I-
19
   DOC:
                                             [(Yeah,)
20
   PAT:
             I- .hhh I- I- get hhh ((continues to cry))
21
             I know we don't get a big break.
   DOC:
22 PAT:
             .hh no. (.) No:.
```

The patient's emotional reaction in reflecting on his past treatment regimens is prefaced with his being "really" bothered that he has gone along with the recommended protocols from his physician (lines 01-02). This frustration is indexed in the context of these recommended protocols all eventually failing. He begins to get emotional when he accounts for this frustration in lines 04-07, citing "watchful waiting and buying time" as reasons for his frustration. He next gestures with both hands up in the air, demonstrating further embodied frustration (line 06), and begins to cry in the next TCU, uttering "I don't know." with a full repeat in line 09. This "I don't know" could suggest some level of relinquishment of his involvement in the decision-making process or potentially signal some degree of despair. At the very least it shows a disinclination to accept the treatment at a point when acceptance is relevant.

In light of the patient's emotional response to chemotherapy, which triggered recollections of his overall treatment course that evoked frustration in the "kabuki dance" he does with his treatment (line 18 of Ex. 2b), the physician offers a second option for treatment:

# (2c)0413

Midoxantrone, the second option, is framed as a gentler version of the first chemotherapy proposed (line 03). The physician does remind the patient that this treatment is still chemo (line 04), therefore insinuating that the patient's concerns about his other chemotherapy treatments could still exist with this option. He also frames the drug as "old" (line 04) which serves to minimize this option in a treatment context that relies on new research and innovation. It is at this point that the physician includes an argument *against* going with the Jevtana option. This is offered in Extract 2d:

```
Yiknow your nerves are beat up,
01
   DOC:
02
   PAT:
            Uh huh,=
03
   DOC: >
            En that would be a disincentive for the Jevtana, (.) cuz I think
            that could actually (0.2) carry further with the numbness thing.
04
05 PAT:
            Eh-the so the Jevtana a disincentive?
            Yeah, = it could actually make that worse.
06 DOC:
07 PAT:
             .hhhh wHHHHHH[HHH
08 DAU:
                          [Neuropathy could get worse with the Jevtana.
```

Here the physician only provides the negative side effects of Midoxantrone as a downside of this option (line 05). Subsequently, the physician does the same with the estrogen option. He only presents the positives and negatives estrogen in lieu of a concrete path forward, as shown in Extract 2e:

## (2e)0413

(2d)0413

```
O1 DOC: Yep. .h okay? .hhh so- >yiknow< estrogens especially if you have patch may actually be kind of an attractive option.=reduces hot flashes, .hh eh the-
O4 PAT: Well that'd be nice.
```

05 DOC: Bu:t w:o w- side effect that- it can be a little troubling is breast growth.
07 PAT: .hh is what?
08 DOC: Breast growth. (0.2) they're estrogens, (0.2) they're feminizing hormones. °yi[know°

Considering that the neuropathy could get worse on Jevtana, the physician offers that estrogen may be a good treatment to pursue because it can reduce the patient's hot flashes (lines 01-03), which he had been complaining about earlier in this visit due to his testosterone blockers. However, the physician next indicates a "troubling" side effect of estrogen in lines 05-06, breast growth. The physician also includes that these drugs are "feminizing hormones" (lines 08-09), also a negative side effect.

Interestingly, after the patient has strongly resisted the first option by citing concern for its side effects, indexing frustration, and crying about his overall treatment course, the physician does not use that opportunity to suggest that the patient consider discontinuing treatment or palliative care. Following the patient's display of overt emotion about going back and forth between treatments that were effective for only a finite amount of time could have been a ripe interactional moment to bring up a palliative care option. Following the display of emotion he offers an alternative type of the same treatment – another chemotherapy drug.

Up until this point, the patient has been told that his bone scans show the disease spreading, a sign of ineffective treatment. Yet the physician instead follows up this clinically bad outcome with option-listing of the choices that are "left", and that there are "kinda" two options, signaling dwindling treatment possibilities and hedging on the number of options which remain. The benefits of each option are minimized, while the problematic nature of each option is highlighted. In this case, the avoidance of launching a discussion about stopping treatment and transitioning to palliative care is reflective of past empirical work on death discussions and prognosticating. Not only does this physician avoid bad news delivery (in the form of treatment cessation) but he supplements it

with three other options for more treatment, a common practice in medicine (for further discussion, see Gawande, 2014).

Recalling an earlier discussion of Maynard's work on bad news delivery and from the analysis in Chapter II, option-listing here could be functioning as a forecast to the patient. Like Extract 1, laying out options with no clear benefit in the context of the inefficacy of the current treatment could activate the patient's awareness of diminishing treatment returns. Yet, in Extract 1, EOL care is put on the table. Here, even palliative care in its most mild form is noticeably absent despite the patient's emotion towards going back and forth between different treatment strategies. While it is possible that palliative care was talked about in an earlier discussion (these are, after all, a cross section of data), if it is not made relevant at a time when treatment decisions are being made, I argue that the option is not relevant in the here and now. More precisely, when the patient has been told that the current treatment is not working and only options for still more treatment are arrayed as the options to choose from – chemotherapy or estrogen – I argue that it is very difficult for the patient to then propose stopping treatment. This would require a very proactive patient – one who is going to propose not treating his/her disease in a context where his/her clinician has proposed treatment options, thus implying ongoing hope.

In general, proactive patients are unique. Even in general pediatrics, Stivers found that parents relatively rarely advocated for treatments outside of those recommended to them, and that was when the advocacy was for something they believed to be curative (Stivers, 2002b). Similar conclusions were made in specialty care contexts. Exploring treatment recommendations in neurologic consultations, Toerien et al. (2011) conclude that the majority of the time, physicians provided options to patients rather than patients proposing their own ideas for treatment.

In some instances patients have reported advocating for treatment. Drawing on interview data of patients in hospice, Spencer (2018) finds that patients claim to have advocated for treatment

recommended, is relatively rare. From an interactional standpoint, not only has advocating for a treatment plan been found to be rare, but asking to stop treatment is apparently difficult. For patients to want to transition to palliative care, two conditions must be true. The patient must first have reached the highest level of open awareness: the state of active open awareness, where "the patient and family members understand the full implications of the impending death and try in one way or another to come to terms with it. The patient no longer hopes for recovery" (Timmermans, 1994: 334). Further, the patient has to be willing to advocate for treatment outside of what has been recommended, resisting the treatment (Stivers, 2005b, 2005a). In this case, not only does resistant behavior counter physicians' epistemic authority, it goes a step further to also counter their deontic authority (see Stevanovic & Peräkylä, 2012; Stivers et al., 2017). Patients do not tend to take on this interactional difficulty, as rates of resistance have been found to be relatively low in contexts such as primary care (Stivers et al., 2017).

I now turn to a third case in which the patient has terminal cancer and treatment cessation and/or palliative care again remain left off the table. Unlike the previous example, where options are listed to forecast the patient's dwindling treatment prospects and treatment cessation is avoided, in this case the interaction itself between oncologist and patient does not overtly demonstrate that treatment options are dwindling. Yet, ethnographic accounts of my interaction with the physician after the visit tell a different story. First, I analyze the encounter in the exam room between physician and patient.

This patient is a former breast cancer patient who now has a metastatic tumor in her pelvis from uterine cancer. Like the patients in the other Extracts 1-2, she is currently at a treatment crossroads. She is experiencing new abdominal pain from the growth of her cancer to other parts of her pelvis, and bleeding from new small tumors on the top of her vagina. Her oncologist is

explaining to her that the drug she is currently on, Cytoxan, is not doing enough to keep her cancer from growing. After this news, the patient offers surgery as a potential solution to remove her uterus altogether, an option that the physician demonstrates skepticism about because her tumor is so large. The physician explains to the patient the nature of her cancer's growth and provides another account for why surgery is a poor choice- because she would not be able to continue her chemotherapy:

```
(3)0130
01
   DOC:
             What's bleeding? hh is that there are ne:w 201ometh:e cancer
02
             pieces in the top of the vagina that are new.
03
   PAT:
             Even with (.) the: uh cyt[oxan,
04
   DOC:
                                       [Even with the 201omethi it's not
05
             covering it enough.
06
   PAT:
             Okay¿
07
   DOC:
             .hhhh so, (.) My concern is that (.) if I (.) do a surgery
80
             you're gonna have to be off treatment. (.) For six weeks. (.)
09
             While you heal.
10
   PAT:
             No cytoxin?
11
   DOC:
             ((Shakes head)) [Not whi-
12
   PAT:
                             [No che[mo,
13
   DOC:
                                     [No che-
14
   PAT:
             Nada.
15
   DOC:
             ((Shakes head)) En I:m (.) nervous that if we do surgery, (0.2)
16
             that- More stuff could happen. There doesn't look like there's
17
             anything going on, .hh we can do more treatment, (.) okay? We
18
             wouldn't use the same thing you had before. (.) Okay we'd use
19
             something new. (0.2) So try something different.=
20
   PAT:
21
   DOC:
             .hh that- you hadn't seen. (.) Um and see if that made a
22
             difference.
23
   PAT:
             Okay,=
24
             And we c- While we do:. (.) Er in between treatment times we
   DOC:
25
             could also do radiation. (.) Which might be a good idea,
26
   PAT:
             Oh reall[y,
27
   DOC:
                     [Mhm,
```

In light of the Cytoxan "not covering it enough" (lines 04-05) and that surgery could cause "more stuff" to happen (line 16), the physician offers more treatment for the patient to pursue (line 17). This treatment is "something new" (line 19) and has the potential to be given with radiation, which is proposed in lines 24-25. After no uptake following the proposal for radiation, the physician indexes radiation as potentially "a good idea" in an increment that pursues uptake. The patient then treats this as news with an oh-prefaced newsmark, "Oh really," (line 26) (John Heritage, 1998;

Jefferson, 1978), which occasions a new understanding by the patient The physician confirms in line 27. On its face, this encounter about changing treatments seems as though the next option offered is a good one. Radiation is even endorsed by the doctor explicitly, although there is some demonstrated uncertainty in her turn with the use of "might" in line 25. Hints of uncertainty about the efficacy of this proposed treatment course are present elsewhere. For instance, when the physician proposes changing drugs to something new, she adds in the next TCU, "and see if that made a difference" (lines 21-22). However, it is made clear that this path forward is reasonable. The patient accepts the treatment regimen and plans are made to arrange for new chemotherapy and radiation appointments.

Before watching this interaction on video, I had a very different picture in my head about what had happened. After consenting the patient and turning on the camera, I waited in the hallway of the clinic until the visit was over, talking with some nurses and residents as I typically did during those quiet periods. When the physician emerged from the room with the physician's assistant and the nurse at the completion of the visit, she walked towards me, rolled her eyes and motioned with both arms to the ceiling, looking frustrated. She made her way to where I was standing (next to the clinic's computer station) and pulled down the keyboard from the wall, periodically shaking her head while she typed the patient's note. She appeared noticeably bothered by something. I asked her what had happened, and she responded, "It's so hard when patients are dying and they know it. There's just nothing you can really do for them." Soon after I jotted this note on the back of an unused consent form because it was such a rare thing to hear about a patient in the clinic hallway.

When I watched the video a few days later, I was prepared to see a palliative care conversation, or a bad news delivery sequence at the very least. However, as is shown in Extract 3 and in the rest of the interaction, only another treatment- a "good" treatment at that- was discussed. At the beginning of the video, the patient does get teary-eyed when the physician tells her she does

not think surgery is a good idea, and these tears start again at the end of the visit when the physician reminds the patient that it is an aggressive tumor. In response the patient offers an upshot, that she is thankful that the tumor has stayed in her lower abdomen and not spread to other parts of her body. I cannot speculate about whether the oncologist may have interpreted the patient's tears as an indication that the patient knew that she was going to die, or if they had had a conversation about this in another visit, but there was no other evidence in this visit that demonstrated the patient's knowledge of her own terminal illness. Yet, the physician believed that the patient knew she was going to die, and did not discuss this.

Based on the evidence in the video, I was also surprised that this oncologist considered this patient to be terminally ill given the treatments that were proposed to her. In the interaction, she offers additional treatment and this is framed as a good way to move forward given that the patient's first treatment is not working. The oncologist makes no indication to the patient during this visit that she has a terminal illness, or more bluntly, that she is going to die. Yet she made that clear to me. Again, perhaps this was discussed at another visit, which, because I only captured a cross-section of visits, is possible. However, if it was, it was notably not put forth as a consideration at this treatment crossroads and neither was treatment cessation.

As with Extract 2, one could speculate that treatment cessation or being terminally ill may have been brought up at an earlier visit, but again we have the problem that when treatment recommendations are being provided, if treatment cessation is not actively discussed as an option then it is not very viable. In these data, no patient susbsequently proposed treatment cessation, and arguably going against a physician's recommendations would always be difficulty for patients. We can only imagine that this would be particularly so in an EOL scenario.

This encounter echoes Glaser & Strauss' findings that physicians and patients occupy different levels of awareness of the patient's impending death (1965). Worse case, this is a

demonstration of the closed awareness context, where only the physician knows the patient is terminally ill but the patient is unaware. However, it could also be argued that the patient had some suspicion that her illness was fatal. She demonstrated emotion during the visit, and her physician told her that her tumor was too complex for surgery and an aggressive one. Given this, the patient may have suspected that she was terminally ill but was not certain of that fact. In that case, this would be an instance of the suspected awareness context (see Glaser & Strauss, 1965).

The three cases just analyzed certainly support prior claims that physicians are reticent to discuss death and dying. In one case, the patient's EOL was talked about through a discussion of hospice. In two cases, it would have clearly been appropriate to put EOL care on the table. These are a subset of thirteen total cases involved Stage IV cancer and treatment discussions. Yet in none of these cases was EOL care broached. I argue that palliative care would have been appropriate to address because these patients had Stage IV, metastatic cancer with statistically low survival rates. Importantly, the parameters that bounded these cases were set conservatively.

One could argue that it would be appropriate to set the parameters for missed opportunities for palliative care discussions to include patients with a lower stage of cancer. If that were the case, there would be even more instances in these data where physicians left palliative care of the table during treatment discussions. It cannot be ignored that the fear of dying as an ultimate consequence inhabits the world of cancer care. Given this, I argue that it is not unreasonable to address the possibility of death, the so-called "elephant in the room", to patients who are at any kind of treatment crossroads. Whether that means that physicians tell patients about the possibility of palliative care when the current treatment has been found to be ineffective and metastatic, or asking patients whether they want to pursue treatment at all even at the beginning stages of treatment, it is arguably appropriate for oncologists to broach these subjects with their patients consistently each

time treatment is considered. At the very least, patient preferences for or against treatment throughout the treatment process would be acknowledged and in line with SDM policy literature.

However, there are inherent interactional difficulties in making treatment cessation a relevant option. If a patient wants to pursue further treatment but the physician makes stopping treatment and palliative care relevant, the patient could hear that option as the physician "giving up". Given the typically longstanding and trusting relationship oncologists and their patients have (Hillen et al., 2012), patients may feel especially betrayed by their physician should palliative care be recommended.

Yet, some best practices literature advocates for palliative care discussions up front and early (Parikh et al., 2013). We could speculate one payoff of this is so that it is less shocking to the patient when the palliative option becomes more necessary later on in treatment. Another could be that bringing in palliative care while continuing chemotherapy treatment can result in longer overall survival (Kang et al., 2012), so familiarizing patients with palliative care early would be helpful if offering it as concurrent treatment. The cases analyzed show patients who are advanced in their disease, so we would particularly expect that the possibility of death, or at least palliative care, hospice care, or stopping treatment would be broached. But in thirteen out of fourteen cases, physicians elected not to talk about these options. Although palliative care, hospice, or the possibility of death could have been broached at other visits, they are not brought to the fore during these visits. As already noted, this treats treatment cessation as not relevant for the decision-making task at hand. When oncologists put only options for further treatment in front of the patient, stopping treatment (should it have been broached at another visit) is no longer interactionally relevant. To consider treatment cessation thus requires a patient to advocate for it, and patients generally have a hard time doing this.

Even in ordinary interaction, there is inherent interactional difficulty in putting an additional option on the table that has not already been offered. For instance, questions put constraints on both the action (Schegloff, 1968) and form of the recipient's next action the recipient should produce next. Polar questions constrain responses to a *yes* or *no* answer (Raymond, 2003) and alternative questions constrain responses to the options provided ("Coffee or orange juice?") (Stivers & Hayashi, 2010). Most often recipients accept these constraints and respond using one of options provided (Stivers & Hayashi, 2010). While using a transformative answer- a response that resists the constraints of the question- can be done in ordinary talk (Stivers & Hayashi, 2010), it requires circumventing the parameters set by the questioner.

Based on these data, we see that physicians very rarely put palliative care and/or hospice on the table as an option. The argument could be made that if patients wanted to end curative treatment and transition to palliative care or hospice they could put it on the table themselves. Yet, given the overall rarity of transformative answers, I put forth that this would be extremely rare. In the higher-stakes setting of the cancer clinic, if the physician put one or more treatment options on offer, one could argue that it would be even harder to reach around those offerings to advocate for a different treatment using a transformative answer. The physician is the expert and someone whose expertise has been sought for care. We could thus imagine that if patients countered this expertise by providing an alternative treatment to the ones proposed-like palliative care- it would be interactionally difficult.

Even in ordinary conversation, transformative answers are relatively rare (Stivers & Hayashi, 2010). It would take a particularly involved patient to ask for a transition to palliative care or hospice if the physician did not provide the option initially. Furthermore, for a patient to ask to stop treatment, the patient must have first come to accept that s/he has a terminal illness and want no further treatments to prolong life, what Timmermans (1994) terms "Active open awareness."

Further, the patient must want to advocate for stopping treatment on their own. These are both hard conditions to meet. It is therefore unsurprising that no patient asked to stop treatment in my data. Only in one case was stopping treatment and transitioning to hospice discussed. However, it is brought up through euphemism and is provided as one of three options- two of which are even more treatment for the cancer. Of the 90 encounters in my corpus, death was broached in an EOL context once and there were thirteen missed opportunities to discuss it. But is this the end of the story? Do these three cases shown cover all mentions of death in my data?

## 4.4 When Death is Invoked to Other Ends

The second question this chapter seeks to answer is, how do physicians discuss death in the context of cancer care if not in an EOL context? In the course of identifying and examining death discussions and the lack thereof in my data, I found that death was being brought up with some regularity, but this was being done outside of EOL discussions. Specifically, one of the primary places I found death being invoked was in the treatment recommendation context where it was being used to push patients towards what a physician recommended treatment. I will argue that physicians in these data that invoking death is actually an interactional practice being deployed to leverage physician authority in the service of treatment. In total, I found 17 instances of this. But before I move to this analysis, I will first investigate how physicians invoke death.

## 4.4.1 What is an Invocation of Death?

When I discuss invocations of death, I mean to capture the range of ways that physicians mention a patient's death. Invocations of death vary on two key dimensions: their level of directness and how immanent they are (see Table I). An invocation of death only involves invocations of dying rather than a reassurance of not dying. Examples of death invocations include: "If the cancer comes back we *non't be able to cure you*", "If we don't treat this cancer it will be *deadly*", and "Chemotherapy is better *than the alternative*".

The following encounter offers a direct and imminent reference to the patient's death in discussing her future health outcome should she decide not to pursue the recommended treatment. In this case, a woman in her mid 30's has just had surgery to remove cancer that had been found on her cervix. As part of this surgery, the surrounding margins were tested to investigate the degree of spread, if any. It was found that the cancer had, in fact, spread to a nearby lymph node. After the physician makes her treatment recommendation, the patient demonstrates resistance (Extract 5a):

(5a)0128

```
DOC:
             fresh .hhhh (.) we talked about (.) your s::. your type of
01
02
             cancer:? (.) what the:. best treatment should be: and the: team
03
             agreed that the best treatment would be a combination of
04
             chemotherapy and radiation at the same time an[d then followed
05
   PAT: >
                                                            [really?
06
   DOC:
             with chemotherapy. .pthhhh because the: overall:.m (.) this is
07
   DOC:
             very rare (.) this clear cell: cancer of the cervix is a very
80
             rare kind.
```

The physician produces her treatment recommendation in a proposal format to the patient (lines 01-04 & 06), that she recommends a combined chemotherapy and radiation course followed by more chemotherapy. In overlap with the recommendation, the patient receipts the news with a newsmark (Jefferson, 1978). This requests confirmation, nominally, but it also fails to indicate acceptance by instead looking for confirmation and expansion (can cite my work on treatment resistance).

Table I: Variations of death invocations

	Imminent	Far off
Direct	"If we don't do chemotherapy this cancer will	"Eighteen weeks of your life is
	come back and if it comes back it will be deadly"	much less than dying from a
		recurrence in three to four
		years"
Oblique	"If you have this, it could threaten your life within	"If we don't do treatment now
	six months"	this cancer might come back
		and we won't get a chance to
		cure you"

The physician responds to this in line 06 with an account, that the kind of cancer this patient has is "very rare" (line 07) and continues to describe the severity of this type of cervical cancer.

Next, the physician underscores the potential consequences of not committing to the treatment regimen as shown in Extract 5b:

# (5b)0128

```
Um (.) if we don't do: the radiation and chemotherapy:
01
   DOC:
02
             (0.8)
             It's (0.4) °w-° (0.4) we may end up with e- a lot of
03
04
             problems: okay it's a very serious diagnosis to have anyway?
             and because there was some cancer already in the lymph node?
05
06
             .hhh (0.2) if we don't do it (.) we:: it will come back,
07
          > (.) and if it comes back it will be deadly.
80
```

The direct death invocation is made in lines 07-08, where the physician explains that if the patient does not treat the cancer, it will come back "and if it comes back it will be deadly." This invocation makes a direct and imminent reference to the patient's death, which is framed as likely. However, in this case, death is invoked as directly responsive to the patient's overt resistance and demonstrates an outcome should she decide not to pursue the physician's recommended treatment course.

The following example of an invocation of death illustrates a direct yet less imminent reference to the patient's death. In Extract 6, the patient is seeing her gynecologic oncologist for two reasons. The first is to follow-up on the hysterectomy and bilateral salpingo-oophorectomy<sup>7</sup> she had a few weeks prior. The second is to discuss next steps in treatment as the mass in her fallopian tube is, in fact, a Stage IIA cancer. In light of the patient's initial treatment resistance, which is responding to a treatment recommendation made earlier, the physician provides an account for why chemotherapy treatment is important for this patient (lines 01-04):

(6)0209

01 DOC: Um the reason is that this cancer .hh without chemotherapy:

<sup>&</sup>lt;sup>7</sup> Removal of fallopian tubes and ovaries

```
02
             there's likely microscopic cells the naked eye cannot see, .hh
03
             and there's a chance those microscopic cells will become active
04
             at some point, (.) en: grow an- and recur.=
05
   SIS:
             =a[nd we don't want that.
06
   PAT:
               [Even though you took it- you don't think it was: like [u:m:.
07
   DOC:
80
             don't think it had spread but but hh we always assume there's
09
             microscopic cells there.=we have to assume. (.) u:m so: that's
10
             the much safer side of valor? .hh u:m if it were me I would do
11
             the- I would without a doubt in my mind do the chemotherapy?
12
             .hh I'm gonna play devil's advocate here and say eighteen weeks
13
             of your lif:e (.) one day a week i:s much less than:. dying from
14
             a recurrence in >three or four< years.
```

Following the physician's account, that chemotherapy is still important in order to destroy microscopic cells that can resurface as cancer at some point (lines 01-04), the patient begins to question whether chemotherapy would be necessary given that the physician removed the visible cancer. Even before she can complete her turn, the physician comes in in overlap in line 07 to address this resistance, that while the cancer had not spread, there could still be microscopic cells in her body. Treating these would be "the much safer side of valor?" (lines 07-09). Once the physician makes his treatment recommendation in lines 10-11, he continues to address the patient's prior resistance by playing "devil's advocate" and weighing the inconvenience and difficulty of the chemotherapy against "dying from a recurrence in three to four years" (lines 12-14). The invocation of death comes in this turn, when the physician tells the patient that the consequence of not pursuing treatment is going to be "dying from a recurrence in three to four years" (lines 13-14). What makes this invocation less imminent as compared to the previous two examples is that death is framed as a possibility several years in the future if the patient has a recurrence. The invocation here is set up as an either/or for the patient in the context of her resistance: she can get chemotherapy and live, or not pursue treatment and die from a recurrence.

While the first two cases discussed were direct invocations of death, Extract 7 offers an oblique- yet imminent- invocation of death. In this encounter, the physician does not explicitly use the word "die" as in the prior three examples, yet the patient's death is framed as an imminent

concern. This female patient has been recently diagnosed with uterine cancer that has metastasized to her lung. This is categorized as Stage IVB cancer, which means that the cancer has spread to distant organs and is very advanced. She is meeting with her gynecologic oncologist to discuss treatment options. He has already explained to this patient that he recommends a hysterectomy, but first he wants her to consult with the other medical oncologist who is responsible for treating the cancer on her lung (Dr. Hamlin). Ultimately, he explains that he wants Dr. Hamlin to decide whether the lung cancer or the uterine cancer should be addressed first. The patient is reluctant to have the surgery, and demonstrates treatment resistance in asking whether the oncologist has done many hysterectomies before, shown in line 01 of Extract 7:

```
(7)0301c
             .pthhh u- uh:. you have done many of surgeries like that.
01 PAT:
02
   DOC:
             Yeah.
03
   PAT:
             Making a man from a woman.
04 DOC:
             I've done [that too.
05
                       [Hheh heh heh heh no:: you're [still a woma:n,
   RES:
06
   DOC:
                                                      [Not for you.
07
   PAT:
             Ye:s (so: [ma-)
08 DOC:
                       [Not for you,
09
   PAT:
             .hhh so now it is for me.=
            =((Coughs)) no [not for you. It's not the [same operation.
10
   DOC:
11
   PAT:
                                                       [.hh uh will you then,
                           [ (
12
             .h give some uh:. (.) hormone therapy so: that I-
13
   DOC:
             May:be- no- not for hormones no not likely.
14
   PAT:
             .hh and what if I grow a beard and mustache,
15
   DOC: >
             You have to live two years before that happens. (.) If you have
16
             this ((points to lung)) it could be:. Threaten your life within
17
             six months to two years.
             .hhhh uh- uh listen I must tell you that seven months already
18
   PAT:
19
             have passed.
             .hh so that's why I'm saying_ (.) Doctor Hamlin has to decide if
20
   DOC:
21
             he wants to treat you for this first .hh and let me- have me do
22
             this ((points to genitals)) second.
```

After the physician confirms that he has done many of these surgeries (line 02), the patient expands on the nature of her question, that the surgery is "Making a man from a woman." (line 03). This suggests that to her the surgery is more consequential than simply the removal of organs; it would also remove her womanhood. The physician treats this literally with the response "I've done that too." (line 04), referencing a different kind of surgery, sexual reassignment. After the resident

counters the patient's claim following several laughter particles, "no:: you're still a woma:n," (line 05), the physician confirms that the surgery that he was referencing just prior- sex reassignment surgery- is not for this patient (line 06), which he fully repeats in line 08. He repeats this again at the launch of his turn in line 10 with expansion, "no not for you. It's not the same operation.", further evidence that he took the patient's initial question about the surgery in lines 01 & 03 literally rather than figuratively, confirming that the two surgeries are not the same.

The patient continues to demonstrate resistance by asking more questions about the nature of the surgery in lines 11-12, ".hh u will you then, .h give some uh:. (.) hormone therapy" and again in line 14, ".hh and what if I grow a beard and mustache,". In response, the physician builds a threat out of the patient's concern for facial hair, "You have to live two years before that happens." (line 15), the first invocation of death which foreshadows that the patient may not live long enough to see that outcome. Following a micropause, the physician expands on the turn with a more granular account, "If you have this ((points to lung)) it could be:. Threaten your life within six months to two years." (lines 15-17). In this TCU, the physician becomes more explicit about the reason behind the patient's limited life expectancy established in the first TCU. Specifically, he accounts for the death invocation by explaining that the lung cancer could threaten the patient's life if left untreated. Here, the physician is invoking the patient's death as an outcome of a decision to not treat (or delay treatment), rather than a possibility. This is similar to the first two cases shown in this section insofar as the patient's death is believed to be imminent. However, in contrast to those invocations, this one does not explicitly use the word "die" or "death". Instead the physician claims the cancer could threaten her life.

A more oblique and less imminent invocation of death is offered in Extract 8. In this encounter, the patient has recently undergone gynecologic surgery to remove a tumor on her ovary and she is at the clinic to follow up with the physician about her treatment plan. The physician asks

whether the patient has been able to consider her treatment options, and she states that she does not want to pursue treatment anymore. Following a physical examination, the physician continues:

01 DOC: Questions about chemotherapy? 02 PAT: No I ( [You're just not gonna do it huh. 03 DOC: 04 05 DOC: Cuz we've talked about it before that I really [I worry that 06 PAT: [I kno:.w, this cancer could come ^back and if we don't do it now we may 07 DOC: not get a chance to- cure you. 0.8

The physician launches a question about whether the patient has questions about chemotherapy (line 01). Here, the physician is attempting to keep the chemotherapy option on the table by giving the patient an opportunity to ask questions about the treatment before outright rejecting it. Her no-response in line 02 indicates further treatment resistance, which the physician confirms in line 03, "You're just not gonna do it huh." Following a period of silence, (line 04) the physician indicates she is concerned that the cancer which was removed could come back: "I worry that this cancer could come 'back' (lines 05 & 07). Further, the physician states, "we may not get a chance to- cure you" line 07-08. Death is invoked in lines 07-08 when the physician tells the patient that if the cancer comes back, it will be incurable, an oblique invocation. Ovarian cancer, if left untreated, is deadly. Therefore, by telling the patient about the possibility of the cancer's recurrence, she is implying that the patient could die. However, the patient's death is framed as less imminent as the possibility of its recurrence is framed in less concrete terms than the other cases in this section.

#### 4.4.2 When Invocations of Death Occur

(8)0108

Similar to the practice of foregrounding medical certainty analyzed in Chapter 3, I argue in these data physicians also invoke the patient's death in a persuasive context and I offer three types of evidence for this claim. First we can examine the phase of the visit in which we encounter death invocations. A majority of these invocations are being made in the context of recommending

treatment. Therefore, for this analysis I examine invocations of death that occur in the treatment recommendation phase of the visit. An example of this is shown below in Extract 9 (Extract 5 shown earlier). Recall that in this case, a woman in her mid-30's has had surgery to remove cancer that had been found on her cervix. Some cancer was found to have spread to a nearby lymph node. After discussing the findings from her surgery and doing a physical examination of her incision, the oncologist begins her treatment recommendation, as shown in Example 9a:

#### (9a)0128

```
01 DOC: fresh .hhhh (.) we talked about (.) your s::. your type of
cancer:? (.) what the:. best treatment should be: and the: team
03 agreed that the best treatment would be a combination of
04 > chemotherapy: and radiation at the same time an[d then followed
05 PAT: > [really?
06 DOC: > with chemotherapy. .pthhhh because the: overall:.m (.) this is
```

Because of the grade and stage of her cancer, the physician recommends chemotherapy and radiation as treatment (03-04) when she discusses that "the team agreed that the best treatment would be a combination of chemotherapy: and radiation at the same time", which should be followed by more chemotherapy (line 06). This is met in overlap with resistance from the patient where she registers surprise and questions the treatment recommendation in line 05. After a brief discussion of the rare type of cancer that this patient has and its propensity to grow, the physician discusses the potential repercussions of not treating the cancer. In so doing, the physician makes an explicit invocation of death, as shown in Extract 9b:

# (9b)0128

01 DOC: Um (.) if we don't do: the radiation and chemotherapy: (0.8)

103 It's (0.4) °w-° (0.4) we may end up with e- a lot of problems: okay it's a very serious diagnosis to have anyway? and because there was some cancer already in the lymph node? (.)

104 .hhh (0.2) if we don't do it (.) we:: it will come back,

0

<sup>&</sup>lt;sup>8</sup> Other invocations of death (made outside of treatment recommendations) included reassuring patients about not being near death in response to a question, or in first position as leverage for good news.

# 08 > (.) and if it comes back it will be deadly.

In lines 01-04, the physician foreshadows what could happen should the patient decide not to pursue treatment, "(0.4) um (.) if we don't do: the radiation and chemotherapy: (0.8) it's (0.4) °w-° (0.4) we may end up with e- a lot of problems: okay. She next makes explicit how serious this diagnosis is to have, "Okay it's a very serious diagnosis to have anyway?" (line 04) and provides an account for this, "and because there was some cancer already in the lymph node?" (line 05). In the next TCU, the direct invocation is made, where the physician says that if the patient does not treat the cancer, it will come back "and if it comes back it will be deadly." (line 08).

Another instance of death invoked during treatment recommendation phase of the visit is shown in Extract 10 (Extract 8 shown earlier). As was discussed earlier, this patient has been already diagnosed with Stage IIA cancer of the fallopian tube. The physician provides a recommendation to treat her cancer in Extract 10a:

### (10a)0209

```
DOC: >
             So that's for you guys. .hhh now moving forward? I still think
             we do need to:::.h do: chemotherapy.=and the reason I say that
02
             is th- i- a fallopian tube cancer there is a much higher risk of
03
             this: .hhh potentially coming back compared to a uterine cancer.
04
05
             (.) now the fact that it's an early fallopian tube cancer is
             \underline{e}xcellent and that's really really \underline{go}od news .hh and I think if
06
07
             we do the chemotherapy? (.) .hh u:m I think you're gonna have a
80
             good chance of this staying away for a long long time en
09
             hopefully if not forever. (0.2) okay,=
10
   PAT:
             =.pthhh well- okay so I had a couple of- (0.6) question[s er,
11
   DOC:
12
   PAT:
             (0.4) thoughts. .hh um:. (0.8) Number one is I'd like to see
13
             what the genetic testing comes back,
```

The physician's treatment recommendation, in lines 01-02, proposes that the patient pursue chemotherapy to treat the cancer, ".hhh now moving forward? I <u>still</u> think we do need to::..h do: chemotherapy." In indexing that he "still" thinks chemotherapy is what should be pursued, the physician is alluding to an earlier recommendation for this same regimen made outside of this encounter. In lines 02-09, the physician provides an account for this recommendation: it has a high

risk of recurrence, the timing to pursue chemotherapy now is in the patient's favor, and chemotherapy has a good chance of, at the very least, putting the patient in remission. The patient overtly resists the treatment recommendation in lines 10 & 12-13 by indexing that she some "Questions er, (0.4) thoughts." She then goes on to discuss that she wants genetic testing before she pursues chemotherapy because her friend underwent chemotherapy yet her cancer came back in a different place. She continues to account for her resistance in Extract 10b:

#### (10b)0209

```
01
   PAT:
             Yiknow I'm not completely opposed to doing the- (.) the: um:.
02
             (0.2)
02
   SIS:
             Ch[emotherapy,
04
   PAT:
               [.h chemotherapy?
05
   DOC:
             Mhm,
06
   PAT:
             I'm tending toward not doing it.
07
   DOC:
             Mm:. (.) .tchhh eh=
             =Because, (0.6) well (.) I- I guess m- I'm tending toward
80
   PAT:
09
             because like (.) yiknow I'm looking at this lady and she (.) had
10
             cancer and she had chemo: and then she had cancer again in a
11
             different place.
((22 lines of talk about the friend who had cancer and treatment omitted))
             Um the reason is that this cancer .hh without chemotherapy:
33
   DOC:
34
             there's likely microscopic cells the naked eye cannot see, .hh
35
             and there's a chance those microscopic cells will become active
36
             at some point, (.) en: grow an- and recur.=
37
   SIS:
             =a[nd we don't want that.
38
   PAT:
               [Even though you took it- you don't think it was: like [u:m:.
39
   DOC:
40
             don't think it had spread but- but .hh we always assume there's
41
             microscopic cells there.=we have to assume. (.) u:m so: that's
42
             the much safer side of valor? .hh u:m if it were me I would do
43
             the- I would without a doubt in my mind do the chemotherapy?
44
             .hh I'm gonna play devil's advocate here and say eighteen weeks
45
             of your lif:e (.) one day a week i:s much less than: dying from
46
             a recurrence in >three or four< years.
```

At the start of this excerpt, the patient displays her stance against the treatment in lines 01-06: that she is "tending toward not doing it." (line 06). She then begins to provide an account for her resistance in lines 08-11, citing a friend, whom she had mentioned previously, and her apparently negative experience with chemotherapy because the cancer came back "in a different place" (line 10). She and her sister, who is with her at the visit, discuss this friend in further detail, which is omitted from the excerpt. The physician counters the patient's account for resisting by providing her

with the alternative outcome, that without the chemotherapy, there are microscopic cells that would "become active at some point, (.) en: grow and recur." (lines 35-36).

In light of this lack of uptake, the physician produces a second treatment recommendation ".hh u:m if it were me I would do the- I would without a doubt in my mind do the chemotherapy?" (lines 42-43). In the next TCU, the physician invokes death by rationalizing his stance on chemotherapy: ".hh I'm gonna play devil's advocate here and say eighteen weeks of your life: (.) one day a week i:s much less than: dying from a recurrence in >three or four< years." Here it is evident that the direct invocation of death is made in the context of recommending treatment, as death is invoked following not one- but two- treatment recommendations.

Extract 11 (Extract 6 shown earlier) offers yet another instance of a death invocation produced in the treatment recommendation context. In this case the patient has metastatic uterine cancer which has spread to her lung, categorized as Stage IV cancer, and she is seeing her oncologist to discuss options for treatment. He first explains to the patient that he recommends a surgery to remove her uterus, cervix, tubes and ovaries:

## (11a)0301c

```
DOC: > So (.) y- see Doctor Hamlin and see if he agrees with me, (.) We
02
         > should take out the uterus and the cervix? .hh the tubes and the
         > ovaries? .hhh through an incision that'll come down like this
03
            ((points downward)), (.) Fix your hernia at the same time, (0.2)
04
         > Why not. (.) Fix it at the same time.=.hh and then look around
05
06
          > everywhere else and do biopsies, hh and see if it's anywhere
07
          > else. (.) At the same time.
08 PAT:
            .pthh where else for example.
09
   DOC:
            In the belly.
10
            ((Cocks head and raises eyebrows)) (0.4)
   PAT:
11
   DOC:
            Anywhere in the belly.
12
             (0.2)
13
   DOC:
            Possible.
```

The recommendation for treatment is produced in lines 01-07. The physician first recommends, using a suggestion format, that "We should take out the uterus and the cervix? .hh the tubes and the ovaries?" (lines 01-03), also known as a hysterectomy and bilaterial salpingo-

oophorectomy. In the next TCU, he details the location of the incision by pointing downward from his lower abdomen (lines 03-04). Adding on to the recommendation, he puts forth that the patient's hernia could be fixed at the same time (line 04) which he repeats in line 05 with stronger endorsement, "Why not (.) Fix it at the same time." Next he explains the final step of the recommended surgery, to "look around everywhere else and do biopsies, .hh and see if it's anywhere else. (.) At the same time." (lines 05-07), so he can see where- and how far- the cancer has spread. In the next turn, the patient demonstrates initial treatment resistance by questioning where the cancer could have spread (line 08). Subsequently, the physician responds, "In the belly." (line 09), to which the patient registers surprise by cocking her head and raising her eyebrows (line 10). The physician elaborates on the severity of the potential spread in line 11, "Anywhere in the belly", which, after a pause, he backs off on by foregrounding some uncertainty (for further discussion, see Chapter 3).

After still more questions from the patient about the nature of her cancer and the recommended surgery, the patient asks whether the physician has done many surgeries like this (line 01):

```
(11b)0301c
```

```
.pthhh u- uh:. you have done many of surgeries like that.
01
   PAT:
   DOC:
             Yeah.
02
03
             Making a man from a woman.
   PAT:
04
   DOC:
             I've done [that too.
05
   RES:
                       [Hheh heh heh heh no:: you're [still a woma:n,
06
   DOC:
                                                      [Not for you.
07
   PAT:
             Ye:s (so: [ma-)
80
   DOC:
                       [Not for you,
09
   PAT:
             .hhh so now it is for me.=
10
            =((Coughs)) no [not for you. It's not the [same operation.
   DOC:
11
   PAT:
                                                       [.hh uh will you then,
                           [ (
12
             .h give some uh:. (.) hormone therapy so: that I-
   DOC:
13
              May:be- no- not for hormones no not likely.
             .hh and what if I grow a beard and mustache,
14
   PAT:
15
   DOC: >
             You have to live two years before that happens. (.) If you have
16
             this ((points to lung)) it could be: . Threaten your life within
17
             six months to two years.
18
   PAT:
             .hhhh uh- uh listen I must tell you that seven months already
19
             have passed.
             .hh so that's why I'm saying (.) Doctor Hamlin has to decide if
20
   DOC:
             he wants to treat you for this first .hh and let me- have me do
21
             this ((points to genitals)) second.
```

Recall that the patient refers to the removal of her reproductive organs in a figurative way in asking the physician how much experience he has with a surgery that involves, "Making a man from a woman" (line 03). This demonstrates continued resistance. In response, the physician takes this literally, that he has done sex reassignment surgery as well (line 04). Once the patient has been reassured by the resident that she will still be a woman after the surgery (line 05), and the physician has clarified that this is not the surgery the patient is having (lines 06-10), the patient asks whether she will get hormones after the surgery (lines 11-12). To this, the physician offers a no-response (line 13). After yet another question about the treatment, ".hh and what if I grow a beard and mustache.," (line 14), the physician provides the death invocation, "You have to live two years before that happens." (line 15). This invocation, as discussed in the prior section, obliquely alludes to the possibility of the patient's death. In the next TCU, the physician becomes more concrete in his invocation by offering an account, that if the patient has the tumor on her lung (from the spread of the untreated uterine cancer), it could threaten her life in a matter of months (lines 15-17).

#### 4.4.3 The Function of Death Invocations

Evidence that physicians invoke death to persuade patients to acquiesce to treatment is not only that they invoke death during treatment discussions, but they do so exclusively in the context of patient resistance to treatment or anticipatory resistance. Of the 17 total death invocations to leverage treatment, 15 (88%) were made in the context of treatment resistance. One example of an invocation of death to persuade in favor of treatment is shown in Extract 12 (Example 8 shown earlier.) As was noted earlier, this patient has had surgery to remove an ovarian tumor and is following up with the physician about next steps in treatment. In the beginning of the visit, the

-

<sup>&</sup>lt;sup>9</sup> The remaining two cases were produced in the context of anticipatory resistance, which I discuss in a subsequent section.

physician poses a question to the patient, directly asking if she has given any more thought to treatment (line 01), orienting to an implied position that the patient does not want to pursue treatment:

```
(12)0108
   DOC:
             Have you given any more thought to getting treatment?
01
02
   PAT:
             ((Shakes head)) I don't want to any[more.
03
   DOC:
                                                 [You don't want to.
04
   PAT:
             °No°=((Shakes head))
             =Okay.>well how are you feeling. Any nausea?
05
   DOC:
((17 lines discussing symptoms and physical exam omitted))
22
   DOC:
             Questions about chemotherapy?
23
   PAT:
             No I (
24
   DOC:
                       [You're just not gonna do it huh.
             (2.4)
25
26
             Cuz we've talked about it before that I really [I worry that
   DOC:
27
   PAT:
                                                              [I kno:.w,
            this cancer could come 'back and if we don't do it now we may
28
   DOC:
29
             not get a chance to- cure you.
```

The physician queries the patient's implied position of treatment resistance in line 01, "Have you given any more thought to getting treatment?". In response, which demonstrates that this is a reference to the treatment from an earlier visit, the patient takes a strong position that she does not want to pursue treatment "anymore" (line 02). Next, the physician requests re-confirmation of this position in a B-event statement that seeks uptake, "You don't want to." (line 03). The patient provides a quiet no-response and shakes her head. After the physician accepts and closes the sequence with a minimal sequence closing third, "Okay", she proceeds to initiate history-taking questions using a well-preface in line 05. This well-preface signals that the issue is tabled, but not concluded (see Heritage, 2015).

Instead of closing the sequence following the patient's refusal, the physician works to reopen the sequence and solicit a change of answer. When the physician wraps up her physical examination, she initiates a post-expansion of the issue of treatment by asking the patient whether she has questions about her treatment (line 22). This attempts to bring reasons for her resistance to the surface. After the physician brings up the chemotherapy option again in line 22 with a question to the patient, the patient provides a no-response in line 23, indicating further resistance which the physician picks up on in line 24 with yet another request for re-confirmation in a B-event statement with a tag question, "you're just not gonna do it huh." After no uptake from the patient in a long silence (line 25), the physician pushes back on this resistance by providing a preliminary warning to the patient: "I really I worry that this cancer could come 'back" (lines 26 & 28). She continues with a conditional, that "if we don't do it now we may not get a chance to- cure you." (lines 28-29). Death is obliquely invoked in lines 28-29 when the physician tells the patient that if the cancer comes back, it will be incurable. Ovarian cancer, if left untreated, is deadly. Thus, by telling the patient about the possibility of the cancer's recurrence, she implies that the patient could die. This is directly occasioned both by the patient's initial resistant stance in line 02 and further resistant behavior as shown by the no-response in line 23 and the patient's lack of uptake in line 25. Here, the possibility of the patient's implied death is linked to not agreeing to treatment.

Like the patient in Extract 12, the patient in Extract 13 also adopts an actively resistant stance towards treatment. In contrast, the patient's stance in this encounter is not framed as already decided but rather that she is leaning towards not pursuing treatment. Similar to the prior case, this physician links the possibility of the patient's death to her initial resistant stance towards the recommended treatment. Recall that this patient has a diagnosis of Stage IIA fallopian tube cancer and the physician proposes that the patient pursue chemotherapy treatment, which has a good chance of effectively treating her early cancer. Following initial resistance where the patient indexes that she is "not completely opposed to doing" the chemotherapy, but she "tending toward not doing it" (line 06), the patient elaborates on the nature of her resistance to treatment:

(13)0209

<sup>01</sup> PAT: Yiknow I'm not completely opposed to doing the- (.) the: um:. 02 (0.2)

```
03
   SIS:
             Ch[emotherapy,
04
   PAT:
               [.h chemotherapy?
05
   DOC:
             Mhm,
06
   PAT:
             I'm tending toward not doing it.
07
   DOC:
             Mm:. (.) .tchhh eh=
80
   PAT:
             =Because, (0.6) well (.) I- I guess m- I'm tending toward
09
             because like (.) yiknow I'm looking at this lady and she (.) had
10
             cancer and she had chemo: and then she had cancer again in a
11
             different place.
((22 lines of talk about the friend who had cancer and treatment omitted))
             Um the reason is that this cancer .hh without chemotherapy:
33 DOC:
34
             there's likely microscopic cells the naked eye cannot see, .hh
35
             and there's a chance those microscopic cells will become active
36
             at some point, (.) en: grow an- and recur.=
37
   SIS:
             =a[nd we don't want that.
38
               [Even though you took it- you don't think it was: like [u:m:.
   PAT:
39
   DOC:
40
             don't think it had spread but but hh we always assume there's
41
             microscopic cells there.=we have to assume. (.) u:m so: that's
42
             the much safer side of valor? .hh u:m if it were me I would do
43
             the- I would without a doubt in my mind do the chemotherapy?
44
             .hh I'm gonna play devil's advocate here and say eighteen weeks
45
             of your lif:e (.) one day a week i:s much less than: dying from
46
             a recurrence in >three or four< years.
```

The patient's position on chemotherapy is made explicit in 01-06, that she is "tending toward not doing it." (line 06), overt resistance. While it is a softened decline, this is generally how refusals are interactionally produced to avoid face-threatening behavior (see Heritage, 1984b). Recall from the earlier analysis that the patient has already established that she first wants genetic testing before considering the chemotherapy option. By delaying considering treatment, the patient continues to resist the treatment recommendation. She offers an account for her actively resistant position in lines 08-11, citing that this friend had chemotherapy in one place and then it came back again somewhere else. Omitted from this excerpt is further detail of this friend's experience with cancer. Rather than accepting the patient's resistant stance towards treatment, the physician responds by pushing back on the resistance and advocating for treatment. He first contradicts the patient by establishing that without chemotherapy, the cancer has a possibility of coming back: "and there's a chance those microscopic cells become active at some point, (.) en: grow and recur." (lines 35-36). In overlap with the patient's response, the patient's sister seconds with this position in line 37, "and we don't want that." The patient continues to resist the treatment recommendation in

questioning whether the cancer could even come back after the surgery that removed it all: "even though you took it- you don't think it was: like u:m:." (line 38). Despite giving the interactional floor to the physician once he comes in via overlap in line 39, we can assume she is pursuing additional questioning about the remnants of the microscopic cells in her body relative to the surgery she just had.

The physician, coming in via overlap in line 39, treats the patient as challenging the idea of chemotherapy, an idea which he quickly addresses in lines 39-41 by offering an account: "I don't think it had spread but- but .hh we always assume there's microscopic cells there.=we have to assume. (.) u:m so: that's the much safer side of valor?" It is at this point, where the patient still has not offered treatment acceptance, that the physician provides a second treatment recommendation: ".hh u:m if it were me I would do the- I would without a doubt in my mind do the chemotherapy?" (lines 42-43). This personal-level endorsement pushes his position in favor of treatment. Just following the core of this treatment recommendation, the physician invokes death by putting the chemotherapy treatment in perspective for the patient in lines 44-46: ".hh I'm gonna play devil's advocate here and say eighteen weeks of your life (.) one day a week its much less than: dying from a recurrence in >three or four< years." Here it is evident that the explicit invocation of death invokes the patient's death as linked to not proceeding with treatment and thus functions as a way to push the patient to acquiesce to his recommendation.

Both Extracts 12 and 13 offer invocations of death as responsive to an initial resistant stance towards treatment. Necessarily, we may assume that physicians are turning to these death invocations for treatment acquiescence only when patients index up front that they are against it. Yet in Extract 14 (Extract 11 shown earlier), death is invoked as responsive to a variety of questions from that patient that challenge different aspects of the physician's treatment recommendation. As was previously laid out, this patient has Stage IV uterine cancer that has metastasized to her lung.

The physician recommends that the patient have both a hysterectomy and a bilateral salpingooophorectomy, and recommends that she see another medical oncologist about her lung cancer:

(14a)0301c

```
01
   DOC:
             So (.) y- see Doctor Hamlin and see if he agrees with me:, (.) We
02
             should take out the uterus and the cervix? .hh the tubes and the
03
             ovaries? .hhh through an incision that'll come down like this,
04
             (.) Fix your hernia at the same time, (0.2) Why not. (.) Fix it
05
             at the same time.=.hh and then look around everywhere else and
06
             do biopsies, .hh and see if it's anywhere else. (.) At the same
07
             time,
80
   PAT:
           > .pthh where else for example.
09
   DOC:
             In the belly.
10
   PAT:
             ((Cocks head and raises eyebrows))(0.4)
11
   DOC:
             Anywhere in the belly.
12
             ((Eyebrows still raised))(0.2)
   PAT:
13
   DOC:
             Possible.
14
           > Why- doesn't it show .hh on the: nuclear pet scan.
   PAT:
15
   DOC:
             Cause scans are not a hundred percent- (0.2) accurate. (.) It's-
             it's probably accurate [but no quarantee. (.) So while we're
16
                                     [((Nods head))
17
   PAT:
17
             there why not take a few samples. .hh [and make sh-
18
   PAT:
                                                    [Of what.
             Of tissue.
19
   DOC:
```

Following the treatment recommendation for surgery (lines 01-07) which makes acceptance normatively relevant (Stivers, 2005b), the patient instead demonstrates initial treatment resistance by mobilizing one of a series of challenge questions beginning in line 08: ".pthh where else for example.". This particular question takes issue with whether cancer could have spread to other locations in her abdomen, challenging the warrant for the surgery. After the physician explains that it could have spread to her "belly", the patient continues to resist passively in the missed opportunity spaces for acceptance in lines 10 and 12 where she embodies surprise in raising her eyebrows and cocking her head but offers no other response. Next, the physician pulls back on his certainty slightly in line 13 by alluding instead to the *possibility* of the cancer having spread to her belly.

The patient continues to actively resist in line 14 by asking another question that challenges the physician's claim of the cancer's spread: "Why- doesn't it show .hh on the: nuclear pet scan." In mobilizing the negative results of the PET scan, the patient continues this resistant line that questions whether this cancer has spread to other parts of her abdomen and thus the warrant for the

surgery. In response, the physician pushes back by leveraging uncertainty, that the scans are "not a hundred percent" and there is "no guarantee" (lines 15-16). Recall from Chapter 3 that this practice is used to make a case for treatment acceptance. He counters this resistant line of questioning by advocating for taking tissue samples in the abdomen in addition to the removal of reproductive organs. In overlap with this, the patient continues to resist by asking where samples would be taken from (line 18). The physician re-iterates that he is taking tissue samples (line 19).

In Extract 14b, the patient maintains her actively resistant stance towards treatment with more challenge questions:

#### (14b)0301c

```
.pthhh u- uh:. you have done many of surgeries like that.
01
   PAT: >
02
   DOC:
            Making a man from a woman.
03 PAT: >
04 DOC:
            I've done [that too.
05
   RES:
                       [Hheh heh heh no:: you're [still a woma:n,
   DOC:
06
                                                     [Not for you.
07
   PAT:
            Ye:s (so: [ma-)
80
   DOC:
                       [Not for you,
             .hhh so now it is for me.=
09
   PAT:
10 DOC:
           =((Coughs)) no [not for you. It's not the [same operation.
11
   PAT:
                                                      [.hh uh will you then,
12
             .h give some uh:. (.) hormone therapy so: that I-
13
   DOC:
             May:be- no- not for hormones no not likely.
14
   PAT:
             .hh and what if I grow a beard and mustache,
15
   DOC:
             You have to live two years before that happens. (.) If you have
16
             this ((points to lung)) it could be: . Threaten your life within
17
             six months to two years.
             .hhhh uh- uh listen I must tell you that seven months already
18
   PAT:
19
            have passed.
20 DOC:
             .hh so that's why I'm saying_ (.) Doctor Hamlin has to decide if
            he wants to treat you for this first .hh and let me- have me do
21
22
             this ((points to genitals)) second.
```

In line 01, the patient further resists by confronting the physician's experience with this surgery: ".pthhh u- uh:. you have done many of surgeries like that." As was discussed in the prior section, the patient demonstrates continued resistance in line 03, by referring to the surgery with an extreme categorization, "Making a man from a woman." The physician takes this literally and confirms that sex reassignment surgery is not the surgery this patient will be having. The patient's overt resistance continues in lines 11-12, ".hh uh will you then, .h give some uh:. (.) hormone

therapy so: that I-" to which the physician tells her he will "not likely" be giving her hormones after surgery (line 13). Next, the patient sustains her resistance by continuing to pushing the point of losing her womanhood with this surgery in her extreme characterization of its side effects, ".hh and what if I grow a beard and mustache," (line 14). The physician pushes back on this continued resistant position by invoking the patient's death: "You have to live two years before that happens." (line 15). This invocation implies that the patient could die from her untreated cancer and thus links her resistance to the possibility of death. The physician elaborates on this in the next TCU, "If you have this ((points to lung)) it could be:. Threaten your life within six months to two years." Here, the possibility of death is made more imminent in the context of resisting the treatment. While the patient does not explicitly resist the treatment plan up front as in the previous two cases, the questions- each with a challenging piece to them- persist when acceptance to the recommendation is due. The physician pushes back on this resistance by alluding to the patient's death from the metastasis of her uterine cancer. The invocation of death here functions as a way of creating urgency in accepting the recommended treatment, thus death is used as a resource to get the patient to acquiesce to the treatment recommendation of surgery.

Following these three cases just discussed, as a matter of course we might wonder whether invoking death to get patients to acquiesce to treatment is a practice reserved for only the most extreme cases of resistance. However, physicians invoke death as a resource to get patients to acquiesce to treatment even when resistance is relatively mild. This is quite surprising given that invoking a patient's death in discussing treatment is a so-called "nuclear option." An instance of this is shown in Extract 15, shown earlier as Extract 9. This patient has been diagnosed with aggressive cervical cancer that has spread to her lymph node, a worrisome progression. The physician begins with a treatment recommendation (lines 05-07), which is subsequently resisted:

(15a)0128

```
01
   DOC:
             .hh yesterday we had our big conference? member I said I was
02
             gonna present your case at the big conference and I did? .hh and
03
             I'm glad you:re >sort of< here so we can talk about it very
04
             fresh .hhhh (.) we talked about (.) your s::. your type of
05
             cancer:? (.) what the:. best treatment should be: and the: team
06
             agreed that the best treatment would be a combination of
07
             chemotherapy and radiation at the same time an[d then followed
80
   PAT:
                                                            [really?
09
   DOC:
             with chemotherapy. .pthhhh because the: overall:.m (.) this is
             very rare. (.) This clear cell: cancer of the cervix is a very
10
   DOC:
             rare kind..hhh your clear cell cancer >member I said< oh
11
```

After invoking the consensus of her colleagues about the proposed treatment, the physician recommends chemotherapy and radiation to treat this patient's cervical cancer (lines 05-07). This is quickly resisted in the patient's response at line 08, "really?" in which she produces a challenge to the recommendation in overlap with the physician with a newsmark (Heritage, 1984b; Jefferson, 1981), which can be mobilized for disagreement (see Schegloff, 1997). While this newsmark is indeed a challenge to the recommendation, it functions as a less overt form of resistance because it does not challenge specific parts of the treatment recommendation. The physician completes the recommendation in line 09 and then begins to respond to the patient's overt resistance by launching an account for the treatment in lines 09-11, that the patient's clear cell cancer is a very rare kind of cancer: ".pthhhh because the: overall:.m (.) this is very rare. (.) This clear cell: cancer of the cervix is a very rare kind". The following extract offers more discussion about the severity of the patient's cancer, which gets no uptake from the patient. As a response to this continued resistant behavior, the physician begins to discuss what would happen if the patient did, in fact, decide not to pursue the treatment recommendation:

#### (15b)0128

```
Um (.) if we don't do: the radiation and chemotherapy:
01
   DOC:
02
             (0.8)
03
             It's (0.4) °w-° (0.4) we may end up with e- a lot of
             problems: okay it's a very serious diagnosis to have anyway?
04
05
             and because there was some cancer already in the lymph node?
06
07
             .hhh (0.2) if we don't do it (.) we:: it will come back,
08
           (.) and if it comes back it will be deadly.
```

First the physician registers that if the recommendation is not followed, the patient could end up with complications (lines 01-04): "Um (.) if we don't do: the radiation and chemotherapy: (0.8) it's (0.4) °w-° (0.4) we may end up with e- a lot of problems: okay". Multiple opportunity spaces exist in this turn for the patient to respond with either some degree of initial acceptance or acknowledgement, as shown by the multiple micropauses in lines 01 and 02. Next, the physician uses a response mobilizing "okay" at the end of a possible turn completion in line 04, which is not responded to. She continues with even more explicit evidence for treatment, "it's a very serious diagnosis to have anyway? and because there was some cancer already in the lymph node? (.)" (lines 04-05). Both the action this turn seeks to accomplish- to demonstrate the disease's severity- and the lexical features of this turn, an upwardly-intoned "anyway?" and in the following TCU "lymph node?" are response mobilizing (see Stivers & Rossano, 2010).

Despite this, the patient does not respond and in so doing continues to passively resist (Heritage & Sefi, 1992). In the next TCU, the physician invokes death in lines with a conditional phrase: "if we don't do it (.) we:: it will come back (.) and if it comes back it will be deadly" (lines 05-06). Here, the patient's death is framed as likely should she not wish to pursue treatment, thus the physician orients to her lack of uptake as resistance. So, what ultimately occasions this invocation of death is the patient's overt resistance of the treatment as shown by her challenge of the recommendation in Extract 15a and by her withholding of acceptance in Example 15b. The possibility of the patient's death, should she decide to not pursue the proposed treatment regimen, is linked to her resistance and thus functions as a way to persuade the patient to accept the proposed treatment.

While most of the time death is invoked to leverage treatment for the patient's cancer, in one instance in my data death is invoked to leverage treatment for a health issue *not* related to the patient's cancer treatment. This case adds further support to the argument that death invocations in

these data are generally used in persuasive contexts. In Extract 16, analyzed earlier in Extract 1, we met this patient in the middle of chemotherapy and radiation for her cancer. While in the excerpt shown below no treatment resistance occurs in her talk, it can be argued that the patient's visible morbid obesity instantiates resistance to a healthy lifestyle. In other words, she is literally embodying resistance. This has had consequences for her overall health and her heart. In the below excerpt, the physician speaks to this resistance:

```
(16)0208
01
   DOC:
           > .hh uhm I n- >yiknow< eating is really the: the na- the thing
           > you should worry about [I know the nausea impacts you, .hh
02
03
   PAT:
                                     [Okay,
04
   DOC:
           > yiknow weight loss <u>is</u> gonna be important for you? .h
05
    PAT:
             [Mhm,
                                        [Yes:
06
    DOC:
             [En so we- I do want ya to[:. at least when this is all said and
07
             done w- focus on that to.=because we know with your heart issues
80
             .hh an:d um: your overall health tha- that's probly: .hh to be
09
          > perfectly frank the more likely thing you'll die from.
10
   PAT:
             [Okay,
11
   DOC:
             [.hh en so I think it's important that we focus on that too?
12
             .hh bu:t I think- en that's why I'm: I'm really encouraged by
13
             the fact that I heard you say that you're gonna k-find healthy
14
             things to eat [and juices en- en that's really good.
15
   PAT:
                            [Yes:.
```

The physician initially acknowledges the patient's resistance in line 01, where he tells the patient that eating is what she should be "really" worrying about. Here, the "really" implies that the patient has not been worried up until this point. Then the physician tells her that weight loss will be important for her in line 04. The emphasis on "is" in this turn is contrastive with the implied position that weight loss has not been important to the patient. The physician continues with a treatment recommendation- that once her treatment is over, she should focus on weight loss (lines 06-07). He accounts for this by telling her that between her heart issues and overall health, that these things are "the more likely thing you'll die from" in line 09. Thus, the patient's resistance via her continued obesity (which has caused her heart and other health issues) occasions this physician's explicit invocation of death. Death is invoked as a resource to advocate for treatment, in this case

weight loss. Should the patient not comply with the recommendation to lose weight, she will be likely to die from her obesity.

Stivers (2005b) found that when parents resisted treatment recommendations, physicians did not simply fold and accept that position. Instead, they used different resources to seek acceptance of the treatment recommendation. For instance, pediatricians would provide accounts for the recommendation, restate the recommendation, provide lists, or explicitly request acceptance of the recommendation. Ultimately these practices were used to push back against patient resistance. These data similarly show that physicians in the context of cancer care push back against resistance, but they do so by invoking the possibility of the patient's death. In thinking about these findings, one could argue that the practice of invoking death is a way to account for treatment. However, invoking death in response to resistance is a more extreme way of accounting for treatment than what Stivers (2005b) found. Further, that physicians invoke death as a resource for treatment acquiescence even in relatively mild instances of treatment resistance demonstrates a practice which fundamentally targets—in a most extreme way—the biggest fear of patients in cancer care.

What is also striking about this practice is a lack of acceptance of patients' resistant positions in the context of cancer care, an area in which SDM and patient involvement has been advocated for (Ejem et al., 2016; Politi et al., 2012). We might therefore assume that in cancer care physicians may be more likely to accept patients' positions of treatment resistance. They do not. It has been found that physicians generally push back against resistance a variety of contexts such as pediatrics (Stivers, 2005b), psychiatry (Thompson & McCabe, 2017), and neurology (Toerien et al., 2011) to seek acceptance of the treatment recommendation. However, the possibility of a patient's death was not mobilized as a resource to counter resistance like incancer care. We might conclude that death is put on the table because the stakes for not treating *are* the highest possible—death—and physicians are capitalizing on this issue. This is apparent not only in that they invoke death as linked to resistance,

but also that they use it as leverage relatively early after patients demonstrate resistance rather than using less extreme accounts for treatment, such as treatment statistics or explicit requests for acceptance.

# 4.4.4 Invocations of Death to Advocate for Particular Treatment Outcomes

Thus far I have analyzed invocations of death in the context of treatment resistant behavior to advocate for particular treatment outcomes. This was the most typical occurrence of death invocations in the data. However, I also find that physicians invoke death to advocate for particular treatment outcomes when there are other mitigating factors. Of 19 total death invocations to leverage treatment, 4 (21%) were made not in response to resistance but when resistance could be anticipated. An instance of this is shown in Extract 17. In this encounter, the patient has been continuing maintenance treatment for ovarian cancer by taking an oral multikinase inhibitor.

Recently her CA-125 level has risen rapidly, which suggests further cancer growth and inefficacy of the current treatment regimen. She is seeking treatment for this with her oncologist, who is new to treating this patient. She had been previously working with another oncologist and it is unclear why she has switched to this oncologist- who she has seen just once before. In Extract 17a, after discussing getting the records from the patient's previous doctor, the physician recommends treatment (lines 07-09):

(17a)0123

```
Okay great. (.) So I do have those records. [Okay.
01
   DOC:
02
   PAT:
                                                           [Yeah >yeah< I mean
03
             he was on vacation fer .hh (.) Ith- uh bout a month, (.) en (.)
04
             en a lotta times on vacation. .hh [a:n-
0.5
   DOC:
                                                 [^Okay,
06
   PAT:
             (.) so.
             Okay so I think carboplatinum will be fine for you like we
07
    DOC:
80
            talked last time. .hhh carboplatinum is a c- chemotherapy
             drug.[=It does not make you lose your hair, .hh but it=uh is a
09
10
   PAT:
                  [Yeah.
11
   DOC:
             real drug. It (.) can cause (.) bone marrow side effects? like
12
             low blood counts?
13
    PAT:
   DOC:
             Anemia low platelets.
```

#### 15 PAT: Mhm,

The treatment recommendation is proposed to the patient, "so I think carboplatinum will be fine for you like we talked last time." (lines 07-08) which subsequently does not get resistance. The patient offers initial acceptance in line 10, "Yeah." just following the physician's reminder that ".hhh carboplatinum is a c- chemotherapy drug." (line 9). Following more explanation of the serious side effects of the chemotherapy (lines 09, 11 &12), the patient acknowledges these side effects in line 13, "Yes." She still does not show evidence of resisting the treatment. The physician continues with more side effects in line 14, which the patient continues to acknowledge (line 15). Following this, the patient begins to complain about her experience with her chemotherapy port the last time she had infusions, and how she had to go to the hospital because it became infected. She continues to explain that the nurses, who would come to the house to help her clean the port at home, did not notice this infection. She even goes to far as to say that her experience with the port was a stressful experience. She continues to recount the issues she had with her port in Extract 17b:

### (17b)0123

```
01
   PAT:
             Finally >of course< I kept tellin her it's all red >en it< red
02
             .hh no one paid attention everywhere I went. .hh finally they
03
             realized it was in- (.) infected,
             [°Oh°
04
   NUR:
05
    DOC:
             [.tch aw I['m sorry (
                        [There I was I it off, .hh hhh
06
    PAT:
07
    DOC:
             Sorry,
80
    PAT:
             .pt but then it was gone .hh ye(h)ah, (0.4) You could shower
09
             properly [en stuff like that.
10
   DOC:
                       [Yeah it feels good when it's off,
11
    PAT:
         > Ye:ah. (0.2) .hh so. [.pt I mean how can it be wonderful ah ha
12
   DOC:
                                   [Alright.
13
   PAT:
             HA HA .hh (.) it can't.
             Not really.
14
   DOC:
   PAT:
             .tch
15
             But (.) sometimes it's better than the alternative.[>ALright
16
   DOC:
17
    PAT
18
    DOC:
             have a good da:y, (.) Ple:ase call, (.) if you have questions,
```

The patient elaborates on the nurse's inaction in adequately recognizing the infected port (lines 01-03), to which the clinic nurse registers surprise (line 04) and the physician registers empathy (line 05) (see Heritage, 2011 for further discussion). The patient next revitalizes her experience of

having to go to the hospital to get it removed (line 06), to which the physician responds with more empathy (line 07). The patient then offers an upshot of getting the port removed, ".pt but then it was gone .hh ye(h)ah, (0.4) You could shower properly en stuff like that." (lines 08-09), a position with which the physician aligns in overlap, "Yeah it feels good when it's off." (line 10).

After providing a yes-response to this, the patient contrasts this bright side of her past treatment with an overall negative assessment of treatment: ".pt I mean how can it be wonderful ah ha HA HA .hh it can't" (lines 11 & 13). Here the laughter particles are evidence for the patient's troubles talk (Jefferson, 1984) in complaining about the downside of her treatment. In response, the physician obliquely invokes death: "But (.) sometimes it's better than the alternative." (line 16). Here, we can infer that the "alternative" to which the physician is referring is the alternative to the thing the patient has been complaining about- her past treatment.

In this case, it can be assumed that the alternative to treatment is the no-treatment option. Not treating ovarian cancer will result in eventual death, therefore this is an oblique death invocation. Given that the possibility of death is produced against the backdrop of just having recommended treatment which involves the very thing the patient complained about- a chemotherapy port- it can be assumed that this physician is anticipating resistance to treatment. Thus, death is invoked here not because the patient resisted the treatment recommendation, but to advocate for pursuing treatment.

Another instance of death being invoked to leverage treatment outside of a patient's proximate resistance is offered in Extract 18. Here, the patient has been diagnosed with a Gleason 6 prostate cancer, which is at the lowest level of what is considered a cancer. Typically, prostate cancers with a Gleason 5 or lower do not warrant treatment per the standard of care (see American Cancer Society, 2017). Following a discussion of where the Gleason scoring system comes from, the

physician explains to the patient that- because he is on the borderline- determining treatments is not as straightforward:

```
(18)0401
   DOC:
           > So you fall .hh right smack in the middle of intermediate=That's
01
02
           > where about fifty percent of men fall. (.) When they're
03
           > diagno[sed.
04
   PAT:
                   [Mhm,
             Okay so you're .hhh you're in good company. (.) .pt The other
05
   DOC:
06
   DOC:
             factor that you have is that you've got only one core. (.) .hh a
07
             little over ha: If the core invol: ved. Okay. (.) . hhhh so- HHH
80
           > this becomes a little bit trickier >as to< how to- how to how to
09
             judge this, .hhh there are some cancers that we find.=En
10
             actually the majority of cancers we find, .hh aren't gonna kill
11
           > someone. (0.2) En I'm not even certain that this cancers going
12
           > to kill you, (.) >But that< (.) i::s, .hhh (.) 234omething- e-
Ι
             don't wanna tell you that this is not a problem.=It is
13
234omething
14
             that- that needs attention. (.) We just have to decide_ .hh what
15
             level of attention is commensurate to where you are in life, en
16
             so I'm gonna ask you some questions,
17
   PAT:
18
   DOC:
              [.hh that kinda help me parse that out,
```

In lines 01-03, the physician explains to the patient that his cancer is at an intermediate level. minimizing the severity of the disease. He continues that the patient has "only one core. (.) .hh a little over ha: If the core invol: ved. Okay." (lines 06-07), which further downplays the severity of this patient's cancer. The physician goes on to explain that this low-grade cancer will be trickier to judge in terms of determining treatment (lines 08-09). Yet, he next goes on to invoke death in lines 09-11: "En actually the majority of cancers we find, .hh aren't gonna kill someone." which has the effect of reassuring the patient that his cancer is likely not deadly. In the next TCU, the physician invokes death in more direct terms to the patient, "En I'm not even certain that this cancers going to kill you," (lines 11-12). Here, he is indexing some uncertainty in whether the cancer is deadly or not, despite previously reassuring the patient that his cancer is low grade. Thus the physician frames this as a danger insofar as it could "kill" him, but then markedly reduces the certainty of this action, "En I'm not even certain that this cancers going

to kill you," (lines 11-12). This indicates a degree of prognostic uncertainty. Overall, the physician here indexes uncertainty in how risky this cancer is to the patient's health. He does this by implying both uncertainty about treatment (lines 08-09) and uncertainty of prognosis (lines 11-12).

The physician continues, ">But that< (.) i::s, .hhh (.) 235omething- e- I don't wanna tell you that this is not a problem.=It is 235omething that- that needs attention." (lines 12-14). This promotes the need to pursue some kind of treatment because it is uncertain whether or not leaving this cancer untreated would result in the patient's eventual death. Subsequently, he adds, "We just have to decide\_ .hh what level of attention is commensurate to where you are in life, en so I'm gonna ask you some questions," (lines 14-16). In the sequence following this excerpt, the physician goes on to ask the patient about his physical health related to his prostate and details a conference he attended where borderline patients were discussed. Ultimately, this excerpt shows the physician setting up the problem by casting treatment for this type of cancer at different levels of attention. The decision that needs to be made is what level of attention is appropriate for treating this cancer.

Here, the invocation of death is produced in the context of the need to pursue treatment and is contrasted with an implied position of leaving this borderline cancer untreated. This invocation has the effect of indexing that the cancer still has the potential to kill this patient- prognostic uncertainty- despite the sequentially prior reassurance that the cancer is right on the borderline of necessitating treatment to begin with. The invocation of death additionally has the effect of imbuing some fear in the patient, that is, that the cancer has a chance of killing the patient so treatment needs to be given proper consideration.

Throughout this sequence, the physician foregrounds the uncertainty of prognosis (for further discussion, see Chapter 3) to justify pursuing treatment. He could have equally foregrounded the necessity of treatment by saying "We should treat because we don't know if this will kill you", yet he instead foregrounds the prognostic uncertainty. Although the prognosis is marked as

uncertain, the fact that he has put prognostic uncertainty on the table moves the possibility of a negative prognosis to the center of the interaction. In so doing, prognostic uncertainty becomes an important lever for advocating for treatment. On the spectrum of death invocations, the possibility of death in this case is framed as the least imminent and threatening. However, like the prior example, it is still used to push the patient to accepting treatment despite no resistance. So, death invocations can also function as a way to anticipate resistance and address a potential future source of resistance.

# 4.5 Discussion

In this chapter, I seek to better understand how death is being broached in the context of cancer treatment. Sociologists have studied death discussions for decades, and have found that discussing the terminal nature of a patient's disease is something that physicians have continued to confront with hesitancy and difficulty and while this chapter shows that reticence to discuss death in EOL care persists, even in an age of increased reliance on hospice and palliative care, it also shows a distinct lack of reticence to *invoke* death when this can be used as leverage to encourage patients to accept a physician-proposed treatment.

In my cross-section of visits only once was death brought up in the context of the patient's EOL. The way the physician broached the patient's death was in line with what the literature might predict: he avoided using the words "death and dying" and instead used euphemism in referencing stopping treatment and the patient's eventual demise. In thirteen other cases, physicians missed opportunities to discuss EOL care in treatment environments where treatment cessation or palliative care discussions would have been appropriate. In one instance of this, the patient showed overt emotion about going back and forth between different treatments. Because the patient was showing frustration upon reflection of his treatments' inefficacies, this would have been a ripe interactional environment to offer stopping treatment as an option. Instead, three options for continued

treatment of his metastatic prostate cancer were put on the table, despite all having minimized treatment benefits. This could have functioned as a way to forecast to the patient (Maynard, 1996) the diminishing returns of treatment without having to confront the possibility of EOL care.

In a second instance, the video-taped interaction did not offer evidence for the patient's diminishing treatment possibilities despite the patient having an aggressive cancer that was too risky to remove via surgery. In the encounter, the physician laid out a treatment plan for the patient- to pursue a new chemotherapy and add radiation. These were indexed as reasonable options for the patient to pursue. Ethnographic notes from my encounter with the physician after she left the exam room told a different story. The physician confided in me that she was frustrated because the patient was dying, and, according to her, the patient was aware of this. Yet, the video provided no explicit evidence for this claim. The patient did show some silent tears at the beginning and end of the interaction, and the physician reminded the patient that her cancer was aggressive. However, there was nothing to suggest that the patient knew that her illness was terminal. More significantly, the physician did not provide any indication to the patient that she was dying.

It is crucial to emphasize that physicians are overall not bringing up stopping treatment in these visits, which is helpful to our understanding of late hospice referrals (Bergman et al., 2011; Wentlandt et al., 2012). Of 90 cases in my cross-section of data, which included 61 treatment recommendations, treatment cessation was brought up just once. Although there is the possibility that palliative care, hospice, or treatment cessation could have been broached at other visits, it is significantly not brought up in 89 visits. Yet, one could argue bringing up these issues with earlier stages of cancer is inappropriate and carries inherent interactional difficulty. So, I set conservative parameters where I argued it would be reasonable to broach treatment cessation, palliative and/or hospice care: patients with Stage IV cancer with whom treatment is being discussed. In total, fourteen cases in the corpus satisfied these parameters. But in only one of these encounters involved

a discussion about EOL care. In the remaining thirteen, palliative care, treatment cessation, and/or hospice care were notably left off the table where discussing them would have been appropriate. This echoes sociological conclusions about reticence to discuss death or avoidance of the topic altogether.

The lack of discussion about treatment cessation, palliative care, and/or hospice by oncologists makes these options interactionally irrelevant treatment options unless patients were to bring these issues up themselves. Spencer (2018) found that patients claim to have advocated for hospice before their physician brought it up. Yet this bypass of physician authority is unique. In general, patients do not circumvent physicians' epistemic and deontic authority to add on their own treatment options. I do not see patients doing this in my data, nor do they tend to do this in other medical contexts (see Stivers et al., 2017). Therefore, if physicians do not put treatment cessation on the table, it is arguably not going to be selected by patients. Even in ordinary interaction, this does not happen. As was discussed earlier, transformative answers are rare (see Stivers & Hayashi, 2010). So, if these EOL options are going to be put on the table, it likely must be done by patients. Further, in order for patients to do this, they also must believe that no other treatments will work and accept their own death. In other words, have active open awareness (see Timmermans, 1994). For a patient to get to this point, we could imagine, would be uncommon.

But these cases of avoidance of palliative care and/or EOL discussions did not mark the end of the story. I also found that death was being brought up outside of EOL discussions. This chapter therefore asked: if death was not being talked about in ways that the literature anticipated, then how was it being discussed? Upon analysis, when death was invoked by physicians, it was done *outside of* end-of-life conversations. Specifically, one of the primary places I found death being invoked was in recommending treatments. When it was invoked in this context I found that it was being used to push patients towards accepting a particular treatment course. Ultimately, I conclude that physicians

in these data invoke death as a bargaining chip to leverage their authority for particular outcomes. The most frequent way that physicians invoked death was in the context of patients' resistant behavior. When patients demonstrated active or passive resistance, physicians would invoke the possibility of the patient's death in order to push back against this resistance and get patients to acquiesce to treatment. Occasionally, physicians invoked death in instances where resistance was anticipated but never actualized. Similarly, death invocations functioned in order to lobby in favor of treatment.

There is a diametric nature to the way death comes up in these data. On the one hand death inhabits these encounters as a way to get patients to acquiesce to treatment. On the other hand, death and the terminality of illness gets written out of these encounters when treatment cessation and palliative care are appropriate to broach. In spite of this, the overall functions of these opposing forces are the same: to get patients to pursue more treatment. Notably, death does become part of these visits, but not through a desire to stop treatment because physicians and patients are acting as though cancer is a treatable condition at both early and late disease stages. Specifically, death inhabits these visits in order to enforce that cancer is and *should* be treated. These data clearly demonstrate that treating is a normative orientation that physicians have throughout different stages of the disease- including Stage IV cancers. When patients show a departure from this normativity with resistance, physicians use death as the ultimate consequence for this departure.

Perhaps this can be explained by how physicians are socialized throughout their years in training. From a Durkheimian perspective, physicians learn particular norms and internalize certain attitudes central to the institution of medical practice. Physicians have been found to share a collective sense-making of error (Bosk, 2003) and collectively manage and control uncertainty (Fox, 1957; Light, 1979). Further, fundamental to physician's everyday practice is solving patients' medical problems and thus acknowledging treatment cessation as more appropriate in some cases is quite

difficult (Hoffmaster, 2009). Notably, as members of a profession, physicians are share a sense of accountability to their peers (Starr, 1982). For instance, oncologists have regular tumor board meetings where particular cases are presented and teams of experts discuss various treatment avenues. Peer accountability is arguably highest at these meetings, where expertise is put on full display. Additionally, the normativity of treatment throughout different disease stages is reinforced by the structure of these meetings as physicians collude with each other to discuss disease treatment. Not only is this problematic for the consideration of quality of life, but also for healthcare spending. Healthcare spending on patients in at its highest in the end-of-life period (Barnato et al., 2004; Cheung et al., 2015; Gawande, 2010). In fact, cancer patients who received aggressive treatment in their final month of life incurred 43% higher costs than did those who received palliative care (Cheung et al., 2015).

This analysis demonstrates that physicians have a fundamental orientation to treatment in the oncology context. The first section established physician reticence to discuss death yet the second showed evidence that physicians do discuss it. While these two phenomena seem in opposition, when the functions of these practices were exposed it was clear that they share the same ends: advocacy for treatment. We can speculate that this is a normative phenomenon with consequences. Because it is almost never discussed by physicians, it is arguably almost never going to be pursued. While it is possible for patients to advocate for treatment cessation, this analysis highlights the inherent difficulties in doing that. In the extremely relevant context of runaway healthcare spending, this analysis suggests that this normative orientation to treatment leaches into interactions where an EOL discussion, or a transition to palliative care, would have been more appropriate. Clearly, physicians are willing to go to extreme lengths to strongly advocate for treatment. This is even true when patients overtly demonstrate an initial stance towards non-

treatment. While oncologists' primary role is undoubtedly to treat cancer patients, we may wonder: does this sometimes go too far?

# References

- Aldridge, M. D., Canavan, M., Cherlin, E., & Bradley, E. H. (2015). Has hospice use changed? 2000-2010 utilization patterns. *Medical Care*, *53*(1), 95.
- American Cancer Society. (2017a). Cancer survival rates, by stage.
- American Cancer Society. (2017b). *Understanding Your Pathology Report: Prostate Cancer*. Retrieved from www.cancer.org
- Annas, G. J. (1998). A national bill of patients' rights.
- Arnold, E., Finucane, A. M., & Oxenham, D. (2015). Preferred place of death for patients referred to a specialist palliative care service. *BMJ Supportive & Palliative Care*.
- Back, A. L., Arnold, R. M., Baile, W. F., Tulsky, J. A., & Fryer-Edwards, K. (2005). Approaching difficult communication tasks in oncology1. *CA: A Cancer Journal for Clinicians*, *55*(3), 164–177.
- Barnato, A. E., McClellan, M. B., Kagay, C. R., & Garber, A. M. (2004). Trends in inpatient treatment intensity among Medicare beneficiaries at the end of life. *Health Services Research*, 39(2), 363–376.
- Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making—the pinnacle of patient-centered care. *New England Journal of Medicine*, *366*(9), 780–781.
- Bergman, J., Saigal, C. S., Lorenz, K. A., Hanley, J., Miller, D. C., Gore, J. L., & Litwin, M. S. (2011).

  Hospice use and high-intensity care in men dying of prostate cancer. *Archives of Internal Medicine*, 171(3), 204–210.
- Bosk, C. L. (2003). Forgive and remember: managing medical failure. University of Chicago Press.
- Brock, D. B., Foley, D. J., & Salive, M. E. (1996). Hospital and nursing home use in the last three months of life. *Journal of Aging and Health*, 8(3), 307–319.
- Centers for Disease Control and Prevention. (2017). CDC.gov Health Statistics. Retrieved

- September 19, 2017, from http://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm
- Cheung, M. C., Earle, C. C., Rangrej, J., Ho, T. H., Liu, N., Barbera, L., ... Mittmann, N. (2015).

  Impact of aggressive management and palliative care on cancer costs in the final month of life. *Cancer*, 121(18), 3307–3315.
- Christakis, N. A. (1997). The ellipsis of prognosis in modern medical thought. *Social Science & Medicine*, 44(3), 301–315.
- Christakis, N. A. (2001). Death foretold: prophecy and prognosis in medical care. University of Chicago Press.
- Christakis, N. A., & Iwashyna, T. J. (1998). Attitude and self-reported practice regarding prognostication in a national sample of internists. *Archives of Internal Medicine*, *158*(21), 2389–2395.
- Clark, R. E., & LaBeff, E. E. (1982). Death telling: Managing the delivery of bad news. *Journal of Health and Social Behavior*, 366–380.
- Clayman, S. E. (2010). Address terms in the service of other actions: The case of news interview talk.

  Discourse & Communication, 4(2), 161–183.
- Dumanovsky, T., Augustin, R., Rogers, M., Lettang, K., Meier, D. E., & Morrison, R. S. (2016). The growth of palliative care in US hospitals: a status report. *Journal of Palliative Medicine*, 19(1), 8–15.
- Ejem, D., Dionne-Odom, J. N., Willis, D., Kaufman, P., Urquhart, L., & Bakitas, M. (2016).

  Differences between women's preferred and actual experience with "shared decision-making": A mixed method study.
- Faden, R. R., Beauchamp, T. L., & King, N. M. (1986). A history and theory of informed consent.
- Finestone, A. J., & Inderwies, G. (2008). Death and dying in the US: the barriers to the benefits of palliative and hospice care. *Clinical Interventions in Aging*, *3*(3), 595.
- Fitts, W. T., & Ravdin, I. (1953). What Philadelphia physicians tell patients with cancer. Journal of the

- American Medical Association, 153(10), 901–904.
- Ford, C. E., & Fox, B. A. (2002). Constituency and the Grammar of Turn Increments. In C. E. Ford, B. A. Fox, & S. A. Thompson (Eds.), *Sound Patterns in Interaction: Cross-linguistic studies* from conversation (pp. 14–33). Philadelphia: John Benjamins Publishing Company.
- Fox, R. C. (1957). Training for uncertainty. In Robert K Merton, George G Reader, & Patricia Kendall (Eds.), *The Student-Physician: Introductory Studies in the Sociology of Medical Education* (pp. 207–241). Cambridge, Mass: Harvard University Press.
- Gawande, A. (2010). Letting Go: What should medicine do when it can't save your life? *The New Yorker*, (August 2).
- Gawande, A. (2014). Being mortal: Medicine and what matters in the end. New York: Metropolitan Books.
- Glaser, B. G., & Strauss, A. L. (1965). Awareness of dying. New Brunswick, NJ: Transaction Publishers.
- Harris, P. S., Stalam, T., Ache, K. A., Harrold, J. E., Craig, T., Teno, J., ... Casarett, D. (2014). Can hospices predict which patients will die within six months? *Journal of Palliative Medicine*, 17(8), 894–898.
- Heritage, J. (1984). Garfinkel and ethnomethodology. Polity Press Cambridge.
- Heritage, J. (1998). Oh-prefaced responses to inquiry. Language in Society, 27(3), 291–334.
- Heritage, J. (2011). Territories of knowledge, territories of experience: Empathic moments in interaction. *The Morality of Knowledge in Conversation*, 159–183.
- Heritage, J. (2015). Well-prefaced turns in English conversation: A conversation analytic perspective. *Journal of Pragmatics*, 88, 88–104.
- Heritage, J., & Sefi, S. (1992). Dilemmas of advice: Aspects of the delivery and reception of advice in interactions between health visitors and first-time mothers. In P. Drew & J. Heritage (Eds.), *Talk at work: Interaction in Institutional Settings* (pp. 359–417). Cambridge: Cambridge University Press.

- Hillen, M. A., Onderwater, A. T., van Zwieten, M. C., de Haes, H. C., & Smets, E. (2012).

  Disentangling cancer patients' trust in their oncologist: A qualitative study. *Psycho-Oncology*, 21(4), 392–399.
- Hoffmaster, B. (2009). Bioethics in social context. Temple University Press.
- How is Hospice Care Paid For? (2017). American Hospice Foundation. Retrieved from https://americanhospice.org/learning-about-hospice/how-is-hospice-care-paid-for/ Jefferson, G. (1978). What's in aNyem'? *Sociology*, *12*(1), 135–139.
- Jefferson, G. (1981). The abominable "Ne?": A working paper exploring the phenomenon of post-response pursuit of response. Occasional Paper No. 6, Department of Sociology, University of Manchester.
- Jefferson, G. (1984). On the organization of laughter in talk about troubles. *Structures of Social Action:*Studies in Conversation Analysis, 346, 369.
- Kang, J. H., Lee, S. I., Lim, D. H., Park, K.-W., Oh, S. Y., Kwon, H.-C., ... Shin, D. B. (2012).
  Salvage chemotherapy for pretreated gastric cancer: a randomized phase III trial comparing chemotherapy plus best supportive care with best supportive care alone. *Journal of Clinical Oncology*, 30(13), 1513–1518.
- Katz, J. (1994). Informed consent-must it remain a fairy tale. J. Contemp. Health L. & Pol'y, 10, 69.
- Kaufman, S. (2005). And a time to die: How American hospitals shape the end of life. Chicago: University of Chicago Press.
- Kelley, A. S., & Morrison, R. S. (2015). Palliative care for the seriously ill. New England Journal of Medicine, 373(8), 747–755.
- Kitzinger, C., & Mandelbaum, J. (2013). Word selection and social identities in talk-in-interaction.

  Communication Monographs, 80(2), 176–198.
- Kubler-Ross, E. (1969). On death and dying. New York: Scribner's.

- Lamont, E. B., & Christakis, N. A. (2001). Prognostic disclosure to patients with cancer near the end of life. *Annals of Internal Medicine*, *134*(12), 1096–1105.
- Light, D. (1979). Uncertainty and control in professional training. *Journal of Health and Social Behavior*, 310–322.
- Lutfey, K., & Maynard, D. W. (1998). Bad news in oncology: How physician and patient talk about death and dying without using those words. *Social Psychology Quarterly*, 61(4), 321–341.
- Manrique, E., & Enfield, N. (2015). Suspending the next turn as a form of repair initiation: evidence from Argentine Sign Language. *Frontiers in Psychology*, *6*, 1326.
- Maynard, D. W. (1996). On" realization" in everyday life: The forecasting of bad news as a social relation. *American Sociological Review*, 109–131.
- Maynard, D. W. (1997). The news delivery sequence: Bad news and good news in conversational interaction. *Research on Language and Social Interaction*, *30*(2), 93–130.
- Maynard, D. W. (2003). Bad news, good news: Conversational order in everyday talk and clinical settings.

  University of Chicago Press.
- Nelson-Marten, P., & Rich, B. A. (1999). A historical perspective of informed consent in clinical practice and research (Vol. 15, pp. 81–88). Presented at the Seminars in oncology nursing, Elsevier.
- National Hospice and Palliative Care Organization. (2014). NHPCO 2014 Facts and Figures.
- Oken, D. (1961). What to tell cancer patients: a study of medical attitudes. *Jama*, 175(13), 1120–1128.
- Parikh, R. B., Kirch, R. A., Smith, T. J., & Temel, J. S. (2013). Early specialty palliative care—translating data in oncology into practice.
- Periyakoil, V. S., Neri, E., & Kraemer, H. (2015). Patient-Reported Barriers to High-Quality, End-of-Life Care: A Multiethnic, Multilingual, Mixed-Methods Study. *Journal of Palliative Medicine*, 19(4), 373–379.

- Politi, M. C., Studts, J. L., & Hayslip, J. W. (2012). Shared decision making in oncology practice: what do oncologists need to know? *The Oncologist*, 17(1), 91–100.
- Pomerantz, A. (1984). Pursuing a Response. In J. M. Atkinson & J. Heritage (Eds.), *Structures of Social Action: Studies in conversation analysis*. Cambridge: Cambridge University Press.
- Raymond, G. (2003). Grammar and social organization: Yes/no interrogatives and the structure of responding. *American Sociological Review*, 939–967.
- Rietjens, J. A., van der Heide, A., Onwuteaka-Philipsen, B. D., van der Maas, P. J., & van der Wal, G. (2006). Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. *Palliative Medicine*, 20(7), 685–692.
- Schegloff, E. A. (1968). Sequencing in conversational openings. *American Anthropologist*, 70(6), 1075–1095.
- Schegloff, E. A. (1997). Practices and actions: Boundary cases of other-initiated repair. *Discourse Processes*, *23*(3), 499–545.
- Shaha, M., Cox, C. L., Talman, K., & Kelly, D. (2008). Uncertainty in breast, prostate, and colorectal cancer: implications for supportive care. *Journal of Nursing Scholarship*, 40(1), 60–67.
- Spencer, K. L. (2018). Transforming patient compliance research in an era of biomedicalization. *Journal of Health and Social Behavior.* 00(0), 1-15.
- Starr, P. (1982). The social transformation of American medicine: The rise of a sovereign profession and the making of a vast industry. New York: Basic books.
- Stephen, N., Skirton, H., Woodward, V., Prigmore, S., & Endacott, R. (2013). End-of-life care discussions with nonmalignant respiratory disease patients: a systematic review. *Journal of Palliative Medicine*, 16(5), 555–565.
- Stevanovic, M., & Peräkylä, A. (2012). Deontic authority in interaction: The right to announce, propose, and decide. Research on Language & Social Interaction, 45(3), 297–321.

- Stivers, T. (2002). Participating in decisions about treatment: overt parent pressure for antibiotic medication in pediatric encounters. *Social Science & Medicine*, *54*, 1111–1130.
- Stivers, T. (2005a). Non-antibiotic treatment recommendations: delivery formats and implications for parent resistance. *Social Science & Medicine*, 60(5), 949–964.
- Stivers, T. (2005b). Parent resistance to physicians' treatment recommendations: one resource for initiating a negotiation of the treatment decision. *Health Communication*, 18(1), 41–74.
- Stivers, T., & Hayashi, M. (2010). Transformative answers: One way to resist a question's constraints. *Language in Society*, *39*(1), 1–25.
- Stivers, T., Heritage, J., Barnes, R., McCabe, R., Thompson, L., & Toerien, M. (2017). Treatment Recommendations as Actions. *Health Communication*, 1-10
- Stivers, T., & Rossano, F. (2010). Mobilizing response. Research on Language and Social Interaction, 43(1), 3–31.
- Sudnow, D. (1967). Passing on. Prentice-Hall.
- Svennevig, J. (2008). Trying the easiest solution first in other-initiation of repair. *Journal of Pragmatics*, 40(2), 333–348.
- Thompson, L., & McCabe, R. (2017). How psychiatrists recommend treatment and its relationship with patient uptake. *Health Communication*, 1–10.
- Timmermans, S. (1994). Dying of awareness: the theory of awareness contexts revisited. *Sociology of Health & Illness*, 16(3), 322–339.
- Toerien, M., Shaw, R., Duncan, R., & Reuber, M. (2011). Offering patients choices: A pilot study of interactions in the seizure clinic. *Epilepsy & Behavior*, 20(2), 312–320.
- Ventura, A. D., Burney, S., Brooker, J., Fletcher, J., & Ricciardelli, L. (2014). Home-based palliative care: a systematic literature review of the self-reported unmet needs of patients and carers.

  \*Palliative Medicine\*, 28(5), 391–402.

- Virnig, B. A., Kind, S., McBean, M., & Fisher, E. (2000). Geographic variation in hospice use prior to death. *Journal of the American Geriatrics Society*, 48(9), 1117–1125.
- Virnig, B. A., Moscovice, I. S., Durham, S. B., & Casey, M. M. (2004). Do rural elders have limited access to Medicare hospice services? *Journal of the American Geriatrics Society*, *52*(5), 731–735.
- Walker, G. (2004). On some interactional and phonetic properties of increments to turns in talk-in-interaction. In E. Couper-Kuhlen & C. E. Ford (Eds.), *Sound Patterns in Interaction: Cross-linguistic studies from conversation.* (pp. 147–169). Amsterdam.
- Wentlandt, K., Krzyzanowska, M. K., Swami, N., Rodin, G. M., Le, L. W., & Zimmermann, C. (2012). Referral practices of oncologists to specialized palliative care. *Journal of Clinical Oncology*, 30(35), 4380–4386.

# **Chapter 5: Conclusion**

This dissertation has exposed the ways in which patient involvement and physician expertise are negotiated in an age of decreased medical authority, evidence-based medicine, and increased patient agency and autonomy under the tenants of shared decision-making. Physicians walk a tightrope to balance their own expertise, experience, and authority while at the same time ensuring patients are involved in their own treatment. This dissertation has shown that in the process of accomplishing this goal, physicians deliver treatment recommendations in distinct ways that work to secure patient acceptance of treatment, at times prioritizing their expertise and at others prioritizing patient agency and involvement.

This dissertation's primary aim is to forge a new direction in the study of health and illness by examining how physicians manage two fundamentally different goals which are both considered important parts of their profession: attending to norms of patients' rights *and* mobilizing their own professional authority to negotiate treatment with patients. My dissertation makes four key contributions to the field of sociology. First, it provides a rigorous and novel systematic analysis of how the paradigm of shared decision-making is worked out in interaction, a phenomenon that has almost always been approached using interview or survey methods.

Second, it expands extant sociological theories about physician expertise. While previous work has largely focused on the deployment of medical authority using retrospective methods, this analysis offers new perspective on how this expertise is communicated by physicians *and* responded to by patients. Third, it has added to existing understandings of medical certainty by uncovering that one's claims to knowledge (e.g., being more or less certain) can be separable from one's inherent access to knowledge. Critically, these claims can be mobilized by physicians in the form of foregrounding levels of certainty to lobby for treatment when patients resist treatment.

Finally, it provides unique insight into how discussions of death and dying are approached by physicians. Grounded in sociological traditions of investigating how physicians confront patients' end of life, this work sheds light on this issue from an interactional standpoint, namely how and when physicians discuss palliative care or hospice care with patients or avoid it altogether. It uniquely has found that while physicians avoid end-of-life discussions in cases when patients have advanced disease, they surprisingly do not avoid mentioning death when patient demonstrate treatment resistance. Because death is brought up to account for the recommendation and in a persuasive context, one could argue that these death invocations are functioning as threats.

#### 5.1 Treatment Recommendations in Cancer Care Visits

How oncologists communicate "sharedness" in decision-making through their actions in recommending treatment, especially ensuring that patients are involved while at the same time marshalling their own expertise, has not been well understood. By examining how physicians balance their authority and expertise while preserving patient agency, we see how they operate in a liminal space, split between commitments to work with patients and professional imperatives to advocate for what they think is best. How do they carry this out?

The analysis examined both when physicians offer multiple options for treatment and when they offer single treatment recommendations. In examining the practice of option-listing, when looking at the context of initial treatment, the analysis found that physicians treated one of the options as more preferable over the others when presenting them to patients. In the context of the initial treatment no longer working and no further standard options to draw on, physicians instead arrayed each option out equally and highlighted the negatives of each. Notably, *only* when no standard options remained did physicians relinquish their deontic and epistemic authority in decision-making by providing an equal framing of remaining options. This could indicate forecasting (Maynard, 1996) by getting the patient to understand that the remaining treatments provide only

diminishing returns. This practice could potentially be beneficial to care providers who would prefer to facilitate the avoidance of broaching something more problematic that signals the end of life: palliative care or hospice care.

This work subsequently looked at single treatment recommendation actions in line with the coding schema established by Stivers and colleagues (2017) and how the actions physicians deployed to recommend treatment revealed their orientations to the role of patient agency in treatment decisions. When stage in treatment process was considered and the data were divided into three recommendation contexts (new, mid-course, and ancillary treatments), it was clear that oncologists differentiated between recommendation actions depending on the context. In this way, physicians demonstrated different orientations to patient participation and thus patient agency depending on the type of decision. Specifically, physicians considered where patients were in the process of their treatment and what the type of recommendation was (i.e., whether it was related to the cancer itself or the result of a side effect).

The results suggest that physicians reflect different norms for patients' rights and responsibilities to be involved in decision-making depending on these variables. In the data, oncologists deployed more agency and were more authoritative in recommendations for changes to treatment and less so when making recommendations for new treatment. Critically, the deviant case analyzed pointed to evidence that the therapeutic partnership between physician and patient—and not just the treatment stage—is also at play in analyzing orientations to patient involvement across contexts. This case is evidence for the relationship between physician and patient superseding the context in which the treatment is given. Further research is warranted in this area to extend our understanding of the therapeutic partnership and its relationship to treatment outcomes.

This analysis does provide meaningful insight into how physicians view their relationships with patients by finding that physicians are quite nuanced in how they present treatment

recommendations. For instance, physicians typically provide initial recommendations for radiation, chemotherapy, or surgery as proposals, inviting patients to align with this plan. Yet, when explaining to patients that existing treatment needs to be adjusted—including major changes—physicians typically use pronouncements that *tell* patients what will be happening as in "I'm going to switch you to X." This suggests that once clinicians get initial buy-in from patients they have carte blanche for subsequent medical decisions. This also means that mid-course in treatment there is less interactional room for patients to put their own treatment preferences on the table, preferences which could include implementing alternative therapies, stopping the current treatment, or considering palliation. Instead, this analysis suggests that the system has the potential to set patients up, even with advanced stage cancers, for prolonged treatment.

This work also builds on an interpretation that reduced resistance is associated with the use of pronouncements (Stivers et al., 2017). The authors speculate that less resistance after pronouncements is either conditioned by the pronouncements themselves or that pronouncements are used in contexts where resistance is already expected to be minimal. My work suggests that in environments where resistance was more likely, such as at the outset for cancer treatment, physicians do *not* use pronouncements. In environments where minimal resistance was anticipated, like when patients have already begun treatment, physicians do use pronouncements.

The lack of pronouncements in the new treatment context could also be explained in terms of securing trust in the treatment regimen and, subsequently, adherence to it. Does handing down a treatment recommendation ex-cathedra by pronouncing it truly secure patient buy-in like a proposal or suggestion would? Proposals and suggestions involve patients explicitly in the final decision, and thus involvement in decision-making is linked to buy-in. If patients explicitly agree to these oftentimes burdensome treatments, they could be more likely to adhere to the treatment regimen then those who are simply told what is going to be done. While proposals could allow for more

negotiation of the treatment, as was found in primary care, suggestions do not see similar rates of resistance (see Stivers et al., 2017). Perhaps physicians are willing to open up the possibility for a treatment negotiation if it means ultimately securing buy-in up front.

In the realm of empirical investigations of physician-patient interaction, this chapter uniquely focuses on physicians' orientations to patient involvement in decisions about cancer treatment and how this reflects medical norms in the preservation of patient rights in a domain of complex decision-making. This analysis also suggests that the treatment context of decision-making is important. Moreover, these data highlight that consideration of the different types of decisions in the treatment process matters in understanding how decisions are made. At a fundamental level, physicians' behaviors appear to be shaped by their understandings of the physician-patient relationship at different stages of the treatment process. This work builds on foundational studies of how treatment recommendations are actually produced across different clinical contexts and implications for facilitating SDM (see Barnes, 2017; Bergen et al., 2017; Stivers et al., 2017; Thompson & McCabe, 2017; Toerien, 2017). This analysis of decision-making in cancer care contributes to the next line of future research on the production of treatment recommendations. In analyzing cancer care, we have preliminary grounds for understanding the additional impact of treatment context in how decisions get made between physician and patient. This analysis can provide a foundation for future studies that look more closely at variables like patient and physician gender, patient socioeconomic status, and patient race/ethnicity and their causal link to physicians' orientations to patient involvement in decision-making.

# 5.2 Foregrounding Medical (Un)Certainty for Treatment Acceptance

The management of medical certainty and uncertainty is an omnipresent facet of doctoring. As a treatment environment, cancer care is rife with uncertainty in diagnosis, treatment, and survivorship rates. Accordingly, cancer care offers a critical site to explore the clinical management

of certainty and uncertainty in the medical encounter. While past sociological inquiry has found that clinical certainty gets mobilized for the preservation of professional expertise, this analysis applies a conversation analytic lens to zoom in to the practices that *occasion* clinical certainty.

First, this work has shown that the knowledge physicians have more or less access to given available information and the knowledge physicians *claim* to know during medical encounters with patients can be *separable* from each other. Second, this analysis has revealed that presentations of medical knowledge and levels of certainty can be foregrounded as cancer treatment gets discussed with patients over the course of the visit, concluding that medical certainty can be foregrounded to patients in a persuasive practice.

Ultimately, the sequential placement of presentations of certainty was following treatment resistance behavior. When patients demonstrated treatment resistance, one way that physicians pushed back on their resistance was to foreground their level of certainty depending on the nature of the patient's resistance. In some cases, physicians foregrounded certainty, and in others, they foregrounded uncertainty. Critically, foregrounding either certainty and uncertainty served the same interactional purpose: to advocate for new treatment or justify further treatment. Accordingly, this analysis argues for a re-conceptualization of clinical certainty as a flexible, rather than static, concept. Interactional evidence suggests physicians can shift from foregrounding more certainty to less (or vice versa) as they respond to different aspects of patients' resistant behavior. At a time when patients are likely to be agentive and their buy-in is sought by physicians, foregrounding certainty or uncertainty can serve as a useful tool for clinicians in responding to patient resistance, addressing patient concerns, and securing their acceptance of the proposed treatment plan.

# 5.3 Invoking and Avoiding Death: Resources for securing treatment acquiescence

In this analysis, I sought to better understand how death was being broached in the context of cancer treatment. While in some cases death inhabited these encounters as a way to get patients

to acquiesce to treatment, in others death and the terminality of illness were avoided. This difference notwithstanding, the overall functions of these diametric forces were the same: to compel patients to pursue more treatment.

I have found that death does come up in these visits, but not as a warrant to stop treatment— both physicians and patients conduct themselves as though cancer is a treatable condition at both early and late disease stages. Specifically, death inhabits these visits in order to establish that cancer is a treatable disease and out to be treated, no matter what. When patients depart from this implicit contract through resistance to treatment, physicians use death as the ultimate consequence for this departure.

The first part of the chapter demonstrated that overall physicians are not bringing up their patients' death in the context of advanced disease. It is crucial to emphasize that physicians are rarely bringing up ceasing treatment in these visits, which reflects a larger trend of late hospice referrals and an underuse of palliative care services. Of 90 cases in my cross-section of data, which included 61 treatment recommendations, supportive, non-curative care was brought up just once. In thirteen encounters, palliative care, treatment cessation, supportive and/or hospice care were notably written out of treatment discussing when broaching them would have been appropriate. While we could argue that EOL care may have been brought up at an earlier visit in these cases, I made the case for why it remains critical during any treatment discussion to remind patients that alternative treatment options *other than* curative ones are feasible. Overall, these findings echo sociological conclusions about reticence to discuss death or avoidance of the topic altogether.

I have also uncovered that when existing parameters to look at death mentions are expanded to include those outside the patient's EOL, physicians *do* put their patient's death on the table.

Specifically, one of the primary places I found death being invoked was in recommending treatments. When it was invoked in this context I found that it was being used to push patients

towards accepting a particular treatment course. Ultimately, I conclude that physicians in these data invoke death as a bargaining chip to leverage their authority for particular outcomes. The most frequent way that physicians invoked death was in a persuasive context. When patients demonstrated active or passive resistance, physicians invoked the possibility of the patient's death in order to push back against this resistance and get patients to acquiesce to treatment. Occasionally, physicians invoked death in instances where resistance was anticipated but never actualized. Similarly, death invocations functioned in order to lobby in favor of treatment.

Stivers (2005b) found that when parents resisted treatment recommendations, physicians did not simply fold and accept that position. Instead, they used different resources to seek acceptance of the treatment recommendation. For instance, pediatricians would provide accounts for the recommendation, restate the recommendation, provide lists, or explicitly request acceptance of the recommendation. Ultimately these practices were used to push back against patient resistance. These data similarly show that physicians in the context of cancer care push back against resistance, but they do so by invoking the possibility of the patient's death. In thinking about these findings, one could argue that the practice of invoking death is a way to account for treatment. However, invoking death in response to resistance is a more extreme way of accounting for treatment than what Stivers (2005b) found. Further, that physicians invoke death as a resource for treatment acquiescence even in relatively mild instances of treatment resistance demonstrates a practice which fundamentally targets—in a most extreme way—the biggest fear of patients in during cancer treatment.

This behavior also reflects physicians' priorities in cancer care and an orientation to their professional role, which is to treat. It also reflects physicians' emphasis on not just treating, but that treating both works and prolongs life, outcomes which can be at times uncertain and precarious. This could potentially expose a point of weakness in medical practice. One could argue that treating cancer is potentially effective, the right thing to do, and the best option going forward. Further, one

could argue that informing patients about a real outcome if they do not accept medical advice is important.

What is also striking about this practice is a lack of acceptance of patients' resistant positions in the context of cancer care, an area in which SDM and patient involvement has been advocated for (Politi et al., 2012). We might therefore assume that in cancer care physicians may be more likely to accept patients' positions of treatment resistance. They do not. It has been found that physicians generally push back against resistance in a variety of contexts such as pediatrics (Stivers 2005b) and neurology (Toerien et al., 2011) to seek acceptance of the treatment recommendation. However, the possibility of a patient's death has not been found to be mobilized as a resource to counter resistance like in cancer care. We might conclude that death is put on the table because the stakes for not treating are the highest possible—death—and physicians are capitalizing on this issue. This is apparent not only in that they invoke death as linked to resistance, but also that they use it as leverage relatively early after patients demonstrate resistance rather than using less extreme accounts for treatment, such as treatment statistics or explicit requests for acceptance.

This feeds into a larger debate in the medical community. All doctors take an oath to maintain beneficence, or doing what is in the patient's best interest at all times. In the realm of more complex diseases like cancer, what does beneficence really mean in treatment? Does it mean giving the patient the longest life possible, or the best life possible, or some of both? It could mean advocating for treatment because the possibility of a prolonged life is kept on the table, or it could mean stepping back and letting the patient decide whether the recommended treatment is best for them while knowing that they might die if they do not pursue treatment. This very problem brings physician authority and patient agency directly into conflict with one another and highlights larger policy concern: in an age of increased patient agency and autonomy, how much physician authority

ought to get mobilized and when during the course of treatment can the line of beneficence get crossed?

### 5.4 Limitations

This investigation is a qualitative one; therefore, I am limited in the claims I can make about whether these practices occur across the population. Geographically, this study took place in one large urban area in the western United States and did not span suburban or rural areas, where care delivery may be different due to different patient populations and access to resources. Along these same lines, both study sites were large, top-tier academic hospitals with a preponderance of resources. The physicians I worked with were among the top in their field; they went to top medical schools and had prestigious residencies and fellowships. The way they practice medicine may be quite different from how those at less-resourced hospitals may practice medicine, and different from those who had different medical training.

The sample was not diverse. These cancer clinics were located in upper and upper-middle income areas of the city. The patient population mirrored these areas. Patients were predominantly white, upper-middle to upper-class, and well-educated. They had private, PPO insurance. Only a few patients were on Medicaid.

The gender breakdown of patients was similarly not representative of the population. I recruited whichever patients consented and I allocated my time to the physicians with the most flexible and frequent clinic hours. A consequence of this was that, of 90 video recordings, just 21 included male patients being treated for urologic cancers, and the remaining 69 were female patients being treated for gynecologic cancers. Because of this, I was unable to look at patient gender in a meaningful way. Further, gender and disease category were covariates. It remains important to decouple these variables and look at both men and women being treated for the *same* cancer to better control for gender in a future analysis.

The data also come from a cross-section of oncology visits. I did not have the resources to collect longitudinal data, but a handful of patients did get recorded twice in the data. It was fascinating to see the difference (or similarities) in behaviors from one visit to the next. For this reason, I believe the pursuit of longitudinal analysis of patients in cancer treatment is critical for better understanding the therapeutic partnership in cancer care.

#### 5.5. Future Research Directions

The goal of this work is to continue the traditions of scholars of social interaction and advance our sociological understanding of how physicians as institutional actors manage to involve patients in their own care while at the same time guiding them towards what they believe to be the best path forward in treatment. This analysis has offered evidence that, in a complex treatment environment, the context in which recommendations are made and the therapeutic relationship between provider and patient both matter in how directive and collaborative physicians are with patients. A foundation has been set up to further explore how power equilibrium or power asymmetry in decision-making power play out. What types of patients get more collaboration, and which types get less?

Given this, I believe it is important to continue to explore how physician authority and patient agency get managed in interaction given other important social variables. Historically, racial and ethnic minorities have had a fraught relationship with physicians given a problematic and not-so-distant past involving unethical and sometimes deadly medical experimentation and forced sterilization. This has resulted in distrust between minority patients and their providers. Further, do inherent racial biases present in our everyday lives get suspended at the clinic door, or do they infiltrate the experiences of physicians and patients? I believe it is important that we take what we have learned in this investigation and use it to explore whether race becomes an explanatory variable

in how much (or little) physicians involve patients in their own care, and what that might mean for our existing understanding of racial inequalities in health care delivery.

In addition, gender is another variable that should be explored from this perspective. Women's unique health concerns continue to be marginalized in our society. Women's health concerns have been understudied or inappropriately treated, sometimes with severe consequences in the case of the drugs DES or thalidomide. Moreover, women's claims of pain have been historically (and still are) written off as a product of "female drama" or "hysteria" by healthcare practitioners when research has indeed found that health conditions like fibromyalgia and endometriosis (among many others) are unbearably painful and crippling. The inclusion of women in drug trial, until just three years ago, was not prioritized for fear that they would become pregnant. This has resulted in inappropriate dosing for some drugs when they go to market because dosages were based on data from male subjects. This has had dangerous consequences as in the case of Ambien, which caused women taking it to still feel its effects the next morning and some to even fall asleep at the wheel. The marginalization of women's unique issues in healthcare has a long and problematic past. While there have been strides in this arena, there is still room for improvement. To what degree might we see gender differences in the delivery of cancer care? Might oncologists treat resistant female patients differently than male patients who resist treatment? Would they recommend treatment differently? There is potential for impactful future research in these domains.

Ultimately, I hope that future work takes the study of how physicians and patients collaborate in decision-making and pursues investigations that shed light on the remaining discordance and best practices in cancer care delivery. By using the contributions of this work on social interaction in medicine as a jumping-off point, I believe researchers will be able to better study marginalized groups in medicine like women and racial/ethnic minorities and improve their health outcomes in cancer care and other complex treatment environments.

# References

- Barnes, R. (2017). Preliminaries to treatment recommendation sequences in UK primary care: A Vehicle for Shared Decision-Making? *Health Communication*.
- Bergen, C., Stivers, T., Barnes, R. K., Heritage, J., McCabe, R., Thompson, L., & Toerien, M. (2017).

  Closing the deal: A cross-cultural comparison of treatment resistance. *Health Communication*, 1–12.
- Maynard, D. W. (1996). On "realization" in everyday life: The forecasting of bad news as a social relation. *American Sociological Review*, 109–131.
- Politi, M. C., Studts, J. L., & Hayslip, J. W. (2012). Shared decision making in oncology practice: what do oncologists need to know? *The Oncologist*, 17(1), 91–100.
- Stivers, T. (2005). Parent resistance to physicians' treatment recommendations: one resource for initiating a negotiation of the treatment decision. *Health Communication*, 18(1), 41–74.
- Stivers, T., Heritage, J., Barnes, R. K., McCabe, R., Thompson, L., & Toerien, M. (2017). Treatment recommendations as actions. *Health Communication*, 1–10.
- Stivers, T., Heritage, J., Barnes, R., McCabe, R., Thompson, L., & Toerien, M. (2017). Treatment Recommendations as Actions. *Health Communication*.
- Thompson, L., & McCabe, R. (2017). How Psychiatrists Recommend Treatment and Its Relationship with Patient Uptake. *Health Communication*.
- Toerien, M. (2017). Treatment Assertions in Neurology. Health Communication.
- Toerien, M., Shaw, R., Duncan, R., & Reuber, M. (2011). Offering patients choices: A pilot study of interactions in the seizure clinic. *Epilepsy & Behavior*, 20(2), 312–320.

# **APPENDIX I: Conversation Analytic Transcription Conventions**

# 1. Temporal and sequential relationships

**A.** Overlapping or simultaneous talk is indicated in a variety of ways. Separate left square brackets, one above the other on two successive ſ lines with utterances by different speakers, indicates a point of overlap onset, whether at the start of an utterance or later. 1 Separate right square brackets, one above the other on two successive 1 lines with utterances by different speakers indicates a point at which two overlapping utterances both end, where one ends while the other continues, or simultaneous moments in overlaps which continue. **B.** Equal signs ordinarily come in pairs -- one at the end of a line and another at the = start of the next line or one shortly thereafter. They are used to indicate tf the lines connected by two equal signs are by different speakers, then the second followed the first with no discernable silence between them, or was "latched" to it. (0.5)**C.** Numbers in parentheses indicate silence, represented in tenths of a second; what is given here in the left margin indicates 5/10 seconds of silence. Silences may be marked either within an utterance or between utterances, as in the two excerpts below: **D.** ordinarily less than 2/10 of a second. **(.)** ((pause)) **E.** In some older or less carefully prepared transcripts, untimed silences may be indicated by the word "pause" in double parentheses. **F.** A hyphen after a word or part of a word indicates a cut-off or self-interruption,

often done with a glottal or dental stop.

**G.** <u>Underlining</u> is used to indicate some form of stress or emphasis, either by increased loudness or higher pitch. The more underlining, the greater the emphasis. Therefore, underlining sometimes is placed under the first letter or two of a word, rather than under the letters which are actually raised in pitch or volume. Especially loud talk may be indicated by upper case; again, the louder, the more letters in upper case. And in extreme cases, upper case may be underlined.

# ex: word, word, WOrd

- H. The degree sign indicates that the talk following it was markedly quiet or soft.
   When there are two degree signs, the talk between them is markedly softer than the talk around it.
- I. The up and down arrows mark sharper rises or falls in pitch than would be indicated by combinations of colons and underlining, or may mark a whole shift, or resetting, of the pitch register at which the talk is being produced.
- < > < J. The combination of "more than" and "less than" symbols indicates that the talk between them is compressed or rushed. Used in the reverse order, they can indicate that a stretch of talk is markedly slowed or drawn out. The "less than" symbol by itself indicates that the immediately following talk is "jump-started," i.e., sounds like it starts with a rush.</p>
- **K.** Hearable aspiration is shown where it occurs in the talk by the letter "h" -- the more h's, the more aspiration. The aspiration may represent breathing, laughter, etc.

  If the aspiration is an inhalation, it is shown with a dot before it. .hhh

# 2. Aspects of speech delivery, including aspects of intonation.

**A.** The punctuation marks are not used grammatically, but to indicate intonation. The period indicates a falling, or final, intonation contour, not necessarily the end of a sentence.

Similarly, a question mark indicates rising intonation, not necessarily a question, and a comma indicates "continuing" intonation, not necessarily a clause boundary. In some transcript fragments in your readings you may see a combined question mark and comma, which indicates a rise stronger than a comma but weaker than a question mark. Because this symbol cannot be produced by the computer, the inverted question mark (¿) is used for this purpose.

**B.** Colons are used to indicate the prolongation or stretching of the sound just preceding them. The more colons, the longer the stretching.

# 3. Other markings.

- (()) A. Double parentheses are used to mark transcriber's descriptions of events, rather than representations of them. Thus ((cough)), ((sniff)), ((telephone rings)), ((footsteps)), ((whispered)), ((pause)) and the like.
- **B.** When all or part of an utterance is in parentheses, or the speaker identification is, this indicates uncertainty on the transcriber's part, but represents a likely possibility.
- ( ) C. Empty parentheses indicate that something is being said, but no hearing (or, in some cases, speaker identification) can be achieved.