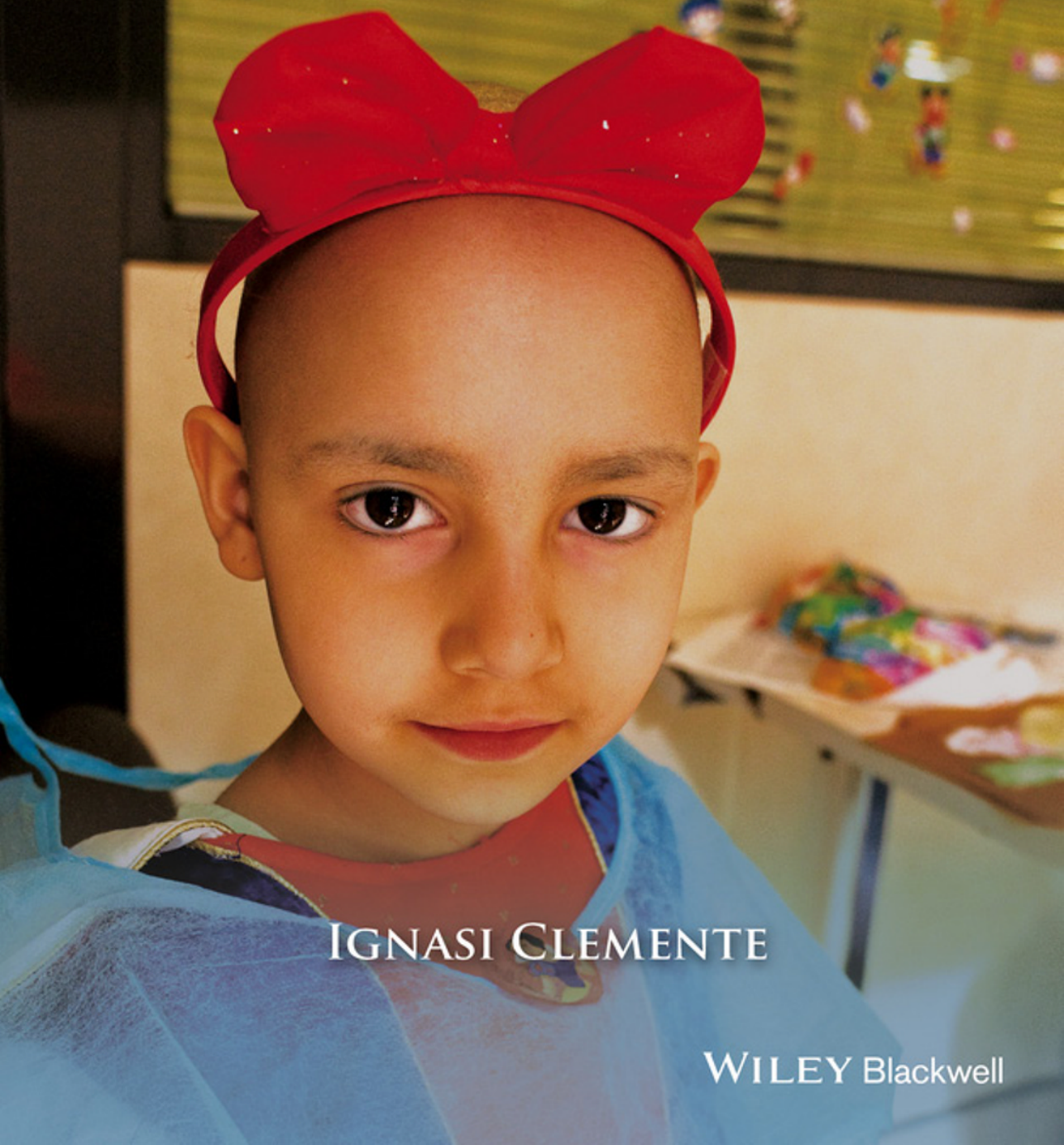


UNCERTAIN FUTURES

COMMUNICATION AND CULTURE
IN CHILDHOOD CANCER TREATMENT



IGNASI CLEMENTE

WILEY Blackwell

Uncertain Futures

Blackwell Studies in Discourse and Culture

Linguistic anthropology evolved in the 20th century in an environment that tended to reify language and culture. A recognition of the dynamics of discourse as a sociocultural process has since emerged as researchers have used new methods and theories to examine the reproduction and transformation of people, institutions, and communities through linguistic practices. This transformation of linguistic anthropology itself heralds a new era for publishing as well. *Blackwell Studies in Discourse and Culture* aims to represent and foster this new approach to discourse and culture by producing books that focus on the dynamics that can be obscured by such broad and diffuse terms as “language.” This series is committed to the ethnographic approach to language and discourse: ethnographic works deeply informed by theory, as well as more theoretical works that are deeply grounded in ethnography. The books are aimed at scholars in the sociology and anthropology of language, anthropological linguistics, sociolinguistics and socioculturally informed psycholinguistics. It is our hope that all books in the series will be widely adopted for a variety of courses.

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James M. Wilce (PhD University of California, Los Angeles) is Professor of Anthropology at Northern Arizona University. He serves on the editorial board of *American Anthropologist* and the *Journal of Linguistic Anthropology*. He has published a number of articles and is the author of *Eloquence in Trouble: The Poetics and Politics of Complaint in Rural Bangladesh* (1998) and *Language and Emotion* (2009) and the editor of *Social and Cultural Lives of Immune Systems* (2003).

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Uncertain Futures

Communication and Culture in Childhood Cancer Treatment

Ignasi Clemente

WILEY Blackwell

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“Call it sentimental, call it Victorian and nineteenth century, but I say that anthropology that doesn’t break your heart just isn’t worth doing anymore.”

Ruth Behar (1996)
The Vulnerable Observer. Boston: Beacon Press.

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Series Preface

Blackwell Studies in Discourse and Culture was launched in 2005, committed to publishing books whose ethnographic approach to language and discourse contributes to linguistic-anthropological theory. Each of the books that has appeared thus far in the series exemplifies that commitment. Now, we are proud to introduce Ignasi Clemente's *Uncertain Futures: Communication and Culture in Childhood Cancer Treatment* as the latest book in the series and an exciting addition to ethnography and theory in linguistic anthropology. It is a book that we hope will leap the fence of academe and find many readers in the world of cancer—particularly the world of pediatric cancer. We foresee *Uncertain Futures* contributing to discussions of childhood cancer by clinicians, family members, and patients, and more broadly to discussions of cancer treatment and its human side and of the ethics of health communication.

Clemente tells us that his book is an ethnographic treatment of communication. Significantly, it is about “the communicative patterns of commission and omission of a community.” And that is largely what marks Clemente's book as a departure. As important as previous studies of “communicative omission” and silence have been in the ethnography of communication and conversation analysis, *Uncertain Futures* differs sharply from its precedents, and in some ways goes far beyond them. Silences in the children's cancer ward at “Catalonia Hospital” are part of a dance—one that could be construed as deadly. We can also think of Clemente as the John Nash of linguistic anthropology. Like Nash (made famous in the Hollywood film *A Beautiful Mind*), Clemente offers an important contribution to a kind of game theory as he describes the “cat-and-mouse game” between children who ask questions persistently, and adults who try to protect them from potentially distressing news.

This is a poignant book, but no story of unmitigated suffering or of the young and weak enduring the total domination of older, more powerful people. Perhaps the best illustration of this is in the way Clemente problematizes concepts that have largely been taken for granted, especially “participation.” What does “participation” mean here, in the lives of young patients whose parents and doctors appear to block their participation, even as we come to see that those apparently blocked patients are not victims but find ways to be active? Pediatric cancer patients' questions, Clemente argues, reveal their communicative competence,

their knowledge of the forms of participation that *are* culturally acceptable and available to them, i.e., what are appropriate ways of talking about cancer in Catalonia (Spain)—without talking about it. Just as *Uncertain Futures* is no story of total domination and submission or subjugation, neither is it a tale of villains and victims, but of younger and older social actors whose agency is both apparent (though appearing in differing forms for healthcare providers, parents, and pediatric cancer patients) and limited (running up against the limits imposed by different organizations of interaction and social action as much as by cancer itself).

This book is not only the first medically themed book in the series, *Blackwell Studies in Discourse and Culture*; it may also be the very first book that combines ethnographic depth with conversation-analytic empiricism in a study of cancer. Some readers may find ethnographic methods foreign; other readers will be unfamiliar with conversation analysis (CA). Clemente gently and effectively introduces readers to both. In many ingenious ways over several decades, CA has uncovered the systematicity of talk-in-interaction. Drawing on that tradition, Clemente shows how each move or conversational turn-at-talk influences the next without determining it. Ironically, as Clemente shows, it is the very system, including the *sequential organization of talk* (page 27) and *preference organization* (page 28) that contains within itself the seeds of danger, perhaps even the undoing of the social-order-in-miniature that any instance of conversation helps to constitute and/or sustain (Goodwin 2006). Questions and answers, says Clemente, may lead to not just more questions and answers in general, but to questions and answers that are potentially more destabilizing. Such “question–answer sequences” Clemente compares to a Pandora’s box. Just as that mythic box has fascinated hundreds of generations, so will readers be fascinated by the struggles documented here—with children on one side laboring to break open that box and doctors on the other, struggling to put the Q–A sequence to sleep, tucked safely back into the box.

In contrast with some work in the tradition of CA, what is new here are the riches of ethnographic depth and poignancy Clemente mines from his painstakingly recorded and transcribed material but especially from sources beyond the recordings—his knowledge of family life and sometimes family breakdown, of shortages of financial resources and their consequences, of medical teamwork and interfamilial solidarity, of adolescent patients’ flirtatiousness, humor, and assertive seeking of sociality. To add one more phenomenon to this list of others so richly described—a phenomenon that so deserves to be introduced with “Finally...”—Clemente allows us to be drawn in, as he was, to the endings of stories begun on the pediatric cancer ward but finished elsewhere, as some patients graduate from hospitalization to health and others die, surrounded by family.

Clemente’s *Uncertain Futures* thus takes its place alongside influential contributions from books in this series to our knowledge of the world—be it knowledge of the hidden life of girls (Goodwin 2006); of the sharing of walls, stories, and songs by Berber women (Hoffman 2008); of white racism, its everyday language, and its survival in the face of social pressure (Hill 2008); of Muslim immigrant

childhoods in Spain (García-Sánchez 2014); or of languages struggling to remain a viable part of different communities (Cavanaugh 2009; Nevins 2013). To the author: Thank you for challenging our thinking about cancer, children, and talk in this powerful book. To the reader: Welcome to—or, we hope, in many cases, *back to*—the dynamic world of *Discourse and Culture*.

James M. Wilce, series editor

Acknowledgments

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I am grateful to the institutions and agencies that sponsored my doctoral studies and research: the Spanish Department of Education and Science; the US-Spain Fulbright Bilateral Commission; the Graduate Division and the Department of Anthropology at the University of California, Los Angeles; the National Science Foundation; the Woodrow Wilson National Fellowship Foundation (Johnson & Johnson Dissertation Grant in Children's Health); and the Alpha Association of Phi Beta Kappa Alumni in Southern California.

Finally, I would like to thank the children, their parents, and the hospital staff at Catalonia Hospital. Because of the focus on children's questions for their doctors, my book does not do justice to the immense work that nurses do in taking care of children and parents and to the critical importance of their role in everyday communication at the hospital. Although I cannot thank the children by name, I want them to know that whenever I became lost in the data, my memories of the times that we spent together playing, eating, and going around the hospital always reminded of the most meaningful reason to write this book.

I dedicate this book to my family. Because I promised my mother I would write something she would understand, I now take a language license and switch from English to Catalan:

Vull dedicar aquest llibre a la meua família. Des de mon pare, com a Secretari de la Col·lectivitat Agrícola de la CNT-FAI durant la Guerra Civil, i President de la PYMEC anys més tard, fins a ma mare, Presidenta de la Joventut Antoniana i de Càritas de Vila-real, tots els de casa hem participat en molts projectes. Hem compartit il·lusions i fracassos: tots recordem l'Operació Reformista, l'incendi del magatzem, el racisme contra els immigrants marroquins, i els petits favors per a Mossén Guillermo, l'escola i els drogaadictes. Sovint hem perdut la batalla, però el que no hem perdut mai és la determinació de lluitar per una societat més justa i més humana. Per tot això, dedique el meu esforç a tota la meua família, que en la distància continua essent la columna vertebral que em sosté.

Preface

Like many people across the world, I have relatives and friends who have or have had cancer. In my case, as somebody who was born and grew up in Spain, how I talk or do not talk about cancer both reflects the ways in which Spanish and Catalan people speak about cancer, and contributes to sociocultural continuities and changes in cancer communication in these societies.

In 1983, when I was 11, my youngest brother and I were pulled out of swim practice in our hometown because our cousin, 15 at the time, had died of leukemia. We had been told she was very sick with “anemia.” Because I did not know what “anemia” was, I thought her wigs and the fact we could not play with her were related to anemia. But I never thought she would die. She just seemed to disappear while my brother and I were swimming. My cousin’s younger siblings and I were not allowed to go to her funeral. We never got a chance to say our goodbyes.

In 2003, twenty years later, I was pulled out of bed by a phone call from my youngest brother. He told me that our father was dying of cancer and to get on the first flight back home. The situation was painfully ironic. When I received my brother’s call, I was completing my PhD dissertation at the University of California, Los Angeles. The topic of my dissertation was the non-disclosure of information to children with cancer in Spain. Because my family was worried that news of my father’s cancer diagnosis would interfere with my dissertation writing, they had decided not to tell me anything. Unfortunately, my father’s health worsened quickly, and my youngest brother decided to call me despite what everybody else in our family was saying.

Once I landed in Spain, I had a row with my family. I was not allowed to “tell” my father that he had cancer or that he was dying. I agreed not to start the conversation, but if my father started it, I would talk to him about these issues. My father knew perfectly well he was dying, and I do not think he cared to discuss the specifics of his diagnosis and prognosis. Since our family members took turns keeping him company at the hospital, I was able to sit alone with him for long hours while waiting to have the “conversation.” But he never brought these topics up explicitly, so we never had the “conversation.”

Having been born during a specific historical period in a society in which not talking about cancer or death is the culturally sanctioned alternative to speaking,

I left my old ways of “not telling” and converted to the North American preference for full, open communication about cancer information during my graduate years in the United States. As I sat with my father during the last month of his life, my fixation with having “the conversation” faded away. Perhaps I was forgetting my adopted North American ways of open and explicit communication, and was slipping back into my old habits of not talking about cancer and death. Or perhaps I realized this was not about what I wanted, but about what my father wanted: to have all of us with him. And this is what we did for him.

As a young academic, I wanted a neat, well-defined theory of open versus closed communication. As an anthropologist, and as a cousin and son, I had to accept that life, including the lives of the children that I studied and my own life, was far more complex and nuanced. In what I observed and experienced, an opposition between open and closed communication would not help me understand why the children with cancer, their families, and their doctors at Catalonia Hospital were doing what they were doing.

My position as a linguistic anthropologist is that a “one size fits all” approach to cancer communication disregards how communication involves not only exchanging information, but is also a way to constitute the world we inhabit and a way of being in the world. Communication is always personal, and is always grounded in the local circumstances in which it occurs. A “one size fits all” approach does not work for the same patient at different points of his or her cancer trajectory, and even less so for two different children. One way or another, children find out that something really bad is happening to them. The dilemma is not whether they know or do not know, but whether they are allowed to talk about it. For those children who ask questions, there should be ways to provide information and involve them. For those children who do not ask questions, there should be ways to let them know that they can be informed and involved as little or as much as they want. By examining in detail the silences, the implicit, the explicit, the subtle allusions, and delicate evasions, I hope that this book helps scholars, health professionals, and people affected by cancer to hear the nuances of what the person in front of them is communicating.

Children: Contributions to Communication and Illness

Key Issues

- *Understanding cancer communication requires approaching it not as a reflection of what is happening, but as an active way of influencing and constituting what is happening.*
- *"Not telling" is different from not knowing.*
- *Information disclosure (or non-disclosure) is not a one-time event but a process that extends over entire cancer trajectories, and it involves highly variable and diverse communication strategies.*
- *A fundamental objective of communication regulation is to manage the pervasive problem of everyday uncertain news.*
- *Children, parents, and healthcare professionals avoid talking about the negative and uncertain aspects of cancer and its treatment, and work constantly to sustain a sense of hope and optimism.*
- *Children's limited participation in cancer treatment conversations illustrates their positioning in society as marginal social actors with reduced agency.*

The doctor told Pedro,¹ a 15-year-old boy with bone cancer in his right leg, that he had a "bump" and would need a year of treatment at Catalonia Hospital in Barcelona (Spain). As he cried, Pedro asked his doctor many questions about the negative and unknown aspects of his chemotherapy and surgery, such as "Chemotherapy makes your hair fall out, right?", "Will it (my leg) be the same way as before (the surgery)?" and "When will I be completely cured?" The doctor's answers were uncertain: she told him that his hair would fall out, but "not now"; that his leg would be "more or less the same"; and that the treatment would take a little less than a year, but she did not give him a date by which he would be cured.

After the medical team left the room, Pedro continued to cry profusely. He was furious. He yelled at his father: "All bad things always have to happen to me." His mother replied that it was not true, that all the other children in the unit were in the same situation. Pedro could not care less. Much of his anger was about having

to undergo an entire year of treatment. Trying to lift Pedro's spirits, his parents began to ask him questions in order to show him that the treatment was the lesser of two evils: "What do you want: that they remove your leg? That if it is a tumor, it spreads throughout your body?"

Suddenly, Pedro asked his parents: "... because it's *cancer*?" His mother answered, "They've told you already. But you only have it here," pointing to her own leg. The medical team and parents never used the word "cancer." Instead, they used "lesion" or "tumor." Pedro's mother's use of the pronoun "it" and her pointing gesture also allowed her to talk about "cancer" without uttering the word. Pedro never asked his doctor if he had cancer. Indeed, I never heard Pedro use the word "cancer" again. Over the following five months of treatment, Pedro's participation in medical interactions decreased dramatically at first, and then slowly increased. In time, Pedro began to ask questions again and to take an active role in conversations about his own treatment.

Pedro is one of the 900 to 950 children and young people who are diagnosed with cancer in Spain every year (Peris-Bonet et al. 2010). With a similar incidence and 5-year survival rates as North America (Pizzo and Poplack 2011), cancer continues to be the leading cause of disease-related death among Spanish children (Peris-Bonet et al. 2010). Pediatric cancer and its treatment are traumatic events that may lead to long-term posttraumatic stress for some survivors and their mothers (Barakat et al. 2000; Zebrack et al. 2002). However, treatment improvements have drastically reduced mortality rates over the last 50 years. For instance, whereas the survival rate for acute lymphoblastic leukemia was practically 0% in the 1960s in the United States, current 5-year survival rates exceed 80% now. A majority of children with cancer survive the illness and become adults.

With limited information about his "tumor" and treatment side effects, Pedro may become one of the many childhood cancer survivors who have significant knowledge deficits about basic aspects of his diagnosis and treatment (Bashore 2004; Gianinazzi et al. 2014; Kadan-Lottick et al. 2002). As adults who will be responsible for their healthcare, cancer survivors need information about what type of cancer they had or what types of chemotherapy treatment they received in order to know their risks for late side effects and to seek and receive appropriate long-term follow-up care. Thus, meeting patients' information needs and involving them in conversation about their own treatment is essential to ensure that they can take care of themselves after cancer treatment.

Information, and more generally, compassionate and effective communication, is also essential for those children who are dying of cancer or treatment complications. Death often comes after an unpredictable succession of remissions, relapses, and painful courses of treatment. Withholding information from the dying patient may increase his or her fears (Fallowfield et al. 2002). Communication and information in uncertain times are compatible with hope and optimism. As brilliantly stated by Miles Levin, an 18-year-old young man who blogged regularly about his cancer until a few days before his death, uncertainty and hopelessness are different. As he approached death, Levin (2011: 89) noted: "We're in a period of uncertainty, which is better than being in a period of certain hopelessness."

In this book, I examine how a community formed by pediatric cancer patients, their families, and caregivers at Catalonia Hospital rely on communication to live and deal with cancer and its multiple uncertainties. By examining communication in a situated manner (i.e., grounding communication in the local circumstances in which it occurs), I illustrate this community's ways of understanding what they are saying, feeling, and doing, as well as the social organization of pediatric cancer at Catalonia Hospital.

Four claims are central to the argument that I present in this book. First, I contend that there is a diversity of pediatric cancer communicative strategies that cannot be reduced to "telling" versus "not telling." These strategies are neither cohesive nor consistent, because they change according to multiple factors, including a child's specific circumstances within his or her own cancer trajectory. Furthermore, the regulation of communication is not limited to information, but also includes the regulation of emotions, particularly negative emotions such as distress and anger.

Second, I highlight that a fundamental objective of communication regulation is to prevent the multiple, overlapping, and ever-evolving uncertainties associated with having cancer from becoming the central focus of talk and social life. Whereas bad news deliveries are limited in time and relatively rare, the regulation of uncertain news—that is, "If you have no fever maybe we'll let you go home," "We still don't have a date (for the next course of treatment)," or "It (the next course of treatment) is scheduled for when you're well"—is pervasive and constant throughout entire cancer trajectories. Furthermore, containing the uncertainties of a cancer patient's future requires a relentless institutional mandate to practice hope and optimism, to sustain the social illusion of certainty, to hide negative emotions, and to restrict talk about the future.

Third, I argue that parents and doctors do not control communication entirely, for sometimes children obtain information from parents and doctors that they—parents and doctors—have not planned to disclose. Children exert pressure with questions to negotiate how much to talk about cancer and how to talk about it. I show the tension that emerges between children's efforts to obtain information, and parents' and doctors' efforts to protect them from uncertain and bad news. Although children do not openly challenge adults' desire to protect them, they still attempt to modify—even just a little bit—the limits of their protection.

Fourth, I contend that children's ability to be informed, an integral part of their ability to participate in treatment discussions, is hampered by parents' and doctors' desire to protect them from the suffering associated with bad and uncertain news. Parents and doctors may not necessarily set out to curtail children's participation in treatment discussions, but they feel that sharing uncertain and bad news with them only creates more suffering.

In the largely under-theorized and under-examined field of pediatric cancer communication (Dixon-Woods et al. 2005: 115), this book breaks new ground in multiple ways. It is the first book to examine pediatric cancer patients in the richly textured ways of ethnography in almost 40 years, since the publication of

Bluebond-Langner's (1978) pioneering ethnography with children dying of cancer. As Bluebond-Langner's book did, this book is also one of the few studies to examine directly communication between children with cancer, their parents, and health professionals, and does so by combining ethnography and conversation analysis (CA). Unlike books that instruct clinicians on how to deliver bad news, this book is the only existing empirical study, qualitative or quantitative, of how news is actually delivered to the pediatric cancer patient in Spain. In addition, this book is innovative because it examines children's cancer trajectories from beginning to end prospectively (i.e., as pivotal moments in children's lives and treatment occur) rather than retrospectively (i.e., interviews after the events, often conducted with parents), and draws upon children's own words.

As a linguistic anthropologist interested in the role that communication plays in who we are, how we experience and feel, and the social worlds that we constitute and inhabit, I show in this book that we can learn much about experience, culture, and sociality by analyzing in detail the kinds of questions children with cancer ask. In addition to filling important gaps in pediatric cancer communication research, children's questions shed light on concepts such as disclosure, participation, childhood, and "patienthood," and the sociocultural dimensions of uncertainty and hope.

If we return to Pedro's questions to his pediatric oncologist ("doctor" hereafter) and his parents, they reveal Pedro's considerable knowledge about cancer treatment, his ability to use his knowledge to make pertinent assumptions about future outcomes, and his competence in understanding and contributing to treatment discussions. Pedro conjectures correctly that his hair may fall out, his leg may not be the same after the surgery, and that his treatment will require a long hospitalization.

In Pedro's questions, we also observe culturally sanctioned ways of talking about cancer in Catalonia. These ways of talking about cancer consist of something between open disclosure (e.g., "Pedro, you have cancer and this is how we are going to treat it") and deceptive non-disclosure (e.g., "Pedro, you have a bump, nothing serious, we'll remove it and you'll be fine"). When Pedro, his parents, and the medical team come together, they use multiple verbal and nonverbal (e.g., Pedro's mother's pointing gesture) resources to communicate about cancer that do not entail using the explicit word, to talk about more optimistic and hopeful aspects of cancer treatment (e.g., cure and recovery), and to avoid talking about the uncertain and negative aspects (e.g., Why do I have cancer? Will I live or die?).

I want to emphasize that patients at Catalonia Hospital like Pedro know that "it" refers to cancer, and they know that you do not use the word "cancer" to talk about "it." Patients, particularly young people, figure out one way or another that they have cancer and that something bad is happening to them. It takes Pedro only a few minutes to figure out he has cancer, and a few more minutes to figure out not to use the word "cancer" ever again.

Pedro's questions highlight the challenges children face in participating in discussions about their own future and about their cancer treatment. Despite Pedro's

explicit requests to have more information and be involved, the doctor gives him information about his treatment after negotiating with his parents. Furthermore, Pedro is not given the opportunity to make any treatment decisions. Instead, he is presented with what the doctors and his parents have previously agreed on.

In this environment of limited communication and opportunities to participate in treatment conversations, Pedro's questions point to a pattern of patients' questions and doctors' answers that increases as patients become very familiar with treatment and with the doctors over the many months, if not years, of treatment. In an expanding chain of question–answer–question–answer, patients and doctors engage constantly in “cat-and-mouse game” negotiations. Patients ask about their future treatment, and doctors respond evasively as they try to stay away from what they perceive as potentially distressing for the patients: uncertain and bad news. Without challenging medical and parental authority, children try, one question at time, to exert a degree of agency in conversations concerning their own treatment and their own uncertain futures.

Alternatives to Speaking

This book is an ethnography of the “communicative conduct of a community” (Hymes 1974: 9) formed by pediatric cancer patients, their families, and caregivers at Catalonia Hospital. In particular, I examine “communicative economy” (Hymes 1974: 4) of not talking and talking about cancer, as well as how to talk about cancer, when, where, and with whom. At Catalonia Hospital, children ask about their uncertain future and doctors evade answering. Children remain silent in doctor–parent conversations that exclude them. Children keep information from doctors and parents, and doctors and parents keep information from children. Doctors, parents, and children participate in a particular way of talking about cancer, including not using the word “cancer,” discussing the more optimistic and hopeful aspects of cancer treatment, and sticking to the present and the most immediate future. In this culturally sanctioned way of talking about cancer, not talking at all about some aspects of the cancer experience constitutes an alternative to talking.

Concurring with Bauman's warning (1983: 11) against the logocentrism of our culture and of the linguistic disciplines, I analyze the strategies of talking and not talking, contextualizing the explicit (i.e., talk) in the context of the inexplicit, and vice versa. In line with earlier ethnographies and communication studies that examine the variable meanings of silence (Basso 1970, 1979, 1996; Bauman 1983; Jaworski 1993, 1997; Philips 1976, 1983, 1990; Tannen and Saville-Troike 1985), I illustrate how strategies of “not talking” cannot be equated with silence, nor can “not talking” and silence be equated with an empty “noncommunication.” Omission, silence, and other ways of not talking do *communicate* something, convey specific and situated meanings (Hymes 1972b). Against this perspective

of non-talking as a communicative void, I argue that the so-called conspiracy of silence around cancer (Fallowfield et al. 2002) is actually a conspiracy of talk. Because remaining silent may be perceived as acquiescing to the idea that something is potentially wrong, participants go to great lengths to continue talking *as if* nothing is potentially wrong. For instance, participants may talk after a question without necessarily answering it, or prevent sensitive questions from being asked at all. Thus, real and potential breaks in the conversation and silences are actively avoided in the non-disclosure of cancer information.

Once the notion of non-speaking as a communicative void is abandoned, a rigid opposition between the said and the unsaid falls apart, and the richly textured and multidimensional meanings of the unsaid emerge (Bauman 1983; Tyler 1978). We uncover a “said” that is designed to make explicit and to keep implicit, a “said” in which uncertainty, indeterminacy, ambiguity, indirectedness, euphemism, allusion, evasion, implicitness, and even silence itself are not anomalies, but interactional achievements (Beach 2009; Clayman 2001; Maynard and Frankel 2003; Peräkylä 1995; Schegloff 1996; Sidnell 2005; Wooffitt and Holt 2010).

My analysis of children’s participation in pediatric cancer conversations stems from a theoretical perspective that regards language—and communication—as action (Levinson 1983). Communication is no mere reflection of thought nor representation of a pre-established and external reality that exists outside language, including thought. Communication does more than classify, name, and refer to objects in the world and cannot be considered simply a denotational, representative, transactional, referential, or classificatory system. Communication is also a mode of action that constitutes social worlds and is consequential for those who live in them (Ahearn 2001; Duranti 1997; Malinowski 1946 [1923]). Communication is performative, creative, and emergent in situated practices and contexts. It is enacted and dramatized with a myriad of verbal and nonverbal resources, is never twice the same, and has the power of creating and transforming social realities. Against “denotative referentialism” (Wilce 1998: 201), referentialist ideologies of language (Hill 2008; Silverstein 1976, 1987; Wilce 2009a), and against “the fallacy of description” (Tyler 1978), linguistic anthropologists have argued that communication is a way of being in and experiencing the world; it is a “set of practices which play an essential role in mediating the ideational and material aspects of human experience, and hence, in bringing about particular ways of being-in-the-world” (Duranti 1997: 4–5). As eloquently expressed by anthropologist William Hanks (1996: 236), “To speak is to occupy the world.”

My conversation analytically informed ethnographic approach to communication as a way of doing, feeling, and being-in-the-world reframes previous debates on whether the doctors are or are not telling the “truth” or whether withholding information constitutes deception (Blackhall et al. 2001; Surbone 2004; Tuckett 2004). These debates are still based on a referentialist theory of language, which is predominant not only in the health sciences, but also in medical anthropology and medical communication (Good 1994; Kuipers 1989; Wilce 1998; Wilce 2009a). My analysis incorporates other kinds of meanings, such as connotative,

social, affective, indexical, and intentional (Tyler 1978). In this book, I show how participants use explicit and implicit communication to constitute, influence, and make sense of the world they inhabit—or that they want to inhabit—as they negotiate talking about some aspects of their experience while avoiding talking about others. I problematize the identification of talk with a purported straightforward transmission of information; explore why and how communication itself can be used to obscure and impede communication; and highlight the micro-political dimension of these negotiations on how to talk about cancer (i.e., each social actor comes to a specific interaction with his or her own political agenda, negotiating meanings and trying to influence courses of action).

Disclosure as a Dynamic and Heterogeneous Process

I argue that disclosure is a historically dynamic, culturally heterogeneous, and locally negotiated process of managing information, particularly bad and uncertain news. I use “disclosure” since it is the most frequent term used in the pertinent literature. However, I consider communication regulation to be a more encompassing term to describe the variability and diversity that I found at Catalonia Hospital. Rather than reducing the diversity and situated variability of communication to a dichotomous opposition of disclosure versus non-disclosure, I argue that the regulation of communication involves varying and often contradictory degrees and types of information disclosure, the regulation of emotions, and the regulation of both the content (i.e., *what* aspects of cancer are talked about or avoided) and linguistic and nonlinguistic form (i.e., *how* aspects of cancer are talked about or avoided).

Disclosure is historically dynamic and evolves as cultural models and biomedical technologies change. Cancer was often associated with death, and in the United States non-disclosure was the predominant communicative strategy with adult cancer patients until the 1970s and until much later with pediatric cancer patients (Bluebond-Langner 1978; Chesler et al. 1986; Mitchell 1998; Taylor 1988). Moreover, Gordon and Paci (Gordon 1990; Gordon and Paci 1997) have described the remarkable changes from non-disclosure to disclosure that were taking place in Italy more than a decade ago, and which are similar to the rapid cultural and communicative changes taking place in Catalonia and Spain that I examine (for a discussion of the multiple causes for these changes, see Chapter 2).

Furthermore, diverse disclosing practices are found within societies, not just across societies. Like many studies of cultural differences in health settings, cross-cultural studies of cancer communication have tended to present culture and communication as homogenous phenomena (Kagawa-Singer 2001). Intra-cultural diversity and dynamism, as well as contextual and individual variation, are considered exceptions rather than characteristics of culture (Ahmad 1996; Kagawa-Singer 2001). The cultures of nondominant peoples may be even turned into problems to be resolved (McMullin and Weiner 2009). Cross-cultural studies have often used the term “truth telling,” which I have already problematized and which is becoming obsolete (Surbone 2006; Surbone et al. 2013). Some studies

acknowledge historical changes in truth telling because of medical, legal, societal, and political factors, as well as differences between health professionals versus patients and their families (Mitchell 1998; Mystakidou et al. 2004; Surbone 2006; Surbone et al. 2004). At the same time, they classify and group large areas of the world as either disclosing, where truth telling and honest disclosure predominate, or nondisclosing, where paternalism and deception predominate. Because nondisclosing countries tend to be countries that have gained access to cancer biotechnology more recently, the dichotomy between disclosure and non-disclosure may portray as cultural differences what are in fact biomedical inequalities in the availability of and access to cancer therapies. In Good et al.'s (1993: 180–181) formulation of the political economy of hope, the authors note that culture influences the ideologies and practices of disclosure, but also that “practices of disclosure in turn influence and are influenced by the availability of treatment choices and investment in anticancer therapies and research.”

Additional evidence of the diverse disclosing practices within societies is found in health professionals' debates over the withholding of prognosis information and false optimism with terminally ill adult cancer patients in countries such as the United States, the United Kingdom, and the Netherlands (Fallowfield et al. 2002; Good et al. 1993; Helft 2005; The 2002; The et al. 2000; Tuckett 2004). Underlying these debates is a problematization of what constitutes honest and truthful prognostic information. Does giving too little information or stalling the disclosure of information constitute deception? When does too much optimism create false expectations?

Ethnographic and qualitative interview studies have also called into question a disclosing/non-disclosing dichotomy, noting that contradictory disclosure practices coexist and that the preferences of an individual patient may not necessarily be consistent (Frank et al. 2002; Good et al. 1993; Gordon 1990; Gordon and Paci 1997). In Gordon and Paci's (1997) analysis of disclosure/non-disclosure among women with breast cancer, their families, and health professionals in Tuscany, Italy, the authors describe how multiple narratives coexist in the same cultural field and with the same person. Specifically, they locate disclosure and non-disclosure practices within two larger cultural meta-narratives that are contested and evolving. Non-disclosure is located within a traditional meta-narrative of “social embeddedness,” with an emphasis on social unity, sparing another suffering and taking it on oneself, supporting a good life and a “good” death, and the protection of society to ensure the adaptation of the community to life's inevitabilities. Disclosure is located within a meta-narrative of “autonomy-control” with an emphasis individual autonomy, control, and sovereignty of one's destiny. Challenging “social embeddedness,” the “autonomy control” meta-narrative is associated with medical practices such as open communication, informed consent, and patients' rights, and is proliferating from the United States worldwide, often in the form of international biomedical protocols.

Disclosure is an unfolding complex process and not “a single event that does or does not occur” (Good et al. 1990: 62), and may include multiple

co-occurring, and often contradictory, communicative strategies that are negotiated locally. Disclosure strategies are adapted to the different periods and circumstances of children's cancer trajectories, such as side effects that delay treatment administration, infections that put children's lives at risk, or specific courses of treatment that fail to reduce or eradicate tumors. Consequently, disclosure is neither a stable nor a cohesive process. Instead, it is a continually negotiated process with ill-defined contours. Parents, children, and doctors may agree on the sociocultural appropriateness of regulating communication, but they do not automatically agree on what needs to be avoided at a specific point of a child's cancer trajectory.

At Catalonia Hospital, I identify six communication strategies used in the presence of children that co-occur and are often contradictory (see Chapter 5). The first strategy entails deception, as for instance, telling the child he or she has a knee infection when there is strong evidence there is cancer. The second is official and planned complete non-disclosure, in which some parents try to conceal all information from their child, particularly when the child is first diagnosed or when he or she is dying. In the third strategy, unofficial leakage and gathering of information, patients gather information by overhearing physicians talking or by collecting information from other patients and parents. The fourth strategy involves unplanned and improvised partial disclosure, as when the specialist abruptly tells the child he has a tumor only after the child refuses to be hospitalized. The fifth strategy encompasses varying degrees of emotion regulation, as for instance, when parents and children avoid crying in front of each other, they do not direct their anger outbursts at doctors, or adopt the institutional mandate to be hopeful and optimistic in public. Finally, the sixth strategy, official and planned partial disclosure, consists of the constant monitoring by doctors and parents of what the child is told, and practices of controlling or limiting the information that a patient is given, such as teasing, reassurances, contingent answers, narrow answers, non-answer responses, piecemeal information giving, and forestalling.

The use of these strategies varies depending on the circumstances and the different periods of the child's cancer trajectory. During pre-treatment, diagnostic deception and complete non-disclosure are followed by the partial disclosure of treatment information, which is stalled for as long as possible. During treatment, talk about overall uncertainties related to the distant future (i.e., cure or death) is avoided, and talk about local uncertainties associated with treatment is minimized in the presence of the child. Whenever local uncertainties are talked about in the presence of the child, it is always in optimistic and confident terms, and completely disassociated from any real or potential references to overall uncertainties. During post-treatment, even more complex strategies of communication are observable as uncertainties evolve. For parents and patients in remission, post-treatment outpatient follow-up visits present an opportunity to talk more openly about the many anxieties that they avoided during the treatment, as well as an opportunity to talk about the new anxieties and uncertainties of relapse. Talk about uncertainties is still peripheral, but far more frequent than during the treatment period. For parents and patients in relapse, parents' desire for complete

and planned non-disclosure to protect patients from bad and uncertain news becomes moot: the relapsed patient knows as well as his or her parents what is happening and what it means. As parents and patients confront death, the knowledge of approaching death coexists with the institutional mandate of optimism and hope in the hospital.

The regulation of communicative strategies according to children's changing circumstances is one among several interrelated ways of managing the challenges and containing the uncertainties of cancer diagnosis and treatment (Chesler et al. 1986; Cohen 1993; Good et al. 1990; Taylor 1988). These processes, analyzed in detailed in Chapter 3, include focusing on the present course of treatment, making guesses about various aspects of children's health, being together, and talking privately.

I argue that containing and avoiding uncertainties, more than bad news, are the objectives of communicative strategies that limit what aspects of cancer are discussed and how they are discussed in the presence of children. At Catalonia Hospital, "protecting" the pediatric patient requires withholding information that is perceived by doctors and parents to be potentially distressing. The withholding of information is more extensive than the withholding of only bad news, because it also includes the delay of uncertain and indeterminate news, which may also be stalled and withheld altogether. I support my claim that communication-limiting strategies are directly related to uncertainties by presenting three types of evidence: doctors and parents withhold information even when treatment is going well, they act as if that there is nothing to withhold, and all participants collaboratively sustain a sense of certainty and optimistic confidence in the treatment. If limiting communicative strategies were only used to contain bad news, the limitations of what aspects of cancer to talk about and how to talk about them would not be as pervasive as they are throughout the entire cancer trajectory. Bad news is only delivered at specific and temporally limited points in time, whereas uncertain and indeterminate news is far more persistent and creates a continuous sense of anxiety and vulnerability. For these reasons, parents and doctors continuously monitor and filter the information given to children and the emotions displayed in their presence.

Disclosure to Children with Cancer

Numerous studies have revealed that information about diagnosis and treatment is routinely withheld from pediatric cancer patients. Chesler, Paris, and Barbarin's (1986) study of communication choices among parents of children with cancer in the United States shows that a significant number of parents choose to postpone informing their children, to limit information, or to withhold it altogether. The authors conclude that more than 60% of the participating parents and families "utilized a variety of euphemisms or avoidances in dealing with the problem of telling" (Chesler et al. 1986: 507). "Relatively full disclosure" is only present in 30% of the parents and 36% of the families. Clafin and Barbarin's (1991: 177)

study of the relationship between age and degree of information disclosure among 43 children from two North American Midwestern hospitals reveals that only 40% of the participating children reported “being told of the cancer or of a specific diagnosis (i.e., leukemia) at the time of diagnosis.” With respect to prognosis and the possibility of death, almost 63% of the children were told nothing at the time of diagnosis.

Information-limiting disclosure practices and preferences have also been found among British children (ages 4–12) and young people (ages 13–19) with cancer, their parents, and health professionals (Aldiss et al. 2009; Dixon-Woods et al. 2005; Gibson et al. 2010; Horstman and Bradding 2002; Young et al. 2003). Among their findings, they report that parents and children may disagree on what information should be disclosed. Young people express a desire for more information, to have doctors give the information to them directly and not necessarily after their parents are told. Young people’s preferences for their parents’ roles in communication are different, fluid, and context dependent (Young et al. 2003). Young people use parents as a resource to manage communication, although parents may or may not cooperate. They describe their parents acting as executives by censoring and filtering information, as facilitators who support children’s questions, as buffers who shield them from the burden of asking questions, as human databases who store illness information, and as brokers who clarify and reiterate information given by health professionals. Gibson et al. (2010) identify two additional parental communication roles: information providers for younger children (ages 4–12) and confidantes for young people (ages 13–19). In the parental role of confidante, “children rely on their parents to listen to private opinions, and to use partnership-related discourse (e.g., ‘we’) to support their expression of preferences” (Gibson et al. 2010: 1405).

Regarding how parents decide what information to disclose and what emotions to display to their children, Young et al. (2002a, 2002b, 2003) underscore the multifariousness and contextual specificity of the process through which parents determine what is appropriate at a particular moment in the child’s cancer trajectory. Factors influencing but not determining parents’ regulation of communication include the emotional distress parents experienced according to children’s age and cognitive development, and to the stage of the illness. Less information is shared during acute periods, and more information is shared during routine treatment periods. Parents also take into account how prepared they feel they are to talk about difficult aspects of cancer, their knowledge and experience of how their child handles problems, their own difficulties in absorbing information, a fear of breaking down in front of their child, a concern with the child cooperating with treatment, and a desire to manage their own identity as strong and optimistic parents as a way to protect their child’s well-being. An interesting finding reported by Horstman and Bradding (2002) is that children were puzzled when researchers asked them what they would want to know from their parents. Horstman and Bradding add that it is apparent from children’s puzzlement that they are rarely asked what they want to know about their illness, treatment, or prognosis.

The fact that children's opinions are rarely solicited during treatment or research is one of the key problems that Dixon et al. (2005) find with a cancer "information-giving" approach in dichotomized "telling versus not telling" debates. Dixon et al. also discuss additional problems with this approach. On the one hand, it tends to characterize the child-patient as a passive recipient of information and focuses on diagnostic and prognostic information rather than the more temporally variable and negotiated information needs of children with cancer. On the other hand, it does not take into account children's differences in type and amount of information, and leaves unexamined individual, contextual, and temporal variation in their information preferences. On the basis of existing literature on children's information preferences, they contend that "approaches that strongly advocate a policy of full and frank open disclosure are not necessarily in line with (all) children's preferences" (Dixon-Woods et al. 2005: 121) (see also Bluebond-Langner below).

Through interviews with the children themselves, participatory research methods, and observation, children's opinions and perspectives have only recently been incorporated in pediatric cancer research. In her review of qualitative pediatric cancer research from 1978 through 1998, Woodgate (2000) stated that the study of children's experiences was still in its infancy at that time. Subsequent work by Woodgate, and the aforementioned work by Dixon-Woods et al. and Gibson et al. have brought about a paradigm shift in which the experience of the child with cancer is now central (Aldiss et al. 2009; Dixon-Woods et al. 2005; Gibson et al. 2010; Woodgate 2006; Woodgate and Degner 2002; Young et al. 2003). Nonetheless, few studies have included actual observations of children, and even fewer have included extensive participant observation (Aamodt et al. 1984; Bluebond-Langner 1978; Kelly and Kelly 2013; Woodgate 2006; Woodgate and Degner 2002).

Written almost 40 years ago, Bluebond-Langner's ethnographic study of a group of dying children (ages 3–9) in the United States continues to stand out as the richest and most detailed account of the everyday life of children with cancer. Building on symbolic interactionist and ethnomethodological approaches to childhood socialization, Bluebond-Langner identifies five stages through which children become aware that they are dying. In this long and difficult socialization process, Bluebond-Langner highlights the importance of children's acquisition of factual information about the disease, experiences of the illness, and their changes in their self-concept. As children become aware that they are dying, they also become aware of the rules they need to abide by and the roles they must enact in order to preserve the social order and maintain membership in society. Despite the fact the child is dying, "mutual pretense" (Glaser and Strauss 1965) allows them to carry on with what society expects: children grow up, parents protect them, and physicians heal them. Bluebond-Langner argues that simply labeling death as an unspeakable taboo cannot explain why children kept their awareness of dying a secret all the way to the end. Instead, she argues that children knew what their parents knew and wanted to hear, and that they were more concerned with

having parents around than with telling them what they knew themselves (Bluebond-Langner 1978: 235). To overcome the threat of exclusion from social interaction and to retain their identity and membership in society, dying children performed according to the North American definition of “child.” Thus, children act as individuals who are in the process of becoming, and who are being molded, readied, and prepared for their future.

Bluebond-Langner’s (1978) ethnography and subsequent collaborations (Bluebond-Langner et al. 2005, 2010) have shown that concealment of information from children with cancer and other life-threatening illnesses takes place in countries where disclosure is supposedly favored, such as the United States and the United Kingdom. Bluebond-Langner has repeatedly cautioned against a disclosure versus non-disclosure dichotomous reductionism, which parallels the “telling versus not telling” debates (Dixon-Woods et al. 2005). A “one size fits all” open disclosure is as problematic as non-disclosure. It ignores that individual preferences change over time, the fact that children and parents have simultaneous and contradictory needs to reveal information to some people and to conceal it from others, and the societal roles and responsibilities that parents and children want to fulfill. Rather than a “one size fits all” form of information, Bluebond-Langner proposes that physicians lead a negotiated process of “shuttle diplomacy” that involves meeting with children and parents separately as a way to establish the groundwork required to make very difficult decisions collaboratively.

Problematizing Participation

My analysis of children’s participation in cancer conversations—which is also an analysis of their exclusion—has brought me into a terminological cul-de-sac. I find myself using the term “participation” while simultaneously being critical of it. My apprehension about the term “participation” began with a series of observations during my fieldwork at Catalonia Hospital, which led me to problematize the relationship between participation, accountability, agency, and responsibility. Although I conceptualize my problematization of participation as being intimately related to debates over culturally variable notions of intentionality, morality, and personhood (Duranti 2004; Duranti et al. 2011; Hill and Irvine 1993; Rosaldo 1982), I limit my discussion, as much as I can and for the sake of brevity, to accountability, responsibility, and agency in relation to participation.

During my fieldwork, I often observed that patient-initiated courses of action did not reach completion. There were occasions in which children asked questions and pursued answers but did not get the information they were seeking. Furthermore, there were more occasions when the children did not even pursue an answer after an evasive response. In this recurrent pattern of no answer by the doctor, there were no accounts for the absence of an answer. In characterizing the question-answer sequence, conversation analyst John Heritage (1984: 250)

notes that speakers regularly offer accounts for the absence of an answer, produce accounts in the place where the answer is due, and exhibit an orientation or sensitivity to the normative accountability of the question–answer structure. However, when children asked questions, participants would often not treat a relevant answer to be officially absent, would provide no accounts addressing why an answer was absent, and did not seem to treat as problematic either the absence of accounts. Children’s pursuits of answers, which clearly show that children were holding doctors accountable for not answering adequately, were more the exception than the norm. This lack of public accountability was occurring in one of the most basic forms of social organization, such as the sequence of a question and an answer, and included doctors, parents, and the children themselves. When compared to other types of children’s accountability and responsibilities in healthcare interactions (Bluebond-Langner et al. 2005; Clemente 2009), at Catalonia Hospital there was an absence of accountability *to children by adults* (e.g., adults neither answered nor accounted for not answering), and an absence of accountability *of adults by children* (e.g., children often did—or could—not pursue answers or accounts for the lack of answers from adults).

The conversation analytic concept of *recipient design* also brought me to problematize the term “participation” in terms of the cultural, situated, and interactive construction of the identity of “child.” The concept of *recipient design* posits that speakers design their talk so as to display an orientation or sensitivity to interlocutors to whom they are talking (Sacks et al. 1974: 727). A speaker designs his or her talk for a particular interlocutor, and because of that, the speaker’s talk contains specific assumptions about who the speaker believes the interlocutor is and what he or she knows. By analyzing how participants design their talk for their co-participants, we can see how they conceptualize each other (Duranti 1997: 299). A close examination of the doctor’s talk to a child reveals that the doctor constructs the child as a member of a particular group or class, to which she does not hold herself accountable. And an examination of the child’s talk to a doctor reveals that the child constructs the doctor as a member of a particular group or class, which the child does not hold accountable. This interactive process shows how both children and doctors are co-constructing social personae such “doctor” and “child” with asymmetrical rights and obligations.

Having observed children’s unsuccessful actions and lack of accountability in their interactions with adults at Catalonia Hospital, it seemed inaccurate to use the term “participation” decoupled from public accountability, and consequently, from agency and responsibility. Furthermore, my reservations about the term increased after realizing that, whereas children’s participation and accountability in cancer conversations were limited, children’s participation in making fundamental treatment decisions (e.g., choosing surgery, radiation, or chemotherapy, or when to transition from curative to palliative care) was zero. In the data under examination here, children might only be consulted for smaller treatment decisions (e.g., to postpone for a couple of days the start of a chemotherapy session

because of a holiday or the child's birthday). Retrospectively, some young people said they were upset about not having been consulted about key decisions. However, I did not observe young people expecting to be consulted as key decisions were about to be made. I only observed young people trying—and often failing—to be informed about key decisions that had already been made.

In this context of children's limited participation in cancer conversations, I would like to discuss a series of theoretical and ethical paradoxes emerging from my findings at Catalonia Hospital. I point out five paradoxes without attempting to resolve their contradictions:

1. Children's participation depends only partially on children's actions.
2. Exposing the limitations on children's participation has the potential to reify and naturalize the perspective of children as incomplete human beings (i.e., the children as not being able to do X or Y).
3. The risks of reducing participation to talking/doing by equating talking with participation and not talking with a lack of participation.
4. The risks of reducing human agency to action by equating acting with having full human agency and not acting with having less than full human agency.
5. The construction of children as non-responsible participants: distinguishing between children's participation and the increasing responsibilities that may come with more participation.

I do not claim that these paradoxes are particular or exclusive to children. As with any other sociocultural construct, children in this study are never just children: they are also patients, sons and daughters, youngsters and young people, working and middle class, speakers of Catalan and Spanish or both. Some of the constraints that I discuss here are associated with the role of patient. Whether a child or an adult, the patient has to fight against deeply ingrained interactional routines (e.g., the chain pattern of physician–question and patient–answer) if he or she is to exert some control over the development of the ongoing interaction (Beach 2001a; Boyd and Heritage 2006; Frankel 1990; Heritage 2003; Roter 1984; Stivers and Heritage 2001).

Other constraints involve the presence of an accompanying third party, which places additional (and sometimes competing) demands on the healthcare professional and the patient (Gabe et al. 2004; Stivers 2001; Tate and Meeuwesen 2000; Tate et al. 2002; van Dulmen 1998). Whether the patient party involves two adults or an adult and a child, the physician has to decide to whom he or she will talk at a specific point of the interaction, as well as decide how he or she will deal with interactional contingencies such as when the members of the patient party start talking to each other or compete to talk to the physician (Greene et al. 1994; Korfage et al. 2013). Finally, it would be naïve not to take into account that some of the constraints that limit children's participation as underage patients simultaneously constrain their parents' participation. Indeed, children and parents in this study belong to the category of non-expert laypersons who spend long

periods of time in and out the hospital as a quasi “total institution” (Goffman 1959a). In what follows, I expand on my five reservations listed above.

1) *Children’s participation depends only partially on children’s actions.* Children’s actions in interactions with adults not only depend on what children actually do, but also on how adults and the children themselves construct children-as-persons with competencies, accountabilities, and responsibilities (James and Prout 1997; Meeuwesen and Kaptein 1996; Pufall and Unsworth 2004). In Western societies, perceptions of children’s competencies and expectations have undergone socio-historical and cultural changes in the direction of increased acknowledgement of the importance of the child’s perspective. However, as Pyörälä (2004) points out in her analysis of pediatric diabetes dietary counseling, much of children’s participation in healthcare encounters continues to depend on what children and adults believe about children’s ability to contribute and the value of such contribution (i.e., Is a child’s potential contribution as valuable as his or her parents’? Is a child’s conversational contribution different from that of his or her parents? Is it worth the extra time and energy to elicit information directly from the child?).

Consequently, children’s participation in any aspect of their own lived worlds needs to be examined in relationship to the specific kinds of cultural constructions of childhood, that is, what a child is perceived to know, feel, understand, and be responsible for, as well in relationship to what children actually are, do, feel, and understand. Because adults often establish limits to what children are allowed to do in everyday activities, an analysis of children’s participation must then include both children’s *potential abilities* to participate as constructed by adults and children, *actual instances* of participation, and *limitations* to children’s participation. However, examining only adult limitations to children’s participation ignores the fact that the children themselves may have a say in how they view themselves, and how much they collude with or contest the ways in which they are constituted in social interaction.

2) *Exposing the limitations on children’s participation has the potential to reify and naturalize the children-as-not perspective.* Against “an excessively idealized version of adult autonomy, independence, and maturity” (Rosen 2007: 299), an emphasis on what children *are not* and *do not* do has the potential to overlook what children *are* and *are actually* doing. In healthcare interactions with children, children’s limited participation has been extensively documented across numerous pediatric settings and conditions (Coyne 2008), including emergency care (Wissow et al. 1998), acute and routine outpatient care (Aronsson 1991; Stivers 2001, 2007; Bates and Meeuwesen 2001; Bates et al. 2002; van Dulmen 1998; Wassmer et al. 2004), family therapy (Cederborg 1997; Hutchby and O’Reilly 2010; Parker and O’Reilly 2012), child counseling (Hutchby 2007), and chronic illness (Beresford and Sloper 2003; Bluebond-Langner et al. 2005, 2010; Pyörälä 2004; Silverman 1987; Young et al. 2003). Doubly immersed in the social institutions of medicine/clinic and the family, and under both medical/clinical and parental authority, children’s marginalization and exclusion result in children being reduced to half-members, peripheral participants, and non-persons in healthcare

interactions (Aronsson and Cederborg 1996; Cederborg 1997; Hutchby and O'Reilly 2010; Strong 1979).

Nonetheless, a half-empty glass implies that the glass is also half-full. To speak of children's limited participation implies that children do participate somehow. Children often use less talk and receive less interactional and scholarly attention. Yet they do participate, without talking (Clemente 2009), when they say "I don't know" or do not cooperate (Hutchby 2002; O'Reilly 2006), and even when they look away and cry, as illustrated in Chapter 5. And parents, when they talk *for* the children and *about* the children in the presence of the children, may still display an orientation to the fact they are talking not as the primary recipient of question addressed to the child, but as secondary recipients (Clemente 2009; Clemente et al. 2012; Stivers 2001).

To counter the risk of perpetuating the view that children *are not* X and Y, or that children *do not* do X and Y, studying children may also involve investigating and scrutinizing their behavior, even when it seems as though they are doing nothing. In addition to opening the social sciences to include children as research partners (Christensen and James 2000; Thomas and O'Kane 1998) and as active co-participants in interactional processes of language socialization (Duranti et al. 2011), "giving voice to children" (Alldred 1998; James 2007; Schwartzman 2001) also includes as aspects of the childhood research agenda observing children-doing-nothing and children-saying-nothing. Children-doing-nothing and children-saying-nothing may then be regarded as evidence of children being competent social actors/agents, and not just as children's failing or being unable to do X or Y. This is an important theoretical contribution that studying childhood makes to anthropology and the social sciences—done with adults and for adults—by challenging conceptualizations of human agency, development, and responsibility (Bluebond-Langner and Korbin 2007; James 2007; Schwartzman 2001).

3) *Reducing participation to talking/doing.* Another paradox of the term "participation" is the potential assumption that if talk is participation, non-talk is non-participation. As a result, the focus is on verbal action at the expense of nonverbal action and on those who speak at the expense of those who do not speak. Notice, of course, how nonverbal action is defined as the negative derivation of the term "verbal." Talk as the starting point and central focus of interactional studies of communication has carried over the logocentrism of the linguistic disciplines (Bauman 1983; Erickson 2010; Linell 2005; Streeck et al. 2011). As talk recipients and the overhearing audience, the participation of those who talk less in an ongoing activity is not just essential to how the activity is co-constructed, but essential to how speakers design and organize their talk (Goodwin 1981, 1986). Furthermore, those who speak less may still retain the primary authority, rights, and responsibilities while having somebody else do most of the talking (Ochs and Taylor 1995) or having somebody else talk for them (Goffman 1981; Goodwin and Goodwin 2004; Hill and Irvine 1993). Very importantly, the overemphasis on talk obscures the contributions and communicative competence of those who, in Rosen's words above, do not meet "an excessively idealized version of adult

autonomy, independence, and maturity” (Rosen 2007: 299) such as children, people with disabilities (Goodwin 2004), or the elderly (Greene et al. 1994).

4) *Reducing human agency to action.* I am also concerned with the fact that action, or borrowing Duranti’s words (2004) “act-constituting agency,” is the most studied type of human agency in linguistic anthropology and CA. Duranti (2004: 455) states that “students of language were so anxious to prove the axiom that ‘language is action (too)’ that they forgot to recognize that language already does something by *being*, before *doing*.” Trying to define, specify, and classify human agency goes beyond what I can achieve here, and I refer the reader to the important work that has been done on this topic (Ahearn 2001; Al Zidjaly 2009; Duranti 2004; Kockelman 2007; Ortner 2001b). Here, I want to bring to the reader’s attention the fact that the focus on action creates the impression implicitly and by default that the most salient—and perhaps paramount—form of human agency is action. Individuals with agency have power, choice, and control. On the other hand, those who act or talk less are less agentive, do not quite have full human agency, and are not quite fully realized humans. This is not an exaggeration, because as I noted earlier, scholars have used the terms “non-person” and “half-member” in describing how children are treated in health encounters. More recently, scholars have highlighted other forms or dimensions of agency, such as Duranti’s (2004) ego-affirming or existential agency through language and Ortner’s (2001b) agency of culturally constituted intentions, projects, purposes, and desires. These other dimensions of agency are not just an extension of a “Western concept of bourgeois individualism” (Ortner 2001a: 272), but an inevitable characteristic of the human condition (Duranti 2004), with a greater or smaller degree of a “sociocultural mediated capacity to act” (Ahearn 2001) depending on sociopolitical inequalities and power differentials.

5) *Children as non-responsible participants.* My last contradiction reflects my ambivalence toward the concept of participation without responsibility. Although I argue throughout this book for the importance of increasing children’s participation in cancer conversations, I want to take stock of the ethical ramifications that increased child participation may entail. Children’s increased participation in healthcare encounters may lead to an increase in their responsibilities, which the children themselves may not be able to take on or want to take on, and which may also conflict with parents’ social roles and responsibilities (Bluebond-Langner 1978; Bluebond-Langner et al. 2005, 2010; Clemente et al. 2008; Clemente 2009).

I take participation and responsibility as related but distinct concepts. In linguistic anthropology and CA, participation has a strong structural component (Duranti 1997; Goodwin and Goodwin 2004; Goodwin and Heritage 1990). Goodwin and Goodwin (2004: 222) define participation as “an analytic concept that refers to actions demonstrating forms of involvement performed by parties within evolving structures of talk.” In this technical use, participation includes the structures or frameworks that organize the total configuration of an activity, and the ways in which a specific individual relates himself or herself to what he or she is doing and saying and to what other participants are doing and saying at any

given moment of an activity. Underscoring the observation that participation is not only coordination but also differentiation, Duranti (1997: 313) takes up a more relativistic approach to participation, one in which interactional arrangements are only constitutive of participants' lifeworlds, and thus, only relatively consequential to the creation and reproduction of social orders beyond that of the most immediate interaction order (Goffman 1983).

Responsibility, on the other hand, has been described in terms of causality, morality, social responsiveness, and the attribution and distribution of authorship and intentionality (Duranti 2004; Hill and Irvine 1993; Ochs and Izquierdo 2009). Numerous studies show situations where participants are involved in communicative events but are not considered by others as holding responsibility, accountability, authorship, or intentionality for their communicative actions. Among these studies, one can find studies based on Goffman's (1981) "footing" deconstruction of speakership and distribution of authorship (Goodwin and Goodwin 2004; Goodwin 1990), analyses of reported and/or authoritative speech (Hill and Irvine 1993; Holt and Clift 2010), and language socialization studies (Duranti et al. 2011; Ochs and Izquierdo 2009; Reynolds 2008; Schieffelin and Ochs 1986; Schieffelin 1990). Reynolds' (2008) analysis of the negotiation of responsibility among Guatemalan Kaqchikel Maya children and adults poignantly shows the fluid and multidirectional nature of children's responsibility. The negotiation not only involves adults holding children responsible or stripping them of responsibility, but also children holding adults accountable for taking disciplinary action, and children deflecting responsibility for their actions.

There is a contemporary general sense that increasing children's participation and responsibilities has positive consequences. Children's ability to take on responsibilities for family practical tasks is fundamental to the process of children becoming moral, responsible, autonomous, and competent members of their communities (Klein and Goodwin 2013; Ochs and Kremer-Sadlik 2013; Ochs and Izquierdo 2009). Furthermore, children's participation in family practical tasks fosters their mastery of these activities. In addition to discouraging a sense of entitlement, giving children responsibilities and holding them accountable for the final outcome teach children that fulfilling—or not fulfilling—their commitments has consequences. In regard to children's health, increased child participation in clinical encounters is also key to children becoming informed and proactive patients (Clemente et al. 2008, 2012; Clemente 2007, 2009; Pyörälä 2004; Stivers 2011; Stivers and Majid 2007), and to preventing important knowledge deficits in children who survive cancer that could jeopardize their health as adults (Kadan-Lottick et al. 2002).

However, ethical, legal, and moral dilemmas arise regarding how much responsibility children should take on and be held accountable for. Rosen's (2005; 2007) analysis of the transnational construction of responsibility in the context of international law, humanitarian advocacy groups, and child soldiers who have committed war crimes poses questions that are difficult to answer: Are child soldiers victims or perpetrators? How does it matter that children understood what they

were doing when they joined a combatant army? The sociocultural and historical variation in the construction of children in terms of agency and vulnerability has been a central concern in studies of childhood (James and James 2004; James and Prout 1997; Pufall and Unsworth 2004; Scheper-Hughes and Sargent 1998; Stephens 1995). As Bluebond-Langner and Korbin (2007: 243) have noted, research on the sociocultural construction of children and childhood reflects “the tension between conceptions of children as developing beings who are vulnerable and in need of protection and of children as in possession of agency, capable and able to make interpretations of their worlds and act on them.”

The participation of children with cancer and other life-threatening and life-shortening illnesses in treatment decisions is another context in which difficult legal and ethical dilemmas arise. Bluebond-Langner and colleagues (2005, 2010) have examined the challenges of involving children with a very poor prognosis (likelihood of survival of 30% or less) in discussions about choosing cancer-directed treatment (i.e., more treatment or participation in experimental clinical trials), or non-cancer-directed treatment (i.e., pain and symptom management palliative and hospice care). They propose a process of physician-led “shuttle diplomacy” that relies on separate and combined meetings with children and parents, in order for children to be involved but without the responsibility of making decisions. Bluebond-Langner and colleagues acknowledge the need to separate child involvement from child responsibility, as child responsibility may be neither possible nor advisable. Parents have full legal responsibility, they may not want their children to be informed and involved at all, and their decisions do not require the child’s agreement. Furthermore, it may not be advisable for a child to feel the burden of making a decision. Consequently, the process of shuttle diplomacy and negotiation allows children to be active players, and if they want to dissent, to have their dissent taken into consideration without feeling responsible for making a decision.

I have raised five concerns about the term “participation” when it comes to children: the acknowledgment that children’s participation depends only partially on children’s actions; the risk of reifying and of naturalizing the *children-as-not* perspective by focusing on what children are not doing; the problems of reducing participation to talking; the possibility of reducing human agency to action; and the ethical dilemmas of how much responsibility children should take on and be held accountable for.

As I close this section, I want to emphasize that I examine here children’s participation, accountability, and responsibility in cancer treatment *conversations*, and not in cancer treatment *decisions*. At Catalonia Hospital, the conception of children with cancer as vulnerable and in need of protection was more important than the conception of children as possessing agency. Children’s agency was evident in their participation in the everyday management of treatment. However, they did not have an opportunity to be involved in making critical decisions because, foremost, they had limited access to the information that is a prerequisite for decision making. Regarding how much responsibility children should take on and be held accountable for, I take children’s questions as evidence that at least

those who are asking questions want to have more information, and possibly, more responsibility, involvement, and participation.

Uncertainty and the Practice of Optimism

I argue that the experience of uncertainty is pervasive for cancer patients throughout the entirety of their trajectories, rather than at discrete moments in time. I also contend that there is not one “uncertainty,” but that there are multiple types of uncertainties, for instance, local (e.g., when treatment will start) and overall (e.g., whether treatment will be successful), and are hierarchically organized (i.e., local uncertainties are seen as requiring immediate attention, which in turn becomes a justification to postpone dealing with overall uncertainties). Furthermore, each of the three treatment periods that I distinguish (i.e., pre-treatment, treatment, and post-treatment) has a different set of overlapping uncertainties. To manage these different uncertainties, patients, parents, and doctors engage in the constant work of hope and optimism, in order to maintain a sense of certainty about the future.

Multiple Uncertainties

Uncertainty is primarily associated with the inability to foretell a cancer patient’s future (Hilton 1988). Yet, pediatric cancer patients and their parents have to come to terms with multiple uncertainties that are associated not only with the future, but also with the past and the present. Most diagnostic uncertainties associated with the past (e.g., Why did I get cancer? What caused it? When did it start? How did it start? Why me? Why now? What could have been done to prevent it? Could it have been diagnosed earlier?) remain unanswered for many patients, because they are frequently unanswerable. Similarly, there are many treatment uncertainties associated with the present (e.g., Is the treatment being effective? Is the treatment working faster than the disease is spreading? Are we losing or winning the battle against time? When is the treatment going to end?).

In her study of the variability of the dimensions of uncertainty among several populations of North American chronically ill children, nursing scholar Marsha H. Cohen (1993) defines these dimensions operationally as event uncertainty, temporal uncertainty, etiologic uncertainty, treatment uncertainty, and prognostic uncertainty. “The multidimensionality of uncertainty” (Cohen 1993) is reflected in most researchers’ definitions (Parry 2003). For instance, Hilton (1988), in her study of uncertainty among North American women with breast cancer, defines the main features of perceived uncertainty in the following terms: perception that ranges from a feeling just less than surety to a feeling of vagueness, not being able to foretell the future, not feeling secure and safe, being in doubt, and being undecided because things are not definite, clear-cut, or determined.

Cohen (1993: 94) underscores the need to study uncertainty as a process, in which the events leading to perceived uncertainty are regarded as “a complex set of changing circumstances that has both a history and a trajectory.” Cohen’s comprehensive definition of the multidimensionality of uncertainty underscores its variability and temporality:

Uncertainty varies in degree of magnitude, intensity, and saliency—from the overarching, existential issues of life and death to the inconsequential contingencies and probabilities that are the substance of everyday life. The source of uncertainty may be internal, as individuals question their beliefs, values, and self-worth, or may arise from conditions in the environment that are perceived as novel, ambiguous, or lacking in information. Uncertainty may be time-limited or persist indefinitely, affecting either critical or non-critical areas of one’s life and having either serious or minimal long-range consequences. It may be an overwhelming source of stress or a welcome challenge that provides an antidote to boredom. The experience of uncertainty may be socially shared or biographically unique. (Cohen 1993: 78)

At Catalonia Hospital, pediatric cancer patients and their parents are faced with managing *local uncertainties*, which are related to unknown aspects of the present or immediate future of treatment. A first subset of local uncertainties is related to grasping the base knowledge required to participate in the complex biotechnology of cancer treatment, such as the treatment protocol schedule, the names and dosage of the chemotherapy and the side effect medication, the medical procedures (i.e., biopsies, major and minor surgeries), and how to use and take care of cancer treatment artifacts, such as chemotherapy catheters (see the section titled “Focusing on Treatment” in Chapter 3). A second subset of local uncertainties involves the temporal but unpredictable development of the different segments of standard chemotherapy treatment. For instance, it is known that a patient will be hospitalized for a chemotherapy session, but it is never known with certainty whether chemotherapy will take place as scheduled or if it will be delayed. Once chemotherapy starts, it is not known when exactly the patient will go home. These local uncertainties demand a complete reorganization of the social lives of the families at the hospital and at home around the medical contingencies of the patients’ treatment (see the section titled “Guessing” in Chapter 3). A third subset of local uncertainties is characterized by the fact that parents and patients struggle with connecting or separating unknowable uncertainties associated with the present treatment (e.g., when will the following chemotherapy start?) from uncertainties associated with a child’s overall condition (e.g., is the treatment working?). Parents and children try to interpret these local uncertainties and establish the outcome of the entire cancer trajectory. For instance, they may try to guess what conditions constitute a poor or good tolerance to chemotherapy and whether the presence and severity of side effects indicate that the present course of treatment is effective or ineffective (see the section titled “*Les llagues* (Mouth Sores)” Section in Chapter 3).

Patients and parents also face serious *overall uncertainties*, which are not necessarily related to the present course of treatment but are related to the larger unknown

aspects of the entire cancer treatment and the causes and conditions of the cancer illness. Many overall uncertainties can be considered “unknowables” rather than simply “unknowns,” because they can rarely be established with absolute certainty. Not even doctors know whether an early diagnosis will make the ultimate difference between survival and death, or whether treatment will act faster than the spread of the cancer. It is also unknowable when the treatment may finish, and if or when the cancer may return, or which patients will ultimately be cured and which ones will die.

Hierarchically Organized Uncertainties

The multiple uncertainties that overlap at any given point in a child’s cancer trajectory are not attended to in the same way. Instead, children, parents, and doctors work to organize uncertainties hierarchically, separating and ranking them according to which will be given immediate attention and which will be avoided. This hierarchical organization is locally managed because uncertainties change and because there is no tacit agreement between children, parents, and doctors on how to rank them. Parents and children also use the hierarchical organization as a strategy to manage uncertainty and to regain a sense of control (see Chapter 3).

The hierarchical organization that emerges in medical visits includes several steps. Doctors lead such organization, but do not accomplish it alone. They do so in negotiation with parents and patients, and may only succeed in uncertainties being organized and talked about in this way during medical interactions. As I discuss in Chapter 3, what patients and parents do and how they talk about uncertainties outside medical visits is a different matter. First, whenever uncertainties arise, they are defined first as local problems associated with the present course of treatment. Second, the immediate need to deal with the local treatment-associated uncertainties is invoked to justify the exclusion of any other form of uncertainty. Third, any association of local uncertainties with the overall cancer trajectory is strongly discouraged for as long as possible. Fourth, the discussion of overall uncertainties is postponed, and if possible, avoided altogether. Fifth, when uncertainties persist and their discussion cannot be postponed any longer, a child’s long-term future is frequently talked about in optimistic and generic terms. Finally, such strong avoidance of overall uncertainties becomes absolute when the child’s prognosis is poor. In my study, dying children were excluded from conversations in which doctors and parents discussed the child’s approaching death.

Variable Uncertainties

Uncertainties do not remain static throughout the treatment, but vary according to the different periods of children’s cancer trajectories. Three periods can be generally distinguished: pre-treatment, treatment, and post-treatment. Unlike the usual standard time span of one year of bone cancer treatment, pre-treatment and

post-treatment vary greatly in length. The treatment also differs from the pre-treatment and post-treatment in that the diagnostic and prognostic uncertainties that characterize these two periods are strongly avoided during treatment.

The first period is the *pre-treatment*, which applies to the events leading to the start of the initial and primary treatment, including diagnostic testing and the treatment interview (see Chapter 5). The length of the pre-treatment period varies greatly from case to case. Some of the pediatric cancer patients that I observed had spent months going from physician to physician without a cancer diagnosis. A few patients had received cancer treatment in other hospitals, and when the patients' physical problems returned, they were referred to Catalonia Hospital for further testing and a more accurate diagnosis. Some pediatric cancer patients were admitted to Catalonia Hospital directly and were diagnosed within days.

The second period is the *treatment* and refers to the initial and primary treatment. For the largest group of patients in this book, the treatment of bone cancer involved 12 months of alternation between chemotherapy administration hospitalizations and home recovery breaks, before and after the surgical removal of the tumor (see Chapters 3 and 6 for a description of additional therapies).

The third period, *post-treatment*, includes the events leading to relapse and additional courses of treatment, remission, and eventually, permanent cure for some children or death for the less fortunate ones (see Chapter 7). Like the pre-treatment, the length of the post-treatment period also varies greatly from patient to patient. Some patients go into remission, never relapse, and after five years of post-treatment follow-up visits finish the post-treatment period. Some other patients do not relapse, but have treatment-related medical conditions that require additional therapies. Other patients go into remission, and after a few months, relapse with either a new occurrence of cancer in the same part of their bodies, or with metastases in other parts of their bodies. If patients relapse, they will start all over again. They will undergo further testing to confirm the new cancer diagnosis, be given additional cancer treatment, and if they go into remission, start post-treatment follow-up visits. These rounds of confirmation of cancer diagnosis, treatment, and assessment may continue for a few years. However, with every round, the prognosis will become worse, and the time between remissions shorter. Eventually, when all available treatments are deemed ineffective, or the damage of the treatment side effects exceeds the benefits, treatment will be discontinued. Some treatment may still be given for palliative purposes, and the patient will be assisted until his or her death.

Pre-treatment and post-treatment are characterized by overall diagnostic and prognostic uncertainties. Most activities in these two periods center around the tasks of discovering and confirming the illness, assessing its gravity, deciding whether treatment is possible, and establishing the necessary course(s) of treatment. During the 12 months of bone cancer treatment, however, diagnostic testing is limited. A few tests monitor treatment-related side effects to the heart and kidneys, some CT (computerized tomography) scans check the appearance of

lung metastases, and a one-time battery of tests checks that the child is ready for surgery. Other than these tests, everyday life during the treatment period revolves around the local uncertainties of chemotherapy administration.

During remission in the post-treatment period, the certainty that many parents and patients hoped the end of treatment would represent emerges slowly. Parents' and children's experience of uncertainty continues and may even increase. During treatment, parents and children have met patients who relapsed and died. Thus, they are aware that remission may be only temporary. Furthermore, having been already through a cancer diagnosis and one year of treatment, they are keenly aware of what having cancer for a second time means and of what lies ahead of them. They know that cancer lurks under one's skin and that it manifests when it is already advanced. They are also familiar—only too familiar—with the anxiety of waiting for diagnostic tests results, and with the physical deterioration and pain of the treatment. Building on Black's (1989: 2) observation that "the term remission implies a temporary reprieve," Parry (2003: 228) notes that the term contains a high degree of uncertainty, "as opposed to the more concrete connotations associated with the word *cure*" [emphasis in the original]. Only time will tell whether remission will become cure.

Practicing Hope and Optimism

Pediatric cancer patients, their families, and caregivers engage constantly in a substantial amount of interactional work (i.e., they speak and avoid speaking) in order to sustain some sense of certainty about the future. They cannot take for granted many aspects of the future because children may die before their parents and never become adults, may not have two arms and two legs, or may not be able to have children because of chemotherapy induced infertility. In the words of photojournalist Tino Soriano (1992), children and their caregivers work hard to sustain a sense that "the future exists." At any given point, however, their communicative efforts to create a shared sense of certainty and confidence in the treatment may be shattered.

In the midst of the vulnerability and the fragility of attempting to beat cancer, the practice of hope becomes central, no matter how paradoxical and fleeting hope may be (Mattingly 2010). The work of hope (Peräkylä 1991), the *mandate* of hope, is both institutionalized and personal (Good 1991; Good et al. 1990, 1994; Mattingly 2010), and is often associated with a moral imperative to be optimistic (Beach 2003; The et al. 2003). To call the optimistic future into question, or even to ask questions that construct the future as uncertain, may be seen as questioning the treatment. More significantly, talking about the future as though it is uncertain may be perceived as calling into question the roles of physician, patient, and parent, and even the very goal of oncology. An oncologist sustains hope (Good 1991; Good et al. 1990; Helft 2005). A cancer patient battles cancer—fights it, struggles with it, and tries to conquer it—with a positive attitude (Byrne et al. 2002; Ehrenreich 2001; Seale 2001; Sontag 1979). A parent of a child with

cancer remains strong and optimistic (Young et al. 2003). Oncologists walk a fine line between instilling hope and acknowledging the uncertainty of the future (Good et al. 1990; Groopman 2004), and patients may interpret these calls to “fight cancer” not as calls to resist the disease, but as calls to resist the expression of their emotional distress (Byrne et al. 2002; Ehrenreich 2001). In the face of incurable cancer, optimism and hope must be maintained even when they are part of an optimistic collusion that creates false expectations about recovery for terminally ill patients, with a shift from the bad news of diagnosis and prognosis to the good news of treatment options (The et al. 2000, 2003; The 2002).

Examining the social construction of the future as certain or uncertain is key in the theorization of the future (Dunn 1992) and the phenomenology of hope (Mattingly 2010). In illustrating the centrality of talk about the future in the present time of pediatric cancer patients, I show that the constant monitoring of how the future is talked about is fundamental to shaping patients’ present experiences, and an essential practice of partial disclosure. The future, the time that has not happened, is unknown and uncertain. However, much of Western thought, including anthropological thought, has assumed time to be linear, progressively smooth, and predictable (Robbins 2001: 529–530). In contrast to the attention given to the study of the past and present, anthropology has often considered the future a “displaced temporal topic, absent from its homeland in the past-present-future relation” (Dunn 1992: 116), and has only recently begun to examine the future as theoretically relevant. Indeed, linguistic anthropological work has contributed to showing how the past, present, and future are interwoven, particularly in narratives and storytelling (Goodwin 1990, 1993; Ochs and Capps 1996, 2001; Robbins 2001).

Ethnography and Conversation Analysis

Building upon the work of anthropologists who have used conversation analysis (CA) in their ethnographies (Goodwin 1990, 2001; Moerman 1988; Sidnell 2005), I use a multilayered approach to the study of situated communication that is grounded in the local circumstances in which communication occurs. I combine ethnographic and interactional analyses in order to provide a threefold contextualization—temporal, personal, and contrastive—to the conversation analytic examination of children’s questions (see Chapter 2). In addition to contributing to the conversation analytic study of interaction among children (Gardner and Forrester 2010; Kidwell 2013), and children’s participation in medical settings (Stivers 2011), I contribute to building avenues of interdisciplinary dialogue between anthropology and CA (Clemente 2013; Sidnell 2007, 2009), institutional talk research, and research on the management of bad and uncertain news, and hope and optimism. Before I discuss these contributions, I briefly introduce the field of anthropology and define the terms *culture* and *ethnography*. I follow with an introduction to CA, and because

the conversation analytic term *recipient design* has been introduced in the section titled "Problematizing Participation," I limit myself here to the terms *sequential organization of talk*, *orientation*, *adjacency pair*, and *preference organization*.

Anthropology can be defined as the study of the human species in its present and past diversity from a holistic and empirical perspective. Central to anthropology is the study of *culture*. Despite the disagreements across anthropological subfields and theoretical approaches, a general understanding exists around a definition of culture as the component of human experience that is not biologically transmitted, but rather learned and passed among and between groups of people (i.e., human societies) across time and space. Two features are present in many definitions of culture. First, culture is dynamically adaptive, which allows human societies to meet social and environmental changes; and second, societies (which are said to "have" culture) are not necessarily culturally homogenous but are rather crosscut by variation in terms of socioeconomic class, gender, age, education, rural/urban setting, religion, and so forth.

To study culture, anthropologists often conduct *in situ* (i.e., where things happen) observation and data collection to create an *ethnography* (Malinowski 1946 [1923]). *Ethnography* is "thick" description (Geertz 1973) of human social phenomena in the natural and local settings within which they emerge and acquire meaning. Once such interpretative, comprehensive, complex, and local "thick" description of a community's meaning-making is achieved, it is subjected to further examination within a cross-cultural perspective. Among the four subfields of North American anthropology (sociocultural, physical, linguistic, and archeology), linguistic anthropologists interested in the "interaction-centered anthropology of language" (Schegloff, Ochs, and Thompson 1996: 7) have the most affinity with conversation analysts. In particular, they are both interested in the different levels of orderliness or organization that underlie social action and interaction, that is, "the procedures and expectations in terms of which speakers produce their own behaviour and interpret the behaviour of others" (Heritage 1984: 241).

With the assumption that "all aspects of social action and interaction can be found to exhibit organized patterns of stable, recurrent structural features" (Heritage 1984: 241), *conversation analysis* is concerned with the description of this "underlying social organization—conceived as an institutionalized substratum of interactional rules, procedures, and conventions—through which orderly and intelligible social interaction is made possible" (Goodwin and Heritage 1990: 283).

The first conversation analytic concept that I rely on is the *sequential organization of talk-in-interaction*. In talk-in-interaction, one participant's talk is followed by another participant's talk, which makes it possible for the researcher to observe how one participant is publicly interpreting what the other is saying (Goodwin 2006). Although this approach to meaning-making can be controversial (Duranti 1997), conversation analysts rely on how participants display for "each other the meaningfulness of a prior action" (Goodwin 2006: 6). Observing in minute detail the sequential organization of talk (i.e., speaker A talks, speaker B talks afterward,

speaker A talks again, and so forth), I examine what a doctor says/does immediately after a patient's question to make claims about what that specific question may be about/doing at that particular moment. Because I take the doctor's action as a public display of how he or she interprets a patient's question, I give analytic preeminence to the doctor's interpretation of a patient's question over my interpretation. Similarly, I examine how a patient interprets publicly a doctor's answer to make claims about what that answer may be about/doing (see Chapter 4). CA's reason for giving analytic preeminence to participants' own interpretations of each other's actions reflects the fact that this is a problem for the participants themselves: in order to know what to do, they need to figure out what the other person is trying to accomplish by speaking.

The second conversation analytic concept to be introduced is *orientation*, which refers to participants' public display of sensitivity to, or the taking into consideration of, some organizational principle of conversation, including the organization of mutual attention. These organizational principles are understood to be structurally normative, that is, they are a "rule-guided system" (Heritage & Stivers 2013: 664) that contains expectations of what is appropriate or inappropriate, and to which interactants hold each other accountable for having conformed to or deviated from it.

The last two conversation analytic concepts are *adjacency pair* and *preference organization*. Adjacency pairs are tightly organized two-utterance sequences produced by different speakers, such as question–answer, invitation–reply, or greeting–greeting. The first pair parts of an adjacency pair (questions, for example) *prefer* some type of responses to others. That is, alternative second pair parts, such as denials, admissions, acceptances, refusals, agreements, or disagreements, are not equivalent, but differentially ranked (Pomerantz and Heritage 2013). Not without controversy (Duranti 1997), Atkinson and Heritage (1984: 53) argue that *preference organization* refers "to a range of phenomena associated with the fact that choices among nonequivalent courses of action are routinely implemented in ways that reflect an institutionalized ranking of alternatives." Dispreferred activities tend to be avoided and withheld, and when they are indeed performed, they tend to be delayed, softened, indirect, and frequently accompanied by hedges and accounts. Therefore, dispreferred responses are routinely longer than preferred responses. For instance, when speakers are asked to accept or reject an invitation, the dispreferred activity of rejecting will routinely take longer than the preferred action of accepting such an invitation.

Building avenues of interdisciplinary dialogue. The present book is innovative in that it is structured not only according to conversation analytic concerns but also according to an ethnographic longitudinal "natural history of illness" approach found in anthropology (Kleinman 1980). The interactional analytic component of my book contributes to moving CA beyond the synchronic analysis of isolated episodes or moments of interaction, toward diachronic analyses based on repeated interactions of a constant group of people/genre/contexts over time (Beach 2001b: 224–225; Maynard 2003: 78–79). This longitudinal approach (Beach 2009; Clayman and Heritage 2002; Wootton 1997), which is clearly "context-sensitive"

(Beach 2001b: 224), has great potential for creating an avenue of convergence between anthropology and CA. Conversation analytic context-sensitive studies are similar to detailed analyses of single episodes that are based on larger data collections, which are found in Goodwin's (1997) longitudinal analyses of speech activities, and ethnographies that incorporate CA (Goodwin 2001; Goodwin 1990; Moerman 1988; Sidnell 2005).

Institutional talk. My book contributes to the study of asymmetrical relations in institutional settings by shifting several analytic foci: (1) from institutional representatives who have expertise and authority, such as physicians, teachers, journalists, and judges, to lay participants, such as patients, students, interviewees, and witnesses (Drew and Heritage 1992; Heritage and Clayman 2010; Heritage and Maynard 2006); (2) from lay participant responses, such as answering questions, to their initiatives, such as asking questions or making proposals (Beach 2001a; Frankel 1990; Gill and Maynard 2006; Stivers 2007); and (3) from adults (e.g., parent or institutional representative) to children (see the earlier section titled "Problematizing Participation").

Managing bad and uncertain news, and hope and optimism. My book also contributes to our understanding of the interactional management of bad and uncertain news, as well as the interactional work of establishing and sustaining hope and optimism (Beach 2003, 2009; Maynard 2003, 2006; Peräkylä 1991, 1995). In particular, my book illustrates that uncertainty, indirectness, indeterminacy, and evasion are not interactional deficiencies but achievements collaboratively produced by participants; and that the interactional asymmetry between social conventions of good and bad news deliveries (Maynard 2003) has a profound effect on the strategies used to regulate communication with children with cancer.

Conversation analyst Douglas Maynard (1996, 2003, 2006) has demonstrated that strikingly different strategies are used to deliver and receive bad news and good news within countries such as the United States and the United Kingdom. Bad news is routinely "shrouded"—with strategies such forecasting, delay, stalling, and bluntness—and good news is "exposed" in both ordinary conversations and institutional talk. Because the "shrouding" of information is more routinely associated with bad news than with good news, I show that patients, parents, and doctors at Catalonia Hospital orient to this asymmetry and associate the withholding of information with bad news, regardless of whether the news is in fact bad, good, or uncertain.

The bearer of news often projects the valence of news (i.e., whether the news he or she is about to deliver is good or bad news), but the valence of news is ultimately a negotiated process between the bearer and the recipient of news, particularly when the news is uncertain (Maynard 2003; Maynard and Frankel 2003, 2006). The recipient of bad news may adopt a stoic and silent restrained stance, display strong affect, or invoke optimism. Both the bearer and the recipient of bad news may also work in unison to formulate the bad news as good news, or to talk about the bad news in as implicit a manner as possible. However, they may avoid aligning themselves as either the bearer or receiver of such bad news.

Lutfey and Maynard's (1998) work provides additional evidence of how news deliveries are interactionally constituted and managed processes. Examining three case studies of the same doctor with three different cancer patients in the United States, these authors illustrate that each patient displays a different willingness to talk about his or her death, and for that reason, the doctor uses three different degrees of "unpacking the gloss" of death and dying: minimal, limited, and extensive but allusive. Lutfey and Maynard show that how speakers will speak about something cannot be established *a priori*, and that speakers can communicate substantial amounts of information in an allusive manner. Similarly, pediatric cancer patients in my study often negotiate what can be talked about and how, and participate in constituting the reality of cancer in appropriately social ways by communicating about it indirectly and implicitly. Furthermore, whereas allusive talk is used when discussing the end of the cancer trajectory in Lutfey and Maynard's study, such talk is used throughout the entire cancer trajectory at Catalonia Hospital: from diagnosis, through treatment, relapse, remission, cure, and death.

Examining bad and uncertain news requires also investigating how hope and optimism are interactionally constituted and managed, or in Peräkylä's (1991) words, how "hope work" is accomplished. In the context of communication among adult cancer patients (Beach and Anderson 2003a, 2003b), Roberts' (1999) and Beach's (2009) work have demonstrated how oncologists, cancer patients, and their families struggle to balance uncertainty, pessimism, and optimism. In her analysis of recommendations for breast cancer adjuvant² therapy in the United States, Roberts (1999: 109) has shown how doctors use their asymmetrical control of the flow of interaction to try to temper patients' optimism and pessimism in order to "walk a fine line between not making any guarantees and still promoting a particular course of treatment." Beach (2009) has examined the changing communicative strategies used to manage optimism and uncertainty in a corpus of 60 phone calls between the members of a North American family from diagnosis to death. In the everyday tasks of informing and updating family members about the cancer patient's constantly changing health status, optimism is as ever-present as uncertainty and bad news. At the beginning of the diagnosis, family members use resistance and delay as an alternative to giving bad news directly, and withhold emotional reactions, displaying a stoic stance. Calls to an optimistic and hopeful outlook become increasingly more pronounced as the woman's health deteriorates. The detailed turn-by-turn analysis of the family's phone conversations as the cancer trajectory evolves unpredictably reveals their struggle with divergent but overlapping types of uncertainties, ranging from local to larger uncertainties, such as not knowing what a specific procedure is called and what it does; not knowing when test results will be ready and whether results will bring good, bad, or uncertain news; and the "primordial question" of "how long do medical staff believe mom has before she dies?" (Beach and Good 2004: 24). By using an interdisciplinary multilayered approach that combines ethnographic analysis and conversation analysis, this book examines the multiple contexts of children's questions, children's

participation in institutional settings, and the interactional management of bad and uncertain news, and of hope and optimism.

Plan of the Book

Thus far, I have introduced the concepts of disclosure, participation, and uncertainty, and the contributions that this book makes to the theorization of these concepts and to the theorization of pediatric cancer communication. I have also presented the contribution that my combination of ethnography and conversation analysis makes to both anthropology and language and social interaction studies. In Chapter 2, I locate the pediatric cancer community at Catalonia Hospital within the larger bilingual context of Catalonia and the sociocultural context of cancer communication in Spain. This chapter also locates my ethnographic fieldwork and theory-driven analyses as a linguistic anthropologist who is both an insider and an outsider, and who observes and participates in the intimate everyday life of a small pediatric cancer unit. In Chapter 3, I discuss four interrelated strategies (i.e., focusing on treatment, guessing, being together, and talking privately) that illustrate how patients and parents, and healthcare professionals at Catalonia Hospital deal as a community with the everyday demands and uncertainties of cancer treatment. Chapter 4 examines the turn-by-turn construction of uncertainty, for instance, with IF-THEN contingent questions and answers; the chain of questions and answers that can lead patients and doctors into discussions of the more uncertain and speculative aspects of future treatment; and how doctors try to avoid talking about the uncertain future.

Taking a longitudinal illness trajectory perspective, Chapters 5–7 illustrate both the commonalities of patients' cancer trajectories and the specifics of their individual experiences. Each chapter examines pivotal moments in the children's cancer trajectories by beginning with ethnographic analyses of several patients at the same point in their cancer trajectory (e.g., how patients found out they had cancer), and following this up with detailed analyses of questions from patients in medical interactions. Chapter 5 analyzes pre-treatment, the events leading to the start of treatment, particularly the diagnostic testing and the interview before the first treatment administration. Chapter 6 describes the events during the first treatment—also known as first line or primary therapy—which often takes patients with bone cancer one year to complete. Chapter 7 examines children's experiences during post-treatment, including relapse, remission, and death.

Over the longitudinal structure of Chapters 5–7, I portray three different aspects of children's lived experiences at Catalonia Hospital. First, I show how the lives of children undergoing treatment are intertwined. Second, these chapters illustrate the variability within the experiences of one patient. Third, although there is uniqueness and diversity in each patient's experience, there also exist commonalities between patients' cancer trajectories.

The book concludes in Chapter 8, where I revisit current theorizations of the concepts of participation, non-disclosure, and uncertainty in light of the findings presented in each chapter. By focusing on how a group of children with cancer, their parents, and healthcare professionals negotiate how to talk about cancer and deal with multiple and ever-changing uncertainties, I illustrate the fundamental role that communication plays in how they constitute, influence, and make sense of the world they inhabit.

Notes

- 1 All institutional and personal names are replaced with pseudonyms to protect the identity of the study participants.
- 2 The term “adjuvant” refers to treatment given in addition to the removal of the primary tumor.

A Linguistic Anthropologist in a Pediatric Cancer Unit

Key Issues

- *The findings of this book are based on 15 months of ethnographic research, including observation, video recording, interviews, and participation in the everyday activities of a group of pediatric cancer patients (children and young people), their parents, and healthcare professionals at a hospital in Catalonia (Spain).*
- *As a Catalan linguistic anthropologist, I am an insider who shares a culture and languages (Catalan and Spanish) with the people I observe, and an outsider because my participant observation is theoretically driven.*
- *To study the specifics of how cancer is talked about and not talked about, I conduct micro-analyses of childrens' questions and longitudinal analyses of the different types of data to create children's cancer trajectories.*
- *The diversity of cancer communication practices and preferences within the hospital are related to larger sociocultural changes taking place in Catalonia and Spain.*

In this chapter, I locate Catalonia Hospital within the Spanish–Catalan bilingual context of Catalonia and the sociocultural context of cancer communication in Spain. I also locate myself as a linguistic anthropologist conducting ethnographic research in the confined and intimate space of a small pediatric cancer unit. As I discussed in the preface, I am both an insider and an outsider: I am Catalan, share a culture and languages with the people I study at Catalonia Hospital, and have experienced the concealment of cancer information as a child and as an adult. At the same time, I am a linguistic anthropologist trained in the United States who uses theoretically informed methods to observe and analyze the talk and activities of this tight-knit community at Catalonia Hospital formed by children with cancer, their parents, and health professionals.

The first part of this chapter describes the bilingual Spanish/Catalan context of Catalonia and the changing preferences and practices of cancer communication in Spain. The second part briefly describes everyday life and research at Catalonia Hospital, and introduces the two groups of patients who participated in my study,

children (ages 3–6) and young people (ages 11–18), their parents, and hospital staff. The third part outlines my multilayered approach, which combines a threefold ethnographic contextualization (temporal, personal, and contrastive) and a detailed conversation analytic examination of children's questions during medical interactions. Lastly, I describe how I rely on this multilayered approach to investigate what is not talked about and avoided. By laying the groundwork for the analytic chapters that follow it, Chapter 2 brings together the theories and generalizable knowledge that inform my methods and analyses, and the unique, richly complex, and intimate experience of everyday life in a pediatric cancer unit.

Culture and Disclosure Practices in Catalonia

Catalonia is one of 17 autonomous regions in Spain that were created in accordance with the Spanish Constitution of 1978. Catalonia's historical aspirations of self-governance have created repeated political conflicts with Spain (McRoberts 2001). For the Catalans, the Catalan language is the foremost symbol of Catalan identity (Boix Fuster 1993; Conversi 1997; Pujolar 2001; Strubell and Boix-Fuster 2011; Woolard 1989). Although Catalan has a strong official presence, immigration waves of non-Catalan speakers have contributed to its minoritization (Cabr   1999; Pons and Vila i Moreno 2005).

The sociolinguistics of Catalonia is apparent in the linguistic choices of the children, parents, and clinical staff at Catalonia Hospital. As part of the Catalan Health Service, Catalonia Hospital's public and official language is Catalan. Relying on 29 factors measuring linguistic usage in Barcelona's health centers, Soler and Sol   Carmadons (2004) report that the percentage of use of Catalan is above 90% for 14 factors, between 90% and 80% for 9, and below 80% for 6. However, Spanish and Catalan are alternatively used in interpersonal communication, and Catalan speakers recurrently switch to Spanish with Spanish-speaking interlocutors. During my fieldwork, monolingual speakers of Spanish or Catalan were rare at Catalonia Hospital, and were typically either very young children or children from outside Catalonia only at the hospital for treatment.

Spain has undergone a process of change in cancer disclosure practices over the last 25 years. As in Italy (Gordon and Paci 1997; Surbone et al. 2004), disclosure has not replaced non-disclosure in Spain, but they have coexisted, evolved, and influenced each other. Because there is a dearth of data that examines communication practices with children with cancer in Spain, I rely on existing research with adults and on illustrating media and public discourse changes in the visibility and the explicitness of cancer representations.

Since the early studies on the disclosure of cancer diagnosis and prognosis in Spain published in the 1980s and the beginning of the 1990s, cancer communication research has revealed complex, often contradictory, and evolving dynamics. Research in Spain reveals that the demand for information is not

uniform; there is an increasing demand for more precise information; patients want more information than they receive; concealment is more often preferred by relatives of patients than by patients themselves; and patients, relatives, and health professionals recurrently talk about cancer without explicitly use the word “cancer.”

Despite methodological and population sample inconsistencies, there are some common themes in studies of cancer communication in Spain. Research conducted in the 1990s shows that only a minority of cancer patients clearly know their diagnosis (Cimas Hernando et al. 1996; Estapé et al. 1992; Pereira Tercero and Marijuán Angulo 1991). Examining the attitudes of primary care users about the disclosure of incurable illness, Fernández Díaz et al. (1996) report that participants want to be told about an incurable illness (69%), but they are less likely (60.8%) to want news of an incurable illness disclosed to a relative. In other words, concealment—as a means of protection from bad news—is preferred more when applied to one’s relative than to oneself. Centeno Cortés and Núñez Olarte’s (1998) extensive review confirms many of these findings: the “truth” is not systematically concealed, but patients tend not to ask for extensive information. Furthermore, they note that an increasingly large number of patients are well informed (25%–50% depending on the reviewed studies), despite the fact that relatives continue to be reticent to disclose information.

Three studies published between 2001 and 2004 illustrate heterogeneous preferences (Castillo Sánchez et al. 2001; Fernández Suárez et al. 2002; Rubio Arribas et al. 2004). Unlike the studies in the 1990s, a significant majority (70.6%–81.3%, depending on the study) of primary care users in rural and urban settings in Spain stated that they would like to be informed in the hypothetical scenario of being diagnosed with cancer and/or terminal illness. These results are similar to disclosure levels of other countries, including English-speaking countries (Fernández Suárez et al. 2002; Rubio Arribas et al. 2004). Furthermore, Castillo Sánchez et al. (2001) report that when given three information disclosure options—yes, no, and it depends—most respondents (59.9%) preferred that information be given depending on several factors: how information was given, the patient’s education, the opinion of the patient’s family, whether it was perceived that information could help the patient overcome the situation, and whether the patient was likely to be cured.

The most recent studies in Spain indicate that a preference for more open disclosure is increasing but not replacing the preferences for and practices of non-disclosure (Baldonado Cernuda et al. 2012; Cuesta Gavino et al. 2012; Montoya Juárez et al. 2010; Peiró et al. 2006). A growing majority of family caregivers deem information a right and an aid to the patient (Cuesta Gavino et al. 2012). In the context of end-of-life and palliative cancer care, 69% of family members who are caring for a patient dying of cancer would want to be informed in detail about diagnosis and prognosis if they were the patient, and 60% were in favor of the patient being informed (Baldonado Cernuda et al. 2012; Peiró et al. 2006). At the same time, these authors also report that several non-disclosure practices

continue: physicians rarely use the word “cancer” with adult cancer patients and often give them only partial information during the delivery of the diagnosis.

No one single factor accounts for these cultural and communicative changes in Spain over the last 25 years. Surbone et al. (2004) note similar changes in Italy, and point out that multiple interrelated factors operate simultaneously and internationally, such as therapeutic advances in the field of oncology, increased public knowledge of the nature and treatment of cancer, increased training of physicians in palliative and end-of-life care, stricter legal requirements for information and informed consent, and patient and public activism. In Italy, Surbone et al. also underscore how patient advocacy, public opinion, and the media have contributed to these changes. New organizations were created to increase patient self-determination, fully informed cancer patients appeared in films and national television, talk shows debated information disclosure and bioethics, and end-of-life and euthanasia issues became heated national controversies.

Although a comprehensive analysis is beyond the scope of this book, Catalan and Spanish public opinion and media and childhood cancer advocacy groups reflect the changes in disclosure preferences and practices in Spain and Catalonia. Inside and outside of Catalonia Hospital, there exists a diversity of communicative preferences and practices, which are often contradictory. These diverse societal preferences and practices constitute the larger sociocultural context of the six strategies of communication regulation that I observed at Catalonia Hospital.

Since the 1980s, cancer has become more present and explicitly represented and talked about in the media. In 1987, the world-famous Catalan opera singer Josep (José in Spanish) Carreras publicly disclosed that he had leukemia. A year after he went public, 150,000 people attended the first leukemia research fundraising concert in Barcelona. In 1992, TV3 (Catalan Public Television) organized the first fund-raiser telethon (*La Marató de TV3*), which was dedicated to raising funds for cancer research and had an average audience of 3 million, half of Catalonia's entire population at that time. *La Marató de TV3* strove to “give a face to cancer” by broadcasting live and recorded interviews with adult and pediatric cancer patients, interviews with cancer researchers, and short videos of the daily lives of cancer patients. Three additional *Marató de TV3* shows in 1994, 2004, and 2012 were also devoted to cancer. In all four telethons, cancer was talked about explicitly, and people living with cancer were identifiable not only because their images were broadcast, but also because they used first and last names, and even named the places where they lived.

In 2003, the writer Albert Espinosa erupted in the media and the public awareness with his movie *Planta 4ª* (*4th Floor*), based on his own experience of having pediatric cancer. *Planta 4ª* was the second highest grossing film in Spain and was watched by over one million people in its first year. After multiple Spanish and international awards, Espinosa has become a household name in Catalonia and Spain. In his writings and TV/radio show appearances, Espinosa is explicit and candid about his cancer, the experience of losing a leg, and his many brushes with death.

Espinosa's work has continued to make pediatric cancer visible and openly talked about. In 2011, Espinosa's TV series *Polseres Vermelles* (*Red Bracelets*) was broadcast in the Catalan TV3. The series became an immediate hit, with an average audience of more than half a million people both in 2011 and 2013 in Catalonia. The show portrays stories of a group of patients sharing their experiences with treatment, friendship, love, and life and death in a pediatric ward. The cast has become teenage idols among high school students in Catalonia. In 2012–2013, the Spanish TV station Antena 3 broadcast the first and second seasons of the *Pulseras Rojas* across Spain, with an average audience of almost 2.5 million for the first season and 1.2 million for the second season.

Espinosa's work has been critical in bringing pediatric cancer to an unprecedented level of public awareness and visibility. However, it is not an isolated instance of how pediatric cancer has become visible and spoken about over the last 25 years. During the late 1980s, the first studies about cancer communication in Spain and the foundation of the first pediatric cancer advocacy groups in Catalonia coincided with the well-published case of opera singer Josep Carrera's leukemia. In 1987, AFANOC (Associació de familiars i amics de nens oncològics de Catalunya, Association of Relatives and Friends of Children with Cancer of Catalonia) was founded, and the Foundation of Childhood Oncology Enriqueta Villavecchia was launched two years later. In addition to helping children with cancer and their families, the two organizations actively work to educate the public about pediatric cancer, stop discrimination, normalize the illness, and integrate children and families into Catalan society. The Enriqueta Villavecchia Foundation broke new ground by explicitly talking about and publishing images of pediatric cancer patients, their families, and health care professionals. At the request of the Foundation, photojournalist and photographer Tino Soriano (1992) published the book *El futur existeix* (*There is a Future*), in which he documented in graphic detail the everyday hospital life of childhood cancer. With its bold black and white images of children receiving cancer treatment, the book was the first of its kind to circulate publicly in Catalonia. To commemorate the 10th anniversary of its original publication, Tino Soriano joined forces with writer Rosa Maria Carbonell, who was the mother of a child with cancer (Soriano and Carbonell 2001). They published a photo essay, *El primer combat. Histories de nens y padres que luchan contra el cáncer, una enfermedad que puede ser derrotada* (*The First Fight. Stories of Children and Parents who Fight against Cancer, an Illness that Can be Defeated*), which became the cover of Catalonia's leading newspaper Sunday magazine, *La Vanguardia Magazine*. Carbonell (2003) also published a book based on the diary she kept during her daughter's treatment. In 2010, Tino Soriano collaborated again with the Enriqueta Villavecchia Foundation to publish a pictorial follow-up story of the 1992 photo essay in color illustrating the advances in pediatric cancer therapies.

AFANOC (Association of Relatives and Friends of Children with Cancer of Catalonia) greatly contributed to creating a new public image of childhood cancer in Catalonia. Since 2000, AFANOC has organized a series of events in

different cities under the rubric *Posa't la gorra (Put Your Cap On)*, to raise awareness about childhood cancer. These events are widely advertised on radio and television, as well as newspaper commercials, reports, and interviews. Celebrities participate in the media campaign wearing AFANOC's baseball caps and also attend the events. Eight thousand people attended the 13th *Put Your Cap On* party at the Barcelona Zoo in 2013.

The public representations of cancer that I have described appearing in Catalan television, in the work of Albert Espinosa, and in the advocacy work of the Villavecchia Foundation and AFANOC reflect and contribute to a new cultural model of "the child with cancer" that coexists with other cultural models and communicative practices. However, media representations cannot be interpreted as evidence that a new cultural model has replaced existing ones. Although the coexisting models (i.e., more communication and visibility of pediatric cancer or less) do influence each other, my research reveals that by no means has one replaced the other. Contemporary images of children with cancer portray them as patients who fight cancer with stoicism and optimism, and not as patients resigned to their fate or slowly dying of cancer (see also Dixon-Wood et al.'s (2003) analysis of the United Kingdom and the United States newspaper accounts that idealize and romanticize children with cancer). The wigs of the past have been replaced with baseball caps, handkerchiefs, and scarves worn by children with cancer who are seen in public, playing outdoors, and mingling with celebrities during televised fund-raising events and *Put Your Cap On* parties. In this model, neither the child with cancer nor the cancer itself is concealed.

Yet at the same time that these media images of children with cancer were being widely circulated in Catalonia (Soriano and Carbonell 2001), diagnostic and prognostic information was routinely withheld from the children involved in my fieldwork, even when there was no immediate threat to the child's health. Most children in my study refused to wear wigs and were keenly aware of what was happening to them, but adults nonetheless tried to "protect" them from bad or uncertain news. Adults did not talk about negative aspects of cancer with the children, and vice versa. Even when everybody knew a child had cancer and knew that others also knew it, they rarely used the word "cancer."

Fieldwork with Children

For 15 months between August 2000 and November 2001, I participated in the daily activities of a tight-knit community formed by children with cancer, their parents, and healthcare professionals at Catalonia Hospital.¹ Within this community, the following people participated in my study: 17 pediatric cancer patients, 22 parents, 8 pediatricians, 2 oncology surgeons, 13 pediatric nurses, 2 hospital schoolteachers, 3 hospital volunteers who had had pediatric cancer themselves, a pediatric psychologist, and a pediatric social worker. People in this community

spent a lot of time together. For instance, most relocated parents lived within walking distance of Catalonia Hospital, and along with hospital professionals, participated in the non-medical activities organized by the Pediatric Cancer Foundation, housed at Catalonia Hospital. In addition, the hospital schoolteachers who ran the school and playroom organized trips outside the hospital. The very strong sense of community continued even after the treatment ended. Both cured children and the parents of children who had died visited the hospital regularly and sometimes became volunteers.

Among the patients who participated in my study, 12 patients, 9 boys and 3 girls, were between the ages of 11 and 18, while the other 5 patients, 4 girls and 1 boy, were between the ages of 3 and 6. Appendix A provides a profile of each patient, including medical, linguistic, and personal information, as well as detailed information about the months that the children participated in the study vis-à-vis the months of their treatment.

A terminological note is necessary to explain my use of the terms “child” and “young people/persons.” From the perspectives of the social sciences and childhood studies, childhood is a social construct that is not defined exclusively in terms of biological immaturity, that is, in terms of the child’s age (Bluebond-Langner and Korbin 2007; James and Prout 1997; Pufall and Unsworth 2004). As a social construct, the definition of what a child is varies cross-culturally and historically in terms of, for instance, when childhood ends, when adolescence begins and ends, or when adulthood begins (Ariès 1962; Lancy 2008; Scheper-Hughes and Sargent 1998; Stephens 1995).

The term “adolescent” has been criticized in childhood studies because it is used arbitrarily and reductively, and because “adolescents” often object to being called “adolescents” (Dixon-Woods et al. 2005; Mayall 1998, 2000). Moreover, “adolescents” are defined in terms of a transition from childhood to adulthood, transient people who are becoming adults, without taking into account cultural practices and understandings that “adolescents” may create and share. They may be defined as neither a child nor an adult, or as both, doing things adults do and things children do. In qualitative studies of child health, the term “young people/persons” is often preferred (Bluebond-Langner et al. 2013; Dixon-Woods et al. 2005; Gibson et al. 2013), although there is no agreement on the exact age range of young people. As Dixon-Wood et al. (2005) do, I acknowledge the arbitrariness in assigning the labels of “child” and “young person” on the basis of age ranges. For practical purposes and to avoid cumbersome reading, I call those in the age range of 3 to 6 “children,” and those aged 11 to 18 “young people.” Although not an ideal solution, I use “patients” and “children” as generic terms when making claims about both age groups, but reserve the term “young people/persons” when making claims that pertain only to the older age range.

The participating patients’ ages and genders reflect the types of pediatric cancer treated at Catalonia Hospital. This small unit specializes in relatively infrequent pediatric cancers: bone and soft tissue cancers, primarily osteosarcomas, which are more common among boys than girls, and most common among young people (Pizzo and

Poplack 2011). Within this small pediatric cancer unit, bone and soft tissue cancers are most common, whereas in the epidemiological statistical distribution of cancer diagnoses for children, leukemias and central nervous tumors are most frequent.

Having two separate age groups without an intermediate group of older children between the ages of 7 and 10, I decided to use data from patients of all ages in the cancer trajectory analysis but to concentrate on the questions and specific communicative practices of the young people aged 11–18. Young people asked the most questions and were most involved in the negotiation of the limits of non-disclosure and uncertainty. I also spent ample time with the younger children, which informed my thinking about children's cancer trajectories as well as about the limits of disclosing uncertain and bad news. Eli, a 5-year old with Wilms' tumor and lung metastases who died shortly after the end of my fieldwork, epitomizes the invaluable contribution of the younger children to this book (see Chapter 7).

The total length of patients' participation in the study was determined by the amount of time they spent at the hospital during my fieldwork. Some patients were finishing their treatment at the beginning of the study, whereas others were not diagnosed until weeks or months after the study began. My contact with them also varied greatly, because during some periods patients were not hospitalized, while at other times they experienced lengthy hospital stays.

Most of the children had been raised in Catalonia in working-class families and were attending school regularly before treatment. In terms of their use of Catalan and Spanish, most children were able to understand both languages, though communicative competence varied greatly from child to child. Three of the five children aged 3 to 6 (Carmen, Eli, and Marc) used either Catalan *or* Spanish, and did not accommodate to their interlocutors. Young people often used both and accommodated. Parents used both languages to talk to hospital staff, but used one language predominantly when speaking to their children. Robert's and Anna's mothers were exceptions: they regularly spoke Catalan and Spanish with their children. Hospital staff represented the most fluid group of bilingual speakers and accommodated to the preferred language of patients and parents.

In regard to the daily activities at Catalonia Hospital that I observed and participated in, medical activities carried out by physicians overrode those of other hospital staff, as well as of patients' and parents' personal and social activities in the hospital. Every day between 9:00 and 11:30 AM, the team of doctors and a nurse made the rounds with the hospitalized patients in the pediatric unit. This visit was unquestionably the most important event of the day. Even though some exceptions were occasionally made, all activities, such as sleep, talk, play, eating, watching TV, and school were interrupted when the doctors entered the room. It was the predetermined time for patients and doctors to talk, because it was difficult for the families to talk to the doctors outside these visits. Thus, parents organized their day's activities, including work, around this morning medical visit. Out of more than a hundred of these medical visits that I analyzed, only two occurred in which parents were absent.

Medical visits also highlighted the differences in status and social norms not only between doctors, parents, and patients, and also between parents and patients. Parental participation was essential, but the participation of the patient was not necessarily required. Doctors still carried out their visit while the patient slept, but rarely without the parents' presence. Whenever word spread that the doctors had initiated medical rounds, parents stood in the hallway waiting if they wanted to talk to the doctors without the patient being present. Doctors and parents also used the hallway as a space to talk after the medical visit, after walking out of the room together. Even when patients could move around easily, they did not join in these hallway conversations. If a patient came out to the hallway while parents and doctors talked, they would shift from medical to non-medical topics of conversation.

Evenings, nights, and weekends were predominantly social times. By 4:30 PM, school was over, the doctors had gone home, and most medical activities had ceased. Nurses still supervised treatment, but the pediatric unit became much more quiet and relaxed. Patients fought boredom by taking naps, watching TV, talking on cell phones, playing games, or hanging out with other patients and parents in the waiting room, in the hallway, or in each other's room. Parents organized games so the patients could play together. For instance, patients played monopoly, or made slingshots and threw pieces of paper through the window.

Playing with adults, especially the nurses, was a favorite form of hospital entertainment for children. Patients hung out at the nurses' station in the evenings, particularly if there were no other hospitalized pediatric cancer patients with whom they could play. Nurses allowed patients to "play doctor," letting them borrow flashlights and stethoscopes. Patients engaged in elaborate cures of imaginary wounds. From time to time, pretend-play cures escalated into saline solution battles in the hallway. There were also wheelchair races in the hallway and the waiting room, as well as wheelchair dexterity contests. Patients competed to see who could stand the longest on only two wheels without falling forward or backward.

During hospitalizations, patients and mothers would often spend more time with me than with their husbands/fathers and other children/siblings. The concept of an anthropologist studying them was quite alien. Some mothers and children thought I was a childhood cancer survivor. Others considered me a surrogate hospital family member, and shared with me daily experiences that they might not share with their own relatives. Children often tested my loyalty: I was a person that they could be angry at and cruel to, because they knew the following day I would be back. As I examine in the section titled "*Acompanyar* (Being at the Patient's Side)" in Chapter 3, what mattered most to parents and children was that I was by their side, keeping them company. My role as anthropologist was understood in terms of "being there" (Woodgate 2006) and maintaining my "obligation of proximity" (Young et al. 2002b).

The pediatric cancer unit was largely a women's world. Mothers were for the most part the parent who stayed with the child during hospitalizations (Young et al. 2002a). In addition, doctors, nurses, schoolteachers, the psychologist, and volunteers were mostly women, which made my presence, as a man, noticeable.

Fathers, who usually continued to work after the child's diagnosis, typically visited the children while mothers were present and only substituted for specific periods of time, usually sleeping at the hospital overnight. Gemma's father was the only one who regularly spent entire days taking care of his child during hospitalizations. Parents and doctors thought my male influence was encouraging for the boys, who were seen as benefiting from the friendship and presence of a male figure. At the same time, being a man also created awkward moments with mothers, who sought my emotional support. They shared with me moments of great emotional intimacy. I became a shoulder to cry on and a constant companion and listener at the hospital. As other ethnographers before me, I struggled with the moral and ethical dilemmas of witnessing suffering (Frank 1995; Kleinman et al. 1997; Scheper-Hughes 1992).

Contexts of Children's Questions

To examine in detail the explicit and implicit ways in which children, parents, and hospital staff talked about some aspects of cancer while avoiding others, I combined different methods to collect multiple datasets. First, I conducted participant observation, taking field notes of what children, parents, and hospital staff did while I participated in their everyday activities. Second, I video-recorded many of these activities. I used these video recordings to expand my field notes and to create detailed transcripts that make possible turn-by-turn analyses of children's questions and doctors' responses. Video recordings also make possible it to analyze what children and adults communicate with their speech and their bodies, for instance, how they use gesture to avoid the word "cancer," when they have difficulties understanding each other, or when they cannot remember a medical term. Furthermore, video recordings are critical for analysis when several people talk at the same time, and because they capture what children are doing while adults talk to each other.

Finally, I regularly conducted non-structured interviews with patients, parents, and hospital staff in order to gain insight into their particular perspectives. A key piece of my findings emerged from these interviews: most children did not talk to me about the negative or uncertain aspects of cancer even when given the opportunity to do so in a safe and private environment without the presence of parents. To explore further the children's reluctance, I carried out additional in-depth video-recorded interviews with hospital staff, and two group interviews with senior pediatric nurses and childhood cancer survivor volunteers who shed light on why children undergoing treatment might resist talking about how they feel (Bearison 1991; Gibson et al. 2010; Phipps and Steele 2002).

Two ethnographically informed complementary analyses were conducted to integrate the different data sets: a *micro-analysis of situated interactional data*, which involved the turn-by-turn analysis of children's questions, and a *longitudinal analysis*, which combined all data sets with the goal of creating the children's cancer trajectories.

Situated interactional data analysis: A corpus of 104 patient–parent–doctor videotaped interactions was transcribed according to the conventions developed by conversation analyst Gail Jefferson (Sacks et al. 1974: 731–733). Approximately 500 patients’ questions and their corresponding responses were analyzed using conversation analysis, particularly drawing from Clayman’s (2001) investigation of evasive answers in news interviews.

Combined longitudinal analysis: Relying on the situated analysis of children’s questions and the different datasets, I carried out a longitudinal analysis to produce each patient’s cancer trajectory. Each trajectory reflected great temporal, experiential, and communicative variability. For instance, some cancer patients underwent treatment for years after relapsing immediately after the first line of treatment. Two died during or shortly after my fieldwork, and others spent years in and out of remission. Furthermore, the experiences of the same cancer patient were different depending on whether he or she was just diagnosed, was undergoing treatment, or was in remission.

My combined longitudinal analysis is built on three intertwined contextualizations of patients’ questions: temporal, personal, and contrastive. The temporal contextualization constructs chronologically the social, communicative, and medical histories of each individual patient. Any changes in the communicative strategies of a patient are linked to the social and medical details of what was happening at that specific point of his or her cancer trajectory, and vice versa. This temporal contextualization is based on the contextual natural history mode (Briggs 1998), the illness trajectory approach (Charmaz 1991; Strauss and Glaser 1970), and the natural history of illness approach (Kleinman 1980). Patients’ questions are embedded in the “series of events from diagnosis to death, which mark critical changes in the social and emotional life of the family as well as in the clinical status of the child” (Bluebond-Langner 1996: 13).

Personal contextualization underscores the drama of lived personal experience by interrelating dramatic events in order to create plots (Briggs 1998; Mattingly 1998). With a constant set of participants and environments, this contextualization brings together a series of situated analyses of specific interactional episodes (Beach 2009; Clemente 2013; Goodwin 1996, 2001; Moerman 1988; Sidnell 2005) as a way to construct, in Bluebond-Langner’s (1978: 13) words, “the dramatic, living quality of that which is taken apart, analyzed, and used to illuminate theoretical issues.” In this fashion, I reconnect the questions, analyzed as part of a collection of interactional phenomena, to the individual speaker who uttered them and the specific moment of his or her cancer trajectory.

I draw on Bluebond-Langner’s (1996) ethnographic analysis of how nine North American families deal with the intrusion of pediatric cystic fibrosis in order to address two challenges in (re)presenting my analyses. One challenge is created by the tension between theoretical issues and individual patients’ personal experiences, and the other results from the tension between the single-case analysis of children’s questions and the longitudinal analysis that places these questions within a larger social context. Bluebond-Langner organizes portraits of the nine families chronologically to illustrate different periods of the illness trajectory while

conveying the specific circumstances of each family. In this manner, Bluebond-Langner strives to produce generalizable knowledge about the communicative strategies used to contain the intrusion of cystic fibrosis, but does so by locating them within the natural histories of each illness trajectory and each family. I create a similar chronological structure by combining observations from a range of different patients with the detailed ethnographic and situated analyses of specific children. This chronological structure also illustrates how patients' cancer trajectories intersect with one another's treatments (e.g., recently diagnosed patients met patients who had relapsed, and patients who were going through first-line chemotherapy forged friendships with patients who were dying).

The contrastive contextualization examines what patients, parents, and hospital staff were and were not talking about, particularly the strategies of information compartmentalization, non-disclosure, and collusion (Bluebond-Langner 1978, 1996; The et al. 2000). Contrastive contextualization involves analyzing where, when, what, how, and with whom the participants chose to talk about specific aspects of the cancer. Special attention is given to comparing the range of topics discussed when children were present or absent, and with whom the children were choosing to communicate more openly. I juxtapose observations of an absence, such as of the word "cancer" or talk about death, with observations of what participants were actually saying. For instance, I examine how Pedro did not use the word "cancer" during his treatment interview but did use it as soon as the doctors and nurses left his hospital room. I also juxtapose what Robert said during a specific medical interaction with what he said before and after it. Outside the medical interaction, Robert, his mother, and I talked about the slow dying process of Felipe, another cancer patient and a friend of Robert, and explicitly acknowledged that he was going to die. However, during the medical interaction, Robert accepted the doctor's advice to hang out with Felipe after his health improved. Eli and her mother found themselves in a similar situation. While mother and daughter talked privately about Eli's imminent death, they agreed with doctors during medical interactions that it was wonderful that Eli was going to see her cousins. Eli was indeed going to see her cousins, but only because her parents had decided to take her home to die.

Investigating Avoidance

My analysis of the regulation of communication and its impact on children's participation in cancer treatment conversations consists of an analysis of two absences: the absence of disclosure (i.e., non-disclosure) and the absence of certainty (i.e., uncertainty). For both non-disclosure and uncertainty, there is an explicit communicative aspect (e.g., not saying the word "death"), an implicit communicative aspect (e.g., talking about death using euphemisms and allusions), and a meta-communicative aspect (e.g., telling children to never use the word death and/or never to say anything that is death-implicative). There are occasions when implicit

communication is the preferred mode of communication. For instance, Lutfey and Maynard (1998), in an article entitled "Bad News in Oncology: How Physician and Patient Talk about Death and Dying without Using Those Words," describe three case studies in which doctors implicitly approach the topic of the patient's death by making references to hospice care, stopping treatment, and keeping the patient pain free. Similarly, patients, parents, and doctors at Catalonia Hospital communicate implicitly about cancer by making references to the tumor, the lesion, or the location of the tumor. Here, patients, parents, and doctors recurrently communicate implicitly about cancer: they all know that "tumor" refers to cancer, but they still do not say the word "cancer." However, there are also occasions when the preferred mode of communication is none at all. At Catalonia Hospital, when it comes to the uncertain and negative aspects of cancer, including death, both explicit and implicit communication with children is mostly absent. Unlike in Lutfey and Maynard's study, the doctors at Catalonia Hospital involved in my study avoid talk about death with children altogether. Instead, they work hard to ensure that they do not make any implicit reference to death *in* their talk with children, and also that the uncertain and negative aspects of cancer are implicitly and explicitly absent.

Furthermore, there is also an absence *of* talk about uncertainty and non-disclosure at Catalonia Hospital. I did not observe any occasion when a doctor explicitly told a child not to talk about death or the uncertainty of the future during a medical encounter. Explicitly discouraging children from talking about death carried with it the risk of actually opening a conversation about it. Consequently, the regulation of what to say about cancer and how to talk about it is mostly done implicitly. Coupland and Coupland (1997) show that physicians rely on implicit communication to discourage geriatric patients from engaging in death-implicative talk. Physicians avoid acknowledging explicitly that the patient wants to talk about his or her death, and also avoid talking about death altogether. Indeed, the most successful type of non-disclosure is the most implicit: participants collude to create a dialogical illusion that there is nothing that needs to be withheld. In his examination of how politicians avoid answering questions and pretend they are not avoiding anything, Clayman (2001: 406) states how "it is thus possible that an act of evasion may occur that is fully apparent to both participants, yet neither party registers that fact in any demonstrable way." Successful non-disclosure, like successful avoidance, evasion, and collusion, leaves no traces.

The absence *of* talk about uncertainty and disclosure and the absence of certainty and disclosure *in* talk create two analytic challenges. First, I do not have explicit statements by the children in which they talk about the absence of uncertainty and disclosure. Children did not talk about the negative and uncertain aspects of cancer with me during my interviews, nor did they talk about what they avoided or felt adults were avoiding. Doctors and parents did give me their insights on what was being avoided and why during my interviews and conversations, and I was also able to observe parents talking to each other about what they concealed from their children (see Chapter 3). However, I came to realize that in the same way children did not discuss these topics with parents, volunteers, and hospital staff, they also did not feel comfortable talking about them with me.

Second, there was little interactional evidence in children's talk with their doctors that the children themselves avoided certain topics or that they thought doctors were avoiding these topics. As mentioned earlier, successful forms of avoidance leave no traces, and from a conversation analytic perspective, claims that participants are avoiding something requires showing "evidence in the ensuing talk that the practice in question has made a difference in the ensuing interaction" (Schegloff 2009: 366). With little implicit evidence in the interactional data—and no explicit statements in children's interviews—a logical conclusion would be that children were not concerned about these absences. To show that children were concerned about these absences but colluded with doctors and parents, my analysis needed to (1) identify exactly what was noticeably absent from the participants' talk from among all the things that could be identified as absent at any point in time, and (2) distinguish between what was absent because it was *irrelevant* to the participants and what was absent because it was intentionally *avoided* by the participants.

The key to addressing these analytic challenges emerged from paying close attention to the children's pursuits of answers. Drawing from Clayman's (2001) analysis of evasions during news interviews, I relied on the sequential organization of conversation to support the claim that children interpreted doctors' behavior as evasive. I relied on what a child said immediately after a doctor evaded answering a question to show that the child treated the doctor's talk as "inadequately responsive" (Clayman 2001). When a child took public action to ask for information with a question, I took that as evidence of the child's desire to obtain information. When a child insisted on pursuing an answer after having asked a question, I interpreted that as the child's public display of understanding that (1) an answer was noticeably absent for the child, (2) his or her question had not been answered yet; (3) his or her question was answerable; (4) his or her question was relevant to what was being discussed; and (5) the physician had more information that he or she was not giving the child. A child's question and pursuit of an answer was thus fundamental to support the claim that at least for the child, talking about a specific detail of his or her experience was relevant at that moment, and that more information was necessary and indeed possible. A close analysis illustrates that children interpreted the information as absent, and that it was absent not because the information was irrelevant or did not exist, but because, from the child's perspective, doctors avoided divulging it.

Children's pursuits of questions and doctor's evasions result in long "cat-and-mouse game" negotiations regarding what to talk about and how. A child asked a question, a doctor evaded an answer, the child returned with a second question, the doctor gave some piecemeal information, the child asked a third question, the doctor lightheartedly teased the child, and and so forth and so on. These "cat-and-mouse game" negotiations also revealed that there was no exact agreement among participants at Catalonia Hospital on the limits of what needed to be avoided; they had different understandings of what needed to be avoided, and they collaboratively negotiated it.

I rely on three different types of evidence to show that there are some questions that are completely absent in children's interactions with their doctors. First, out of a corpus of 500 questions addressed by children to their doctors, no queries explicitly targeted overall uncertainties, such as why one has cancer or whether one will die. Second, doctors strongly resisted and discouraged children's questions that can potentially lead to the discussion of long-term prognosis. Doctors often attacked questions that project a pessimistic future or cast doubt on the effectiveness of treatment. Because doctors were successful in challenging these questions, children do not ask questions that explicitly address overall uncertainties, not even after finding out their diagnosis. As a consequence, there is no observable evidence that children were about to ask these questions, because they never explicitly do. The only indirect observable remnant of this back-and-forth is doctors' explicit rejection of specific questions that may lead to questions about overall uncertainties. Thus, the key piece of evidence is the substantial presence of interactional work carried out by the doctors to ensure that uncertainty and the negative aspects of cancer are not a central focus of talk.

Third, as noted in the aforementioned contrastive contextualization, a few of the children on rare occasions did talk about overall uncertainties and death in interactions with other people, but they did not talk about these aspects with the doctors. Robert talked about Felipe's impending death with his mother and me, and Eli talked about Jesus' death with her mother (see Chapter 7).

My analysis of positive and negative observations of what is talked about (i.e., the absence of the word "cancer" but the presence of "tumor") does not resolve the issue of determining with precision the degree of children's imposed or voluntary acquiescence to doctors' avoidances. Children often neither contest doctors' avoidance of overall uncertainties nor make active attempts to bring them to the fore. My conversations with them do not reveal much either: I was not able to have children talk to me about these issues. Because of that, although my extensive observations reflect that overall uncertainties are not a central focus of talk, I do not attempt to interpret whether children are intentionally or unintentionally participating in avoidance. In other words, I refrain from trying to determine precisely the degree to which children find themselves unable, though often wanting, to talk about an aspect of their experience, or the degree to which children willingly avoid addressing it in the first place.

Multiple Ways of Talking about Cancer

In this chapter, I have located Catalonia Hospital within Catalonia and Spain, and my research and my presence within Catalonia Hospital. The fluid Catalan-Spanish bilingualism of the hospital, in which speakers recurrently accommodate to the language of his or her interlocutor without one language being particularly

dominant, reflects the bilingual patterns found in institutional settings across Catalonia. Relying on studies with adult populations, pediatric cancer advocacy groups, and media representations of children with cancer in Spain and Catalonia, I have examined from a sociocultural perspective the rapid changes in cancer communication preferences and practices over the last 25 years. Rather than disclosure practices replacing non-disclosure ones, multiple practices coexist even when they contradict each other. This diversity of communication preferences and practices beyond *talking* and *not talking* in Catalan society is also found in the diversity of communicative strategies I identify at Catalonia Hospital.

My ethnographic research and presence at Catalonia hospital reflect my dual positioning within this community of patients, parents, and hospital caregivers. I am Catalan and share a culture and languages with this community. At the same time, I am an outsider on two accounts: as a man in a women's world, and somebody who is not a parent, or a doctor, or not a child, not even a childhood cancer survivor or a volunteer. My identity as a linguistic anthropologist is framed instead as somebody who keeps them company and who is by their side.

Since I take up in more detail the everyday experiences of patients and parents in Chapter 3, I have limited myself in this chapter to introducing the 17 children who participated in my study, their parents, and hospital caregivers, as well as a schematic description of an ordinary day at the hospital. Finally, I describe how I conduct two ethnographically informed analyses of the contexts of children's questions, in order to create cancer trajectories that integrate the multiple ways of talking—and not talking—about cancer.

Note

- 1 Research began after obtaining approval from both the UCLA Human Subjects Protection Committee and the Catalonia Hospital Clinical Investigation Committee. Informed written consent was obtained from all participating parents, healthcare professionals, and volunteers; oral assent was obtained from children younger than seven, and older children provided written assent.

Participants in this study often interacted with other individuals who were at the Catalonia Hospital but were not part of the study. To protect the identity of these individuals, my analyses do not contain any of their personal information, such as gender, age, and medical condition. In the few instances when it was necessary to refer to some of this information, gender, age, and medical conditions have been changed so as to render these participants unidentifiable.

Living and Dealing with Cancer

Key Issues

- *In the pediatric ward—a social space for living and dealing with cancer—four strategies help parents and children deal with pervasive treatment uncertainties: focusing on treatment, making guesses about the patient’s health, being together and caring for each other, and talking privately.*
- *By sustaining a sense of control and normalcy, these activities help everyone stay busy, live almost exclusively in the present moment, and keep at bay overall uncertainties (i.e., treatment effectiveness).*
- *Sustaining normalcy is more than a way to deal with treatment uncertainties; it allows children, parents, and health professionals to fulfill different roles, expectations, and responsibilities that are imbued with deep moral values.*
- *As the child-patient and parent-caregiver negotiate their new cancer-related identities, regulating communication to “protect” children from distressing news and embodying hope and optimism become fundamental aspects of parents’ identities.*

With a focus on the everyday routines of patients, parents, and health professionals, I examine four interrelated strategies with which they manage as a community the demands and uncertainties associated with treatment: (1) focusing on the present course of treatment, (2) guessing about different aspects of patients’ health, (3) being together, and (4) talking privately. These strategies are observable in everyday interactions at Catalonia Hospital, beyond medical interactions. For instance, parents and patients administer some medication, monitor side effects, and fight with each other over eating. Furthermore, unlike the primary role of talk (Duranti 1997: 289; Hymes 1972a: 56) in medical interactions, talk plays a subordinate role in some of the activities examined here, such as the aforementioned activities of administering medication and eating. I also highlight how the hospital is a shared social space in which families live and deal with cancer

together, and how children's and parents' social identities become deeply intertwined with the illness-defined identities of cancer patients and caregivers.

The strategies that I identify here are not specific to pediatric cancer, but are similar to strategies used by families dealing with the demands and uncertainties of cystic fibrosis, another life-threatening chronic illness. Bluebond-Langner (1996) identifies strategies such as routinizing of treatment-related tasks; redefining normal; compartmentalizing information about the illness and the child's condition; avoiding reminders of the illness and its consequences; reassessing priorities; and reconceptualizing the future. These strategies help parents and children deal with the everyday demands of treatment and the uncertainties associated with it. Especially at the beginning of treatment, parents and patients face multiple local uncertainties *all at once* because of the complexity and variability of cancer therapies, and come *under pressure* because treatment cannot be stalled until they have time to learn the different therapies.

Dealing with the everyday demands and uncertainties of treatment helps parents and children put aside the overall uncertainties of having a life-threatening chronic illness (Bluebond-Langner 1996; Charmaz 1991; Strauss 1984). Overall uncertainties do not go away, because a medical crisis (e.g., an infection) can bring them to the fore. However, living one day at a time and focusing on the present course of treatment allows parents and children to create a sense of normalcy and control. As Bluebond-Langner (1996: 188–189) notes, strategies such as the routinization of treatment-related tasks and the compartmentalization of information provide “a way for the ultimate questions that CF [cystic fibrosis] raises to go out of awareness” and “lend a sense of control not only over the disease and over one's daily life, but also over one's thoughts.” Cohen (1993: 85) poignantly describes what “living in the present” entails for parents of children with life-threatening chronic conditions:

The span of the child's life, presumed and unquestioned before, is suddenly the main focus of parental concern. Time is experienced as discontinuous, for while the rupture prevents parents from returning to life as it was before the illness, future-oriented thinking or planning becomes too frightening given the multiple uncertainties that exist. Parents are virtually tethered to the present and the very proximate future by the rupture behind them and the uncertainties that lie ahead. Initially, the organization and practice of medicine forces the restructuring of time into shortened units that may be measured by the intervals between laboratory tests and medical examinations. Eventually, parents come to realize that by adopting a “one day at a time” philosophy and living life in shortened units of time the perception of uncertainty can be reduced.

Strategies such as “living life in shortened units of time perception” (see also Good et al.'s (1994: 855) “expression of time without horizons”) and focusing on what can be controlled and routinized (i.e., the everyday administration of treatment in the present moment) help reduce uncertainty and therefore are often described as coping strategies in the clinical literature on pediatric cancer (Bearison

and Mulhern 1994; Chesler and Barbarin 1987; Ishibashi 2001; Stewart 2003; van Veldhuizen and Last 1991; Woodgate 2000). Social scientists also underscore the importance of these strategies in creating and sustaining social roles and identities. Parents and children rely on them to contain the intrusion of the illness, and to prevent the illness from ruling their lives and defining who they are (Bluebond-Langner 1996; Charmaz 1991; Strauss 1984). These strategies also play a role in the larger and ongoing process of figuring out new identities, as parents and children come to terms with the fact that cancer has changed who they are and who they will be. The future they had imagined awaited them before the cancer diagnosis has vanished, and with it, their (former) sense of who they were (Charmaz 1991). For patients, the present and the future—if there is a future—also involve inhabiting bodies radically altered by the disease and its treatment (Dixon-Woods et al. 2005; Larouche and Chin-Peuckert 2006; Williamson et al. 2010). For both parents and patients, the present and the future involve inhabiting new identities and struggling with how much or how little they want to be redefined by cancer.

Social scientists also argue that the significance of normalcy, of acting normal and having normal lives, is far more than a coping strategy. In parents' and children's understanding of who they are (Dixon-Woods et al. 2005; Young et al. 2002a, 2002b), normalcy becomes a moral requirement to maintain the social order at all costs when death looms closer, even if this requires putting on a front before the child and engaging in mutual pretense, that is, all the parties involved act as if the child is going to live when they all know that he or she is dying (Bluebond-Langner 1978; Glaser and Strauss 1965; Strauss 1984).

Finally, my emphasis on living and dealing with cancer together as a community does not mean that parents, children, and hospital caregivers engage in exactly the same way in the activities that I have described. Both the family and the hospital are hierarchically organized institutions, and children rank at the bottom of both. There are obvious asymmetries in treatment information and decision-making between a doctor and parent, and a parent and his or her child. Moreover, members of this community have different roles, expectations, and responsibilities that are deeply imbued with moral values. These are not just derived from "outside" societal expectations, but from members' own understandings and moral expectations of themselves, including the expectation to be stoically strong and to embody hope and optimism (Gibson et al. 2010; Good 1991; Good et al. 1990; Young et al. 2003). As Bluebond-Langner (1978: 230) emphasizes, "the social order is a moral order," even more so when it comes to matters of parenting and of saving children-patients' lives.

Focusing on Treatment

A first strategy to deal with demands and uncertainties of cancer involves remaining focused on the present course of treatment. It is expected and necessary for parents and patients to turn their full attention to treatment, because cancer

treatment is complex, demanding, and time-consuming. Parents and patients quickly become medical experts and use their newly acquired medical mastery to exert some control and normalcy: they know what needs to be done, how it will be done, and their part in doing it. Furthermore, focusing on the present course of treatment also gives parents and patients activities to be occupied and preoccupied with, to fight cancer in tangible ways, and to postpone the overall uncertainties of whether the patient will survive or die.

Parents and children are busy learning enormous amounts of medical knowledge, administering medication and/or overseeing its administration, monitoring side effects, and trying to prevent infections and other treatment complications. The administration of treatment, particularly chemotherapy drugs, is a highly complex cluster of medical procedures that requires constant monitoring and frequent readjustment (Dixon-Woods et al. 2005; Pizzo and Poplack 2011).¹ This constant monitoring demands the active involvement of parents and patients, who are continuously reporting back to the doctors any observable changes in the patient's health. Parents and patients are not only involved in scrutinizing the patient's health to detect side effects associated with chemotherapy toxicity, but they are also frequently involved in establishing the required dosage of side effect medication. In brief, parents and children find themselves immersed in learning and applying enormous amounts of biotechnical medical knowledge (Kadan-Lottick et al. 2002; Kästel et al. 2011; McGrath et al. 2007; Ringné et al. 2011).

Pedro, a 15-year-old boy with bone cancer, illustrates patients' knowledge of cancer biotechnologies and of what is expected to take place during treatment, not just during his own treatment, but also during other patients' treatments. In order to have a safe and direct access to a vein for chemotherapy and for drawing blood, most children at Catalonia Hospital undergo minor surgery to implant a subcutaneous central line venous catheter. This special catheter, called "port-a-cath" or just "port," sits under the skin of the child's upper chest, and is placed around the time of the first chemotherapy sessions.

Pedro's port-a-cath was not implanted until his fifth month of treatment, during a double surgery in which his leg tumor was also removed. Long before his double surgery, Pedro knew everything there was to know about ports from conversations with other patients, especially Robert. About a month and a half after Pedro had started treatment, Robert came one day to Pedro's room to hang out. He showed Pedro his port-a-cath, just a lump under his chest's skin, and told him about the benefits of having a port. Pedro and Robert talked about the port frequently, because Pedro was unhappy about seemingly being the only patient who did not have a port. The administration of chemotherapy sessions was frequently painful for Pedro, because nurses had to find a vein where they could insert the external catheter. One evening, a nurse had tried to find a vein for more than half an hour without success. Pedro was in pain after repeated needle injections. When the nurse left the room to find more help, Pedro complained about the poking and added that he had recently learned from another patient that he could easily pull the needle of the external catheter out and fracture the vein with

any sudden movement. Thus, Pedro had gathered substantial information about the port through conversations with other patients long before he even had one.

Pedro's exchange of medical information about the port-a-cath with Robert was not unique. I also observed other children talked about their ports while on a skiing trip for children with cancer from several hospitals in Catalonia. In the same manner that they talked about whose hospital was the best, the nicest, or had the best doctors, they compared notes about their ports, talking about where theirs had been implanted or about how big or small the surgery scar was. Children also shared with each other stories about their port infections and troubles, because ports seemed to be subject to capricious and invisible problems. In an unpredictable twist, a port might develop an opportunistic hospital-acquired infection, or might stop working without any apparent explanation.

Children and parents also had to master the names of the different chemotherapy drugs. They relied on *el protocol* (short for "the treatment protocol chart"), which was part of the treatment guidelines issued by the International Society for Pediatric Oncology and the Sociedad Española de Oncología Pediátrica. For bone cancer, the protocol chart contained different types of information: the schedule of the surgery and of the alternation of chemotherapy sessions and recovery intervals, the different types of chemotherapy drugs, and dosage information (e.g., how much of each drug the patient will be given, when and how often he or she will get it). Parents carried the protocol chart around with them and used it as a referencing tool for the treatment throughout the entire cancer trajectory. In general, it took several months for patients and parents to learn the names of the chemotherapy drugs. By the third or fourth month of treatment and with constant checking of their own copies of the protocols, parents and patients engaged in long discussions among themselves and also with the hospital staff about how many "methotrexates" they had done, and how many "cisplatins" or "ifos" (short for ifosfamides) they had left.

In addition to learning about the chemotherapy drugs, parents and patients learned about the multitude of side effects and the medications that treated them. The effectiveness of chemotherapy depends on its toxicity and on its ability to kill both cancer and healthy cells. Chemotherapy doses are prepared individually because the dose of effective chemotherapy must be very close to one that can damage seriously the patient's health.² Patients experience multiple side effects, but no two patients—nor the same patient at different points in his or her cancer trajectory—respond to chemotherapy in the same way. A patient's immediate response to chemotherapy drugs (i.e., short-term side effects) is unpredictable, his or her ultimate response (i.e., long-term effectiveness in curing cancer) is unpredictable, and the relationship—if there is one—between short-term and long-term treatment effects is unknown and unknowable.

Overseeing the treatment to ensure it was delivered appropriately was another activity in which parents and patients were involved at the hospital and outside the hospital. For instance, receiving the chemotherapy drug methotrexate required abundant intravenous hydration. Parents and patients measured and wrote down

all the intake of liquids and collected all the urine, which nurses checked and measured, to ensure a patient was not retaining liquids and his or her kidneys were not being damaged. Doctors also relied on the information collected by parents, patients, and nurses to determine whether or not they should increase, diminish, or change the side effect medication. Whenever changes in medication took place, parents and patients felt it was their duty to remind nurses of the latest modification. Hospital staff members were in charge of many patients, and regularly needed to look up patients' individual medical histories and chemotherapy protocols to recall the specifics of treatment.

Patients and parents often argued about medication as they vigilantly oversaw the delivery of treatment. Hospital staff watched with amusement the daily disagreements that parents and patients engaged in during medical visits. Parents complained about their children, and children complained about their parents to the doctors. When doctors asked how the patient was, parents and patients frequently provided different answers. They reported different problems that the patient was having, and they often engaged in long discussions about what had caused this or that, or when the patient had taken a medication or missed it. These conflicting and elaborate answers reflected how most parents and young people kept an impressive record of their medical treatment, tracing every minuscule change in the course of treatment.

Robert, a 17-year-old boy with bone cancer and lung metastases, and his mother illustrate the disagreements that frequently occurred over medication. They were constantly debating how much side effect medication Robert was supposed to be taking. Both claimed that the other did not really know what was going on, and shook their heads or their index fingers from side to side while the other was talking. The constant readjustment of side effect medication made keeping track of the dosage difficult not only for parents and children, but also for hospital staff. Despite the fact that hospital staff used the written medical histories to update each other about the latest changes, different members of the pediatric oncology team might not all have been up to date with the latest dosage at a particular time. However, whenever Robert and his mother disagreed, they blamed each other instead of taking into account that different members of the pediatric oncology team might have recommended different dosages.

Patients also tried to circumvent parental authority by obtaining the support of doctors directly. Patients were keenly aware that parents shared with doctors decisions about patients' lives and treatments, and thus frequently deferred to doctors' expert opinions. Young people, who were more articulate than younger patients, often rebuffed parental authority in front of doctors by arguing that parents were not following treatment instructions appropriately. Parents also appealed to medical authority. Because parents regularly had a hard time enforcing limits with their children, they invoked the treatment and medical authority to legitimize their own parental decisions.

Overall, most parents and patients did not challenge medical authority. They felt they lacked the medical expertise required to make health decisions, and in

moments where patients' lives were at stake, doctors were perceived as the only ones who could save them. Out of the 17 patients that I observed, only two families questioned medical decisions. In both cases, the child's health was deteriorating rapidly, and the treatment provided at Catalonia Hospital seemed to be ineffective. The parents did not openly challenge the pediatric oncology team at Catalonia Hospital, but made their dissatisfaction known by taking their children to another hospital for a different course of treatment.

However, both patients returned to Catalonia Hospital after a few months because the treatment at other hospitals was no more or less successful than the treatment at Catalonia Hospital. Hospital staff, as well as patients and parents who remained at Catalonia Hospital, attributed these transfers to the great distress the parents were experiencing owing to the deteriorating health of their children, which interfered with their ability to make appropriate treatment decisions. These transfers were not considered problems due to medical decisions made by doctors, or stemming from how doctors discussed treatment choices with parents and patients. A hospital staff's proverb captured this belief that only the parents of children whose health was deteriorating questioned doctors' authority: "If the child is doing well, parents don't complain."

Guessing

Guessing activities constitute a second set of strategies to which parents and children devote significant time, attention, and talk. Guessing activities share with "focusing on treatment" activities a concern with local uncertainties associated with the present and near future. However, whereas "focusing on the present course of treatment" activities work toward understanding the unknown but knowable aspects of treatment (e.g., names, doses, and side effects of chemotherapy drugs), guessing activities are used for the unpredictable and unascertainable aspects of treatment.

Parents and children engage in three main forms of guessing. The first involves guessing whether a patient is healthy enough to begin a chemotherapy session. Nobody knows with certainty the precise start date, because it is contingent on when the patient's blood cell counts have recovered enough from the previous chemotherapy, and on whether the patient shows signs of infection. The second entails guessing the significance of particular chemotherapy side effects vis-à-vis the overall effectiveness of treatment. Parents sometimes are conflicted when undertaking this second form of guessing because it contradicts doctors' efforts and their own efforts to focus exclusively on treatment and its associated local uncertainties, and to postpone or avoid thinking about overall uncertainties. Unless a medical crisis occurs, parents manage to keep these uncertainties separate for the most part, but on occasion they cannot help themselves and look for signs of what the future holds for them. The third consists of guessing who may be developing a fever and/or infection before even the first signs appear.

With each postponement of chemotherapy, the end of the treatment needs to be recalculated. All this variability results in accumulated delays in treatment administration and makes it impossible to know with exactitude when the entire treatment will end. Furthermore, because unknowable uncertainties associated with the present treatment (e.g., when will the next chemotherapy start?) are never too far removed from overall uncertainties (e.g., does a delay in the start date of the next chemotherapy mean that treatment is not working and that the patient will die?), patients and parents struggle with connecting or disconnecting the significance of local complications vis-à-vis a patient's chances to overcome cancer.

Cancer treatment requires much waiting: parents and patients wait to be admitted to and discharged from a chemotherapy session. They wait for diagnostic imaging test results. And, of course, they wait to see if the treatment is ultimately effective and the cancer disappears. Moreover, the fear that cancer or an infection may be lurking under the patient's skin reinforces a desire to "see" and foresee what is invisible, because once is visible, it is already too late: the child has cancer, has relapsed, or has an infection that can kill him or her. Some parents, even after the cancer is in remission, feel they failed as parents because they were not vigilant enough to detect the first symptoms of cancer (see the following section titled "Talking Privately" and also Chapter 7). To manage the uncertainty created by the invisibility of the progress or regression of cancer, parents and children make guesses as they struggle to make sense of visible signs of treatment such as side effects and to "see" and foresee the invisible.

Estar baixet (Having Low Blood Cell Counts)

Blood cell counts are used as indicators in determining whether the patient can tolerate another chemotherapy session, or whether the patient's health has deteriorated too much to survive a new round of destroying cancerous and normal cells. Blood tests were always carried out first thing in the morning on the day a chemotherapy session was scheduled to take place. Patients and parents waited for hours until the doctor determined if the patient would be admitted to start chemotherapy that same day, or would be sent home and asked to come back a few days later. This procedure would be repeated until the patient's blood cell counts were deemed to be high enough to start a chemotherapy session that afternoon.

Patients and parents used a euphemistic diminutive to soften this condition of low blood cell counts. They referred to it as being a little low, "*estar baixet/baixeta*." Guessing whose blood cell counts were too low for the patient to be hospitalized for a chemotherapy session was a pastime of parents and patients. Blood was drawn first thing in the morning, but the results could take hours to process. In the meantime, parents and patients congregated at the outpatient clinic with nothing to do except wait to find out whether the results indicated that the patient would be hospitalized. Patients and parents claimed to know before the test results came back who was fine and who was too low for chemotherapy.

It was quite an entertaining game: parents guessed their child's blood cell counts, patients guessed their own blood cell counts, and everybody tried to guess those of other patients. There was a kind of rebellious nature in the guessing game, and it could even be argued that patients wanted to display their knowledge of their bodies, to show that they knew better than the laboratory test technicians what was happening in their bodies. Anna, a 16-year-old girl with bone cancer in her left leg, protested that she had spent more than two hours inside an ambulance in her drive from her hometown to Catalonia Hospital, even though she knew her blood cell counts were too low and that she would be sent back home on the same day (another 60–90 minute ambulance ride). Why did the doctors still insist on making her come to the hospital for “scientific” blood tests? Why not listen to her guesses and let her stay home?

Part of guessing who was too low to start a chemotherapy hospitalization was to make sure, or at least to express a desire, to be hospitalized with friends. Mothers also hoped that their children's hospitalizations would overlap with the hospital stays of other mothers with whom they had developed close friendships. The strongest friendships seemed to develop when both the patients and their respective mothers were close friends. This was the case for Quique and Santi and their mothers, and for Robert and Pedro and their mothers. If one was hospitalized for a chemotherapy session at the same time as the other, it was a cause for celebration. Among young people, friendships were the target of teasing and rumors of romance. Sometimes these guessing games worked to the disadvantage of the patients. Patients were teased about being able to manipulate their own physical condition in some mysterious psychosomatic way, because there seemed to be no other explanation for some patients' accurate guesses of blood test results.

Robert was very explicit in expressing that he knew right away when his blood levels were too low for him to be hospitalized to start chemotherapy. He was correct in his guesses most of the time. One of his scheduled chemotherapy sessions was delayed by two weeks because his blood cell counts were too low, and his mouth sores did not heal completely. During those two weeks, another patient with whom Robert was supposedly having a romantic friendship, mainly via text messaging, could not be hospitalized either. Because the blood cell counts of Robert and his “friend” were too low, they were teasingly accused of waiting for the other to be hospitalized. Eventually they were not hospitalized for chemotherapy at the same time. However, Robert continued to be teased: his mouth sores improved or worsened, depending on whether his “friend” was going to be hospitalized or not.

Les llagues (Mouth Sores)

Patients and parents also engaged in trying to guess the ongoing effectiveness of chemotherapy drugs, and the reasons for the disparity of the side effects between patients. To do so, they paid close attention to how individual patients tolerated treatment and drew comparisons between them. They spent a lot of time attempting

to theorize which side effects were indicators of the effectiveness of treatment. Pedro's and Robert's experiences with chemotherapy illustrate several types of guessing.

Although Pedro and Robert had similar chemotherapy treatments, their side effects were different. Whereas Pedro slept through the administration of chemotherapy, did not have nausea and vomiting, did not lose his appetite, did not lose much weight, and did not have problems with his mouth and his gums, Robert was quite the opposite. Robert's mother or the nurses covered the bag of the intravenous chemotherapy drug with a towel because just by looking at it, Robert would get nauseated. He lost his appetite and considerable weight, had numerous gum and mouth problems, and from time to time developed infections. Robert was very afraid of mouth sores (*llagues* in colloquial Catalan) because he had them regularly. Despite taking medication to eradicate the mouth sores, Robert's chemotherapies were often delayed because of them. On a few occasions, his mouth sores were so bad he could barely talk. Robert's appetite, which was already diminished by the chemotherapy, worsened with the onset of mouth sores.

Both mothers did not know what to make of such different degrees of tolerance to chemotherapy. In addition to side effect divergence, Robert's and Pedro's tumors differed. Pedro's tumor was not getting smaller at the same rate that Robert's tumor did with the pre-surgical chemotherapy. Their mothers tried to discover patterns that could help them know more about what was to come, to read into the future by interpreting the "typical" rate of tumor shrinkage or the standard chemotherapy side effects. They spent a lot of time comparing their situations, speculating about the meanings and significance of these treatment-related issues. Were Pedro's minimal chemotherapy side effects an indication that the chemotherapy was ineffective, because it was not killing the normal cells along with the cancer cells? Did Robert's severe side effects indicate that he would die eventually because of the aggressive treatment?

Doctors discouraged patients and parents from interpreting local complications in terms of the overall prognostic assessment and from comparing the differing degrees of tolerance patients had to treatment. However, this did not stop parents and patients from engaging in guessing games and comparisons. Instead, they just moved these speculations into private conversations, out of doctors' and nurses' earshot.

La febre (Fever and Infections)

In the third guessing activity, parents and patients tried to guess when a patient had developed an infection even before it became a serious problem, and if possible, even before the first symptoms manifested. The depletion of blood cells by the chemotherapy impaired a patient's ability to fight infections, a task that is carried out by white blood cells. The presence of any type of microorganism, even one that under other circumstances did not usually cause infections, had

life-threatening consequences for an immunosuppressed patient with cancer. A cancer patient who presented even the slightest fever or other symptom of infection was taken immediately to the emergency room to start a course of treatment while continuing tests to discover the cause of symptoms.

Quique, a 13-year-old boy, was a patient who experienced complications from his immunosuppressed system. He lived in a city in northern Catalonia, near a large medical center where his mother worked as a nursing aide before she went on leave in order to take care of him. This medical center did not offer treatment for pediatric cancer. When Quique developed a fever a few days after receiving chemotherapy during a recovery interval, he had to be taken to the emergency room at Catalonia Hospital.

Quique's entire family strove hard to prevent infections. Quique's mother was constantly on "infection patrol," because he could suddenly develop a fever that soared quickly out of control. She regarded everybody and everything, including her son's body, as a potential source of infections. Like other parents, Quique's mother took great care to separate Quique from his sisters whenever they developed an infection. If possible, the sick sibling would sleep in a bedroom alone as a preventive measure. There were many other precautionary measures to prevent infections that Quique's family, and other families, had to observe, such as maintaining the child's good oral health, avoiding cuts, protecting the child from the sun, and keeping the child's skin hydrated to avoid rashes.

Quique's mother's infection patrol involved detecting the earliest signs of fever. She would even try to guess whether Quique might develop a fever even before he had one. Quique's fevers escalated so quickly that she tried to act faster than the fever, and kept a small kit of clothes and toiletries so as to be always ready to go. At the slightest sign, Quique's parents would drive down to the Catalonia Hospital emergency room (E.R.). All parents were strongly advised to take their children immediately to the E.R. at Catalonia Hospital under any troubling circumstance—infection related or not—no matter how minor. An infection could kill the patient, and patients' medical histories and courses of treatment were so complex that doctors preferred patients be taken to Catalonia Hospital rather than to the E.R. of a local hospital. The sooner the child was admitted for an infection at Catalonia Hospital, the better. For families like Quique's that lived far from Barcelona, guessing when a child might have an infection rather than waiting for the earliest signs was part of a strategy to avoid wasting time. It was better to guess wrong and make an unnecessary trip than to drive panic-stricken with a child with a rapidly escalating fever.

Beside the risk fevers and infections posed to Quique's health, each infection resulted in the chemotherapy treatment being suspended until the infection had completely healed. Quique's entire cancer treatment was considerably lengthened because of the numerous delays from fevers and infections. These, like cancer itself, were invisible sources of anxiety and uncertainty for parents and patients, who were relentlessly on the lookout.

If the infection could be controlled with antibiotics without the need for hospitalization, the patient went home. Sometimes patients had strong enough immune systems that they stayed home during the infection, but came to the hospital everyday for an intravenous administration of antibiotics. However, cancer patients with infections frequently required isolation in a hospital room for a 10-day course of antibiotics, especially when the patient's immune system was so compromised that any microorganism could unleash massive opportunistic infections.

Toni, a 15-year-old boy with Hodgkin's disease, developed herpes that covered almost half of his upper body and kept him in preventive isolation for two weeks, and was back again in preventive isolation for three weeks near the end of his cancer treatment because of concurrent infections. Each infection made it easier to develop another one. Anna, a 16-year-old girl, had to be isolated several times during her 12 months of treatment, and several more times after the end of her cancer treatment for other infections. Marc, a 6-year-old boy, spent almost three weeks hospitalized for an infection. During those weeks, Marc was not allowed to leave his hospital room, windows were sealed, and the door was kept closed. He could not receive any visits and would talk to other hospital friends through the glass in the door. His mother, caregivers, and hospital staff wore mouth masks, sterile hospital clothing, and covers for head and shoes.

Being Together

A third set of activities involved different ways of being together and caring for each other, which allowed parents and children to fulfill the culturally sanctioned roles of "parent" and "child" at Catalonia Hospital, and to construct normalizing routines that give a sense of orderliness and control. These activities were being at the patient's side, ensuring that patients eat, and paying visits to support other parents and patients. Especially for young people and their mothers, these activities were continuous sources of bickering.

Cancer treatment at Catalonia Hospital required families to live and deal with cancer together. For families who wanted more privacy—and also for young people who were trying to get away from their mothers—it felt like too much "togetherness." Not only did parents and children share medical expertise and some aspects of the administration of treatment, but they also lived together in the small confines of the hospital room during hospitalizations. For families that moved to Barcelona because of treatment or stayed in Barcelona during hospitalizations, this "togetherness" also involved living with each other in apartments for displaced families across the street from the pediatric ward.

I want to emphasize that this "being together" created a social space that was more than a physical space and more than a space of juxtaposed co-living. It was

the social geography of their living and dealing with cancer as a community that reflected how this community occupied and “owned” the physical space. Patients with cancer and their parents shared the pediatric ward with people who were not part of this community. The pediatric cancer unit was located in a pediatric ward, and the rooms of cancer patients were next to the rooms of other children hospitalized for other reasons, who were cared for by pediatricians and nurses of other specialties. Some of these children with non-cancer conditions were chronically ill, were admitted for long hospitalizations, and in some cases, they came to be seen as another member of the community. For the most part, however, children with cancer and their parents distinguished between *els fixos* and *els de pas*, that is, permanent patients and temporary or transient one-time patients (see the section titled “*Fer una visita* (Visiting)” on page 64). Doctors and nurses came to work and went home, patients with non-chronic conditions (i.e., appendicitis surgery or a bone fracture) were admitted and discharged, but *els fixos* were at the hospital 24/7 for weeks at a time.

There was another reason that made children with cancer occupy the pediatric ward differently and feel that it was *their* social space. While they were in the hospital, there were some prying eyes, but not as many as outside the hospital. As soon as patients were hospitalized, they put away headscarves, baseball caps, clothes covering scars, and even leg prostheses. Treatment permitting, cancer patients went in packs around the pediatric unit bald-headed, in wheelchairs, or with crutches, wearing hospital pajamas that revealed scars, and sometimes even pushing intravenous poles up and down the hallways. Although they still attracted some unwanted attention from transient patients and their families, children did not feel the same need to control meticulously their physical signs of cancer as they felt outside the hospital.

Acompanyar (Being at the Patient’s Side)

The Catalan verb *acompanyar* encompasses different activities, including being at the patient’s side, attending to the patient, and keeping the patient company so that he or she does not feel lonely. *Acompanyar* was regarded as a highly important and deeply moral activity of a parent during treatment, as attested in diaries written by parents (Carbonell 2003; Gili 2002; Larreula 1997). Horstman and Bradding (2002) show that, for children with cancer between the ages of 6 and 10, the presence of a mother is important to feel safe and not feel lonely. Woodgate (2006) identifies different ways in which the act of others (family, friends, hospital staff) “being there” is important for younger people with cancer between the ages of 12 and 18: comforting them, holding their hand, preventing them from feeling lonely, helping them feel like they have a life, keeping him or her positive, and being there for them despite everything. “Being there” is thus a key element of social support for patients but may also become a source of stress, for instance, when patients struggle wanting to be with their parents and wanting to be with their friends.

At Catalonia Hospital, Young et al.'s (2002b) "obligation of proximity" extended beyond the first weeks or months after diagnosis. Patients were never to be alone for long periods of time, regardless of their age. This meant that a parent, or another adult who could stand in for the parent, would be with a patient at all times. For example, the mother of 6-year-old Marc was a single parent with a network of friends and relatives who substituted for her when she was unable to be with her son in the hospital. Parents also asked other parents of hospitalized children to watch over their child while they ran a quick errand. The only justification to leave a child without an accompanying adult for a relatively long period of time was when parents tried to get some sleep on a bed rather than on the chairs of the hospital. Unlike children who were never alone, young people, like 17-year-old Robert and 16-year-old Anna, started to sleep alone after their fifth or sixth month of treatment. Their mothers, who stayed in the apartment for displaced families across the street from the pediatric ward, tried to persuade their children to let them go to the apartment to sleep. After many months of treatment, mothers of young people often managed to get some proper sleep on a bed in the apartments during hospitalizations, but they never did so consistently. If the young person had an infection, particularly bad side effects, or simply was sad or having a bad day, his or her mother stayed with him or her overnight in the hospital.

Out of more than 40 patients that I met over the years in Catalonia, I only observed 2 patients (another patient and Anna) who spent considerable amounts of time alone. Their isolation was a source of great concern among hospital staff, and of moral outrage to many parents. The parents of the first patient had to work and take care of their other children, and did not organize a substitute adult to accompany the patient. The patient was an extroverted, gregarious young person who did not like to be left alone. This patient constantly wandered around the pediatric ward, seeking the company of others: hanging out with nurses while they conducted their tasks, sitting at the doctors' desk in the nurses' station, talking to anybody who happened to be in the waiting room, or hanging out with other pediatric cancer patients and their parents. The fact that even this patient who was often left alone by his parents found company, further reinforced the sense, in the eyes of parents, patients, and hospital staff, that patients should never be left alone.

Keeping the patient company not only implied being within the perimeter of the hospital with the patient, but being physically next to him or her. Anna had many screaming fights with her mother and sisters because they were not by her side during hospitalizations, keeping her company and tending to her. Anna's sisters took turns being with her because their mother was frequently unable to come to Catalonia Hospital to be with her. She was busy taking care of six daughters, a baby grandson, and her chronically ill and disabled husband. Anna's mother and sisters, who were from a small rural hamlet with fewer than 20 inhabitants, used their trips to Barcelona, where Catalonia Hospital was located, to go for walks and sightseeing. Even when on the hospital premises, Anna's mother would leave Anna alone for long periods of time while she talked to other patients and parents. Her sisters, only a few years older than Anna and about the same age

as other cancer patients, behaved in the same way: instead of being with Anna, they hung out with other patients. The behavior of Anna's mother and sisters, especially their walks around Barcelona, not only drew Anna's rage but were also sharply criticized by other parents, who described it as immoral.

Conversely, problems would arise when patients did not want to be continuously with their mothers. For instance, Robert did not want to have his mother next to him when he was getting to know girls. Robert's mother, who quit her job to attend to Robert during every chemotherapy hospitalization and hospital appointment, was often infuriated by how she felt Robert treated her. She complained that Robert used her. When he needed her, he acted like a "*nen petitó*" (a young little child). When he did not need her, he pushed her aside. Robert's mother was even more aggravated because for many months she had tried to sleep at night in a proper bed in a shared apartment for displaced families down the street rather than having to sleep on an uncomfortable chair next to Robert's bed. She would jokingly say that if Robert was old enough to flirt with girls, he was old enough to sleep alone.

Menjar (Eating)

Ensuring that patients ate was another way parents enacted care. It dominated much of their time and was a source of great anxiety for them (Gibson et al. 2012), but it was also was one of the few things left in their control that could contribute to their children's health. Additionally, "not eating" was one of earliest signs that alerted parents there was something wrong with their children (Dixon-Woods et al. 2001). Consequently, the assumed practical activity of ingesting food had great symbolic significance: it was a symbol that the patient was doing well (i.e., very sick and dying children do not eat), a symbol of normalcy (i.e., children eat and parents provide for them), and a symbol of identity (i.e., a parent is an individual who feeds his or her offspring, and a child is an individual who is fed by his or her parents).

Eating was also a socially negotiated activity, because parents wanted children to eat, and most children refused to eat hospital meals. Their senses of taste and smell were altered by chemotherapy. Some patients could not even tolerate the smell of hospital meals, despite the fact that food was covered with lids. Hospital food was neither particularly good nor particularly bad. Many parents cooked for their children, or bought food from outside and brought it into the hospital. To ease the financial burden of buying food every day, many parents ate the hospital food while their children ate something else. Moreover, because many patients had lost their appetite and consequently a substantial amount of weight, parents took on the role of food providers with urgency, stocking anything that a patient might be willing to eat or drink, such as snacks, chips, cereals, cookies, and juice. For instance, a few days after a new milk drink had been advertised on television as an immune system booster, parents spread the news around the pediatric unit, and many pediatric cancer patients began to consume it with every meal.

Parents interpreted eating as a direct sign that a child was in good health, and an indirect sign that treatment was going in the right direction. For instance, Robert did not tolerate chemotherapy well. He was frequently nauseous, vomited, and lost considerable weight during the first four months of treatment. Doctors had tried numerous drugs to treat these side effects to no avail. When they finally found a drug that greatly diminished Robert's side effects, Robert started eating well, and his weight rose dramatically. Robert's mother took this as a sign that Robert's treatment was finally working, and that they were on the right track toward Robert's cure. However, Robert's mother was still not satisfied. She complained to doctors that he was not eating "real meals," but only snacking here and there. As Robert made it clear to his doctors in the medical rounds, he thought his eating was fine, and accused his mother of making things up. Like with other parents and young people, eating became a regular source of endless bickering between Robert and his mother.

Doctors played a decisive role as ultimate decision makers in the conflicts that arose around eating between parents and children. For instance, Pedro did not want to eat because he thought he was too fat, even though he was quite thin. Pedro's mother appealed to the authority of the doctors to get him to eat. However, neither his mother nor the doctors were successful in getting Pedro to gain weight, and he was still very thin when I left after five months of observing him. When Anna, who was obese, cheated on the diet that doctors had given her, Anna's mother asked the doctors to intervene. She hoped that Anna would at least obey the doctors. However, despite the doctors' strong admonitions, Anna's weight was only under control for brief periods of time during her treatment and post-treatment.

Eating was so strongly associated with healing and health that some parents disobeyed doctors' orders. Toni was constantly fed by his mother, who hoped that eating would improve his health despite the fact that doctors warned too much food could be counterproductive. Nonetheless, whenever Toni's mother thought his blood count might be low, even before the test results came back, she would cook him steak. Toni did not want to upset his mother and ate all she gave him. Toni's mother never challenged doctors openly; she always conceded and agreed that she was giving Toni too much food. However, a few days after the warnings, Toni would resume eating copious meals several times a day, with his mother standing next to him.

Fer una visita (Visiting)

A third way of being together involved a reciprocal system of visitation by parents and children with cancer to other parents and children with cancer while at the hospital. This system both constituted and reflected the strong bonds that existed between them. These bonds of mutual support and affection were extremely important for parents and children, especially as other forms of social support and social time with "non-cancer-affected" friends and relatives outside diminished.

When a child made the transition back to “normal life” at the end of cancer treatment, many parents and patients expressed sadness because the end of treatment meant less frequent contact with the support system that helped them through their traumatic experience.

As noted earlier, parents and children with cancer shared the physical space of the pediatric ward with other parents and children who did not have cancer, but they occupied it differently. For the cancer patients and their parents, the pediatric areas of the hospital (waiting rooms, playrooms, hospital school, outpatient clinic, and rooms of the pediatric ward) reproduced the social geography of a small Mediterranean village. The waiting rooms and playrooms were the village’s public squares, the hallways the streets, the hospital school was the village’s school with one classroom for children of all ages, and patients’ hospital rooms were private dwellings. Whenever a villager returns from an outside stay, he or she goes around the village paying visits to the houses of relatives and friends, checking who is also at home, inquiring about their well-being and also being updated about the latest news—and gossip—of the village. It is the obligation of the returning villager to make those visits, and if he or she does not visit a particular relative or friend, this causes offense. This system of visitation ensures mutual bonds of reciprocal support and affection.

Whenever a parent and a child came to the hospital, it was their social obligation to visit as many cancer patients and parents who were also at the hospital as possible, or at least to ask hospital staff and other parents about them. For instance, while waiting for blood test results in the outpatient clinic, Anna and her mother would go to the pediatric ward to see who was hospitalized on that day to pay a visit to them. There were different ways for patients and parents to visit each other and to congregate in the hospital. They gathered at the outpatient clinic when they came to the hospital for check-ups, appointments, treatment preparations, or outpatient treatment. Hospitalized children and parents gathered in the pediatric ward, and there was a flow of parents and children from the outpatient clinic who visited the hospitalized children and parents in the inpatient pediatric ward.

At the outpatient clinic, parents and patients had the opportunity to spend time together. The clinic was full of energy, noise, and people coming in and out. Toni, a 15-year-old boy with Hodgkin’s disease, and Bruno, an 11-year-old boy with acute lymphoblastic leukemia, were often at the outpatient clinic, because part of their chemotherapy treatment did not require hospitalization. If they were feeling fine, Toni and Bruno looked forward to spending time in the clinic, as their social time was limited to the outpatient clinic and the hospital school. They could not attend school because of immunosuppression, and spent most of their time at home with one adult who accompanied them. Toni spent most of his time with his mother, and Bruno with his aging grandmother. Eli, a 5-year-old girl with Wilm’s tumor in her kidney who spent all her time with her mother in the hospital and at home (see Chapter 7), also liked the energetic atmosphere of the outpatient clinic. For patients with bone cancer who were close friends and wanted to be hospitalized together, like 15-year-old Quique and 16-year-old

Oriol, or 17-year-old Robert and his 16-year-old girlfriend, time in the outpatient clinic was special because it could be the only time they would spend together in weeks. For example, if Quique was too sick to start a chemotherapy session at the same time as Oriol did, Oriol might have finished his hospitalization by the time Quique finally started his.

In the pediatric ward, patients kept the doors of their rooms open, if treatment, side effects, and infections permitted it. Patients hung out outside their rooms, visiting each other. Because of immunosuppression, children with cancer rarely shared a hospital room with another patient, unless he or she was also a cancer patient. For the children, sharing a hospital room for the 5–10 days of a chemotherapy session was thrilling, especially if paired up with a friend. Otherwise, a patient had to spend the days when side effects prevented him or her from moving around, alone with his or her mother in an individual room. Quique and Oriol shared a room whenever they could, as did Robert and Santi (see Chapter 6). Pedro, who kept to himself during the first months of treatment, was paired up with Robert or Santi in shared room as a way to break his isolation. Many patients in wheelchairs roamed around the pediatric ward freely, wheeling along their intravenous poles and medication pumps. Like mothers going around a small village gathering their children before mealtimes, whenever medication needed to be given, nurses and mothers looked for the patients in the rooms of other patients, the waiting room, and the outdoor stairway steps. In contrast, non-cancer patients and parents hardly left the hospital room, and kept the door closed for privacy.

There were only a few occasions when cancer patients closed their doors: while sleeping, undergoing immunosuppression preventive isolation care, or if they were very sick or dying. Recently diagnosed cancer patients also kept their doors closed at the beginning of treatment, but it was a practice that did not last long. After they began treatment, Pedro's and Dani's rooms were closed during the first 3–4 chemotherapy hospitalizations. Dani's mother found it was too depressing to see other children with cancer, and Pedro's mother kept the door closed because Pedro spent most of the time of chemotherapy administration sleeping—his way of dealing with cancer was to sleep, even when doctors visited for morning rounds. With repeated hospitalizations, Pedro, Dani, and their respective parents started to pay and receive visits from patients and parents, and slowly, their room doors began to be left open.

The waiting room in the pediatric ward was like a village's main square, the center of social life. Parents and children gathered there to talk, eat, and spend time together. During my fieldwork, the pediatric unit was temporarily housed in a different building before returning to its permanent building after years of construction work. In the pediatric ward of the temporary building, there was a large playroom where families of cancer patients held large dinners at night, sharing food, drinks, and lively conversations. When the pediatric service returned to its permanent building, parents and children found themselves without a dedicated playroom and only a small waiting room in the pediatric ward. If hospitalized

children wanted to play, they had to walk across the street to the building of the pediatric outpatient clinic, which housed the only playroom for both inpatient and outpatient children.

The small waiting room in the building of the pediatric ward did not have tables, and the chairs were attached to each other in long rows. Parents and children still managed to convert this unfriendly place into the center of social life. They moved the rows of chairs so that they faced each other, used the chairs as tables, and used the room as lounge, dining room, smoking room, solarium, and playroom. The waiting room had an exit to an outdoor stairway. The steps of the stairway became the place to gather for sunlight, privacy, and smoking. Patients during hospitalizations were not allowed to leave the hospital premises, a restriction that was enforced even more strictly during chemotherapy and immunosuppression. *Les escales* (stairway steps) became the patients' outdoor area. One summer afternoon, Gemma, a 15-year-old girl, and Santi and Quique, two 13-year-old boys, were bored. Gemma's mother decided to move the chairs to the sides of the waiting room and mark the lines of a tennis court with duct tape so that her daughter, Santi, and Quique could play tennis together. They had a great time trying to play tennis, despite the fact that it was quite a challenge: Gemma, Santi, and Quique were all in wheelchairs, and both Gemma and Santi had had a leg amputated. According to the three of them, much of the fun was derived from shocking other non-cancer hospital patients with their missing legs and bald heads.

By paying visits to each other and spending significant amounts of time together at the hospital, parents and children with cancer created a strong sense of community that provided them with friendships and a system of mutual support and affection. With time, parents and children increasingly relied on other parents and patients with whom they shared the everyday experiences of cancer treatment and with whom they felt they did not need to explain what for them had become normal: playing tennis in wheelchairs in the waiting room of a pediatric ward.

Talking Privately

In addition to focusing on treatment, making guesses about patients' health, and being together, there were some occasions in which parents and patients discussed "unspeakables" and displayed negative emotions privately. These private conversations are clearly part of the regulation of communication at Catalonia Hospital, and offer a contrast to the communicative strategies found in public activities in the presence of children (see Chapter 5). Since I examine a few private conversations about death between children and parents in Chapter 7, I concentrate here on "parental asides," that is, activities during which parents sat with one another and talked without their children.

Parental asides were quasi-concealed practices. They took place informally when the pediatric ward was quiet and somewhat empty, in the late afternoon or late at night. These were times when there were no visitors, and only a few nurses and a doctor remained at the medical station. For the most part, it was mothers who congregated, although occasionally a father would join. While their children were sleeping or napping, playing videogames together, or supervised by somebody else, mothers wandered into the waiting room, some to have a smoke in the outside area next to it, to take a break from their children, or to see which other mothers were around.

In a relaxed environment without anything in particular to talk about, mothers exchanged tips about food that their children successfully ate and about how to prevent infections. They complained about hospital staff, things that did not work, their children, their stress, and their boredom. Sometimes, the conversation turned to topics and emotions that were seldom spoken of elsewhere. These were topics and emotions that I was rarely able to observe because mothers tried to keep them hidden from their children. The only context in which mothers were more open to talking about negative emotions and unspeakables in front of children was during post-treatment medical visits (see Chapter 7). Mothers also phoned each other, and those who lived together in the apartments for the displaced families had opportunities to talk without their children being present when they would go home late at night to sleep in the apartments.

Parental asides were clearly activities of mutual support and caring, but they stood in sharp contrast to the gregarious and jovial atmosphere of reciprocal visits, collective meals, and shared playtime. The activities that were more visible and public were full of jokes, loud overlapping talk, laughter, teasing, and playfulness. However, behind this more visible and public *front stage* (Goffman 1959b) of upbeat jokes and laughter, there was a less visible and more private *back stage* of fears, worries, and anxieties. The regulation of information was intimately tied to the social regulation of negative emotions. In public events that included children, such as medical visits or collective dinners, positive emotions were the norm. In private events without children, such as during parental asides, parents talked openly about negative experiences and expressed their negative emotions.

Parental asides also provided insight into how mothers came to terms with their new identities as mothers of children with cancer (Dixon-Woods et al. 2005; Young et al. 2002a, 2002b). Mothers struggled to determine how they were like other mothers of children with cancer and how their child was like the other children with cancer (e.g., Will my child's fate be like the fate of other children who are getting better or worse? To what degree is my child an exception, for better or for worse?). Part of figuring out who they were as mothers of children with cancer was figuring out how much they differed from the people they used to be, and from the parents of children who did not have cancer.

On a hot Friday night in the middle of August, I had the opportunity to observe one of these parental asides. Four mothers congregated in the waiting room: Dani's mother (see Chapter 5), Pedro's mother (see Chapter 6), the mother of a 15-year-old boy who had a fast-growing brain tumor, and the mother of a

2-year-old girl with leukemia. On that night, there were no husbands in the waiting room gathering; two husbands (Dani's father and Pedro's father) who were at the hospital stayed in the room watching TV with their sons.

These four mothers talked about a wide range of topics, including their desire to withhold information from their children, their suffering during the period between the first symptoms and the cancer diagnosis, their anguish of not being able to protect their children, their struggles adjusting to the new identity of "a mother of a child with cancer," and their commitment to both being strong and avoiding any display of negative emotions. The first topic of conversation was how they preferred for their children not to be told about the diagnosis. They believed they were sparing their children some suffering by withholding the bad news from them. They also believed that a mother whose child did not know about his or her own diagnosis suffered less. Because a mother's suffering was directly correlated to the suffering of her child, increasing a child's suffering by disclosing his or her diagnosis to him or her increased the suffering of the mother as well. As mothers of two young persons, Dani's mother and Pedro's mother expressed envy of parents whose children were too young to be aware of what was happening. Dani's mother explained that her son's life had been interrupted, and that she thought it would be harder for her son to move on with his life because he knew what he had. Talking to the mother with the 2-year-old girl, Pedro's mother added that she did not have to tell anything to her daughter. Whenever her little girl had a good day, it was like nothing had happened, like she did not have cancer. Pedro's mother took the opportunity to complain about how she resented the fact that physicians addressed many of their explanations to her son and not to her and her husband. According to her, physicians were distant and cold with parents but were warm with children and gave them plenty of explanations.

The second topic of conversation involved the range of emotions that they felt during the period when they first started to notice symptoms until treatment began. All four mothers recounted in detail the first symptoms, but their interpretations of the events were different. The mother of the 2-year old girl felt there was some "luck" because the apparent tonsil inflammation that would not go away led to a quick diagnosis of leukemia. According to Dani's mother, the mother of the boy with the brain tumor was "lucky" because the fact that the tumor was growing outwardly led to the cancer diagnosis. Otherwise, they would not have noticed, as in the case of her son's tumor. Dani's cancer was only diagnosed after the removal of a tumor that was thought to be benign at first. Pedro's mother did not feel very "lucky". She was furious because so much time (almost four months) had passed since she first noticed a small bump on her son's knee. She was told that it was a growth-related issue and that it would go away with rest. When she was first shown an x-ray of the tumor, it was the size of her fingernail, but when the cancer was finally diagnosed, the tumor was the size of an egg. Although the other mothers disputed it as a way to comfort and console her, Pedro's mother argued that if they had found her son's tumor earlier, perhaps his treatment would have been shorter.

A third topic of conversation was the suffering stemming from the uncertainty of their children's lives, the lack of control over what was happening to their children, and their inability to protect them. They emphasized how they would have preferred that they were the ones with cancer instead of their children. Not only were they unable to protect their children, but they also had to witness their children suffer without being able to do much for them. Mothers were limited to accompanying and comforting their children. They had little control over the diagnostic process, and could not control how much their children knew. Dani's mother talked about how she could not protect her son from strangers' stares. Dani had shaved his head and refused to wear a baseball cap in public. She emphasized that seeing people staring at her son was more agonizing than if she were the one being stared at. Pedro's mother was upset because she could not even control who came into her son's hospital room. The mother of the boy with the brain tumor said that she seemed not to be able to prevent her son from catching all the infections that were going around.

A fourth topic was their sense of who they were as mothers of children who had cancer. Dani's mother, whose son had been diagnosed only a few weeks earlier, emphasized the difference between those who did not have a child with cancer and those who did. She felt that she could not share what she was going through with other friends and relatives from outside the hospital. She was even more upset when she told them that she was fine and they believed her. She exclaimed, "How can they believe that I am fine?" She talked about how some relatives did not know what to tell her, others avoided her, and still others cried inconsolably and made her feel even more depressed.

As Dani's mother distinguished between "them" and "us," she also stressed the sameness of their experiences as mothers. She said, "*Todas estamos metidas en lo mismo*," which translates as "We all are stuck in the same thing." However, the other seasoned mothers did not agree that they shared a sameness, and noted that even when receiving the same treatment each child was different. Dani's mother's experience of "sameness" was very painful for her. When the mother of the 2-year-old girl with leukemia started to talk about another boy who had died of leukemia recently, Dani's mother started to cry. The other mothers tried to console her but did not themselves cry. Later on, Dani's mother cried again when she explained that, when she looked at her son, she felt fine because he looked fine—he had only been through a couple of chemotherapy sessions—but when she looked at the other children with cancer, she became very depressed. While the mother of the boy with the brain tumor told the other mothers that her son could not walk, eat, move his arms, or even brush his teeth, Dani's mother cried continuously. She cried out, "*Qué mierda es todo esto! Qué injusto es el mundo!*" which translates as "How shitty is all of this! How unfair the world is!" The similarity of her son to the other children with cancer was a terrifying prospect. In his future—and her future as his mother—there might be physical deterioration brought on by the disease and the treatment, and even death.

The mothers talked about how they avoided crying in front of their children. This emotional restraint was for their children's benefit. When Dani's mother cried during their conversation, Pedro's mother told her that she needed to be strong for her son. Dani's mother said she did not cry in front of her son, but her husband did during Dani's treatment interview (see Chapter 5). During the interview, she said she could not cry because Dani seemed very scared, and instead of looking at the doctor who was talking to him, Dani looked straight at her. At some point, she felt her legs were giving way, and she sat down. Pedro's parents did not cry either during his treatment interview (see Chapter 5). In fact, Pedro's mother said she did not cry in front of him despite the fact that Pedro cried all the time during the first months of treatment. Dani's mother also added that whenever Dani was out of their house, she and her husband would cry. Both Dani's mother and Pedro's mother acknowledged that the head doctor encouraged the concealment of crying. She had told them separately to cry privately, but not in front of their children.

Doctors' discouragement of crying in front of children suggests that parents were not only being strong and stoic to protect their children, but were following doctors' mandate to be hopeful and optimistic. Doctors infused medical visits with a strong preference for optimism and a strong discouragement of uncertainty and pessimism. Although some parents cried when meeting with the doctors alone (see Chapter 7), the mandate of optimism and hope meant that doctors did not have to deal with children's and parents' crying (for children's avoidance of crying, see Chapter 5). Crying occurred during medical visits of the pre-treatment and post-treatment, but there was little crying during the treatment itself.

Uncertainties of Treatment

The interrelated strategies of focusing on treatment, guessing, being together, and talking privately illustrate the everyday activities that patients, parents, and their hospital caregivers engage in as they live and deal with cancer as a community. For this community, the small pediatric cancer unit is a social space of living and sharing, not just a physical space for treatment administration. In the community's social geography, doctors and nurses participate in everyday activities beyond medical interactions. Furthermore, the rationale for some activities may not be talking (i.e., morning rounds with doctors or chatting with other parents in the waiting room), but feeding a child, being physically near him or her, or overseeing treatment administration.

Parents and children immerse themselves in the daily management of treatment, learning vast amounts of medical knowledge and using it to participate in and oversee the administration of treatment. For those aspects of treatment that are unknowable and unascertainable, such as knowing precisely when a patient's

blood counts will be replenished enough so the patient can start the next chemotherapy session, patients and parents try to guess and predict what may happen in the immediate future. Parents consider regulating the flow of information and emotions as a way to deal with treatment uncertainties. As parents, they want to protect their children by sparing them the suffering associated with bad and uncertain news, and from the suffering associated with displays of negative emotions (i.e., the effect on children if they see their parents crying).

The four interrelated strategies that I have described in this chapter allow children, parents, and hospital caregivers to perform and fulfill the different expectations and moral responsibilities that come with each distinct role (Bluebond-Langner 1978). A child is somebody who is vulnerable and needs care, and somebody who has his or her whole life ahead of him or her and does not die before his or her parents. A parent is somebody who cares, protects, and provides for his or her vulnerable child, who keeps it together stoically, and who embodies hope and optimism for the child (Young et al. 2003). A healthcare professional is somebody who instills hope and optimism (Good 1991; Good et al. 1990; Helft 2005), heals patients, and save their lives.

As a community, children, parents, and health professionals engage in these interrelated strategies together—but *asymmetrically*. Each distinct role, with its different expectations and responsibilities, is asymmetrically positioned in the hierarchically organized institutions of family and hospital, with children ranking at the bottom of both institutions and having the least amount of treatment information and power to make decisions.

Throughout the frenetic busyness of treatment, parents and patients try to figure out how much or how little remains of who they were and the social world they inhabited before the intrusion of cancer and the disruption of their quotidian life. Children's bodies are altered by cancer and its treatment, and so are their identities and those of their parents. They try to figure out new identities, as they inhabit a new social world in which their life is now organized around cancer treatment at the hospital and in which their everyday companions are other children with cancer and their parents, and the hospital professionals.

In this "new" reality that is punctuated by the alternating chemotherapy hospitalizations and home recovery periods, this pediatric cancer community keeps busy and lives constantly and almost exclusively in the present and the immediate future. Living in the present and for the moment (Bluebond-Langner 1996; Cohen 1993) results in "expressions of time without horizons or of time with highly foreshortened horizons as they [oncologists] seek to create an experience of immediacy rather than of chronology" (Good et al. 1994: 855). Being busy with the current treatment also helps patients and parents to create and sustain a sense of control and normalcy, and provide a way for overall uncertainties to go out of awareness (Bluebond-Langner 1996). As long as treatment uncertainties are kept separate from overall uncertainties, patients, parents, and health professionals adjust to dealing with the "predictable unpredictability" (Stewart 2003) of treatment itself.

Notes

- 1 At the time of my fieldwork in 2000–2001, the treatment for bone tumors (occurring mostly in the femur, tibia, and humerus) consisted of the surgical removal of the primary tumor, pre- and post-surgery chemotherapy (usually the drugs methotrexate, ifosfamide, adriamycin, and cisplatin), immunotherapy to increase the production of blood cells, and stem cell transplantation therapy. After the surgery, patients required extensive rehabilitative physical therapy in order to regain movement, whether therapy was for an external prosthesis that replaced the amputated extremity, or for an articular bone graft-prosthesis.
- 2 The list of chemotherapy drug side effects can often seem endless. There are common side effects shared by many drugs, such as nausea, vomiting, low blood counts, infertility, hair loss, fatigue, skin changes, diarrhea, and taste alterations. In addition, there is also a long list of side effects specific to each drug. In regard to the four drugs most used in the treatment of bone tumors, adriamycin may cause mouth sores, skin sensitivity to sunlight, and tissue burns if it leaks out of a vein. Methotrexate may cause blurred vision, kidney and liver problems, mouth sores, skin sensitivity to sunlight, and inflammation of the cornea. Ifosfamide may cause bladder problems, vein irritation, and confusion and hallucinations. Cisplatin, which is the only one out of these four drugs that does not cause hair loss, may cause hearing loss, numbness or tingling in hands or feet, and allergic reactions.

Co-constructing Uncertainty

Key Issues

- *Patients, parents, and healthcare professionals co-construct and negotiate turn by turn how much or how little uncertainty there is in their talk.*
- *Patients' questions make doctors' answers relevant, and doctors' answers may lead to additional patient questions, which can steer the discussion to uncertain topics which doctors may not want to address.*
- *Children may interpret doctors' answers as evasive, and doctors may interpret children's questions as reflecting their anxiety.*
- *To "protect" children from bad and uncertain news, doctors may offer limited or evasive answers. Because only bad news is regularly withheld, not answering at all could alarm children—and their parents as well.*

In this chapter, I illustrate how participants co-construct uncertainty. By examining the turn-by-turn local production and negotiation of uncertainty, I illustrate the interactional work that participants carry out to include or exclude uncertainty from their talk. For instance, children and doctors use IF-THEN contingent questions and answers, and doctors try to avoid answering questions that venture too far into the uncertain future while also avoiding being perceived as uncooperative and evasive. In examining uncertainty in relation to the topic of a question–answer and the progressive chain of actions a question may initiate, I emphasize that participants have choices regarding how to speak about what is happening to them, and often individuals have different opinions about how to talk about it. Moreover, talk never just entails participants describing what is happening to them, but also serves as an active way to construct, modify, and influence what is happening to them. In emphasizing the social dimension of the experience of uncertainty, my objective is to show that participants co-construct the social worlds they inhabit.

To highlight the interactional work of managing uncertainty, I examine how participants locate, display, and co-construct uncertainty (Sidnell 2005). I use

conversation analysis to investigate the sequential organization of talk and participants' public interpretation of what others are saying: a participant's subsequent action contains an interpretation of another participant's prior action. Therefore, I rely on the doctor's response after a patient's question to put forward an interpretation of the patient's question, and I rely on the patient's subsequent action after the doctor's response to put forward an interpretation of the doctor's response.

My use of the term *interactional work* is deliberate on three accounts. I want to highlight that the absence of uncertainty in medical interactions occurs not because uncertainty does not come up (i.e., it is irrelevant for the participants), but because patients, parents, and doctors invest time and effort to ensure that it comes up as little as possible (i.e., it is avoided by the participants). Furthermore, patients, particularly young people, do a substantial amount of interactional work to obtain answers. They actively pursue answers whenever they consider that the doctors' responses are either not answering their questions at all, or are not answering them with sufficient conclusiveness and certainty. I give analytic preeminence to how a patient interprets what the doctor is doing (i.e., answering sufficiently or insufficiently) over whether the doctor is indeed answering or not. Figuring out if the doctor has answered his or her question and what to do about that are first and foremost problems that the patient has to deal with himself or herself. I argue that patients' pursuits of an answer illustrate how they treat their question as answerable, whether certain or not, and how they orient to the fact that if they want to obtain an answer, they may need to exert questioning pressure. Doctors also perform a substantial amount of interactional work to avoid answering and to avoid being perceived as evasive and uncooperative, which often results in disproportionately long responses by doctors. The length and force of the doctor response makes it evident that doctors find some patients' questions problematic.

Young people's pursuits of answers constitute an unequivocal piece of observable evidence to demonstrate the relevance of non-disclosure and uncertainty for those young people pursuing answers. At least for some patients, conclusive answers are noticeably and publicly absent. Moreover, young people's pursuits of answers also reveal that they interpret the absence of conclusive answers as more related to doctors' evasiveness than to the "unanswerability" of their questions; children pursue answers because they believe more information exists and can be ascertained. Because young people do not challenge medical authority openly in these data, it is also important to make clear they may still interpret doctors as being evasive even if they do not pressure doctors in their pursuits of answers (see Chapters 5 and 7). Although patients collaborate with doctors and parents to sustain a sense of certainty and optimism, they do not necessarily agree on the limits of what cannot be talked about and of how to talk about cancer. The constant negotiation and reaffirmation of these limits makes possible to observe the *interactional work* of containing and ensuring that uncertainty and the negative aspects of cancer do not become a central focus of their talk.

The control of the progress of the medical interaction is key to understanding young people's questions and doctors' evasions. If the doctor answers a question, his

or her answer will likely lead to another patient question, and so forth. A chain of questions and answers can result in patients, parents, and doctors moving progressively from topics doctors are willing to talk about to topics they are not. Furthermore, by initially preventing a question from being asked, doctors can put an end to any question–answer expansion even before it happens. Preventing a question from being asked (e.g., Toni stops asking questions about a possible treatment delay after the doctors attack his questions; see Chapter 7) has the additional advantage that one is less at risk of being accused of avoidance. Although the turn-by-turn nature of conversation makes it difficult for any participant to control completely the progression of an interaction (i.e., what will be talked about next), doctors can avoid a stepwise progression (e.g., question by question, or chains of question–answer) into the more uncertain and speculative future by focusing on safe topics and keeping the interaction brief. More generally, these strategies are used to control the progression of an interaction by controlling action (i.e., a question makes an answer relevant) and controlling the topic (i.e., talk about topic X may lead to talk about an X-related topic). Before I turn to an analysis of how uncertainty and its avoidance are interactionally co-constructed and negotiated, I establish the conversation analytic technical use of the terms “question” and “answer.”

Questions and Answers

Questions are the most prominent and frequent type of action initiated by patients when negotiating what can be talked about and how. Questions set topical and action agendas (Boyd and Heritage 2006). When a speaker asks a question, he or she chooses to inquire about a specific topic among the countless topics from which he or she could choose. In doing so, the speaker makes further talk about that particular topic relevant. Even if the topic has already been set, the questioner chooses to continue talking about a specific topic when he or she asks a question. Moreover, when a speaker poses a question to a question recipient, the question recipient is expected to carry out a particular action, such as “answering yes or no, giving substantial information, explaining, clarifying, justifying” (Boyd and Heritage 2006: 156–157).

Because questions set topical and action agendas, they can be used to control the overall progressivity of an interaction (i.e., what happens next). Setting expectations of what needs to come after them, questions are “powerful tools to control interaction: they pressure recipients for response, impose presuppositions, agendas and preferences, and implement various initiating actions, including some that are potentially face-threatening (Brown and Levinson 1987)” [citation in the original] (Hayano 2013: 401). Using the analogy of driving, the person asking questions is in the driver’s seat, and the person answering them is in the passenger’s seat. In the institutional context of medical interactions, Mishler (1984: 95) notes that, “physician’s control of structure is matched by their control of content. The relevance and appropriateness of information is defined through

what physicians choose to attend to and ask about.” For these reasons, asking questions is not only about obtaining information, but also about establishing the relevant topics to talk about.

As long as physicians ask questions and patients answer them, physicians are in the driver’s seat (see Frankel 1990). But when patients ask questions, who is driving is less clear, even though physicians still retain a considerable amount of control. Young people—and parents—at Catalonia Hospital display an awareness of the initiative asymmetry (Robinson 2001a) between the question–answer sequences they initiate versus those initiated by doctors. As a consequence, they place their questions at boundaries of official doctor-initiated activities (e.g., before the doctors initiate the closing of the medical visit, or after the doctors have closed it). Furthermore, young people’s questions also display an orientation to the delicate nature of some of their questions. As illustrated by Robert’s question at the end of this chapter, Pedro’s question in Chapter 5, and Toni’s questions in Chapters 4 and 7, young people wait until the end of the medical interaction or even after the medical interaction is closed to ask doctors questions about important concerns that the young people may feel anxious about. In a parallel manner to the “by the way” phenomenon described in primary care (Byrne and Long 1976; Robinson 2001b; White et al. 1994), questions that target the most delicate and uncertain aspects of the cancer treatment come at the end of medical visits.

In addition to establishing topic and action agendas, young people’s questions introduce another level of complication vis-à-vis the control of the medical visit. At least from the doctors’ perspective, young people’s questions may stall the progress toward completion of the medical visit. When doctors are transitioning to a new phase of the medical visit (closing one phase and starting another), or closing the medical visit altogether, young people do the opposite when they ask a question. Young people refuse to go along with doctors’ moves toward closure (i.e., let’s stop talking about topic X, and let’s move on to topic Y), and instead they propose expansion (i.e., let’s continue talking about topic X). Furthermore, young people may carry out subsequent actions that further stall the progressivity of the medical visit without openly challenging the doctor’s authority and control of the visit. When young people consider a response to be insufficient, they may pursue an answer (Chapters 4, 6, and 7) and/or may refuse to be the recipients of such responses (Chapter 5). In brief, young people’s questions not only constitute an essential way through which they obtain information, but also represent their efforts to participate in the daily management of their cancer treatment without openly challenging doctors’ authority.

Questions versus interrogatives. It is important to distinguish between a question as a type of action, and an interrogative as a type of grammatical structure (Heritage and Roth 1995). Questions, as a type of action, may be used to solicit information (Hayano 2013) and be shaped in an interrogative grammatical structure. Typical examples of questions with an interrogative grammatical structure are yes/no questions (e.g., Toni’s question: “Is the day of the autotransplant going to be delayed?”), tag questions (e.g., Anna’s question: “I’m fine, aren’t I?”), alternative “or” questions (e.g., Robert’s question: “Is it cisplatin or not?”), and

wh-questions, which start with words such as “when,” “where,” or “who” (e.g., Pedro’s question “When will I be completely cured?”).

However, interrogative grammatical structures can be used to carry out actions other than soliciting information (Freed and Ehrlich 2010; Schegloff 1984). For instance, Clayman and Heritage (2002: 223–224) illustrate questions that are used to make accusations during a news interview about a businessman’s fraudulent liquidation of his business: “How do you get rid of your moral responsibility?” and “How do you sign a bit of paper that gets rid of past moral responsibility?” Therefore, as has been extensively demonstrated (Austin 1962; Duranti 1997; Levinson 1983; Schegloff 1984; Searle 1965), there is no one-to-one correlation between the grammatical structure of an utterance (e.g., an interrogative grammatical structure) and its function (e.g., soliciting information with a question).

Answers versus non-answer responses. Regarding talk following a question, an answer is a specific type of response that advances or quickly moves forward the action started by a question (Stivers and Robinson 2006). In doing so, answers contribute to close the question–answer sequence, and that promotes the progress of the activity at hand. However, a non-answer response (e.g., “I don’t know”) displays an orientation to the subsequent relevance of an answer but impedes the closure of a question–answer sequence and does not move the activity at hand forward. Besides answers and non-answers, there are other types of responses in which the speaker who answers resists the grammatical and action constraints of the question (Lee 2013; Raymond 2003). For instance, speakers may answer yes/no interrogative questions with type-conforming responses (i.e., responses that contain the words “yes,” “no,” or an equivalent) (Raymond 2003). But they may also respond with non-conforming responses that depart from, disappoint, or avoid the grammatical constraints of a yes/no question, and consequently, alter the course of action initiated by such a yes/no question. Stated more simply, speakers answer in their own terms, but not in the terms proposed by the speaker who asks the question. These types of answers that answer the question but not according to the expectations of the questioner are the source of much negotiation between patients and doctors: the doctor may feel he or she has answered sufficiently and conclusively, but the patient who asks the question may feel differently.

Drawing from instances that I examine in detail below, a doctor’s smile after a patient’s question “☺ ‘I’m well, aren’t I.’ ☺” is occasioned by and is responsive to her question, but does not answer it. When another patient asks “how many chemos do I have left, the ones listed in the protocol, or_or or or or one more.” and the doctor responds, “☺ he keeps asking time a(h)nd a(h)ga(h)in h. ☺” the doctor’s response is occasioned by the patient’s question, but does not answer it. When the patient insists, the doctor responds, “I don’t remember.” which is an account for the absent answer, but it still does provide an answer. Although the distinction between answer and response may be difficult to discern at times, it will nevertheless be useful to distinguish between, for instance, the answer “no” and the response “I don’t remember.”¹

Non-answer responses are a key maneuver that doctors frequently use when they are not quite answering patients' questions. Doctors are committed to some degree of disclosing information as accurately as possible, while simultaneously protecting their patients from what they perceive as potentially uncertain and bad news. As they discussed in the interviews I conducted with them, they withhold information in an attempt to spare patients unnecessary anxiety and suffering. Whenever possible, doctors answer partially or evasively, because openly refusing to answer a delicate question can be especially alarming to patients. My analysis of the sequential location of non-answers where answers are strongly expected provides a fundamental piece of evidence to support the claim that doctors may be trying to avoid alarming the patient. Because good news is not routinely delayed or withheld (Maynard 1996, 2003), the doctors' refusal to answer can be equated easily with bad news being withheld. Thus, the ideal conversational method of withholding information is one that goes unnoticed.

Uncertainty and the Topic of Questions

Having established the technical use of the terms "question" and "answer," I make five observations on the relationship between the turn-by-turn construction of uncertainty by patients and doctors, and the topic of question-answer sequences (i.e., what a question asks about and whether an answer deals with the topic of the question). Specifically, I show that some patients' questions may be easier to answer than others; some patients' questions can be answered with more certainty than others; a doctor may choose (or not) to formulate his or her answer as certain and definitive; a patient may not accept the answer that doctor gives him or her as certain, definitive, and final; that patients' questions and doctors' answers may project a high degree of uncertainty. Contingent questions and answers, for instance, IF-THEN utterances that formulate a provisional event that depends on certain prior conditions that need to be met, exemplify both the turn-by-turn co-construction of uncertainty and the negotiation of how much or how little uncertainty patients and doctors may be willing to include in the talk. Because doctors use contingent answers more often than patients use contingent questions, I reverse the question-answer order and introduce doctors' contingent answers before introducing patients' contingent questions.

In an analysis of topic and uncertainty, some questions may be *easier* to respond to than to others. For instance, the topic of these two questions makes the question, "Should I get on the bed?" easier to respond than the question, "What is better, a cold or pneumonia?" Sixteen-year-old Oriol asks the first question as he requests instructions from the doctor before the start of the physical exam. Fifteen-year-old Toni asks the second question at a highly uncertain point in his cancer trajectory. Toni has already relapsed once, is undergoing a second line of chemotherapy treatment, has an infection with an unknown cause and an

unknown course of treatment, and whose unknown infection is presenting symptoms that are similar to symptoms for the type of cancer he has.

If some questions are easier to respond to than others, it should also be noted that some questions can be answered with more certainty than others. In a very basic sense, no one knows what is going to happen tomorrow. This fact, however, does not prevent speakers from answering questions about the future. However, in the context of pediatric cancer, where patients and parents hold doctors accountable for *what* they say is going to happen and for *when* they say it is going to happen, the certainty with which doctors are willing to answer some questions is of great importance in the type and form of the answers given. For instance, when Anna, a 16-year-old patient, asks her doctor “*no me pongo ninguna tiri:ta,*” (“I’m not putting on any ba:ndage,”) her doctor may not need to consider in great depth the degree of certainty and the consequences that the doctor’s answer will have for Anna (see Excerpt 4.6). In contrast, when Anna, in a different medical visit, asks her doctor “☺°I’m well, a:ren’t I.°☺” with a big smile, he smiles back at Anna and withholds his answer (see Excerpt 4.7). As the doctor will explicitly tell Anna later, he cannot answer that question because he does not know the answer yet. Before he can respond to Anna’s confirmation request for a positive evaluation with the maximum degree of certainty and accountability, he needs to first see the nurses’ daily written reports to check if Anna had a fever the night before.

Contingent Answers

Independently of whether the recipient of a question does or does not know the answer to that question, he or she may or may not formulate his or her answer as being certain and definite. In this sense, doctors formulated many of their answers as contingent answers. Contingent answers can be defined as statements in which a provisional answer is formulated dependent upon certain conditions that need to be met. In Excerpt 4.1, doctor 2 provides an IF-THEN contingent answer after Toni, who is trying once again to find out about the source of his infection, implicitly asks about the cause of his fever.

A note about the transcription conventions used for Excerpt 4.1 and all following excerpts is necessary. In each line of the excerpts, the reader will find italicized talk in Catalan or Spanish followed by a nonliteral English translation. I use conversation analytic conventions developed by Jefferson (Sacks et al. 1974) and supplemented by Hepburn’s (2004) conventions for the transcription of crying. Both can be found in Appendix B. I also want to alert the reader that punctuation marks are used to indicate intonation in the excerpts and also in direct quotes from the excerpts, and therefore, text between quotation marks do not follow standard orthographic rules of writing. Finally, DOC1 stands for the most senior doctor in the interaction, usually the chief pediatric oncologist. Less senior doctors are named accordingly, DOC2, DOC3, etc. I use the child’s name, MOM and DAD for the child’s parents, and NUR for nurses.

Excerpt 4.1

- 1 TONI: → un moc, dóna febre:,
 mucus, can it cause a fever:,
- 2 DOC2: >home depèn d'on te'l tinguis<, sí::,
 >well depending on where you have it<, ye::s,

Doctor 2's answer is a contingent one. In this case, the fitting and preferred yes/no answer comes after a hedge and a conditional statement that qualifies and limits the certainty of the answer “ye::s,”. Mucus may cause a fever, but it may cause a fever depending on where the mucus is in the respiratory tract. As a result, Toni is still not given much more information about the cause of his fever, because it is *not* known at this time whether (a) Toni's mucus is what is causing the fever, and (b) if indeed the mucus is the cause of the fever, whether Toni's mucus is in his lungs or in his nose and throat.

In Excerpt 4.2, the doctor's contingent response is even more vague and uncertain, to the degree that it is unclear whether the response is answering Robert's question at all. Throughout the last part of the medical visit, Robert has been relentlessly interrogating his doctors about the future course of his treatment: how many chemotherapy sessions he has left, what chemotherapy drugs they will involve, how long the sessions will last, and when they will be carried out. Doctors, while partially answering some of these questions, have also complained jokingly about being subjected to such relentless interrogation, and have countered some of Robert's questions with teasing. Robert has played along with the doctors' teasing, and his persistent interrogatory pressure has partially succeeded in obtaining some concrete information about the future chemotherapies. Robert now tries to get specific information about the length of the recovery intervals at home between chemotherapy sessions.

Excerpt 4.2

- 1 ROB: → i quant temps estaré a casa,
 and how long will I be home,
- 2 (0.3)
- 3 ROB: → mentres em:: (.) recupero,
 while I:: (.) recover,
- 4 (.)
- 5 DOC1: hng ((brief single token of laughter with semiclosed
 6 mouth))
- 7 (0.4)
- 8 DOC2: mp ia vorem, depèn. (.) depèn de lo ràpid que
 mp we'll see, it depends. (.) it depends how fast you
- 9 sigui::s,
 are::,

Doctor 2's response is considerably delayed (lines 4 & 7), which is frequently associated with a dispreferred answer, and only comes after Robert's first questioning attempt (line 1), and a following pursuit (line 3) in the absence of a response (line 2). Moreover, doctor 2's turn (lines 8–9) does not give Robert any concrete time reference, for instance, a week, a month, or even some more vague temporal reference such as a few days, for a while or not long. Instead, doctor 2's response is contingent in two ways. First, "mp we'll see," proposes a conditional evaluation (we'll see how it goes, we'll decide later) that is left unscheduled for some time in the future. Second, doctor 2's turn formulates the length of Robert's recovery interval at home as contingent on Robert's rate of recovery. If Robert's health recuperates quickly, he will be home for a short time. If he does not recover quickly, he will be home for a longer, undetermined period of time. Even if we consider doctor 2's response as just teasing and not a real answer, doctor 2's response takes the shape of a contingent answer that is formulated as uncertain (i.e., it cannot be definitively ascertained at this point) and dependent on a series of conditions that need to be met in the future before the length of Robert's recovery period at home can be known.

The certainty or uncertainty of an answer does not only depend on how the "answerer" formulates his or her answer. In the turn following an answer, the next speaker can challenge and dispute it. Thus, the next speaker may cast doubt on the certainty of an answer, or may make a contingent answer even more uncertain. Regardless of whether one can know if it is going to rain tomorrow, when asked "is it going to rain tomorrow?" the recipient of the question can answer "yes." What happens to the certainty of such an answer when the questioner says immediately after the recipient's answer, "are you sure?" To what degree is the certainty of an answer compromised by a following question that challenges or recasts the previous answer as questionable in itself? It at least casts a shadow of uncertainty, because repeats of questions can function in such a way as to formulate the previous response as being inadequate and evasive (Clayman and Heritage 2002: 198, 229). If an answer is going to be interactionally construed as certain and unproblematic, the person who has asked the question and now is the recipient of an answer needs to treat it also as certain.

In the management of pediatric cancer, patients often interpret the doctors' responses as not having answered the question at all, or having answered the question but without the certainty and conclusiveness that they were seeking. To complete the project or activity that a question starts, it is not sufficient for the recipient of a question (1) to treat the question as having an answer (i.e., the recipient could dismiss the question on the basis that the question is problematic or unanswerable), and (2) formulate his or her answer as certain, definite, and final. The questioner must also (3) accept his or her question as having been answered, and (4) accept the answer as being sufficiently certain, definite, and final.

In Excerpt 4.3, which is a continuation of Excerpt 4.2, Robert treats doctor 2's contingent response, ("mp we'll see, it depends. (.) it depends how fast you

are::,”) as not having sufficiently answered his question. He pursues a more definite answer by providing a candidate answer (Pomerantz 1988), that is, by providing a model of the type of answer for the question he himself has asked the doctor. He offers doctor 2 a candidate answer with a final rising intonation “a month” (line 4), and accompanied of a broad smile, which displays Robert’s orientation to the fact his questions are occurring in the middle of teasing.

Excerpt 4.3 (continuation of Excerpt 4.2)

- 1 DOC2: *mp ia vorem, depèn. (.) depèn de lo ràpid que*
mp we’ll see, it depends. (.) it depends how fast you
- 2 *sigui::s,*
are::,
- 3 *(.)*
- 4 ROB: → *un mes*
a month
- 5 *(1.3)*
- 6 MOM: *n:o: que vols ser mo:lt le:nt*
n:o: do you want to be ve:ry slo:w
- 7 *(.)*
- 8 MOM: *hhh hhh hhh lo per lo que ve::lig, h h*
hhh hhh hhh from what I se[e::, h h
- 9 ROB: *[no: (a) (ver [si no).*
[no: (let’s) (see [if not).
- 10 DOC1: *[.h e:ns ho*
[.h we:’ll
- 11 *pensare:m.*
think about it.

Robert tries again, but does not have better luck the second time. After a long silence, Robert’s mother intervenes with a rejection of Robert’s temporal formulation, and with a question that takes the interaction fully into the activity of teasing and provides Robert with no certain answers at all. Robert will not give up a good fight easily. After doctor 1’s turn (lines 10–11), he pursues an answer to his original question three more times (not shown here).

However, even when doctors give definite answers, patients may not accept the definite answer as the final answer to their questioning. For instance, when Robert asks his doctor, “is it cisplatin, or not,” requesting confirmation about the types of chemotherapy drugs that will be given to him in his last chemotherapy session, Robert’s doctor answers, “no, it’s not cispla:tin.” (see Chapter 6). Robert treats this answer, despite its firmness, as not being the final answer. He pursues a more

detailed answer with another question, “have you gi- have you given it to me befo:re,”. By continuing to pursue an answer, Robert’s next question manages to underscore that *something remains to be answered*, that the doctor’s answer has not managed to dispel the uncertainty, that something remains to be known, and that “no, it’s not cispla:tin.” is not sufficient to answer the question with any finality.

Refusal by patients to treat doctors’ answers as final and certain not only occur with dispreferred answers, but also with preferred answers. In Excerpt 4.4, Toni, who is also pursuing information about how many infections he has, how he contracted them, what types of infections they are (bacterial, viral, fungal, or parasitic), and what types of treatment they will require, obtains a confirming answer from his doctor. Toni (line 1 and 3) formulates a declarative question that contains his interpretation of what doctor 1 has said. He prefaces it with a periphrastic reformulator “o sigui” (English literal translation “or + subjunctive grammatical mood of the verb ‘to be’”), and in doing so requests confirmation that Toni has had more than one infection. Doctor 1’s answer (lines 6 and 9) confirms what Toni has proposed in his question (line 1 and 3): she believes that Toni has had more than one infection. However, doctor 1’s confirmation is uncertain, because she disclaims knowing the answer and distinguishes between what she does not know (line 6) and what she believes (line 9).

Excerpt 4.4

- 1 TONI: → [o si [gui que he=
[that is [I’ve=
- 2 MOM: [(ara)
[(now)
- 3 TONI: → =tin[gut més de un virus.
=ha[d more than one virus.
- 4 MOM: [((clears throat))
- 5 (0.5)
- 6 DOC1: e no ho sé:,
e I don’t know,
- 7 (0.2)
- 8 NURSE: pots comptar.=
go figure.=
- 9 DOC1: =però io crec que sí:,
=but I believe so:,
- 10 NUR: mai [(ho havia) vist.
I’ve [(never) seen it before.
- 11 DOC1: [ho veus.
[you see.

- 12 DOC1: e:,
e:,
- 13 (0.9)
- 14 MOM: *és que quan (.) quan s'hi po: [sa,*
it's that when (.) when he ge:ts [it,
- 15 TONI: → *[i no n'aGA [:fo:?*
[I don't CA:tch [any:?
- 16 MOM: *[és*
[he really
- 17 *tremen [do.*
gets [it.
- 18 TONI: → *[i: de cop n'agafo tots,*
[a:nd suddenly I catch them all,
- 19 (0.5)
- 20 TONI: → *els a↑do:pto.*
I ↑fo:ster them.

By following doctor 1's confirmation (lines 6 and 9) with more questions on the same topic of his infections (lines 15, 18, and 20), Toni displays that he does not take doctor 1's confirmation as the conclusive and final answer. His subsequent questions manifest an understanding that doctor 1's confirmation is not sufficient, and more information can still be ascertained: for instance, why has he suddenly become so susceptible to infections? With these questions, Toni requests confirmation of a second interpretation of what is happening. His persistent line of questioning takes away whatever little certainty is contained in doctor 1's confirmation and contributes to creating a heightened sense of uncertainty.

Robert's and Toni's subsequent questions immediately after the doctors' answers underscore the fact that the producers of questions negotiate locally what constitutes a certain, sufficient, and final answer, which does not depend solely on the producer, but on both the party who asks the question and the party who answers it. Robert's and Toni's subsequent questions may or may not succeed in obtaining additional information, but they manage to recast the previous answer as uncertain in and of itself. Regardless of whether a certain answer exists, Robert's subsequent questions continue to exert pressure on the doctor to produce a sufficiently certain and conclusive answer. Even when the doctor produces a preferred answer, Toni's subsequent questions treat the doctor's answer as strictly fitting to the task of answering, but as failing to answer his question fully. Toni's subsequent questions are attempts to exert pressure on the doctor to expand her narrow answer and to provide details about his infection. Both Robert's and Toni's questions therefore

treat the doctor's narrow answers as insufficient and not forthcoming. Their questions manage not only to recast doctors' answers as insufficient, but also as failing to dispel uncertainty.

Contingent Questions

A question in itself may already project a high degree of uncertainty. In the same manner that the doctors use contingent answers, patients often use contingent questions, that is, questions that request confirmation of a "Y" subsequent event, which is contingent on a previous event "X" that needs to occur first. The most frequently used format by patients is "IF contingent event X happens, THEN subsequent event Y happens."

In Excerpt 4.5, Toni has just asked how many days he needs to be hospitalized for the antibiotic treatment of his infection (data not reproduced here). He gives a rationale for his question: he tells the doctors he wants to calculate the number of days of hospitalization. Toni receives a contingent answer: the number of days of hospitalization will depend on the presence of fever. Creating a hypothetical future scenario with the structure IF-THEN (lines 1–2), Toni requests confirmation of an additional contingent condition, the presence of coughing, under which he would also have to remain hospitalized. Toni's IF-THEN contingent question heightens the sense of uncertainty in three ways: it projects an uncertain answer by requesting confirmation of a hypothetical scenario, makes Toni's future more unpredictable by increasing the number of "twists and turns" that may result in different aftermaths, and reinforces an overall sense of uncertainty by coming after doctor 1's contingent answer about the presence of fever.

Excerpt 4.5

- 1 TONI: → [*i si la fe:bre se'n [va però: encara tinc to:s, encara em=*
[and if the fe:ver go[es bu:t I still have a cou:gh, I=
- 2 DOC4: [h
[h
- 3 TONI: → =*quedo aquí:.*
=would still have to stay here:.
- 4 (0.7)
- 5 DOC1: .*h si està:s sense febre: a lo millo:r °et deixem anar cap a*
.h if you ha:ve no fever: maybe °we'll let you go
- 6 *casa.° però: [tens que portar dos o tres dies sense febre:=*
home.° bu:t [you have'd to go two or three days without=

- 7 TONI: [a::.
[oh::.
- 8 DOC1: =almenys.<o sigui [que compta, si avui=
=fe:ver at least.<in other words [count on, if today=
9 TONI: [hm,
[hm,
10 DOC1: =encara tens febre, compta dos o tres dies aquí:. mé:s.
=still have a fever, count two or three days he:re. mo:re.
11 TONI: hm: inte[ressant.
hm: inte[resting.
12 DOC1: [vale?
[okay?

Doctor 1 responds to Toni's IF-THEN contingent question with another contingent answer. Once again, the doctor's response is delayed after a 0.7 second silence (line 4), and does not provide a yes/no answer (lines 5–6, 8, and 10). Instead, she chooses to repeat some elements of Toni's question, but also makes significant changes. First, the structure IF-THEN is repeated, but without any reference to coughing. Second, doctor 1 adds "maybe" to the THEN-clause, which upgrades the uncertainty of her answer. Finally, doctor 1 adds a long contrastive "but"-prefaced explanation that places even more conditions that need to be met. Toni's fever must go away, but Toni also must not have a fever at all for at least three more days. Altogether, the number of "ifs" has multiplied, and it is not surprising that Toni's assessment after doctor's 1 response is so ambiguous. Toni's "interesting" seems to be neither affiliative nor disaffiliative.

In conclusion, I have made five observations about pediatric cancer patients' questions and their doctors' responses and answers. First, some questions may be *easier* to respond to than others. Second, some questions can be answered with more certainty than others. Third, independently of these two observations about the topic of a question, the recipient of a question may or may not locally formulate his or her answer as certain and definite. Fourth, independently of the three prior observations, the producers of questions also may or may not locally treat the given answer as certain, definite, and final. The fact that a recipient of a question produces a definite answer does not make it necessarily so in the eyes of the questioner. The producer of the question may also call into question the certainty of the answer. Finally, the question itself can project a high degree of uncertainty. I have supported these observations with an analysis of some questions and answers from medical visits. Of special relevance for this analysis is the presence of contingent questions and answers. Contingent questions and answers underscore the uncertainty that patients, parents, and hospital staff face in the everyday management of an event as traumatic as pediatric cancer.

Uncertainty and the Action of Questions

In the previous section, I addressed the topic of questions and answers. However, the topic of a question and an answer cannot be analyzed separately from who asks the question, how the question is constructed, where it occurs within a sequential interactional context, and by whom and how it is answered. For these reasons, I examine now the relationship between talk-as-action and turn-by-turn negotiation of uncertainty.

First of all, patients' questions are unsolicited, volunteered courses of action that take place in the institutional context of medical interactions. Patients' questions are not equal to physician's questions (Frankel 1990). The institutional goal of a medical encounter is that the physician establishes the patient's condition and makes a treatment recommendation. Therefore, the task of asking questions is what defines the role of the physician, and the task of answering them with relevant information that can be used in treating a health condition is what defines the role of the patient. Patients and physicians have different levels of expertise, knowledge, and authority. This asymmetrical relationship between doctors and patients has a clear impact on the frequency and distribution of patients' questions.

Frankel (1990), in his analysis of patient-initiated utterances in medical interviews, builds upon Sacks' "chaining rule" to explain why patient-initiated questions (and any type of patient-initiated utterance) are greatly dispreferred in medical interviews. Sacks (1992: 264) describes the chaining rule as follows: "A person who has asked a question can talk again; has as we may put it, 'a reserved right to talk again,' after the one whom he has addressed the question speaks. *And*, in using the reserved right, he can ask a question." The chaining rule is combined with the rule that "if one party asks a question, when the question is complete, the other party properly speaks, and properly offers an answer to the question, and says no more than that" (Sacks 1992: 264). These two rules together "provide for the occurrence of an indefinitely long conversation of the form Q, A, Q, A, Q, A, Q, A..." If the question-answer sequential chains are initiated by the doctor, this interactional mechanism creates a "deference structure"ⁱⁱ (Frankel 1990) in which doctors are by default in the "asking" position and patients in the "answering" position. In this manner, when the doctor initiates a series of questions, he or she will be by default the speaker who imposes a set of sequential obligations on the recipient of the question (i.e., the patient). As long as the questioner-answerer roles are not reversed, the interactional asymmetry created by these rules will favor the doctor's control of the interaction.

The asymmetry between who asks questions and who has to answer them is key to physicians' ability to exert control over the agenda of the medical visit, controlling *what* is to be talked about, *how*, and *when*—through the use of questions. Because a question, as the first pair part of an adjacency pair, creates a context for the talk that is to follow, the party who has to answer is placed in a subsequent second position. Parties in the second position may find it more difficult to change the ongoing course of action, because before that party initiates an alternative course of action,

the party has to first deal with the one which has already been initiated; and whatever the party does in the second position will be interpreted in terms of what came before in the first position. Thus, with the use of the medical sequence of a physician's first position question, the patient's second position answer, and the physician's third position closing sequence turn, physicians have an interactional default mechanism that allows them to control locally the development of the interaction. Physicians recurrently find themselves to be initiators of courses of action, whereas patients find themselves to be followers of courses of action.

However, this interactional mechanism is reversed when a patient initiates a course of action. With patient-initiated courses of action, such as questions, patients are launching first position turns and initiating courses of action, and physicians find themselves in the second position having to decide whether to go along with the course of action initiated by the patient, or to try to steer the already-initiated course of action in a different direction. Using the analogy of driving, a physician is in the passenger's seat during a patient-initiated course of action. The physician can still steer the topic and direction of the interaction, but it will require more interactional work than if he or she were steering it from the driver's seat. In any case, the direction that the interaction will take is not preset from the beginning, but whoever initiates courses of action has certain advantages over the other speakers by virtue of having more direct control of the interaction. To a considerable degree, first position speakers *act*, and second position speakers *react*.

Consequently, questions, as patient-initiated courses of action, are not only questions about something, but they do something. For instance, Anna repeats several times "I'm not putting on any bandage," after her doctor has just finished examining the open infection in her leg wound in Excerpt 4.6 below. Anna's question is not only asking for the confirmation of her negatively formulated question and asking for the doctor's expertise on the need to cover the wound with a bandage, but also Anna's question is treated as a pre-request to have a bandage placed over her wound. Anna never formulates an explicit request, such as "will you put a bandage over the wound?" The doctor is the one who has removed the old bandage to examine Anna's wound, and Anna is not carrying another bandage. If the answer to Anna's question is "no," which is the preferred grammatical answer, no further action is necessary. However, if the answer to Anna's question is "yes," simply saying "yes" is not a sufficient answer. Besides saying "yes" something needs to be done. And this is how Anna's doctor answers:

Excerpt 4.6

- 1 ANNA: *no me pongo ninguna tiri:ta,*
 I'm not putting on any ba:ndage,

- 2 NUR: *como [tienes que baj:ar al hospital de día.*
 since [you have to go do:wn to the outpatient clinic.

- 3 DOC: → *[sí:, ahora te trae: la Sita ((nurse's name)).*
 [ye:s, Sita will bri:ng it to you now.

The doctor's turn (line 3) displays her understanding that Anna's repeated question (line 1) is a pre-request for bandages, by adding to her "yes" answer an announcement: the nurse will bring her a bandage now. The doctor's answer preempts the need for Anna to explicitly ask for a bandage to be placed over her wound. The doctor deals in this manner with the more immediately relevant action first, which is to answer yes or no. Once doctor 1 has dealt with this first action, she moves to deal with the following next action, which is to have a bandage placed on Anna's open wound. And the doctor carries out all these actions in such a way that she never makes explicit either that a request or a pre-request was ever made. The doctor does not say "I am going to put a bandage on you now," but implicitly directs nurse Sita, who is assisting her, to bring Anna bandages and place one on Anna's wound.

When after a few minutes, the nurse fails to bring the bandage, Anna comes back again with another question, but this time addressed to the nurse, "There are no bandages?" (data not shown here). In this manner, Anna's latest question treats her previous questions as indirect pre-requests for bandages, and also treats the doctor's answer as having been insufficient in dealing with her pre-requests. Even though it has been agreed she needs a bandage for her open wound, she still does not have one.

Patient-initiated questions, as courses of action, are not simply about something but they do something. A question makes an answer relevant right after it. Furthermore, as I examine in the following section, a question may set in motion a chain of actions.

Answers that Lead to Subsequent Actions

A doctor may avoid answering a question, not necessarily on the basis of what actions the patient's question makes relevant, but on the basis of what actions the doctor's own answer may lead to. As mentioned before, physicians are in the passenger's seat when they are placed in the position of answering questions. They still have considerable control over the direction of the interaction, but in order to regain control of the interaction, they frequently move out of the second position as recipient-answerers. Every time the doctor answers a question, he or she faces the possibility that a patient may ask a subsequent one. To some degree, when doctors are in the second position as recipient-answerer, they may be concerned with the subsequent actions and topics that their answers may lead to. Doctors may wonder: "If I answer this question, where is my answer going to take us?" and "What's next?"

If the reader recalls Anna's question requesting an assessment of her medical condition, "☺°I'm well, a:ren't I.°☺", we can start to distinguish the different reasons why a doctor may withhold an answer. Doctors may try to avoid setting in motion courses of action that they do not want initiated right then at that

particular point of the interaction. A different matter is how much time the doctor can buy by withholding an answer if the patient exerts questioning pressure. When Anna asks, “☺°I’m well, a:ren’t I.°☺” in Excerpt 4.7, Anna’s doctor is keenly aware that both yes and no answers will cause subsequent actions that he does not want to initiate. Doctor 1 has multiple reasons for smiling back at Anna and saying nothing.

Anna, right from the beginning of the medical interaction of which Excerpt 4.7 is a part, had made it clear that she believed she was being retained unfairly in the hospital for no good reason. Anna had developed a fever after her last round of chemotherapy and the subsequent neutropenia, that is, an abnormally low number of white blood cells. She completed the antibiotic treatment and did not currently have a fever. However, the day before this interaction, Anna’s body temperature did reach at one point the limit between what is considered the standard body temperature and a slight fever. To every question the doctor asked, Anna replied that she was fine. She complained that the doctors would not let her go home.

On the other hand, Anna’s mother did not want to go home yet. Anna’s mother expressed her fear that if Anna had a fever again, she would have to call an ambulance to drive them back from their home in Central Catalonia, about a one-and-a-half-hour drive, to the Catalonia Hospital Emergency Room. Anna’s mother would rather wait for another day in the hospital, and avoid altogether having to go through the hassle of going back and forth with ambulances. Doctor 1 was caught in the cross-fire between mother and daughter, and had hardly made any progress with the medical business at hand: collecting information about Anna’s health and symptoms, examining her, and assessing her condition. A terminological note is necessary for Excerpt 4.7: in line 11, doctor 1’s term “chemo dro:p.” refers to the reduction in white blood cell that follows chemotherapy administration.

Excerpt 4.7

- 1 MOM: *m’expli:co.*
 do I make myself *cle:ar*.
- 2 DOC1: [*sí sí:*,
 [*yes ye:s*,
- 3 ANNA: → [*☺°a: que estic bé.°☺*
 [*☺°I’m well, a:ren’t I.°☺*
- 4 ((Anna turns her head around to make eye contact with
- 5 doctor 1. She smiles while she asks her question))
- 6 DOC1: ((doctors 1 looks down, makes eye contact, and smiles
- 7 back at Anna))
- 8 MOM: *i CLa::r és lo que em farie por, si IO: visqués*
 and of *CQu::rse* what would *worry* me, if *I:* lived

- 9 MOM: *per* [*quí::*,
 around [*here::*,
- 10 DOC1: [*home, el que passa que la baixa:da de la químió ia*
 [*well, what happens is that she must have already*
- 11 *l'ha d'ha(ver)fe:ta.*
 done the chemo dro:p.
- 12 MOM: [*sí.*
 [*yes.*
- 13 DOC1: [*e:¿*
 [*okay¿*

At this particular point of the interaction, doctor 1 is transitioning from the first part of Anna's physical exam, examining Anna's mouth and neck, to the second part, listening to Anna's back and chest. While Anna's mother directly asks doctor 1 for a confirmation that he is actively listening to her with the question, "do I make myself *cle:ar*." (line 1), doctor 1 is busy trying to move along with the physical exam. Doctor 1 removes his hands from Anna's neck, lowers his head in order to place the stethoscope earpieces into his ears, and answers Anna's mother's question without looking at her (line 2).

Doctor 1's transition creates a short window of opportunity for Anna to talk. Anna could not talk while the doctor was examining her mouth and neck, and she will not be able to talk while the doctor listens to her back and chest with the stethoscope. However, Anna's mother has continued to pressure the doctor during the mouth and neck examination, and seems determined to continue pressuring him as he listens to Anna's back and chest. Anna's mother does not stop talking even when doctor 1's actions clearly indicate he is trying to listen Anna's chest and back.

Anna acts upon her brief interactional opportunity created by the transition between medical activities carried out by doctor 1 to exert her own pressure for a discharge and to counter her mother's pressure for an extension of Anna's hospital stay. At line 3, Anna slightly turns around, looks up at doctor 1, smiles, and talking in overlap with the doctor's talk, formulates her question in a soft and cheerful tone.

If doctor 1 answers yes, he is aligning with Anna, and his answer will likely lead to talk about Anna's discharge. If doctor 1 answers no, he is aligning with Anna's mother, which is not going to go unchallenged by Anna. If he gives a contingent answer, his answer may be contested by either Anna, her mother, or both of them. Doctor 1 has hardly been able to examine Anna so far. As long as he answers, there is little he can do to move along the medical visit. Generally, doctors wait to finish the physical exam to deliver an assessment of patient's condition and a treatment recommendation. However, doctor 1 has not even been able to complete the physical examination. By responding with a smile to Anna's smile, doctor 1 may be accomplishing different actions: acknowledging

Anna's question, displaying his affiliation, and communicating that he understands—and perhaps is even sympathetic to—her overall project (i.e., to go home as soon as possible).

Doctor 1's response with just a smile makes it clear that, at this point, he is passing the opportunity to advance further Anna's project. In line with the pattern of staying out of parent-child disputes during medical visits (see Chapter 6), doctor 1 may refrain from doing more at this point because he is trying not to become involved in the dispute between mother and daughter, and he does not want to prolong the dispute. He may also refrain from answering until he completes the physical examination, which is what doctor 1 eventually does (data not reproduced here). After having completed the physical examination, doctor 1 proposes a contingent plan: if the nurses' daily written reports confirm that the increase in Anna's body temperature the previous night was not a fever, he will discharge Anna. Still, doctor 1's contingent plan does little to bring the medical visit to a close. Doctor 1's answer opens a new and long discussion concerning when doctor 1 will have the discharge medical report ready, and what time they should schedule the ambulance to pick them up from the hospital and take them home.

I have shown in this section that patients' questions are volunteered courses of action, which, as the first pair part of a question-answer sequence, make subsequent actions relevant (e.g., answers or accounts for the absence of answers). Furthermore, I have shown that an answer, as an action in itself, may lead to additional subsequent actions. Questions may set in motion a turn-by-turn chain of subsequent actions; where these questions may lead, no one can anticipate, nor can anyone control how talk will progress.

Avoiding Answers and Avoiding Silence

There are occasions when withholding an answer may not be a viable option. In the example of Anna's question, “☺°I'm well, a:ren't I.°☺”, I have argued that patients' questions can place doctors in uncomfortable situations, in terms of what actions and topics may follow the question or the answer. Even trying to stay away from those topics and actions may make doctors uncomfortable, because once a question has been asked, it is on the interactional floor and cannot be withdrawn; either answering or trying to stay away from answering will take interactional work; and whatever doctors do or do not do will be interpreted in relation to the question.

When dealing with delicate matters, such as a question about a bad cancer prognosis, silence is as meaningful as talk. Doctors find themselves in situations where not saying anything may be more problematic than saying something, independently of whether they answer the question or go off on a tangent. Therefore, doctors will be in the passenger's seat, trying to do the best they

can to control the situation without openly refusing to answer the patient's question.

However, doctors will simultaneously try to carry out "damage control" in relation to what they say (that is, to avoid feeding an overwhelming sense of uncertainty, fear, anxiety, and pessimism while still providing patients with some accurate information), because part of what it means to be a doctor in Catalonia is to protect children from unnecessary suffering. And protecting children from suffering involves sustaining optimism in the medical treatment, and as far as possible avoiding talking about the uncertainty of the unknown future or bad news.

In Excerpt 4.8, the doctors find themselves in the delicate situation of having to deliver bad news unexpectedly. During morning rounds, the doctors visit two patients, 17-year-old Robert, who is undergoing presurgical chemotherapy for a bone tumor in his leg, and 13-year-old Santi, a bone cancer patient who has relapsed and now is back for second line chemotherapy. Robert and Santi are sharing a hospital room, and each is accompanied by his mother. Santi is seen first and then Robert.

Both visits have been uneventful and routine. Interspersed with routine medical activities, such as listening to the back and chest, there has been plenty of talk about non-medical issues, such as books and car shows. After doctors complete the physical exam, Robert tells the doctors about how the day before he was pretending that he was a physician, curing a very small cut that I had on my finger. Around the time of this video recording, Robert had become fond of pretend playing to be a physician, and regularly wore a stethoscope that he borrowed from a nurse.

By the time Robert finishes describing his experience as a *pretend* doctor, the *real* doctors begin to try to move the medical visit to a close by (1) ceasing to engage in eye contact with Robert, (2) turning from the bed, (3) walking away toward the door of the room, and (4) making a vague announcement of future plans. At the precise point when doctors are facing the door, Robert's mother asks a question about Robert's lung CAT scan (see Figure 4.1). During the visit, the doctors have not made any reference to the test results from Robert's lung CAT scan. The fact that they are about to walk out of the room shows that they do not plan to discuss the test results, even though they already know that the test results confirm that Robert has lung metastases and will need additional surgery. After hearing the question, doctor 1 abandons her course of action (i.e., closing down the medical visit and walking out of the room), and instead aligns herself with the unplanned and unexpected course of action initiated by Robert's mother's question (line 1).

Two notes of clarification are necessary for Excerpt 4.8. In line 1, Robert's mother's "yesterday?" refers to the test results from the CAT scan that Robert underwent the previous day to determine if his lung metastases changed after the start of chemotherapy, and consequently, if he needs to undergo lung surgery to remove these metastases. In line 34, his last question "o::r i::n the same one have

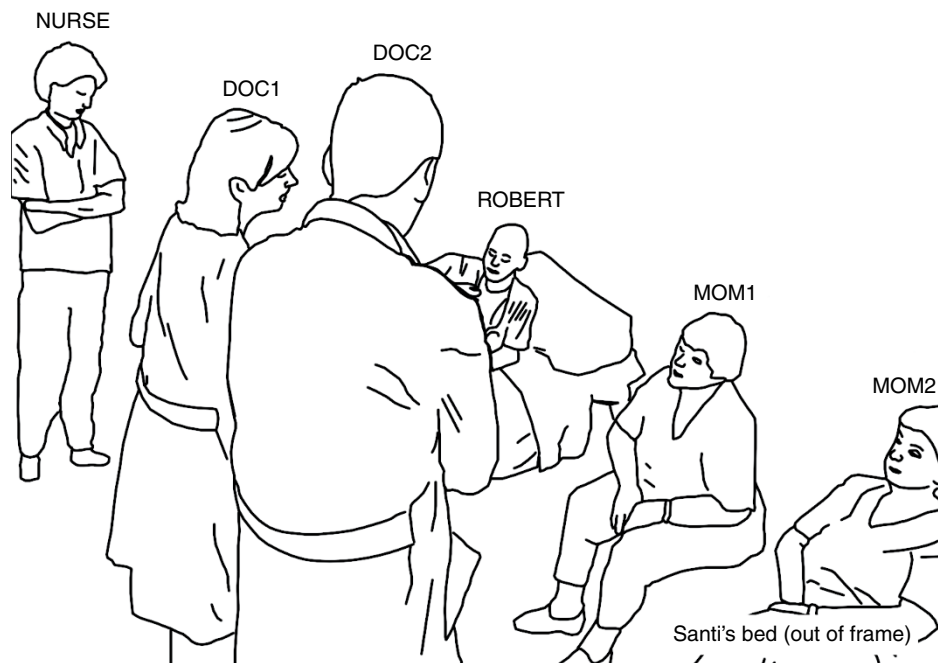


Figure 4.1 Robert and his mother asking questions as doctors and the nurse leave the room.

two.”, Robert asks whether he is going to have the primary bone tumor in his leg and metastases in his lungs removed during the same surgery, or whether he will have two independent surgeries.

Excerpt 4.8

- 1 MOM: *sa:↑ e: sabeu a:lgo de lo de ahir?*
do you ↑kno: e: do you know anything about yesterday?
- 2 (1.0)
- 3 DOC1: *.h bueno a::: el TAC està:: °més o me::nys.°*
.h well a::: the CAT results a::re back °more or le::ss.°
- 4 (0.6)
- 5 DOC1: *e::, o sigui que en principi:: mm °hi haurà: la cirurgia*
e::, in other words in principle:: mm °there'll be surgery
- 6 *també.<que una miqueta el que està[vem pendent.°*
too.<which was what we're waiting for a [little bit.°
- 7 ROB: → *[d' aquí:,*
[from here::,
- 8 *[((pointing to his*
left lung))

- 9 DOC1: ((nods head vertically, agreeing with Robert and answering
10 his question))
- 11 ROB: °joder.°
°fuck.°
- 12 (1.9)
- 13 ROB: → *és més peti:t més gr:an,*
is it sma:ller bi:gger,
14 (0.7)
- 15 DOC1: *és difícil de valo:r:ar. (.) °més o menys° ia s'ha vist*
it's difficult to asse:ss. (.) we've been seeing it
16 *veient °igual.° (.) e:, però de difícil de: de valora:r.*
stay °more or less the same.° (.) e:, but it's difficult
17 *.mh perquè e- tu pots veu:re la imatge igualment,<el*
to assess. .mh because e- one can also see the image,<what
18 *que passa és que no saps quina quantitat d'activitat hi ha.*
happens is that it's not known how much activity there is.
19 (0.3)
- 20 DOC1: *m'entens,<que això sí que pot s[e:r secundari a la:: (0.8)*
you know,<that can be secondary [due: to the:: (0.8)
- 21 ROB: [mhm
[mhm
- 22 DOC1: °a la medicació. °
°to the medication.°
- 23 (1.1)
- 24 DOC1: *va:le:*
oka:y:
- 25 (0.3)
- 26 ROB: → *i Quan:: m'ho faran doncs això?*
and Whe:n will they do this then?
27 (0.6)
- 28 ROB: [a
[uh
- 29 DOC1: [d e s [pré:s.
[a:fter[wards.
- 30 ??? [(cough))
- 31 DOC1: *hem de parlar amb [els toràcics,*
we need to talk to [the lung specialists,

- 32 ROB: → [*despr:és de la cama.*
[*af:ter the leg.*
- 33 (.)
- 34 ROB: → *o:: e::n la: mateix fer dos.*
o::r i::n the same one have two.
- 35 (.)
- 36 DOC1: *no. h [h*
no. h [h
- 37 MOM: [*hm.*
[*hm.*
- 38 ((the interaction continues with a discussion of Robert's
- 39 surgeries))

In line 1, Robert's mother starts her question twice, as a way to achieve mutual gaze with doctor 1 (Goodwin 1980). By the beginning of her second "do you know" doctor 1 has turned around, is facing her, and moves closer to where Robert's mother is sitting. Robert's mother's question opens up a number of subsequent actions and topics that the doctors have not raised during this medical interaction, such as the CAT scan test results that will be used to determine if Robert's lung metastases need to be removed surgically. Doctor 1's answer (lines 3, 5–6), which is delayed by a full second (line 2) and is prefaced with a dispreferred "well" (Pomerantz and Heritage 2013), announces that indeed the CAT scan test results are back, but qualifies this news with "more or less."

The ensuing interaction is complex, containing series of subsequent actions and topics that both the patient's questions and the doctors' responses are leading turn by turn. Throughout the interaction, doctor 1's carefully crafted responses display her orientation to the delicacy and "bad newsness" of her information delivery (Maynard 2003; Silverman and Peräkylä 1990). Among other features, her responses includes long delays and pauses (lines 2, 4, 13, 15, 21, 24, and 28), stretched-out vowels (lines 3, 5, and 21), rushed-through transitions marked in the transcript with the "<" symbol (lines 6, 18, and 21), very soft tone marked in the transcript with the "°" symbol, and turn components that are abandoned, repeated, reformulated, and/or replaced with new ones (lines 5–6, 16–19, 21, and 23):

- Line 1: TEST RESULTS DELIVERY. Robert's mother's question makes any talk about the CAT scan test results relevant.
- Lines 3, 5–6: DELIVERY OF BAD NEWS. Doctor 1, in a dispreferred manner and with some vagueness ("°more or le:ss.°") announces that the test results are back. She paraphrases herself with the reformulator "o sigui" (equivalent to "in other words" in English) to interpret the significance of the test results and clarify how the test results will affect Robert's treatment. She

delivers the bad news that Robert will have to undergo lung surgery. The news is delivered using the general and theoretical preface “in principle::” (as opposed to “in fact,” “in practice,” “or in your case,”) and the impersonal verbal tense “°there’ll be surgery” (as opposed to “you’re having surgery”). The delivery is also formulated as a confirmation of prior contingent information (“>which was what was pending a little bit.°”) No more information is volunteered by doctor 1. However, by referring to treatment (surgery), her answer leads to more talk about the treatment.

- Lines 7–9: TREATMENT. Robert’s first question makes relevant a confirmation concerning treatment, by asking if there will be surgery in his left lung.
- Lines 10–11: TREATMENT. Doctor 1 confirms nonverbally with a vertical nod that her mention of surgery refers to Robert’s left lung. No more information is volunteered by the doctor.
- Line 14: DIAGNOSTIC ASSESSMENT. Robert’s second question makes a diagnostic assessment of the CAT scan test results with prognostic implications relevant. When he asks if “*it*” is smaller or bigger, he is asking explicitly whether the lung metastases have continued to grow despite chemotherapy or have shrunk with the chemotherapy, and (b) implicitly, whether chemotherapy has been effective in fighting the cancerous metastases. Robert’s “*it*” is another example of participants carefully avoiding words such as “tumor,” “cancer,” or “metastases.” Another instance of this avoidance is Robert’s references to his leg instead of talking about the tumor or the cancer in his leg.
- Lines 16–19, 21, 23: DIAGNOSIS AND PROGNOSIS. Instead of conforming to the choices given by Robert (i.e., smaller or bigger) doctor 1 explains that at this point, she can only provide indeterminate and uncertain news in regard to how to assess the CAT results.
- Line 27: TREATMENT. Robert’s third question, after the doctor’s response about diagnosis, returns to the previous topic of his surgery. Robert uses an “and-preface” to mark his return to more relevant talk about treatment. Now, Robert’s question targets the time of the surgery.
- Line 29, 31: TREATMENT. Doctor 1 responds to Robert’s question with “*afterwards*.” and follows with a contingent explanation. Before she can answer that question, she needs to talk to the lung specialists. Doctor 1 volunteers no more information.
- Lines 33, 35: TREATMENT. Robert’s fourth question, after the doctor’s contingent response about the time of the treatment, latches onto the doctor’s minimal response “*afterwards*.” In Catalan, the same word “*després*” can function both as the adverb “afterwards” or the preposition “after.” With his recycling of doctor 1’s “*després*.”, Robert pressures for any more details about the time of the lung surgery: is it going to be *after* his leg surgery or will the doctors perform two surgeries in one operation?

In this manner, despite doctor 1’s attempts to avoid getting herself involved in continuously expanding sequences, it seems that, short of walking out of the

room, there is little she can do to avoid discussing Robert's CAT scans, and consequently, Robert's surgery to remove his lung metastases. As long as she continues to *answer*, she does not seem to be able to avoid creating a situation in which every time she answers one question, more questions appear.

Doctor 1's predicament is not over yet. As we have seen, Robert and his mother have not aligned themselves with the doctors in bringing the medical visit to a close. When Robert's telling is brought to a close, he and his mother have the choice to remain silent, and align themselves with the doctors' pre-closing moves. Not initiating a new sequence would allow the doctors to deliver a quick "no-problem" assessment of the patient's condition, close the medical interaction, leave the room, and visit the next patient in their rounds of the pediatric unit. Routinely, doctors carried out "no-problem" assessments (no need to carry out special tests, no need to readjust medication) on their way out of the patient's room. If the patient's parent had something to say to the doctors that he or she did not want to say in front of the child, the parent would get up and follow the doctors out of the room at this point.

However, neither Robert's mother nor Robert align themselves with the doctors' pre-closing moves. Robert's mother does not rise from her chair. Instead, she reopens the interaction with her question, and her son further expands the visit with his multiple subsequent questions.

Next, Santi's mother, who has been quietly following the development of Robert's medical visit, decides to reopen her son's visit after Robert's questions (data not shown here). Just as the doctors' interaction with Robert and his mother reaches a point when closing becomes pertinent again, Santi's mother starts asking her own set of questions. Santi's mother did not ask any of these questions during her son's own visit before Robert's visit began. Santi's mother carefully marks her question as occasioned locally by the discussion of Robert's treatment with her use of "also." She asks doctor 1, "Uh, listen to me. And I, at what point am I now also," referring to the phase of treatment her son Santi is currently undergoing, and requesting information about Santi's future course of treatment. Although Santi's mother's question targets treatment explicitly, talk about the future course of treatment may lead to prognostic questions about Santi's condition, because Santi's second-line chemotherapy will be extended or shortened depending on how effective chemotherapy is in treating the new reoccurrence of cancer.

Finally, after doctor 1 tells Santi's mother that Santi still has another round of chemotherapy before any prognostic assessment can be made, Robert comes back into the conversation with a new set of questions about his leg tumor. Spurred by the discussion of his lung test results, or by the discussion of the surgeries of his leg tumor and his lung metastases, Robert now asks about the test results of an MRI that was conducted to measure the degree of bone tumor necrosis. Doctor 1 announces that the MRI test results are not back yet, and with a reference to future plans, "let's see if before you are discharged we can tell you something about it," doctor 1 initiates the exchange of goodbyes and

closes the interaction. In sum, Robert's mother's question began a series of unplanned deliveries of bad and uncertain news about Robert's and Santi's prognoses, just when the doctors were attempting again to close their medical round and walk out of the room.

Stepping into the Uncertain Future One Turn at a Time

In this chapter, I have examined the locally negotiated process through which participants co-construct how much or how little uncertainty there is in their talk in the context of questions and answers in pediatric cancer treatment (see also Sidnell (2005) for an analysis of the co-construction of uncertainty in giving and receiving advice sequences in a non-medical context). I highlight three features of this process: (1) *progression*, or local development, turn by turn, of talk-in-interaction (e.g., no speaker controls exclusively how an interaction will unfold or how something will be talked about); (2) *negotiation* (e.g., a speaker may want to talk in more uncertain ways than another one, and one speaker may want to influence how another speaker talks about uncertainty); and (3) *production*, or interactional work that speakers do to have or not have uncertainty in their talk. By underscoring the social dimension of the experience of uncertainty, I argue that speakers say and do things to constitute the social worlds they inhabit, or that they want to inhabit. The presence or absence of uncertainty in a particular interaction does not just happen “naturally”; speakers invest time and effort to make it happen one way or another. Because there is no “natural” predetermined way to speak about something, but only a negotiated one, speakers may disagree about *how to talk about it* (i.e., what is uncertain and requiring avoidance for one speaker often does not match what is uncertain and requiring avoidance for another) and about *whose way to talk about it* (i.e., one speaker tries to persuade the other to avoid or not to avoid uncertainty).

I have also examined uncertainty in relation to the topic of a question (i.e., what a question asks about) and the action of a question (i.e., the project that a participant is trying to accomplish by asking a question). In regard to topic, I have illustrated the step-by-step construction of uncertainty, examining utterances such as IF-THEN contingent questions and answers. In regard to action, I have examined the actions that a question makes relevant next, and the subsequent additional actions that either a question or an answer may lead to. Like Pandora's box, once a question-answer sequence is opened, it can take much interactional work to close. Questions and answers about test results may lead to questions about diagnosis, and questions and answers about diagnosis may lead questions about treatment and prognosis. This expanding chain (discovery of condition → diagnosis of condition → assessment of importance of the condition → appropriate treatment) may be in itself a problem for doctors who are carrying out

their medical rounds and are pressed for time, yet young people persist in pursuing answers to questions that they deem answerable and that have not been answered sufficiently well from their perspective.

Moreover, in the treatment of pediatric cancer, the more this expanding chain of questions and answers ventures into talk about the future, the fewer answers doctors have. Doctors' answers become more uncertain with each step into a speculative and unknown future. Participants orient not only to the uncertainty with which doctors can answer the current question, but also the uncertainty of the potential forthcoming subsequent questions that have not yet been asked.

When answering questions, doctors try to be two steps ahead of the patient's next question. Doctors attempt to stay away from diagnosis and prognosis, because these aspects of cancer are the most unknown and uncertain, the most delicate, and the ones that can potentially be bad news. All the while, they try to avoid being perceived as uncooperative or evasive. With respect to treatment, doctors stay as close as possible to the current local course of treatment, because any overall discussion of far-into-the-future treatment will only lead to more questions and more uncertainty. And because patients and parents pressure for answers that are as final and certain as possible, participants engage, turn by turn and day by day, in elaborate negotiations over the limits of the uncertainty associated with having cancer.

Notes

- 1 In these data, doctors rarely used "I don't know" as an account for the absence of an answer (Mary Hardy, personal communication, 2005). Although accounts for an absent answer such as "I don't know" or "I have no idea" occur in ordinary conversation (Heritage 1984: 248–253), they would cause alarm in the institutional context of pediatric cancer. "I don't know" would be an explicit acknowledgment of uncertainty.
- 2 Frankel (1990: 258) defines "deference structure" in the following terms: "In the context of this analysis of speaking practices during medical interviews, the concept of deference is limited to the recurrent sets of sequential obligations placed upon a recipient with the introduction of a question operating as a first part in a paired sequence, Q-A. Thus, the obligation to respond, insofar as it characterizes and constrains the speaking opportunities of one member of the dyad and not the other, may be treated as a type of sequential deference."

Engaging in Communication at Catalonia Hospital

Key Issues

- *During pre-treatment, patients find out, in a variety of ways, that they have cancer, which often proves to be a confusing, uncertain, and traumatizing experience.*
- *Six strategies are used to regulate communication: deception, official and planned complete non-disclosure, unofficial leakage and gathering of information, improvised partial disclosure, official and planned partial disclosure, and concealment of emotions.*
- *The treatment interview, a turning point in the cancer trajectory, is the pivotal communicative event during which cancer patients are informed that they will begin treatment; implicitly, it is an acknowledgement that the patient has cancer.*
- *Children may resist doctors' reassuring, optimistic, and hopeful talk about the future with actions such as avoidance of eye contact and crying.*

In this chapter, I describe six communicative strategies for managing diagnostic and treatment information in the presence of children, particularly uncertain and bad news. Patients encounter these strategies during the pre-treatment period, that is, the diagnostic events that precede the beginning of cancer treatment. These six communicative strategies are as follows: (1) *deception* (e.g., telling the child he or she has a knee infection when there is strong evidence there is cancer); (2) *official and planned complete non-disclosure* (e.g., doctors and parents withhold as much information as possible); (3) *unofficial leakage and gathering of information* (e.g., patient overhears physicians talking or gathers information from other patients and parents); (4) *unplanned and improvised partial disclosure* (e.g., the specialist tells the child he has a tumor only after the child refuses to be hospitalized); (5) *regulation of negative emotions* (e.g., children avoid crying in front of their parents, and parents avoid crying in front of their children; children and parents avoid directing their anger outbursts

toward doctors); and (6) *official and planned partial disclosure* (e.g., doctor and parents determine and monitor what the child is told).

I begin by describing the first five communicative strategies as I examine how Robert (a 17-year-old boy with bone cancer and lung metastases), Dani (a 16-year-old boy with soft tissue cancer), and Pedro (a 15-year-old boy with bone cancer) find out they have cancer. I follow with an examination of the sixth and final communicative strategy, official and planned partial disclosure, in which I discuss the *treatment interview*, a special meeting designed to inform patients about the imminent start of treatment. The treatment interview is not a cancer diagnosis delivery. It is neither designed to inform explicitly those patients who do not know already that they have cancer, nor to confirm it for those who already do. However, by telling patients they are about to start treatment, the treatment interview becomes an official—through implicit—delivery of a cancer diagnosis, and the communicative event closest to a full and open diagnosis delivery.

Consistent with the book's analytic focus on children's participation, the third part of this chapter illustrates, turn by turn, the contrast between what Pedro wants to know and what the doctor wants to tell him during his treatment interview. Consequently, rather than taking the doctor's news delivery as the main analytic focus, I concentrate on Pedro's last attempt to obtain information and his subsequent refusal to go along with the doctor's response. On the patient's side of the interview, Pedro challenges the way the news is delivered and asks questions about the negative and uncertain aspects of the treatment that the doctor does not talk about. For the doctor's part, she tries to focus Pedro's attention on the present course of treatment, she offers reassurances, lightheartedly teases him, downplays his fears, evades answering by making optimistic remarks, and produces a highly predictable version of how Pedro's future treatment will proceed. I conclude the chapter by bringing both the ethnographic-longitudinal and situated analyses together. The experiences of Robert, Dani, and Pedro illustrate how patients push the limits of what they are told as they encounter the communicative strategies used to talk about cancer at Catalonia Hospital.

Learning the Diagnosis

The pre-treatment period is characterized by a flurry of diagnostic testing activity. The types of uncertainties encountered during this period included finding out whether the child had cancer and figuring out how much everybody else knew about it. Although there were often suspicions, during this period nobody knew with certainty if the child had cancer—not the physicians (specialists and pediatricians), not the parents, and not the patients. Suspicions grew stronger as the testing period went on. Many patients reported they felt there was something wrong, even if they did not know what. They made inferences from what was happening, such as repeated visits to the hospital, frequent hospitalizations for

testing, continuing pain, and an unusual silence among incessant testing activity. Parents and physicians were busy but nobody was telling the children anything directly. Physicians tried to gather information from the diagnostic tests, and parents tried to gather information from physicians. At the same time, both parents and physicians concealed as much information as possible from patients, despite constant accidental leaks of information.

The pre-treatment period might have started months before with some unexplainable symptoms: pain, swelling, or in some cases, bone fractures. Parents and children started a pilgrimage that took them from one physician to the next, trying to find out what was causing the problem. Even when parents and children went directly to Catalonia Hospital, children underwent a myriad of tests: MRI (magnetic resonance imaging), PET (positron emission tomography scan), CAT (computerized axial tomography scan), ultrasounds, x-rays, and pathology lab tumor tissue sample analysis. There were continuous blood tests and x-rays. The tests continued until information on the tumors (i.e., number, location, size, tissue type, stage of development, and invasion of adjacent tissues) was obtained.

This first flurry of testing concluded with a biopsy. A sample of the bone tumor was removed using minor surgery and analyzed in the pathology laboratory. The average 10-day waiting period for the biopsy test results resulted in a slowdown of testing but also a heightened sense of uncertainty. Confirmation of the cancer diagnosis unleashed a second episode of intense testing. Doctors needed to ensure that the patient would be able to endure the most aggressive therapies of bone cancer treatment: namely, surgical management of the primary tumor and adjuvant chemotherapy. Patients underwent a complete physical examination, with special attention given to the heart and kidneys, and tests for other medical conditions.

I now turn the commonalities and differences in how Robert (age 17), Dani (age 16), and Pedro (age 15) found out they had cancer. Robert described to me how he found out he had cancer accidentally. The period leading up to his cancer treatment began when Robert was referred from another hospital to an orthopedic surgeon ("surgeon" hereafter) at Catalonia Hospital. The specialist who referred Robert to the surgeon advised his mother to tell him he had a knee infection, so he would be less worried. The premise of a knee infection sounded reasonable because Robert was being referred to an orthopedic trauma and surgery unit, and not to a pediatric cancer unit. The surgeon was in charge of diagnostic testing and surgeries, but the chief of the pediatric oncology unit was in charge of the overall organization of the treatment, including the administration of the chemotherapy.

The surgeon told Robert that he needed to be hospitalized immediately in order to conduct a biopsy. Thinking that he just had a knee infection, Robert refused to be hospitalized. He told the surgeon that he did not have his pajamas and his belongings with him, and asked if he could go home, pick them up, and come back the following day. The surgeon challenged Robert's refusal and asked him, "What do you think you have?" Robert did not answer. To make sure that

Robert comprehended the urgency of the biopsy, the surgeon said, "You have a tumor, boy." When the surgeon saw Robert's face, he realized that Robert had not been told about the possibility of having cancer. Robert stormed out of the surgeon's office, walked to the waiting room, and started crying and screaming at the people who were looking at him, "What the fuck are you looking at?" He said he realized at that moment he was "the boy with cancer." Soon after and while awaiting the biopsy tests to confirm his cancer diagnosis, Robert dyed his hair blue. He was aware he would not have hair for much longer.

Unlike Robert, Dani came to Catalonia Hospital already diagnosed with cancer. Dani had already undergone surgery at another hospital for a benign tumor, but when the post-surgical results came back, it was diagnosed as a malignant tumor. At the other hospital, Dani's parents met with his surgeon alone and were informed that their son had cancer. Because that hospital did not provide treatment for pediatric cancer patients, the surgeon advised his parents to take him for treatment at Catalonia Hospital. Dani's parents told me that they had known Dani had cancer for over a month before they came to Catalonia Hospital. During this time, they made sure he did not suspect anything about his cancer diagnosis, for instance, by hiding away whenever Dani's mother had "inconvenient" phone calls. They also concealed their emotions and made sure Dani did not see them cry.

During his first visit at Catalonia Hospital, two surgeons conducted Dani's physical examination in the presence of his parents. As the surgeons examined him, they discussed with each other details of Dani's chemotherapy and possible surgery. Dani's eyes filled up with tears and he remained quiet and sniffled, but did not sob. When the surgeons saw him crying, one of them told Dani directly his tumor was malignant and that he would be given a more detailed explanation later on by his pediatric oncologist.

Dani's hospitalization was scheduled to start after the surgeon's visit. However, his parents thought they were coming only for the surgeon's visit and did not come prepared for Dani's first chemotherapy. His hospital admission was moved from a Friday to the following Monday. Dani and his parents apparently did not talk much about the cancer over the weekend, even though the surgeon had already told Dani he had a tumor. As soon as Dani was hospitalized, he asked to meet with the doctors alone. The only information that I was able to gather was that Dani cried during the meeting, and that he very much feared talking about the tumor with his parents. Later on, I found out that it took the doctors several meetings to persuade Dani's parents to agree that some level of disclosure was necessary. In fact, the chief doctor made an explicit appeal for "clear" communication with Dani during his treatment interview, although she still did not use the word cancer. A few weeks later, Dani's parents told me that they had worked very hard to protect their son from being informed about the cancer diagnosis and that they were adamant about keeping as much information as possible from their son. Furthermore, they continued to be upset about information having been disclosed to their son months after the treatment interview.

Pedro's case illustrates the same strategies but a different process of "finding out." Pedro, an only child from a rural village in Western Spain about 500 miles from Barcelona, was hospitalized as soon as he arrived at Catalonia Hospital. He had been in a wheelchair for some time, unable to walk with a large swollen knee that stood out in comparison with his thin legs. Pedro was receiving pain medication while the physicians waited for the biopsy result. Despite the frantic testing activity, physicians and parents had only talked to Pedro about the knee swelling. Pedro had not asked them for much information either. Like Dani's parents, Pedro's parents were strongly opposed to giving him any information. Months after the treatment interview, Pedro's mother still talked about her reluctance to give Pedro information in her private conversations with other parents (see the section titled "Talking Privately" in Chapter 3). At the time of his treatment interview, Pedro was under the impression that they were going to remove the bandage around his knee, and that he would be able to put his foot on the ground and go home. Unlike Robert and Dani, Pedro was only told he had a tumor during his treatment interview (see the following text).

Regarding the five strategies used before the treatment interview, the first strategy of deception is apparent in Robert's account. Robert explicitly said he felt he was brought to Catalonia Hospital under deception (see also Felipe in Chapter 7). In two other cases, the patients did not explicitly say they felt deceived, but the circumstances were very similar. Pedro was also brought to Catalonia Hospital for the same reason as Robert was. He was told it was just a case of a swollen knee lesion, even though there was a strong enough suspicion of cancer to travel 500 miles (see also Eli in Chapter 7).

The second strategy of official and planned complete non-disclosure can be seen in the attempts made by Robert's mother, Dani's parents, and Pedro's parents to conceal information completely. As illustrated by Dani's case, the reluctance—or inability—to talk about cancer continued even after Dani's parents had witnessed how the surgeon broke the news to him that he had a tumor. During numerous visits to hospitals, regardless of whether it was over a two-week period or over several months, most parents and patients reported that there was no open discussion of the possibility of a cancer diagnosis. Most parents, deciding on their own or following the advice of a primary care doctor, chose to wait until a cancer diagnosis was confirmed, because there was no reason to expose the child to such a traumatic event unless it was absolutely necessary. As a result, future patients, especially young people, moved in and out of hospitals, carrying with them the unspeakable fear that something was very wrong with them, but no one was willing to talk to them about it. For weeks or months, patients waited for some kind of news.

Physicians (i.e., primary care physicians, specialists, and pediatric oncologists) were somewhat more forthcoming than parents, but they did not challenge parents' wishes for official and planned complete non-disclosure during the pre-treatment period. As the available diagnostic information changed, physicians and parents negotiated and filtered daily what the children would be told. Discussion

of the diagnosis was completely restricted, even in the cases of Robert and Dani, who had already been told that they had a “tumor.” This strategy of official, complete, and planned non-disclosure was not successful in preventing patients from finding out about their cancer diagnoses. Patients ultimately learned about the diagnoses thorough unofficial leakage and gathering of information, and unplanned and improvised partial disclosure.

In the third communicative strategy of unofficial leakage and gathering of information, patients found out about the cancer diagnosis via physicians’ *slips of the tongue* and conversations with other patients and parents. In Robert’s and Dani’s cases, the surgeon talked about the tumor in front of them because he assumed that the previous physicians who referred them to his practice at Catalonia Hospital had already given them some kind of diagnostic information. However, neither Robert nor Dani had been told anything, a decision justified by the reasoning that it was not necessary to tell them until the start of chemotherapy. The surgeon’s *slips* show that there was no coordinated effort by the multiple physicians involved to report to each other what they had discussed with the patients regarding the mounting evidence for a cancer diagnosis.

Conversations between new and experienced patients and their families provided a way to gather information unofficially. For instance, Dani met Anna and her mother one day before his treatment interview. Anna was hospitalized for her last chemotherapy after 12 months of treatment. Because neither Dani nor Anna lived in Barcelona, Dani’s parents and Anna’s mother stayed together in a shared apartment for parents of long-term hospitalized children. Dani’s parents shared their despair and suffering about Dani’s cancer with Anna’s mother. Anna’s mother told Anna about *el nou* (the new cancer patient), and Anna and her mother decided to pay a visit to Dani in his hospital bedroom. They chatted about side effects, including hair loss, about other patients that Dani would meet, and about how to obtain favors from physicians and nurses. Other pediatric cancer patients also remarked that even though they may not have realized fully that they had cancer, seeing bald patients in wheelchairs worried them.

The fourth communicative strategy during pre-treatment was unplanned and improvised partial disclosure. During Robert’s and Dani’s visits at the orthopedic trauma and surgery unit, the surgeon confirmed the presence of a tumor to both Robert and Dani after realizing that they had just heard about it for the first time. The surgeon had clearly not planned to deliver the cancer diagnosis during the visit. The surgeon also passed on the opportunity to deliver the cancer diagnosis officially, and in Dani’s case, told him that the pediatrician would later inform him in more detail. Furthermore, the surgeon neither retracted his words nor pretended that he had not said anything. Unlike Dani’s parents, who continued not to talk about the tumor even after the surgeon confirmed the diagnosis to Dani, the surgeon chose not to participate in deception or in complete non-disclosure.

The surgeon's unplanned and improvised confirmation of the presence of a tumor also illustrates that communicating the cancer diagnosis did not require the explicit use of the word "cancer." Robert's account makes it clear he understood right then and there that he had cancer, that he was "the boy with cancer." Dani's and Pedro's tears after hearing doctors use the words "chemotherapy" and "tumor" also illustrate the implicit communication of a cancer diagnosis. Indeed, Pedro used the word "cancer" to ask his parents for a confirmation of the diagnosis once the doctors and the nurses left the room.

In regard to the fifth strategy of regulation of negative emotions, all three young people (Robert, Dani, and Pedro) and their respective parents tried not to cry in front of one another throughout the entire cancer trajectories, beginning with the pre-treatment (see also the discussion of anger displays regulation in Chapters 3 and 6). I do not know if there was a moment when the boys cried with their families at home, but I did not observe a single occasion when a patient and his or her parents cried together at the hospital. This does not mean that patients and parents did not cry. Patients cried during medical procedures, and when the children were not around, parents did cry with hospital staff, other parents, and me. All three young people, Robert, Pedro, and Dani, cried in front of their parents when they were first told about a tumor; Robert and Dani during the visit with the surgeon, Pedro and Dani—a second time for Dani—during the treatment interview. In his account of how he was told about the tumor, Robert proudly told me that one of the few times he let his mother see him cry was during the visit with the surgeon and after he stormed out of the office. I never saw Robert cry: I was not present during those events, and Robert never cried during the following eight months. Dani cried profusely during the meeting with the doctors alone, but only sniffled with tearful eyes in the presence of his parents during the surgeon's visit and the treatment interview. Both Dani's father and mother cried often when talking to me and other parents. Dani's mother did not cry during the treatment interview, but his father did and tried to hide his tears by lowering his head and looking down and away. Pedro cried profusely during and after his treatment interview (see my analysis of Pedro's crying in the following text), but his parents did not. Pedro's parents seemed uncomfortable with Pedro's crying, and I never saw them cry. Furthermore, Pedro's and Dani's mothers mentioned that they (i.e., Pedro and Dani) cried often at the beginning of treatment, but I never saw them cry again during the many months of treatment. Although they likely cried during painful procedures, as other patients did, I did not see them cry again during medical and social interactions.

Having established these five interrelated strategies during the period of diagnostic testing, I now focus on the treatment interview and identify the sixth communicative strategy: official and planned partial disclosure.

***L'entrevista* (The Treatment Interview)**

The treatment interview—or *l'entrevista*, which was the term used at Catalonia Hospital—can be defined as the communicative event during which cancer patients (age 13 and older) are informed officially that they are about to start chemotherapy treatment. For children who were younger than 13, doctors recommended talking about treatment with the child, but did not pressure the parents to have a treatment interview. For older patients, doctors strongly cautioned parents against starting treatment without giving them some kind of information about it. The treatment interview mainly included a description of the different types of therapies that the patient would receive during the following 12 months. The interview occurred a few minutes before the start of the treatment, and the patients were the last ones to be informed officially by the doctors.

L'entrevista was neither an open and full diagnosis delivery that informed the patient that he or she had cancer, nor a discussion of treatment options that allowed the patient to make informed decisions about schedules and courses of treatment. Instead, doctors described the future course of treatment, which was most often a combination of chemotherapy and surgery. Thus, doctors presented the treatment to the young person officially, publicly, and explicitly—but implicitly delivered and confirmed the cancer diagnosis. For instance, the doctors delivered the diagnosis implicitly to Pedro, who heard for the first time he had a tumor during the interview, and tacitly confirmed the diagnosis to Robert and Dani, who had been told about the tumor by the surgeon. If mentioning the tumor was not enough to communicate the cancer diagnosis implicitly, patients could infer syllogistically that they had cancer (Gill and Maynard 1995). Because chemotherapy is administered to people who have cancer, a person about to be administered chemotherapy can infer the cancer diagnosis. Thus, the interview constituted a public but inexplicit affirmation that the patient was indeed a *cancer* patient.

The doctors constructed the treatment interview as a turning point. On the one hand, it marked the end of the uncertainty, anxiety, and suffering that characterized the pre-treatment period. On the other hand, the interview marked the beginning of a period of certainty brought about by the treatment. The treatment was the optimistic beginning of the end of the cancer. In a sense, it represented the future. This future was framed as somewhat certain by circumscribing it within the most immediate future (i.e., just weeks and a few months ahead) and by associating this future with the concreteness of the treatment administration protocol that laid out the upcoming cycles of chemotherapy treatment. In opposition to the uncertainty of the pre-treatment events, doctors offered the certainty of the most immediate future and the concreteness of the treatment administration protocol.

Three strategies continued in the same way before and after the treatment interview: unofficial leakage and gathering of information, unplanned and improvised partial disclosure, and concealment of emotions. However, doctors did not use deception and planned and official complete non-disclosure during the treatment. Instead, they introduced a sixth communicative strategy: official and planned partial disclosure, primarily with young people and not necessarily with the youngest children. On practical grounds, they argued that a minimum of information should be given to young people. Doctors regarded complete non-disclosure as an obstacle to their work, because it would interfere with the appropriate administration of treatment. Moreover, doctors argued that sooner or later, young people would find out, if they did not know already.

Despite doctors' pressure for planned and official partial disclosure, most parents, regardless of the child's age and how much their child already knew, did not want their child to be told anything else (see the earlier text and also the section titled "Talking Privately" in Chapter 3). Some parents only agreed to the interview after the doctors' repeated warnings against starting treatment without some information being given to the young person. In most cases, doctors and parents reached a compromise, and negotiated what the young person would be told before the interview.

The compromise between parents and doctors brought with it important limitations regarding what could be talked about during the interview. These limitations were put in place not only in response to parental resistance, but also owing to doctors' beliefs that their role was to protect patients from the suffering of uncertain or bad news. A first limitation involved not using the word "cancer," and using instead words such as "the bump," "the swelling," "the tumor," "the lesion," "that disease," or simply "it." A second limitation on how to talk about cancer during the interview involved emphasizing the present course of treatment. Information about the cancer diagnosis itself was minimal, consisting of only a brief presentation of diagnostic test results that justified the need for the immediate start of treatment. There was little or no discussion of what had happened until that point. When the past was talked about, it was the most immediate past (i.e., only the last few days leading up to the treatment interview). A discussion of what might have caused the cancer (i.e., Why me? Why do I have cancer? Why was the cancer not detected earlier?) could lead to prognostic-implicative questions for which doctors had no answers, such as whether the patient would be completely cured or whether the cancer would return. Similarly, there was no discussion of the long-term future. The interview was centered around treatment, and specifically around the treatment occurring in the present moment in time. Doctors could not offer certainty about what had caused the cancer in the past or what might cure it completely in the future, but they could offer a concrete medical treatment plan.

The use of the sixth communicative strategy of official and planned partial disclosure should not be interpreted as part of an evolution toward ultimate full disclosure. Children's cancer trajectories were unpredictable, and this unpredictability kept

doctors and parents worried. Even when the treatment went well, doctors and parents still used the hallways to meet in the absence of the children, who were bedridden during chemotherapy administration. When the treatment did not go well, doctors and parents shifted to deception and to official and planned non-disclosure (see Chapter 7).

As an ethnographer, I was naïve and unprepared to comprehend how traumatic the interview would be for all patients, for those who had been told about the tumor, like Robert and Dani, and for those who just had strong suspicions, like Pedro. Maynard (2003) argues that the transition between suspicions and confirmation of bad news creates a “noetic crisis,” and opens a period of experiential disorientation and suspension of belief in the solidity and obduracy of the “real world” and their quotidian lives. During this process of experiential disorientation, children and parent exit their everyday world and enter a new and dreaded one. I believe that the treatment interview made the new “reality” of cancer all the way more concrete and tangible. The treatment interview served to some degree as a symbolic moment in their process of transition from suspecting or knowing the cancer diagnosis to realizing they were cancer patients or the parents of a child with cancer. As mentioned earlier, all three young persons cried when they were told that they had a tumor. Furthermore, Dani’s mother told me that she had to sit down because she felt her legs were about to collapse during her son’s interview, and Dani’s father hid his tears. During parental asides (see Chapter 3), parents commented on the fact that their own suffering was worsened by knowing that their children had been told that they had cancer.

In Pedro’s case, I assumed that he knew something was very wrong because of the evidence previously mentioned (e.g., his inability to walk, hospitalizations, and traveling more than 500 miles from his hometown to Catalonia Hospital). I also mistakenly assumed that somehow, knowing something was very wrong would make the cancer diagnosis delivery less traumatic for him. I tried to ask Pedro about what he knew and/or suspected, but like other patients who were still receiving treatment, Pedro did not seem interested in talking about those events. Whether Pedro did not know anything, preferred not to know, or suspected something was wrong but never imagined that it would be cancer, the fact is that Pedro was tremendously upset during the interview, as were his parents.

“And When Will I Be Completely Cured?”

Pedro’s treatment interview did not give him a chance to process the news or to ask for any changes to the immediate course of treatment. He and his parents were in shock. The treatment “ball” was rolling, and rolling fast. After months of testing and waiting, there was a strong sense of urgency. Immediately after

Pedro's interview, the nurse started intravenous hydration as the first step of the first chemotherapy session, and the doctors handed his parents consent forms required for treatment.

Pedro's treatment interview was brief, lasting about 14 minutes, just a few more minutes than a regular morning ward round. It could probably have been shorter without Pedro's questions, because the chief doctor's first move to close the interview took place after seven and a half minutes. As discussed at the beginning of the book, Pedro asked many questions that introduced the negative and uncertain aspects of treatment. For instance, after the doctor described a positive effect of the treatment (i.e., pain reduction), Pedro brought up a negative one that the doctor had not talked about: "Chemotherapy makes your hair fall out, right?" After the doctor explained the benefits of surgery (i.e., replacing the bad bone with a bone graft), Pedro introduced an unknown and unknowable effect of the surgery: "Will it (my leg) be the same way as before (the surgery)?"

With his six topically relevant questions, Pedro was not going along with the doctor's optimistic and hopeful presentation of treatment. The contrast between Pedro's questions and the doctor's presentation increased as the interview progressed. Eventually, Pedro avoided looking at the doctor and refused to be the recipient of her talk, which is one of the most basic forms of interactional involvement (Goodwin 1981). With this refusal, Pedro questioned the doctor's optimistic treatment presentation and the very purpose of the treatment interview, which was to inform him about the surgery and chemotherapy administration. In Pedro's treatment interview, the doctor ended up talking with his parents, who were not the intended news recipients and who already knew about it. In doing so, the doctor deviated from the norm that one only tells news to somebody who does not know it (Terasaki 2004).

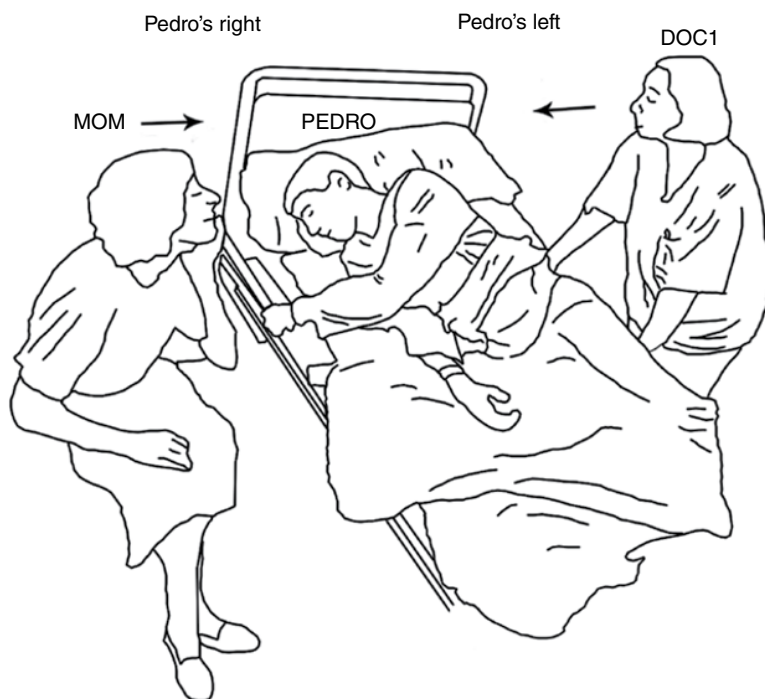
Pedro's refusal to look at the doctor began while she tried to reassure him that losing his hair was only a transitory and minor problem. Pedro started sobbing, which became shrieking after multiple rounds of reassurances. Unable to stop Pedro's crying, the chief doctor tried to engage with Pedro by making a pre-announcement: "let's do something, Pedro," (line 4 in Excerpt 5.1). The doctor followed this up by announcing that she was going to leave, to give him some time to calm down and think, and that she would return later. Pedro, however, did not align with the doctor's second attempt to close the interview, and instead asked one final question: "and when will I be completely cu:red." (line 53 in Excerpt 5.3).

In the following extensive transcript, which has been divided into several excerpts for the purpose of analysis, I examine in detail Pedro's question, the subsequent responses, and Pedro's refusal to go along with them. Pedro and his parents (MOM and DAD) are accompanied by the head doctor (DOC1), as well as a second doctor and a nurse who mostly observe and do not intervene. They talk in Spanish, because Pedro and his parents are from Western Spain and do not understand Catalan. Taking Pedro as he lies down on his bed as the central point of spatial reference, the ecological arrangement of the participants is as follows. On Pedro's right, his mother sits next to his bed and his father stands behind her.

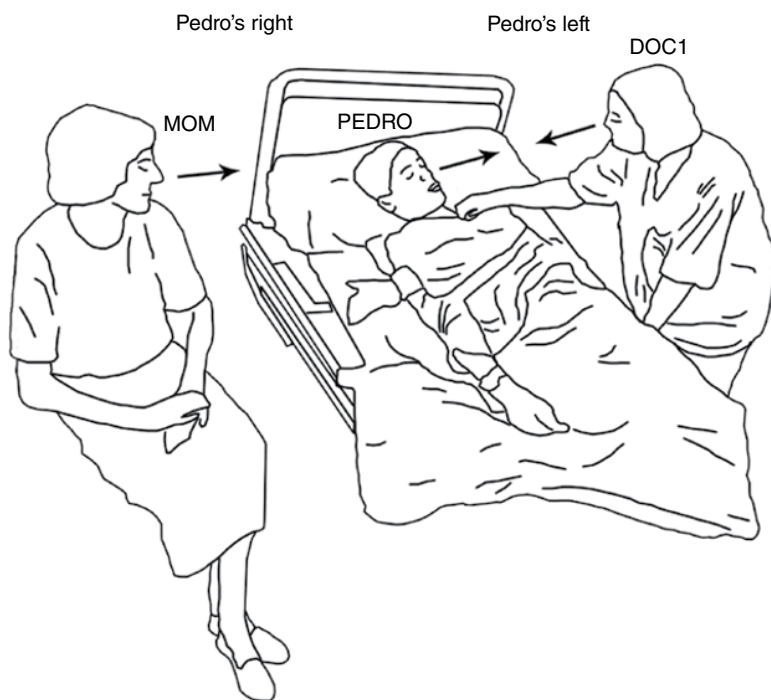
On Pedro's left, the chief doctor stands and leans on his bed. While crying, Pedro lies down on the right side of his body (see Excerpt 5.1, line 1, and Excerpt 5.5, line 97). His face and torso are oriented to his right. His right cheek, shoulder, hip, and leg are resting on the bed. With the left side of his body raised, Pedro's left arm is fully extended and crosses over his entire body and his right arm, as he grabs the lowered bedrail on his right. Because she is standing on Pedro's left, the doctor can only see his back. Unless the doctor moves to the right side of the bed, it is impossible for her to make eye contact with Pedro. Instead, she will try to enter his field of vision by leaning forward, almost hovering over Pedro's body, and by making Pedro turn around and face her.

In Excerpt 5.1, the doctor announces her plan to change the course of the treatment interview and to start moving to closure with "let's do something, Pedro," (line 4). The doctor's directive contains the first person plural of the verbal form "vamos" to include Pedro. Pedro may not know that the "vamos" includes him because he does not see that the doctor is staring at him. Pedro only turns his body around to look at the doctor after she summons him with the address term "Pedro," (line 4). In line 8, Pedro indicates with "e:::?" that he has some trouble hearing or understanding doctor 1's turn. While Pedro is turning, doctor 1 starts a second "let's do s-" in line 9 but does not finish it because of the overlap with Pedro's "e:::?". She starts and finishes a third "let's do something" after the end of the overlap and after Pedro has completed the turning around of his body.

Excerpt 5.1



- 1 PEDRO: [iXX
[iXX
- 2 [((back turned to DOC1))
- 3 (1.5)
- 4 DOC1: → [vamos a hacer una cosa, Pedro,
[let's do something, Pedro,
- 5 PEDRO: [hhh
[hhh
- 6 PEDRO: ((turns his body towards DOC1 while looking at her))
- 7 (0.9)
- 8 PEDRO: [(e:::?)
[(e:::?)
- 9 DOC1: [vamos a ha- [vamos a hacer [una cosa.
[let's do s- [let's do [something.



- 10 PEDRO: [((fully turned toward DOC1))
- 11 DOC1: [((places hand on
12 Pedro's shoulder))
- 13 (0.5)
- 14 DOC1: *te dejo un ratito.*
I'm going to leave for a little while.

- 15 (0.6)
- 16 DOC1: *vale¿*
okay¿
- 17 (1.5)
- 18 PEDRO: ((nods once))
- 19 DOC1: → *Pie:::nsa, (.) después vuelvo y si tienes más preguntas*
Thi:::nk, (.) I'll come back and if you have more ques-
tions
- 20 → *me las haces. [vale¿*
you can ask me. [okay¿
- 21 PEDRO: [((nods and starts to look away from DOC1))

Standing on Pedro's left at all times, the doctor places her hand on Pedro's left shoulder gently with her third repeat (lines 9 and 11–12). She does so affectionately but also locks Pedro in a body position that enables her to see Pedro's face. Pedro's new position facing the doctor (see Excerpt 5.1, line 10) is a provisional modification of his home position while crying (see Excerpt 5.1, line 1, and Excerpt 5.5, line 97). In this provisional position, Pedro's shoulders and torso are oriented toward the ceiling, as Pedro lies in a supine or face-upward position. His left arm continues to be oriented to his right, but he now grabs the right side of the bed instead of grabbing the lowered bedrail as he had done in his home position of crying. With a slight turn to his left, Pedro's face is visible to the doctor while in this provisional position. The fact that Pedro does not adjust his body completely in the direction of the doctor—abandoning the upward orientation of his torso and face and the rightward orientation of his left arm—is evidence that Pedro is not aligning himself for extensive talk with the doctor.

In line 15, Pedro produces no response after the doctor's announcement that she is leaving him for a bit. She pursues an agreement with "okay¿" in line 16, to which Pedro responds with one nod after 1.5 seconds of silence. The doctor instructs Pedro to follow a course of action while she is gone with the imperative "*Thi:::nk*,". She also adds that she will return later so that he can ask her more questions. In line 20, the doctor uses "okay¿" at the end of her turn to make a response from Pedro more pressing. Pedro is already nodding during the doctor's "okay¿" but also turns his head to his right and withdraws his gaze from the doctor.

Excerpt 5.2

- 22 DOC1: [*quieres [que te deje un ratito tranquilo¿°*
[*do you want [to be left alone for a little quiet time¿°*
- 23 PEDRO: [((continues nodding but his head is away from DOC1))
- 24 DOC1: [((lifts hand from Pedro's shoulder and
- 25 touches his cheek))
- 26 (0.2)
- 27 DOC1: [*sí¿°*
[*yes¿°*

- 28 DOC1: [((places hand on Pedro's arm and massages it))
 29 (0.9)
 30 DOC1: [*pe:ro_*
 [*bu:t_*
 31 DOC1: [((places hand on Pedro's chest))
 32 PEDRO: [((glances briefly at DOC1))
 33 DOC1: [*mmm_*
 [*mmm_*
 34 DOC1: [((grabs collar of Pedro's pajamas as Pedro looks
 35 away toward his parents))
 36 DOC1: → [*óyeme lo que te he dicho.*
 [*hear what I've said to you.*
 37 PEDRO: [*hh.Hh* ((looks towards his parents))
 38 DOC1: → [*lo más importante es que estés tranquilo=*
 [*the most important thing is that you=*
 39 DOC1: [((holding Pedro's pajamas collar))
 40 PEDRO: [((makes eye contact with DOC1))
 41 DOC1: → =*y confíes en nosotros.*
 =are calm and you trust us.
 42 (.)
 43 DOC1: [*va[le¿*
 [*ok[ay¿*
 44 PEDRO: [((starts to look away from DOC1))
 45 PEDRO: [*>sí sí<.*
 [*>yes yes.<*

In line 22, the doctor changes strategies verbally and nonverbally as she continues to pursue Pedro's alignment to close the interview. Instead of telling Pedro that she is leaving, she now asks Pedro if he wants her to leave him to have some quiet. She ceases holding Pedro's left shoulder. Her touch becomes less constraining as she touches his face (lines 24–25) and massages his left arm (line 28). Despite all of this, Pedro simply nods and looks away. The doctor insists on pursuing Pedro's alignment by giving him the answer that she wants to hear, “*óyes¿*” in line 27. However, this last move fails to make Pedro even look at her.

The doctor seems to admit failure and abandons her second attempt to close. She opens a new sequence, expanding the interview and transitioning to a different strategy of reassuring with “*bu:t_*” and placing her hand on his chest (lines 30–31). The doctor's “*bu:t_*” and gesture succeed in making Pedro glance briefly at the doctor. However, Pedro does not hold her gaze for long. The doctor seems to hesitate or search for a word in line 33. Pedro immediately withdraws his gaze and starts

Excerpt 5.3

The doctor now moves to reassure Pedro that he will be cured (line 46) and acknowledges that it must be hard for him to think about his hair falling out (lines 49–52). This reassurance again fails to draw Pedro's gaze, but introduces the topic of a cure. Apropos of this topic, Pedro asks a question that will create

later problems for the doctor (line 53): “y cura:o cu:rao al final pa cuándo.” A literal translation of Pedro’s question would be “and cure:d cu:red the end for when.” but I have chosen a more idiomatic translation: “and when will I be comple:tely cu:red. ”

Pedro begins to turn toward the doctor during the pause within the doctor’s turn. Even though the doctor’s turn has clearly not reached completion, he interjects his question. The doctor pauses for a full second (line 55) before responding that the treatment lasts a little less than a year. The doctor’s response does not quite fit Pedro’s question (Fox and Thompson 2010). Pedro asks when he will be completely cured, which precisely fitted to the doctor’s earlier answer “you will be cu:red,” (line 46). Whereas the referent of Pedro’s question is himself, the referent of the doctor’s response is the treatment. Moreover, his question also solicits a point-in-time reference for his cure, as opposed to asking for the duration of treatment. The doctor’s answer does not address the cure question, and instead of a point-in-time reference, provides a length of duration. There is more certainty in stating the date of the end of treatment than in stating the duration of the treatment. In brief, the doctor answers Pedro’s question with two key changes that are not too evasive. The doctor commits herself to what she knows, even if such a commitment results in an uncertain response.

There is stark contrast between Pedro’s interjecting question before the doctor actually finishes her turn, and his complete silence after the doctor’s answer. There is no acknowledgement of the doctor’s answer in line 57, not even after the doctor’s prompt in pursuit of some kind of response (line 58). In the absence of a response from Pedro, the doctor begins an extended reassurance in line 60. The doctor tells Pedro that after he ends the treatment, he will alternate between Gijón, where he will live, and Barcelona, where he will go from time to time for checkups. Unlike her previous reassurance “you will be cu:red,” (line 46), in which she states that Pedro will be cured, she now illustrates in detail how Pedro will have a predictable and uneventful future. Whereas illustrating Pedro’s future conveys more certainty than simply stating it would, the fact that the doctor does not use the verb “to cure” contributes to a sustained sense of uncertainty.

The doctor also inserts a quick joke addressed to his parents by saying that Pedro may like living in Barcelona and decide to stay there permanently (lines 61 and 64). Pedro does not join in the laughter, and stops looking at the doctor. In fact, he adopts again his home position of crying (see Excerpt 5.1, line 1, and Excerpt 5.5, line 97), and withdraws his gaze during the doctor’s joke, signaling a shift in Pedro’s alignment vis-à-vis the doctor’s talk. Before his question, Pedro looked at the doctor for short periods of time. During his question and the doctor’s answer, Pedro looks firmly at the doctor, and sustains his gaze until the doctor turns her eyes away to look at Pedro’s parents as she tells the joke. After the joke, Pedro withdraws his gaze not only from the doctor, but also from everybody in the room. He will not look at anybody even when his mother, the chief doctor, and a second doctor talk to him.

Excerpt 5.4

- 60 DOC1: → *y una vez acabado el tratamie:nto, (0.3) te irás a*
and once you've finished the treatme:nt, (0.3) you'll go to
- 61 *Gijó:n, (.) si qui[eres >a lo mejor le gusta y se queda=*
Gijó:n, (.) if you wa[nt >maybe he likes it and he stays=
- 62 DOC1: [((looks at parents, then MOM))
- 63 PEDRO: [((continues to look at DOC1))
- 64 DOC1: =v*ivir ya aquí en Barcelona.<[hhe::*
=to live here in Barcelona.<[hhe::
- 65 DOC1: [((looks at Pedro))
- 66 PEDRO: [((looks away from DOC1))
- 67 DOC1: *te irás a Gijón, (.) y en[tonces vendrá:s a visita=*
you will go to Gijón, (.) and th[en you will return to =
- 68 DOC1: [((looks at MOM))
- 69 DOC1: =*de ta:nto en ta:nto, (.) para ir contro[lándote.*
=visit from ti:me to ti:me, (.) to be che:cked on.
- 70 MOM: [sí:.
[ye:s.
- 71 (0.5)
- 72 MOM: → *[pero es que tampoco no estás todo el t tiempo [aquí.*
[but it's not that you will be here all the time [either.
- 73 PEDRO: [((complete gaze withdrawal, though MOM talks to him now))
- 74 DOC1: [NO:: no::
[NO:: no::
- 75 PEDRO: [((looks
- 76 at DOC1))
- 77 DOC1: [NO: no estás un año: aquí::_ [e::¿ ntx
[NO: no you're not here::: for a yea:r_ [e::¿ ntx
- 78 MOM: [*es un () después,*
[it's a () afterwards,
- 79 PEDRO: [*.shih* [iggk
[.shih [iggk
- 80 [((starts looking
- 81 towards DOC2))
- 82 DOC2: [()
[()
- 83 *ingresado [e::,*
hospitalized [e::,
- 84 DOC1: [No:.
[No:.
- 85 MOM: [No::[:.
[No::[:.

- 86 PEDRO: [iggk
[iggk
- 87 MOM: [(s)i te vas al pi::[so.
[but you go to the apa::rtme[nt.
- 88 PEDRO: [((complete gaze withdrawal, though MOM talks to him))
- 89 PEDRO: [Hhhuhh
[Hhhuhh
- 90 DOC1: no estás aquí un año aquí ingre[sa::do e::,
you won't be here hospit[ali::zed for a year e::,
- 91 PEDRO: [.hh .hh
[.hh .hh

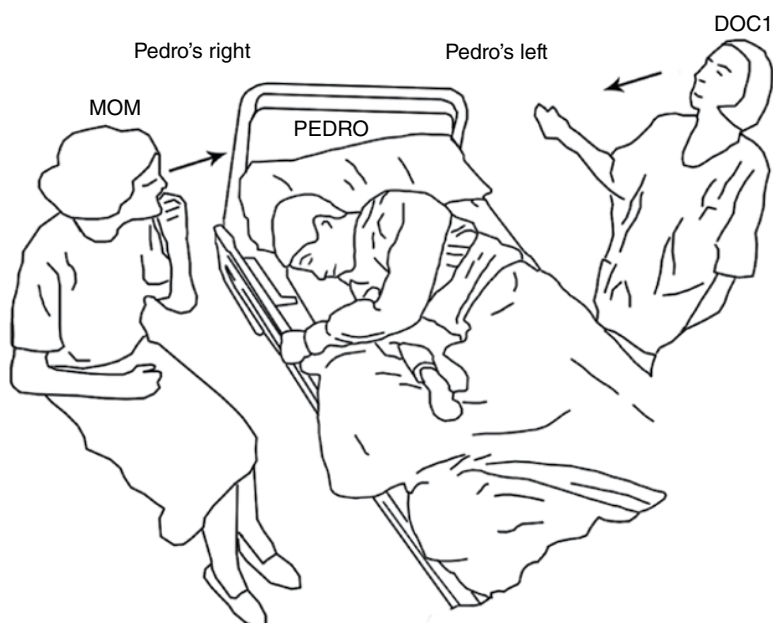
In line 67, the doctor indicates that she is picking up where she left off with a repetition of “you will go to Gijón,” but with Pedro looking away from her, she looks at Pedro’s mother, even though the doctor continues to address Pedro by using the second person singular. Overlapping with the doctor, Pedro’s mother agrees with her in line 70 and launches a second extended reassurance in line 72, illustrating another form of alternation between two locations in Pedro’s future. In a competitive environment of intense overlap, this second reassurance exemplifies and reiterates the doctor’s idea of alternation and constitutes an upgraded agreement beyond “yes” (Aiarzaguena et al. 2013). Pedro’s mother begins by telling him that he will not be at the hospital all the time during the treatment itself. In the doctor’s illustration, Pedro alternates between Gijón and Barcelona after the end of the treatment. In his mother’s illustration, he alternates between hospitalizations for chemotherapy administration and periods of rest in the apartment for the families next to the hospital during the treatment. However, Pedro’s mother’s illustration can be heard as including an implicit criticism of the doctor’s first illustration, because she states that the alternation between two locations starts during the treatment and is not limited to what happens to Pedro after the end of the treatment. In terms of securing Pedro’s alignment, his mother’s illustration does not fare much better than the doctor’s. The mother starts addressing Pedro using her gaze and the verbal second person singular, but by the end of the turn she looks at the doctor. Neither of the two extended reassurances that illustrate Pedro’s future elicits any aligning response from him.

Pedro’s mother’s turn (line 72) unleashes an intense choir of negations that Pedro will be continuously hospitalized for an entire year. The overlapping—and overwhelming—negations made by doctor 1, doctor 2, and Pedro’s mother extend from line 74 to line 85. The negation of continuous hospitalization dominates the rest of the interview. In line 90, the doctor uses it to launch a third predictable and uneventful illustration of Pedro’s future treatment (line 92). She returns to the negation of the continuous hospitalization one final time as she produces a summation during her third attempt to close the interview (see lines 121 and 125 in Excerpt 5.5).

In line 79 of Excerpt 5.4, Pedro starts crying again with all the commotion of “NO:: no:.” From now on, Pedro’s in-breathing and out-breathing sobs overlap at places of possible completion, for instance, as somebody else’s turn is finishing or starting. Despite the litany of negations, Pedro’s mother continues with her illustration of alternation between two locations. Subsequently, the head doctor modifies a repetition of her previous turn from line 77 “NO: no you’re not here::: for a year: r e::¿” and incorporates in line 90 the word “hospitalized” used by doctor 2.

Excerpt 5.5

- 92 DOC1: → = [estarás aquí [unos día::s,=
= [you’ll be here [for a few day::s,=
93 DOC1: [((leans forward to enter Pedro’s field of vision))
94 PEDRO: [.hhh [.shih
[.hhh [.shih
95 PEDRO: [((continues complete gaze withdrawal))
96 DOC1: = [para hacer la medi[cació:n, [se i:r[á::¿
= [to take the medi[catio:n, [and he’ll [go::¿



- 97 DOC1: [((leans back)) [((makes eye contact with mother))
98 DOC1: [((here-there hand gesture))
99 PEDRO: [HHuh [hh
[HHuh [hh

- 100 MOM: [después se va::¿
[after he goes::¿
- 101 MOM: [((here-there hand
102 gesture))
- 103 (0.2)
- 104 DOC1: [>al cabo de unos días< volverá::, >le haremos [un<=
[>after a few days< he'll return::, >we'll do [a<=
- 105 PEDRO: [hhhih [hhh
[hhhih [hhh
- 106 DOC1: =aná:li:si:s, [>se volve:rá a< ma:rcha::r,
=t:e:s:t, [he'll lea:ve< a:ga::in,
- 107 PEDRO: [Hhhuhhh
[Hhhuhhh
- 108 DOC1: >una semana más tarde< volverá a ve:ni[::r, e iremos=
>a week later< he'll co:me ba[::ck, and we will=
- 109 PEDRO: [.hhh
[.hhh
- 110 PEDRO: [((stops complete
111 gaze withdrawal and
112 lifts head to look
113 at nurse walking in))
- 114 DOC1: =haciendo así,
=continue like this,
- 115 (0.3)
- 116 PEDRO: hh[hhhh
hh[hhhh
- 117 DOC1: [e::¿
[e::¿
- 118 DOC1: ((leans forward to make eye contact with Pedro, as he is
119 still with his head up looking at the nurse walking in))
- 120 (0.5)
- 121 DOC1: [no no es estar ingresado todo el [tiempo, <ni=
[no you won't be hospitalized for the whole [time, <by=
- 122 DOC1: [((stretches neck to be in Pedro's visual field))
- 123 PEDRO: [((still holds head toward door)) [((full gaze
124 withdrawal))
- 125 DOC: =mucho menos, faltaría má:s.
=no means, not at all.
- 126 (0.3)
- 127 DOC1: [e::?
[e::?
- 128 (1.8)

- 129 PEDRO: [((continues complete gaze withdrawal))
 130 NUR2: [((outside conversation))
 131 DOC1: → *yosotros los papá:s* (0.4) [*teníais que hacer=*
 you the pa:rents (0.4) [did you have=
 132 PEDRO: [((turns to look at DOC1))
 133 DOC1: → *=al[guna pre[gunta?*
 =*an[y ques[tions?*
 134 PEDRO: [.hhhh
 [.hhhh
 135 PEDRO: [((turns to look at MOM))
 136 MOM: No.
 No.

Beginning at line 92, the chief doctor relies on an array of verbal and nonverbal resources to construct a detailed and extended reassurance that illustrates Pedro's highly predictable future treatment. The doctor not only describes Pedro's predictable and unproblematic future treatment, but also creates an experience of such a future. Relying on prosodic, gestural, and grammatical constructions, the doctor crafts an illustration of Pedro's future that exemplifies predictability and repetitiveness.

The illustration is highly melodic and rhythmic with a cyclical upward-downward intonation. The rhyme is achieved with (1) the Spanish morphology of the future tense with all the verbs ending with “-rá” for the third person singular and “-rás” for the second person singular; (2) the word stress on this last vowel “á,” which rhymes also with the stress on the last syllable of verb form “va” (line 101) and “marchar” (line 106); (3) the elongation and repetition of the same sound “a”; and (4) the prosodic stress and contour of the entire turns, with a dramatic rise and drop of this last vowel “a.” Another prosodic feature that contributes to this predictable rhyme is the multiple turn constructional units that have a similar semi-falling final intonation indicated in transcript by the “,” or “¿” symbols. This intonation is often used to list items.

The doctor also repeats the verb “volver” three times. Alone, “volver” translates as “to come back,” but in the periphrastic construction “volver + infinitive verb,” it translates as “to do something again.” The turns have predictable and parallel syntactic constructions, as in “he will do this again, and he will do that again, and he will do this again ...” The circularity of “coming and leaving” and “here and there” is emphasized gesturally with the doctor's rotation of her arms horizontally over each other. At the same time, the circularity is not completely close-ended, with the beginning and end coinciding. Instead, it is a cyclical moving forward with vague temporal references “for a few day:s,=” (line 92), “[>after a few days<” (line 104), and “>A week later<” (line 108). The doctor closes the illustration of Pedro's most immediate future with an open-ended and cyclical “and we will continue like this,” (lines 108 and 114).

As with the doctor's illustration of what will happen after the end of treatment, and Pedro's mother's illustration of what will happen during the treatment, this third illustration of Pedro's uneventful and predictable future is a joint production of the chief doctor and Pedro's mother. Pedro cries and refuses to look at anybody, despite the fact that his mother is talking to him (line 87) and that the doctor begins her telling while simultaneously leaning forward to enter his field of vision (lines 92–93). In addition to aligning herself as a recipient, Pedro's mother collaborates in other ways. For instance, she offers another event in the doctor's list of repetitive events. The doctor says "he'll go::ɹ" (line 96), and Pedro's mother adds "after he goe::sɹ" (line 100). Despite the difference in verbal tense and the additional word "later," the two formulations are quite similar. Collaboratively completing somebody else's turn (Lerner 1991, 1996), Pedro's mother displays that she is so well aligned with the doctor that she can "read and guess" what the doctor is going to say next.

Moreover, Pedro's mother quotes the same here–there gesture that the doctor produces, moving her hand from the front of her chest to indicate "here," to a "there" with an extended arm away from her body. More importantly, they seamlessly transition from a shared focus on Pedro to a recognition of each other as the two people who are going to keep the telling going. They both use the third person singular to refer to Pedro, whereas seconds earlier, they spoke to Pedro using the second person singular. Although there is no verbal acknowledgment, the doctor does not continue until the mother has finished.

This last extended reassurance illustrating Pedro's future ends with the open-ended "we will continue like this," (lines 108 and 114). The doctor returns with a variation of the earlier theme of "you won't be hospitali::zed a for year e::," and moves to close Pedro's interview for the third time (line 121). This time, though, she does not address Pedro, who is not looking at anybody at that moment. Instead, the doctor addresses his parents, who align themselves with a succinct "no." spoken by Pedro's mother. At this interactional crossroad, the head doctor finds herself in the predicament of closing the interview with Pedro visibly disengaged, or trying to obtain Pedro's alignment to close it again. She tries a fourth and a fifth time (data not shown here), and is eventually able to elicit an "okay" and "see you later" from him. Pedro's treatment interview, which was designed to inform Pedro, continues for a more few minutes and concludes with his minimal engagement while the head doctor talks mostly to his parents, who already know this information.

Following my turn-by-turn analysis of the excerpts, I want to make two observations on the entire exchange concerning the organization of Pedro's crying and its impact on the ongoing talk, and the contrast between Pedro's question and the doctor's responses. In regard to Pedro's crying, Pedro is participating in the interaction with his crying. His crying is organized in reference to the ongoing talk and simultaneously has an impact on how the talk

progresses. In other words, Pedro's crying does something in addition to expressing his emotions (Heath 1989; Hepburn and Potter 2007; Katz 1999; Peräkylä and Sorjonen 2012; Wilce 2009b). The sequential placement and intensification of Pedro's sobbing could be interpreted as displays of disagreement with—perhaps disapproval of—how the interaction is proceeding, first with him and later without him. Pedro does not begin to cry after the response to his question, but rather once the chorus of “you won't be hospitalized for a year” begins. The louder the conversation, the more reassurances, and the more people reassuring him that the treatment will be unproblematic, the more Pedro cries. Before that happens, the doctor tries hard to have Pedro look at her and act as the recipient of her talk. Pedro does not align himself with the doctor's move to close the treatment interview; he does not come in with uptake or acknowledgment of her talk at silences, pauses, or the doctor's many pursuits of some kind of uptake; and he hardly responds to her commands to remain calm and to trust the doctors. Pedro only holds the doctor's gaze during and after his question about when he will be completely cured. Furthermore, Pedro's sobbing comes at places of possible completion, at the point of possible transition between speakers. Despite the fact that he is not looking at anybody in particular, Pedro could be trying to elicit displays of sympathy and empathy (Hepburn and Potter 2007). He could also be looking for acknowledgments of his suffering, or his anger, rather than reassuring talk designed to make him feel better. Another interpretation, which does not preclude the previous ones, is that Pedro could be protesting that the doctor and his mother have continued talking despite his own stopping (e.g., I am stopping, and I want you all to stop too).

In regard to the contrast between Pedro's question (“and when will I be completely cured.”) and the doctor's (“the (.) treatment la:sts (0.8) a little less than a year.”), both turns are remarkable. On the one hand, Pedro asks a question that does not have an answer. Nobody knows if and when Pedro will be cured. By asking about something that is unknowable, Pedro requests information about the most uncertain aspect of his *new* future, as somebody who *now* has cancer. Perhaps because of the doctor's prior lexical choice of “cure,” and perhaps to the doctor's relief, Pedro's question is at least positively formulated: he does not ask if he will be cured, or if he will die. Pedro asks when he will be completely cured, which presupposes or assumes that he will in fact be cured.

On the other hand, the doctor's answer (“the (.) treatment la:sts (0.8) a little less than a year.”) constitutes an answer—evasive, partial, and narrow, but an answer after all. As observed in responses to the questions of other children, the doctor could have responded with a reassurance or a lighthearted tease. The doctor's answer is brief and narrowly focused. Almost camouflaged syntactically, her answer makes a temporal reference to match Pedro's “when,” but it is temporal reference for something that Pedro has not asked about.

The brevity and flat delivery of the doctor's evasive and partial answer stand in contrast to what comes next. First, the doctor moves unilaterally without waiting for Pedro's acknowledgment that she has just answered his question, to construct Pedro's uneventful and routine life after the end of the treatment. Second, the doctor dwells on her illustration of Pedro's future, which is more expanded than her answer. Third, in its routineness and predictability, the doctor's illustration of Pedro's future is certain, optimistic, and lively: Pedro is alive, without complications, going back and forth between Barcelona and Gijón, and liking Barcelona so much that he may move there. Fourth, whereas the doctor does not address when Pedro will be cured in her answer, Pedro leads an unproblematic life after the treatment in her illustration of Pedro's future. Fifth, I believe that the doctor's serious answer is evasive, brief, and flatly delivered, whereas the melodic and rhythmic illustration works as a reassurance. Finally, neither her serious answer nor her expanded reassuring illustration contains much specific information about the treatment and the post-treatment period. The only specific detail is Pedro's hometown Gijón. Otherwise, this generic optimistic illustration of Pedro's future could be any other patient's future.

The doctor's generic uneventful illustrations of Pedro's future during and after his treatment exemplify the interest of clinicians to co-construct future experiences as part of the therapeutic process (Mattingly 1998). They demonstrate that narratives about the future are not merely descriptions of future plans, but *preconstructions* of future experiences (Ochs 1994: 108, emphasis in the original). However, the doctor's illustrations of Pedro's future also show the failure of the patient's cooperation and alignment with such preconstructions. In contrast to his mother's collaboration, Pedro refuses to provide the most basic form of interactional involvement, which is to look at the person who is talking.

In addition to the question "and when will I be comple:tely cu:red."), Pedro asked many other pertinent questions during his treatment interview, such as "Will it (my leg) be the same way as before (the surgery)? or "Chemotherapy makes your hair fall out, right?" However, what happened during his interview and after it was strikingly different. As I describe at the beginning of the book, Pedro asked his parents to confirm he had cancer immediately after the doctors left, even though the doctors never used the word "cancer" during his interview. Pedro never asked his doctors if he had cancer, and I never heard him using the word "cancer" again over the following five months. Furthermore, Pedro stopped asking questions. In the 14 subsequent medical visits I recorded, he did not start to ask questions again until the last two visits in October 2001. During these four months, his strategy—or his depression or his way of coping, I am not qualified to say—was to sleep through everything. To the envy of other parents and patients, he slept through chemotherapy treatment, but also slept through many morning ward rounds, as well as through the visits from the pediatric psychologist and from me. He only began to ask questions again after his tumor was removed, and as he was getting ready for a trip to his home in Western Spain.

Six Communication Strategies

I began this chapter by describing how three young people—Robert, Dani, and Pedro—found out they had cancer during the pre-treatment period. Robert and Dani were told about their cancer diagnosis during the period of testing, whereas Pedro found out during his treatment interview. Despite the difference in how they “found out,” these three young individuals’ experiences reflect the five interrelated communication strategies that I have identified for the management of diagnostic and treatment information, especially bad and uncertain news. During pre-treatment, a highly uncertain and terrifying period of endless testing, patients encountered deception, official and planned complete non-disclosure, unofficial leakage and gathering of information, unplanned and improvised partial disclosure, and the concealment of emotions. This combination of often contradictory strategies illustrates the absence of a concerted effort to keep patients informed or to hide information from them. The different physicians involved (i.e., primary care physicians, specialists, and pediatric oncologists) neither knew nor tried to find out how much the other physicians had already told the patients. In the chaos of diagnostic testing, parents and physicians had not coordinated how information would be handled either. Patients, underinformed or misinformed, found out about their diagnosis in improvised news deliveries, or gathered information unofficially from other patients.

The treatment interview, designed to inform the young person about the treatment, was a turning point in young people’s cancer trajectories and represented the introduction of the sixth communicative strategy of official and planned partial disclosure. Patients were told they were about to start treatment, and implicitly, that they had cancer. A closely negotiated and monitored form of partial disclosure, strongly advocated by doctors and often against parents’ wishes, replaced deception, official and planned complete non-disclosure, and unplanned and improvised partial disclosure. The unofficial leakage and gathering of information and the concealment of negative emotions continued.

If patients did not know already, they learned quickly how to talk about cancer without using the word “cancer,” what to talk about (i.e., a focus on certainty and the present course of treatment), and what not to talk about (i.e., the uncertain past and future). However, like Pedro, there were some young people who were not willing to accept some of the features of these strategies, although they did not challenge them openly. Instead, with question after question, they pushed the limits of disclosure and the uncertainty that was kept at bay. On other occasions, they manifested their unwillingness to go along with doctors, as Pedro’s crying and his avoidance of eye gaze illustrate.

Through the ethnographic analysis of the five communicative strategies that Robert, Dani, and Pedro encounter as they begin their cancer trajectories, as well the turn-by-turn analysis of the sixth strategy of partial disclosure during Pedro's treatment interview, I have presented the different and often contradictory strategies that were adjusted according to patients' changing circumstances over the approximately 12 months of bone cancer treatment.

Patient Pressure and Medical Authority

Key Issues

- *During treatment, both planned and improvised strategies of partial disclosure predominate.*
- *As months of treatment go by, children, parents, and hospital professionals come to know each other very well, and medical and personal aspects of their lives become intertwined.*
- *In their social position at the bottom of family and medical hierarchies, children exert pressure on doctors by initiating courses of actions (i.e., by asking questions) and by insisting on completing them (i.e., by pursuing answers).*
- *Without challenging medical authority, patients engage with doctors in “cat-and-mouse game” negotiations over when a patient’s question has been conclusively and sufficiently answered.*

Focusing on the local uncertainties associated with the present or immediate future of treatment, this chapter examines how patients exert pressure on doctors. Patients, especially young people, try to find their place in the treatment “chains of command” of family and hospital. As they do this, they also push the limits of what doctors may be willing to talk about with them. These negotiations take place over approximately 12 months of treatment for first line, or primary, treatment of pediatric osteosarcomas, which involve multiple therapies, including the surgical removal of the bone tumor and alternating hospitalizations for chemotherapy administration and recovery periods at home or in the apartments for displaced families. Unlike in the pre- and post-treatment periods, doctors do not resort to deception and complete non-disclosure during first line treatment. Instead, partial disclosure of treatment information, both planned and improvised, predominate. Unofficial leakage and gathering of information, as well as the concealment of negative emotions, occur in all three periods.

In the first part of this chapter, I examine ethnographically Robert’s and Anna’s experiences to illustrate how life intersects with treatment at Catalonia Hospital.

As they deal with treatment and its unpredictable problems, patients, parents, and doctors become very familiar with each other. Young people become immersed in the world of friendships and dating, they fight constantly with their parents and engage in mutual—but asymmetrical—teasing and joking with doctors. I pay special attention to the management of anger displays, which are regulated differently than other negative emotion displays, such as crying or talking about fears. Whereas patients of all ages frequently display anger with parents and volunteers, they are rarely seen to cry during treatment. In 15 months of fieldwork, I never saw Anna or Robert cry once. Anna never spoke about her fears with the doctors, and only once did Robert talk about his fears with them (see Excerpt 6.5). Another aspect of the management of anger displays is that patients and parents display their anger with each other in front of doctors, but they never direct their anger displays at doctors.

In the second part of this chapter, I focus on a situated analysis of an interactional *back-and-forth* negotiation between Robert and the head doctor. Robert exerts pressure by using different strategies of questioning as he progressively tries to corner the head doctor into answering his questions. The doctor responds with teasing, reassurances, contingent answers, narrow answers, non-answer responses, and forestalling in order to give as little information as possible without appearing overtly evasive. Being seen as evasive has the risk of alarming the patient. Because the delivery of bad news is often postponed and/or withheld, recipients of news tend to assume that if news is withheld, it must be bad. Therefore, the doctor withholds information while simultaneously avoiding silence.

Everyday Life in Treatment

The experiences of Robert and Anna are similar, yet distinctive. Robert is a 17-year-old with bone cancer and lung metastases. He dyed his hair blue after finding out he had cancer, and went through a difficult period when his close friend and fellow cancer patient Felipe died in the hospital room next to his. Robert was a consummate flirt who acted like a “*nen petitó*” (a young little child) when he needed his mother but pushed her aside when he was pursuing girls (see Chapter 3). His mother fought with him not only because of how he treated her, but also because of constant disagreements over treatment administration. Anna is a 16-year-old girl with bone cancer who was often alone in the hospital because her mother or one of her sisters left to talk to other people around the hospital, or to go sightseeing and shopping in Barcelona. Anna fought with her mother and sisters because she often felt abandoned, and because they were not as well informed as she was about the details of treatment.

Anna and Robert were young people from working families who lived in small rural towns in central Catalonia, a 60- to 90-minute drive from Barcelona. The logistics of both of their treatments were highly complex. Unlike families

who lived in Barcelona's metropolitan area, Anna's and Robert's mothers lived too far to go home to shower and rest, and needed to stay in the apartments for displaced families during chemotherapy hospitalizations. However, their homes were not far enough to justify living in the apartments during the recovery periods between chemotherapy sessions. Anna's and Robert's mothers were constantly shuffling their things between the apartments and their homes. Furthermore, neither mother drove, which meant that their lives were dominated by a dependency on scheduling taxis and ambulances to take them back and forth.

The complicated logistics of treatment led both mothers to stop working altogether and become full-time caregivers, which added financial strain to their many other sources of stress. Both mothers also were the primary parent taking care of their children. Robert's parents were separated; I only saw Robert's father once in the hospital. Robert's mother was in a new relationship, but her partner only started to come to the hospital later in Robert's treatment and was not involved in decision-making. Robert's mother was the sole parent making decisions, which may also explain why she shared her decision-making with Robert. Anna's mother was also making decisions alone and involved Anna in her decision-making. She was taking care of six daughters, her disabled and chronically ill husband, and often her grandson. To help their mother, Anna's older sisters, both in their early 20s, would accompany Anna to the hospital from time to time. Among other factors, the alternation between her mother and sisters meant that nobody knew all the details of Anna's treatment as well as she did. Thus, Anna's mother relied heavily on Anna's knowledge to make decisions.

Anna and Robert were immersed in the world of dating, but their experiences were quite different. Robert, as a consummate flirt in a pediatric cancer unit run by women, used his charm with the doctors and even his mother. His flirting was somewhat naïve, and was rarely sexual in nature. More often than not, he used his charm to convince others to agree with him and to obtain favors. He was also the first to laugh at himself when his flirting led nowhere. Robert always had a girlfriend, or a prospective one. At the beginning of treatment, his romantic interests were other patients with cancer, but later, his interests expanded to young nurses and girls from his hometown. Anna, on the other hand, had a harder time dating. She lacked the self-confidence to flirt, although she was a very funny and outgoing girl. She also had an ongoing weight problem, about which she, her mother, and her sisters made negative comments. Anna had to compete for attention from the few men in the pediatric unit not only with other female patients and the young nurses but also with her mother and sisters. Anna's sisters were only a few years older than the patients and a few years younger than the nurses. Anna's sisters exchanged text messages with other patients and nurses, and hung out with them without Anna. This infuriated Anna on many levels: she felt abandoned and left out. Whereas Robert was an active player in the hospital dating scene, Anna focused her time collecting information about who was speaking to whom, and who was interested in dating whom.

Patients and parents had to contend with the uncertainties associated with chemotherapy, and also with the uncertainties associated with the prosthesis that was placed after the surgical removal of the bone tumor. Anna's left leg was salvaged and, with the placement of an internal articular graft prosthesis, amputation was avoided. Prostheses can become infected, loose, or broken, which requires additional treatment, surgeries and amputation if nothing else works. When everything goes well, the internal prosthesis still requires additional surgeries to lengthen it as the child grows up. Oriol, a 16-year-old boy with a bone tumor in his left leg, and Anna developed wound infections, necrosis (death of soft tissue), and dehiscence (wound ruptures along the surgical suture). They were unable to walk for a long time even after the end of chemotherapy, and eventually Oriol required plastic surgery. Quique fell down but did not require surgery, but when Marc fell down, his prosthesis became loose, and he underwent more surgery. Gemma's leg was ultimately amputated after her wound from the internal prosthesis surgery did not heal. Anna's problems with her prosthesis were physically but also emotionally painful. Because of her weight, she spent additional time in a wheelchair, which exacerbated her weight problem. She later started walking with two crutches, and began walking with one crutch during the last few months of treatment. After the end of chemotherapy, she began to walk freely but was soon confined to the wheelchair again because of another wound infection. Oriol, Marc, and Quique also were in wheelchairs after the end of first line chemotherapy, and Santi and Gemma, who had already relapsed once, were able to walk—with external prostheses after amputation—after the end of their second line treatments.

The intersection of everyday life and treatment over a period of at least 12 months resulted in patients and doctors becoming very well acquainted with each other's idiosyncrasies. As evidenced by the medical interactions with seasoned patients such as Robert, Anna (Chapter 4), and Toni (Chapters 4 and 7), doctors and patients often developed joking relationships of reciprocal teasing (Radcliffe-Brown 1940, 1949). This teasing is asymmetrical but occurs in a context in which doctors and patients display their fondness and affection for each other. The familiarity between patients and doctors is also evident in other ways. Patients know the hierarchy within the pediatric staff, including the differences between head doctors, attending doctors, and residents. Patients also become more assertive as they learn how doctors react and figure out how much they can—and cannot—get away with.

With the passing of months of treatment and the added strain of confined hospital life, children become more comfortable displaying their anger with their mothers (most commonly) during medical interactions. During his treatment interview, Pedro was furious, but waited until the doctors were out of his room to unleash his fury with his parents. Robert stormed out of the surgeon's office after he found out he had cancer. Marc, a 6-year-old boy with a fiery temper, wore his mother out to the point where she asked for help because she could not control him. Mother-child "yelling" relationships are typically asymmetrical:

mothers sometimes yell at their children, but most of the time, children yell at their mothers. Like Robert and his mother, Anna had long arguments with her mother about her medication, what side effects she was experiencing, when she would be well enough to be discharged, who was at fault for her weight problem, and when to schedule ambulances or taxis to go home. As in Robert's case, Anna and her mother's arguments during medical visits were heated (see Chapter 4). In such situations, doctors wait until parent and child resolve their issues themselves before moving on, or try to broker an agreement if the argument goes on for too long.

Anna did not direct her anger at the doctors, but nonetheless held them accountable for their actions without openly confronting them. She relentlessly asked questions, and used charm, teasing, and humor to let them know what she wanted. Around the time of her hospitalization discharges, Anna often told doctors she was fine and tried to convince them using questions such as “☺°I'm well, aren't I.°☺” (see Chapter 4), with a broad smile and a charming voice. She even jokingly corrected junior doctors and residents. She told a resident that he owed her several written reports without which she could not be discharged, and asked him not to leave them for the last minute so she would not be home too late in the evening. When Anna was admitted to Catalonia's Hospital ER for a wound infection, a junior doctor forgot to include the night of the ER in the total number of days Anna had been on medication for her wound. Anna corrected her, and although it took a while, the junior doctor admitted in front of two senior doctors that Anna was right.

Like Anna's strategies to pressure doctors and hold them accountable without confronting them, Robert used questions to pressure doctors for information. He engaged in a “cat-and-mouse game” with the head doctor as he tried to find out as much information as he could about his next course of treatment. In this context of asymmetrical teasing relationships and great familiarity between patients, parents, and doctors, Robert demonstrated his knowledge of the treatment and of the doctors, and his expertise in pushing the limits of what doctors are willing to talk about, without confronting medical authority.

“How Many Chemos Do I Have Left?”

I now turn to the situated analysis of Robert's questioning pressure that takes place during morning rounds. Robert's question “How many chemos do I have left?” marks the beginning of a long interrogation consisting of several lines of questioning. Robert uses different types of questions to exert pressure and to obtain information. When one line of questioning yields no more information, Robert shifts questioning strategies. Robert's questions do not explicitly cast doubt on the effectiveness of the treatment, project a pessimistic future, or target the overall uncertainties associated with cancer. He carefully remains within the limits of talking about the present course of treatment and the immediate future.

Still, doctors treat Robert's questions as implicitly referring to or potentially leading into delicate matters. As I show in the following excerpts, doctors respond to Robert's questions with playful teasing, downplays of his fears, invitations to optimism, and confident reassurances. In this manner, doctors treat Robert's questions, and the very fact that he is exerting so much pressure, as displays of Robert's anxiety and worry. To understand how and why interactions between doctors and young people can be fraught with tensions and frustration, it is important to examine the particular ways in which social actions such as questions and answers are initiated, pursued, and dealt with. In the turn-by-turn analysis of the negotiation between Robert, his doctor—and to a lesser degree, his mother—we can observe the specific features of his doctor's answers that Robert interprets as unforthcoming, and the specific features of Robert's questions that his doctor interprets as displays of anxiety.

As with Pedro's extensive transcript in Chapter 5, the transcript of Robert's interaction with his doctors has been divided into excerpts for the purpose of analysis. To contextualize these excerpts, I need to provide some background information about a special chemotherapy, referred to as transplant or autotransplant, that is the subject of Robert's questions. Robert's autologous peripheral blood autotransplant is a type of stem cell transplantation therapy in which he receives his own stem cells after a period of very intense high-dose chemotherapy (Pizzo and Poplack 2011). The autotransplant is a complex, long, and painful treatment. During much of the hospitalization (which can last from about three or four weeks up to seven weeks or longer, depending on the patient's ability to create new blood cells), the patient is so severely sick that strict preventive isolation is enforced to prevent any type of infection. The patient cannot leave his or her room at all, doors and windows are permanently closed, and the very few persons who are allowed into the patient's room wear mouth masks, sterile hospital clothing, and covers for head and shoes.

Excerpt 6.1 begins after the doctors have examined Robert's mouth. Robert has already completed seven months of first line chemotherapy treatment, and is expected to finish in four more months. Robert is a high-risk patient because of his diagnosis of bone cancer and lung metastases. Having recovered from multiple surgeries, Robert tolerates treatment well, has had no recent infections, and can sleep through the chemotherapy sessions. Robert's appetite has increased dramatically, and he has even gained weight.

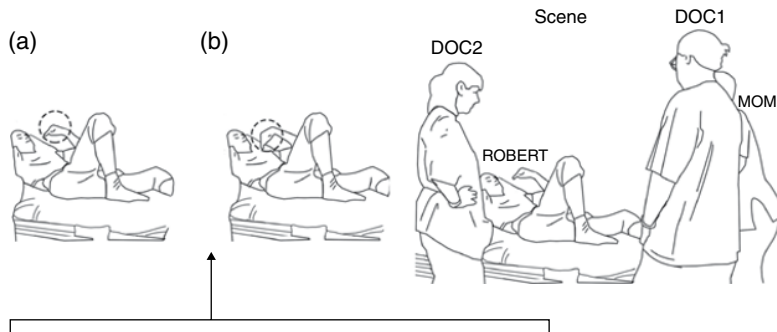
During the exam of Robert's mouth, the doctors and Robert's mother have joked about the bad condition of Robert's teeth. His teeth are in even worse shape because of the chemotherapy. Robert's mother asks whether she can take Robert to the dentist or if she needs to wait until the end of the cancer treatment. When Robert's mother asks her question, she stands next to doctor 1 at the foot of Robert's bed (see "Scene" in Excerpt 6.1, line 3). Robert's mother and doctor 1 face Robert, who is lying down, and doctor 2, who stands next to him.

Robert takes advantage of the interactional occasion created by his mother's questions to launch his own questions about the end of treatment. In his first question

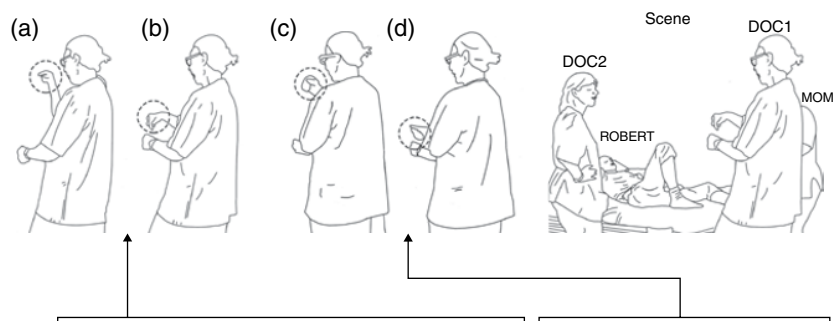
(line 3), Robert asks about the date of the autotransplant that will constitute the official end of his treatment, but he does not use the word “autotransplant.” Instead, he uses a gesture to indicate the autotransplant, embodying the action of sticking a catheter into his collarbone. The autotransplant requires the placement of a special central venous catheter in the patient’s subclavian vein, right below the collarbone. Accompanying his gesture, Robert asks the question “when wi:ll (.) they stick me with that:.” Robert’s question overlaps with his mother’s talk, as she describes a previous visit to the dentist (lines 1–2). Doctor 2 is the recipient of Robert’s mother’s talk, while doctor 1 is the recipient of Robert’s question. When Robert’s mother and doctor 2’s conversation comes to a close (line 5), they both turn their attention to the exchange between Robert and doctor 1.

Excerpt 6.1

- 1 MOM: *i de seguida:=*
right away:=
- 2 MOM: *=[amb els antibiòtics (.) va [pr[endre això,*
=[with the antibiotics (.) he [to[ok this,



- 3 ROB: → *[quan em:::ll (.) clavaran a[ll[ò:..*
[when wi::ll (.) they stick me with [th[at:..
- 4 DOB2: *[millorar.*
[improved.
- 5 MOM: *va anar molt bé de [seguida,*
it went very well right [away,
- 6 DOB1: *[què vols que et*
[what do you want them to stick you
- 7 *claven,*
with,
- 8 (0.3)
- 9 ROB: → *allò, (.) no m'ha(s) de: (.) posar un:::a cosa aquelles,*
that, (.) don't you have to: (.) put o::ne of those things,
- 10 (0.3)



- 11 DOC1: *a[::, diu quan em cla[varan allò l'e:sta:ca:.=*
oh[::, he says when they'll st[ick me with that the sta:ke:.=
- 12 DOC2: *[una estaca al cap, [h h h*
[a stake in the head, [h h h
- 13 MOM: *[mhh h hh*
[mhh h hh
- 14 DOC2: *=[l'estac(h)a,*
=[the stak(h)e,
- 15 DOC1: *=[n(h)i qu(h)e(h)- ni que fossis un vampir[o=*
=[l(h)i k(h)e- like you were a vampir[e=
- 16 MOM: *[h*
[h
- 17 DOC1: *=di(h)u h [qu(h)an em cla(h)var(h)an=*
=he s(h)ays h [whe(h)n w(h)ill they st(h)ick m(h)e=
- 18 DOC2: *[h h h h h*
[h h h h h
- 19 DOC1: *=[allò. tsh h h*
=w(h)ith [that. tsh h h
- 20 ROB: *[re no sé com es di[u.*
[nothing I don't know what it's [called.
- 21 DOC1: *[vaig a buscar*
[hey I'm going to
- 22 *l'estaca tu, i ia et [clavaré.*
look for a stake, and [sure I'll stick you.
- 23 MOM: *[el catèter.*
[the catheter.
- 24 *(.)*
- 25 DOC1: *[.h:::*
[.h:::
- 26 ROB: *[do::ncs això.*
[so:: that.
- 27 DOC1: *el catè:ter, pues no me'n recordo.<ara miraré: el*
the cathe:ter, so I don't remember.<I'll loo:k up the

28

protoco:l:, e:l programa com el [tens.
pro:tocol now, the: program how [you have it.

Robert's question (line 3) encounters problems from the beginning. Doctor 1 fails to recognize what Robert is inquiring about, and initiates a repair insertion sequence to find out what Robert is saying (line 6). Repair is a set of practices through which speakers address problems in speaking, hearing, and understanding (Kitzinger 2013). With the repair initiation, Robert's question is suspended until the problem of understanding is resolved. Robert tries to address doctor 1's confusion. He answers her repair question by repeating "that" (line 9), but seems unable to recall the lexical item "catheter." Robert backtracks and launches a second question (line 9), which is a negatively formulated downgrade that calls into question what he assumed in his first question. In his "when" question, Robert assumed that a catheter was going to be implanted, but he now asks about whether there is going to be any catheter implanted at all. Neither his first nor his second question is answered, even though doctor 1's "oh::," (line 11) indicates that she now knows what Robert is talking about.

Robert's difficulties in obtaining answers are only just starting. Instead of answering his question, doctor 1 follows her "oh::," with an amused quotation of Robert's question and of his index-finger gesture of sticking a catheter (see Excerpt 6.1, line 11, drawings a–b). Simultaneously, doctor 2 starts a separate teasing sequence in line 12 that also focuses on Robert's unusual choice of the verb "stick" to refer to the action of implanting a catheter. Doctor 2 teasingly proposes that "a stake in the head" is the lexical item that Robert is unable to recall. Doctor 1 picks up doctor 2's tease, and as she says "the sta:ke:," she embodies with her hands the action of driving a stake with a hammer (line 11, drawings c–d). At this point, the doctors and Robert's mother are laughing, while Robert simply smiles. The teasing is further developed by comparing Robert with a vampire (lines 12–22), until Robert's mother comes to her son's rescue. Robert has previously said that he does not remember the term "catheter" (line 20), and agrees with his mother (line 26) when she answers doctor 1's repair insert sequence (line 23). After the repair sequence is closed and the laughter subsides, doctor 1 finally responds to Robert's first question. She first repeats Robert's mother's "the catheter," explains why she cannot answer, and announces her intention to look at Robert's medical records without specifying when she will do it (lines 27–28). Even though it is implicit, the fact that doctor 1 announces that she will check Robert's records suggests that there will be an autotransplant.

Robert does not waste any time. Occasioned by doctor 1's reference to the protocol and the program—or formulated to appear as occasioned by doctor 1's reference—Robert attempts again to obtain information about the end of the treatment. In final overlap with doctor 1's turn (line 25), Robert launches his next question, the multi-unit question "how many *chemos* do I have left, the

I have three chemos left or do I have four?") to his first question "how many chemos do I have left,". However, if the doctors were to agree with the first or second choice in Robert's alternative question, he would be able to look up his copy of the protocol, and find out exactly how many chemotherapies he has left.

It is unclear whether the second question in Robert's multi-unit question (lines 29–30) is designed to be an alternative "or" question right from the beginning. Robert encounters problems finding a recipient for this second question. Before Robert's second question is finished, doctor 1 withdraws her gaze from Robert, looks at doctor 2, and produces a single token of laughter (lines 31–32). Robert may have changed it *in media res* and transformed a yes/no question into an alternative "or" question as a way to project that he is not finished with his questioning. Robert may have also changed his second question when he sees doctor 1, the recipient of his question, smile and shrug her shoulders, as if she is about to burst out laughing.

In line 33, doctor 1 responds with a teasing complaint about Robert's insistent questioning. Robert displays that he can indeed be persistent by holding on to his "or" (line 29, three times in line 34, and one final time in line 38). "Or" projects that he is not finished with his questioning, and it renews the expectation that an answer will be relevant whenever he does finish. No matter what kind of response he is given in the meantime, the doctors have to respond again when he formulates the second part of his or-choice question. After the doctor's teasing complaint, Robert comes back with "or" in final overlap (line 34).

Robert's mother provides a candidate answer with "one more." (line 35), which is addressed to him. It neither presents a rising final intonation, as in requesting confirmation from Robert that "one more." is what Robert was going to say, nor is it addressed to doctor 1, who is the recipient of Robert's question. For these reasons, it seems more plausible that Robert's mother's "one more." is answering Robert's question rather than offering an alternative as the second choice in Robert's unfinished question. Robert's mother's "one more." may also be indirectly helping Robert to obtain answers. By answering "one more." to Robert's question, his mother positions the doctors as an overhearing audience. If what she is saying is wrong, doctors, as the experts, have a responsibility to intervene and correct her.

Robert does not acknowledge his mother's turn at this point but keeps his gaze narrowly focused on doctor 1 (line 34). A potential contributing factor to Robert's lack of uptake after his mother's "one more." is the fact that doctor 2 starts talking in overlap after his mother has started her turn. In this fast sequence of events, Robert starts his question in final overlap with doctor 1's turn (line 34), Robert's mother starts her turn in final overlap with Robert's turn (line 35), and doctor 2 starts her turn in overlap with Robert's mother's turn (line 36). Doctor 2's response does not help much because it is not an answer, but a second teasing complaint (lines 36–37, 39). Moreover, Robert and doctor 2 are competing for doctor 1's attention. When Robert finally completes his alternative question, doctor 1 is not looking at him but at doctor 2 (line 38). Robert recycles his mother's turn "one more," but carefully prefaces it with his signature mark "or."

By completing his own turn after his mother's "one more," he renews the relevance of obtaining an answer to his question, indicating that an answer is still expected. Even though his mother answered his question, an answer from doctor 1 is still missing. Despite Robert's *six* attempts to obtain answers from the doctors, he has only obtained an answer from his mother.

Yet Robert does not give up and tries a new questioning strategy. Instead of continuing to pursue the alternative question, "the ones listed in the protocol or one more?" he launches a declarative question with a final tag question, "one more than the ones listed there:: (.) in the sheet isn't there," (lines 44–45 in Excerpt 6.3). He tries to start at line 41 when his mother reaches a point where she could have completed her turn, but continues to talk (line 40). Doctor 2 is still talking at this point, in overlap with Robert's mother's talk (line 39). Robert waits until doctor 2 finishes and until his mother is almost finished. In final overlap with his mother, Robert succeeds in fully launching his question without any additional interference (lines 44–45).

Excerpt 6.3

- 41 ROB: → [u-
[o-
- 42 [(Robert raises his index finger to
43 indicate the amount "one")]
- 44 ROB: → [una més de
[one more than
- 45 → *les que surten allà:: (.) en la fulla no,*
the ones listed there:: (.) in the sheet isn't there,
- 46 DOC1: *no me'n recordo. una més per què.*
I don't remember. why one more.
- 47 ROB: → *perquè hi ha la:: lo de l'autotrasplant*
because there is the:: the of the autotransplant
- 48 *aquell, (.) no,*
thing, (.) isn't there,
- 49 (0.3)
- 50 DOC1: *a: sí.*
o:h yes.
- 51 (0.7)
- 52 MOM: *és una mé:s, (.) e:: ia: [li dit io.*
it's one mo:re, (.) e:: I've: [told him already.
- 53 DOC1: [el autotrasplanta- a::, la
[the autotrasplan-- o::h, the
- 54 fulla, i després una quimioteràpia
sheet, and afterward one autotransplantation
- 55 *d'autotrasplantament. [(això ma-)*
chemotherapy. [(that's i-)

Robert's questioning efforts have now yielded some results. Doctor 1 has told him that he has the autotransplant chemotherapy, in addition to whatever chemotherapy sessions are listed in his treatment protocol. Robert immediately launches into a series of questions on the nature of this special autotransplant chemotherapy. As doctor 1 continues past her turn completion to add an additional turn "(that's i-)" Robert starts his new question, "and WHich chemo is this." (line 56). Doctor 1 abandons her incomplete turn "(that's i-)" in line 55, possibly because Robert has already started a new question. Doctor 1 responds straightaway and starts a teasing response in final overlap with Robert's question (line 57–58).

Excerpt 6.4

- [illegible]

- 60 DOC1: [(io t'ho he dit), io de tu ia començaria a pati:r.
[(I've told you), if I were you I'd start wo:rrying now.
- 61 MOM: [h h h h
[h h h h
- 62 (0.3)
- 63 ROB: → [que és la cisplatino, o no.
[is it cisplatin, or not.
- 64 DOC1: [h h h
[h h h
- 65 DOC1: no, no és cisplati:no.
no, it's not cispla:tin.
- 66 (0.5)

Robert's "and"-prefaced question, "and WHich chemo is this." initiates a new questioning line. His question marks a subtle but important shift of topic. So far, Robert has been asking about chemotherapy as an event that takes place in time (i.e., chemotherapy sessions). Now, Robert starts inquiring about chemotherapy as individual drugs (i.e., chemotherapy types). Despite the use of the same reference "químio," Robert targets the chemotherapy drug that will be used during the autotransplant chemotherapy.

Two aspects of this next series of questions are especially significant. First of all, Robert is faced again with a series of responses that are not answers. Doctor 1's teasing response, "buagg it's a bo::mb," provides no information about the type of chemotherapy drugs that will be administered to Robert during his autotransplant (lines 57–58). Doctor 1's response to Robert's next question does not answer Robert's question either. Her turn, "(I've told you), if I were you I'd start wo:rrying now." seems to be designed to lighten the mood and to dismiss any anxiety or worry he may have (line 60). Her joking dismissal of Robert's fears constructs his questions as prompted by excessive anxiety, and those excessive fears as unfounded. Furthermore, Robert's future treatment is going to be so good that one can poke fun at Robert's excessive worry, which is what doctor 1 and Robert's mother do (lines 61, 64). Their laughter, however, does not elicit any laughter from Robert. He does not even smile. He is busy pursuing any relevant information about the drugs to be used in his autotransplant.

A second noteworthy aspect of this questioning series is the skillful interactional and grammatical maneuvering that Robert uses to narrow his line of questioning step by step. Starting with an open-ended question (line 56), he then moves to a "but"-prefaced multi-unit question, which sets up a contrast between what he is asking about and what the doctor has responded to (line 59). Robert's turn "but what is it, <cisplatin." still overlapping with doctor 1's previous response, rushes from the "but what is it," open-ended question into the "cisplatin" yes/no question, which is a candidate answer to Robert's "but what is it," question. Robert then moves to ask a different type of yes/no question, "is it cisplatin," (line 63).

Whereas the question “cisplatin.” (line 59) is elliptical and grammatically dependent on the previous “but what is it,” question, the question “is it cisplatin,” (line 63) stands on its own.

Robert continues to exert questioning pressure, focusing on the chemotherapy drug cisplatin. His preoccupation with cisplatin stems from his ongoing problem with mouth sores, as he eventually says (line 80 in Excerpt 6.5). Although he has experienced mouth sores with other chemotherapy drugs administered for metastatic osteosarcoma (see Chapter 3), Robert describes the highly toxic cisplatin as causing the worst side effects. To pursue a line of inquiry about cisplatin, he adds the increment “or not.” to his question “is it cisplatin,” which is a tautological yes/no question under the guise of an alternative question (line 63). The question “is it cisplatin, or not.” is a stronger, more polarized version of the same yes/no question. In an “or not” question, the only possible choices are “yes” or “no,” but these two alternatives are made explicit and mutually exclusive. Doctor 1’s answer “no, it’s not cispla:tin.” (line 65) is specific, grammatically fitting, and conforms to the question, but is also uncooperative. She states that it is not going to be cisplatin, but her minimal answer provides no information as to what the drug will be.

In Excerpt 6.5, Robert seems to reevaluate the success of his narrowing down. Robert has now been told that cisplatin will not be administered during the autotransplant chemotherapy. His line of questioning focused on the cisplatin yielded this important result, but also failed to yield any additional information about Robert’s autotransplant beyond the fact that cisplatin will not be used. Doctor 1 has not told him what drugs will be used or any other details about the autotransplant.

Unlike in Robert’s previous questions, in line 67 he does not begin with another question in overlap, but waits for half a second before he tries a new line of questioning. It is also possible that he is waiting for doctor 1 to add something else. However, doctor 1 does not expand her minimal answer, and Robert finally decides to try again. Unlike before, Robert designs his next question as a new move that widens the scope of his questioning, and asks a more general question about whatever drug he may be given, “have you gi- have you given it to me befo:re,”.

Excerpt 6.5

- 66 (0.5)
- 67 ROB: → *me l’ha- me l’ha u posada algun [co:p,*
 have you gi- have you given it to me [befo:re,
- 68 DOC1: *[mentre no sigui*
 [as long as it’s not
- 69 *cisplatin ia està. no:: em sembla que:: no.*
 cisplatin that’s it. no:: I believe:: we haven’t.
- 70 (0.5)

- 71 DOC1: alguna: sí:. (.) però són vàries. (.) és que no és
some: ye:s. (.) but there are several. (.) it's not just
- 72 una sola °quimioteràpia.<són vàries.
one °chemotherapy alone.<there're several.
- 73 (0.6)
- 74 ROB: °hm, °
°hm, °
- 75 (0.3)
- 76 DOC1: °però bueno, °
°but anyhow, °
- 77 (0.8)
- 78 DOC1: però io de tu ia començaria a pati:r per si
but if I were you I would start worrying now just in
- 79 de CAS↑↓.=[(més que re_)
CASE↑↓.=[(just so_)
- 80 ROB: [no, io tinc po:r a les llagues e:,
[no, I am afra:id of mouth sores e:,
- 81 (0.3)
- 82 DOC1: @a les llagues tens por, @=
@you're afraid of mouth sores, @=
- 83 MOM: =sí.<és que pobre quan: li surten les llagues, mi[ra que_
=yes.<poor thing whe:n he gets mouth sores, lo[ok really_
- 84 DOC1: [a- ara
[no- now
- 85 ia no faràs llagues. ia es[tà.=
you won't have mouth sores again. that's [it.=
- 86 ROB: [°nu a
[°well we'll
- 87 veure.°((Robert's entire turn is muffled))
see.° ((Robert's entire turn is muffled))
- 88 DOC1: =xò està arreglat.<ia has passat. el mal moment
=that's been fixed.<you're done with it already. you're
- 89 ia l'has passat.=
done with the bad times.=
- 90 DOC2: =de totes maneres les llagues depèn del dia estan millor
=in any case his mouth sores are better or worse depending
- 91 pitjor.
on the day.
- 92 DOC1: clar.
of course.

With his question “have you gi- have you given it to me befo:re;”, Robert seems to offer doctor 1 a respite. Taking a more interpretative approach, I want to contrast Robert’s question with three alternative courses of questioning that he does not take. He does not narrow further his line of questioning with specific questions about the alternatives to cisplatin (e.g., “If it not cisplatin, is it ifos-famide?” or “If it is not cisplatin, what is it?”). Furthermore, he does not intensify or become more confrontational with his questions (e.g., “Are you sure it won’t be cisplatin?” or “Why don’t you tell me what it is?”). He does not even request the name or specific details about whatever chemotherapy drug may be used in the autotransplant (e.g., how many times it will be given or how long it will take for this drug to be administered).

Returning to what Robert does ask, he seems to agree to settle down to the game of “cat-and-mouse” in exchange for information about whatever drug that may be used in the autotransplant. Robert’s shift in questioning may be the first move of a new strategy to uncover new details about the autotransplant step by step. Robert has already taken four chemotherapy drugs. If the autotransplant drug is one of these, there are three more possible options about which he can inquire. However, in view of the amount of questioning pressure Robert exerted to obtain the important detail that cisplatin will not be used during the autotransplant, it seems unlikely that the doctors will expand their answers and provide a detailed description of Robert’s autotransplant after Robert’s question in line 67.

Three aspects of Excerpt 6.5 are significant. First, Robert obtains new information that doctor 1 has not volunteered so far. He asks whether he has ever been given the unspecified autotransplant drug before, with the assumption that it is a single autotransplant drug, and not several. After doctor 1’s joking remark that Robert seems not to be concerned with drugs other than cisplatin, she answers Robert’s question “no:. I believe:: we haven’t.” (lines 68–69). After a silence (line 70), she produces a second answer “some: ye:s.” (lines 71–72), which reveals that there is more than one drug, something she did not say in her first answer; and that indeed, Robert has already taken some of the same drugs that will be used during his autotransplant. His yes/no question, “have you gi- have you given it to me befo:re;” yielded some unexpected information, but doctor 1 once again is not forthcoming with details about Robert’s autotransplant. Robert is not told how many drugs there will be in total, or which ones will be used.

This crucial piece of information comes very late in Robert’s questioning efforts and contributes to the sense that doctor 1 is withholding information. Taken together, there are three pieces of evidence to support the claim that doctor 1 not only has known all along that there was more than one autotransplant drug, but also that she knows far more about the autotransplant than she is willing to discuss: (1) doctor 1’s late disclosure that several drugs are involved; (2) doctor 1’s unwillingness to volunteer any information beyond what it is strictly required to avoid being perceived as uncooperative or evasive; and (3) when she finally volunteers this piece of information, she rectifies a previous answer that did not contain it.

The doctors accompany their answers with additional talk that is responsive and occasioned by Robert's questioning, but provide no new information about Robert's autotransplant. The doctors reassure, tease, and downplay Robert's concerns throughout the interaction, even after Robert stops asking questions. This task of making sure there is no room for concern, fear, doubt, or discouragement starts with doctor 1's contrastive "°but anyhow,°" (line 76), which separates the information she has just given Robert about the autotransplant from what she is about to tell Robert. In lines 78–79, Doctor 1 reuses her previous "if I were you I would start worrying now." from line 60, prefacing it with the contrastive "but," and upgrading it with an emphatic and stressed "just in CASE↑↓" (capital letters indicate loud talk, and the ↑↓ arrows indicate a sharp intonation rise and fall, which combined together make doctor 1's delivery of the word "case" highly dramatic).

After Robert explicitly says that he is afraid of mouth sores (line 80), doctor 1 does not downplay Robert's concerns, but asks Robert a question with high affect, including a soothing voice quality and a broad smile (line 82). Doctor 1 follows this question with a succession of reassurances (lines 84–85, 88–89), which are strung together back to back: "no- now you won't have mouth sores again. that's it. that's been fixed <you're done with it already. you're done with the bad times." Robert's mother answers doctor 1's question, corroborating the legitimacy of Robert's fears (line 83). However, doctor 1's reassurances make Robert's mother's answer inconsequential for subsequent talk, deleting it sequentially. Doctor 1 never looks at her nor says anything to acknowledge that she has just spoken, which may be related to the fact that doctor 1's question is addressed to Robert. Doctor 1 may also ignore her answer as a way of avoiding feeding into Robert's fears. Although she deletes it sequentially, doctor 1 nevertheless orients to Robert's mother's answer. Doctor 1 starts her turn with a very slight delay after Robert's mother has finished the first part of a two-part turn constructional unit, "<poor thing whe:n he gets mouth sores," which clearly projects a second part. Doctor 1's overlapping talk is therefore not situated randomly, but synchronized with Robert's mother's talk.

Doctor 2 acknowledges Robert's mother's answer by making eye contact with her, but does not say anything that makes her answer consequential for subsequent talk. Doctor 2 latches on to doctor 1's last turn constructional unit and initiates another teasing sequence that downplays the seriousness of the threat of mouth sores (line 90–92). Doctor 2 claims that Robert's mouth sores improve or worsen depending on the day, which implies that Robert's mouth sores are not such a severe problem, because he complains less on the days that he and his love interest are both hospitalized. Doctor 1 aligns with doctor 2's new attempt to make light of the situation. Doctor 1 displays her alignment as recipient for Robert's teasing with her "of course" and mutual eye contact (line 92).

In the end, Robert backs off and lets the doctors get away with their piecemeal information giving and optimistic attempts to cheer him up. However, he neither embraces the doctors' actions nor openly rejects them. Whereas in the previous sequences, Robert asked multiple questions, even launching them in final overlap

to ensure he had a turn to talk, here Robert says little. Notice the silences in lines 70, 73, 75, 77, and 81, where Robert could have jumped in. He does not ask any more questions either. Instead, he explicitly verbalizes his fear. He rejects doctor 1's upgraded downplaying of his concerns (line 78–79) with an unmitigated “no,” states explicitly that he is scared of mouth sores, and ends his turn with the emphatic final interjection “e:,” to underscore his point (Cuenca 2002). This is the only instance that I observed in a corpus of 18 medical interactions between Robert, his mother, and his doctors in which Robert explicitly and unambiguously said that he was afraid of something, and is one of the very few explicit expressions of fear by any patient that I observed during all 15 months of fieldwork.

There are two other ways in which Robert refrains from either embracing the doctors' actions or rejecting them. The first one is Robert's softly spoken “°hm,” continuer (line 74), which simply acknowledges that doctor 1 has spoken, and that she may continue to talk if she wishes to. As such, Robert's continuer indicates that he is forgoing the opportunity to talk. Second, Robert's “°well we'll see.” (lines 86–87) is muffled, with almost no visual contact with doctor 1, since for part of his own turn, his eyes are closed and his hand is in front of them. Robert's “°well we'll see.” is not affiliative either. Robert is not confrontational, but expresses a vague reservation about doctor 1's claim that there will be no more bad times. His concessive “°well we'll see.” leaves the future open and uncertain. Robert accepts that he has not obtained as much information as he wanted in this interactional “cat-and-mouse game” with the doctors. However, his “°well we'll see.” also indicates that his struggle for specific answers about the autotransplant is not over.

Robert's break from exerting questioning pressure does not last long. After doctor 1 and doctor 2's teasing about Robert's mouth sores ends, doctor 1 tries to close the interaction (data not shown in the excerpts). However, Robert's mother does not align with the doctors, and with a question about the autotransplant, she reopens the discussion about Robert's future treatment. Robert follows his mother's lead, and starts asking questions about his last scheduled chemotherapy before the autotransplant. A long sequence ensues in which Robert teasingly asks for a vacation between his last chemotherapy and the autotransplant. The doctors reject Robert's request and another discussion begins about Robert's plans once he ends the treatment. After the doctors, Robert, and his mother engage in an optimistic and hopeful conversation about all the things Robert wants to do after the treatment, the doctors finally succeed in closing the interaction.

The temporal, personal, and contrastive contextualization provided by the ethnographic analysis, as well as the situated analysis of Robert's questions during subsequent medical visits, support the findings that I have shown in the detailed analysis of Robert's questioning pressure. First of all, even if the doctors' reassurances are designed to diminish Robert's fears, Robert's questions during subsequent visits reveal that he is still very much concerned about the severity of the autotransplant. As illustrated in Table 6.1, Robert continues to ask questions over the

Table 6.1 Robert's questions about the autotransplant

5 September	18 September	19 September	16 October
<ul style="list-style-type: none">• When will you stick me with that (autotransplant catheter)?• And which chemo (autotransplant drug) is this?• But what is it (autotransplant drug), cisplatin?• Is it (autotransplant drug) cisplatin, or not?• Have you gi- have you given it (autotransplant drug) to me before?• And after I finish my last chemo, you'll give me another one (autotransplant procedure)?• How long will I be home while I recover? (Home recovery period between the last chemotherapy session and the start of the autotransplant procedure)	<ul style="list-style-type: none">• What about the last chemo (autotransplant procedure)?• What is it (autotransplant drug) like?• Like five cisplatins (autotransplant drug)?	<ul style="list-style-type: none">• Until I finish the two chemos that I have left, you won't implant it (autotransplant catheter), right?• So all together I have three chemos left (the two chemotherapies sessions plus the autotransplant procedure)?	<ul style="list-style-type: none">• When am I going for the autotransplant?• Around December? (date of the autotransplant procedure)

following month. He starts to ask about it on September 5, 2001, which is the date of the visit I have focused here. More than a month later, on October 16, he is still asking about the autotransplant.

Furthermore, Robert seems to become increasingly worried. On September 18, two weeks after his first questions about the autotransplant, Robert wonders if the autotransplant is going to be as painful as five cisplatin together. Roberts persistently asks about cisplatin and states that he is very afraid of the painful mouth sores he had. Two weeks later, Robert asks if the autotransplant is going to be five times as bad as one of his worst experiences.

Second, the doctors' piecemeal responses fail to meet Robert's information needs. His questions during subsequent visits clearly illustrate that he feels he does not have sufficient information, and that doctors have more information to give him—he might not have continued to ask questions if he felt that there was no more available information. Third, even though Robert does not openly challenge his doctors, he does not ease up on his pressing questions. In fact, Robert's questions across subsequent visits show the back-and-forth negotiation that is at the core of my argument: the constant regulation of communication creates significant obstacles to children's participation in conversations about their own cancer treatment.

In my analysis, I have shown that doctors interpret Robert's questions primarily as evidence of Robert's worries, and that Robert interprets doctors' responses as insufficient. Because the autotransplant is a complex, long, and painful treatment, the doctors try to avoid talking about or dwelling on the negative aspects of the treatment. A complete disclosure of information would only feed Robert's fears. On the other hand, not answering Robert's questions would also feed his fears, because it would directly draw attention to the fact that the doctors were withholding information (and withholding information could be equated with withholding bad news, because good news is neither delayed nor withheld). Doctor 1's withholding of a response could be as alarming as saying something. For this reason, doctors engage in long sequences in which they respond to patients' questioning pressure with responses that patients may—or may not—interpret as answering their questions sufficiently and conclusively. If we recall Robert's questions “is it cisplatin, or not.” and doctor 1's answer “no, it's not cispla:tin.” in Excerpt 6.4 above, doctor 1 indeed conforms to the action of answering, but she does not provide any new information and does not deal with the additional implications of Robert's question (i.e., Robert wants to know if he will be administered cisplatin, and if not, he probably wants to know the chemotherapy drug he will be administered instead). To the degree that doctor 1 is not advancing Robert's interactional project of learning more about the autotransplant, her answer is uncooperative. But at the same time, because she does answer, she avoids being overtly uncooperative, and does not alarm the patient with no response at all.

This precise, non-random sequential location of doctors' responses where answers are expected, as well as the fact that Robert treats doctors' responses as

insufficient, are fundamental evidence to understanding why doctor 1 and doctor 2 may not be more forthcoming. In general, doctors at Catalonia Hospital may be perceived as unforthcoming because the technical complexity of cancer treatment cannot be easily explained in a few turns, and doctors are often pressed for time when conducting morning rounds. Because of such technical complexity, doctors do not always remember all the details of each individual patient's treatment. Indeed, doctors routinely respond to patients' questions by saying they cannot remember and they need to check the patients' medical records, and often answer them at a later medical visit.

Furthermore, doctor 1's and doctor's 2 teasing lightheartedness, downplays, optimism, and reassuring confidence may be interpreted as circumventing the specifics of Robert's questions about the remainder of his treatment. His doctors jump ahead to address what they perceive as the underlying motivation behind Robert's questioning pressure. The doctors anticipate what Robert is *really worried about*, long before Robert explicitly says, "I am afraid of mouth sores e;,". Instead of spending time with the specifics of treatment, his doctors move to the predictable end of Robert's line of questioning. In this manner, they address the anxiety and fear that they seem to perceive lie at the core of Robert's questions. Further evidence that doctors treat Robert's questions as displays of anxiety is observable after Robert expresses his fear of mouth sores in Excerpt 6.5. The doctors do not take time to ponder what Robert and his mother are saying. Instead, doctor 1 responds to Robert's expression of fear with an affectionate smile and the question "☺ you're afraid of mouth sores, ☺", and immediately launches a back-to-back series of reassuring statements, even overlapping with Robert's mother's talk. Robert's questions may implicitly seek reassurance in the face of his anxiety and fear, but they explicitly request information about treatment.

Robert's questions carefully remain within the limits of the present course of treatment and the immediate future, and within an optimistic outlook for the distant future. He stays away from questions that target overall uncertainties, such as the possibility that the treatment may be delayed or not successful. However, doctors treat the very fact that Robert asks so many questions as a display of Robert's anxiety and worry. Whether Robert's questions make it explicit or not, the doctors treat Robert's questions as implicitly referring to or potentially leading into delicate and uncertain realms. Robert's questions may be displays of his fear and anxiety, and his questions may be based on unsubstantiated fears and worries that need constant reassurance. Dismissing the patient's fears on the basis that they are excessive or unfounded seems to be more a rhetorical strategy than a reality. Robert's autotransplant lasted more than a month and a half. He lost twenty kilos. He described it as "a bad dream with some good times." A secondary effect of constructing Robert's questions as *only displays of anxiety and fear* is that such constructions invalidate the explicit content of what Robert is asking about and the very action of asking questions. As doctors attempt to dispel Robert's anxiety and fear, they also negate the validity of his participation in the treatment.

In their responses, the doctors treat Robert's efforts to participate in the management of the cancer as not sufficiently important to prevail over the doctors' own concerns to protect him from uncertainty and bad news. Trying not to alarm the patient by either answering or avoiding answering, the doctors undermine the patient's attempts to deal with the cancer treatment on his or her own terms. Pediatric patients need to be protected, and even though doctors themselves support the disclosure of information to patients (see Chapter 5), such disclosure can only go so far. As we see in Robert's case, a qualified and partial form of disclosure is a fundamental communicative strategy in dealing with potential uncertainties and bad news.

Seeking Answers Without Challenging Medical Authority

During the 12 months of first line treatment, everyday life and treatment intersected for young people with cancer, such as for Anna and Robert, their parents, and the hospital staff in charge of their care. Anna, her mother, and sisters, as well as Robert and his mother, lived between the hospital and the apartments for displaced families and their homes outside Barcelona. They came to the hospital for scheduled appointments, were never quite sure when they would start a chemotherapy session, and never knew when they would actually finish it. They also came to the hospital because of the unpredictable ramifications of treatment, such as Anna's wound infection or Robert's poor tolerance to the chemotherapy drug cisplatin.

Over the year spent in and out of the confines of the hospital, patients, parents, and hospital staff experienced both the Spanish proverb "*el roce hace el cariño*" (friction or close contact breeds affection) and the English proverb "familiarity breeds contempt." Patients developed asymmetrical but affectionate joking relationships with their doctors that included mutual teasing. Everyday contact with other patients, families, and hospital staff also resulted in the development of friendships and romantic interests among some young people. However, mothers were not so lucky. Children and parents—mostly mothers—were constantly in each other's space and often irritated each other. If crying displays disappeared from medical and social interactions, anger outbursts increased. Anger displays did not target doctors, but children and parents increasingly argued more often in front of doctors as months of treatment went by.

In the context of local uncertainties during first line treatment, I show that the predominant strategies used to give information are planned and improvised partial disclosure. Patients exert pressure on doctors to obtain answers to their questions, and doctors respond with teasing, reassurances, contingent answers, narrow answers, and non-answer responses. Without confronting medical authority, patients rely on persistence and their joking relationships to test the waters and see

on what ground they stand. Anna and Robert negotiate the limits of what adults will discuss with them while they also negotiate their place in the treatment decision-making hierarchy. They neither openly challenge the doctors' partial disclosure nor reject their overriding optimism. With his questions about the auto-transplant, Robert tries to venture into the local uncertainties of the future, but runs into the doctors' unwillingness to be more forthcoming with details. When his doctors continue to reassure and tease him, Robert does not escalate into adversarial questioning or open rejection. Instead, he resists with his not very enthusiastic "°hm,°" and "°well we'll see.°". Such regulation of communication creates obstacles for patients' participation in everyday treatment interactions. However, as Robert's questioning persistence and pressure illustrate, patients actively work to overcome these obstacles. Robert's "°well we'll see.°" is only a temporary reprieve: he will try again to obtain more information in the next medical interaction.

The Limits of Optimism at the End of Treatment

Key Issues

- *Post-treatment (remission, relapse, and death) brings with it different uncertainties: the more uncertain and ominous the child's future, the more parents and doctors try to control what and how to talk about cancer and its treatment.*
- *During remission, the child and his or her parents wait to see if this period without treatment leads to a permanent cure or relapse.*
- *During a relapse, concealing information and emotion becomes more difficult, and optimism becomes more categorical.*
- *As death approaches, categorical optimism becomes optimistic collusion, when deception and complete non-disclosure are used to sustain the public pretense that the child is not dying.*

Children's cancer trajectories do not stop with the end of first line treatment but continue in different ways that are not necessarily separate from each other. Some children go directly from first to second line treatment if the cancer persists. Other children go into remission and relapse months or years later. Eventually, some of these children go into remission permanently, and others continue in and out of remission until they die.

What is common to these trajectories is that the end of first line treatment brings to the fore the overall uncertainties of life and death that may have been kept aside during treatment. Children, parents, and doctors can no longer focus exclusively on local uncertainties associated with the treatment. The relative predictability of alternating chemotherapy hospitalizations and recovery home periods gives way to a period of prognostic activity during which remission or relapse is assessed. Paradoxically, the end of the treatment makes the future even more uncertain. The relapsed child's chances of overcoming cancer diminish with each relapse. A child in remission faces a future without the drugs that have kept the cancer away. An enduring cure, which sustains patients and families through

the difficulties of treatment, is not there—at least, not there yet—at the end of chemotherapy. For parents and patients, the end of treatment and the post-treatment period unleash the same fear that the initial diagnosis and the pre-treatment period raised: the fear of cancer lurking invisibly under the surface of the skin once again. It takes only a few diagnostic tests to go from remission into relapse. Fortunately, most patients stay in remission, and after five years of post-treatment follow-up visits, finish the post-treatment period.

During the post-treatment period, strategies continue to be regulated and adjusted to the new uncertainties of remission, relapse, and death. As I examine in the following, there are continuities but also differences when comparing the strategies of post-treatment to those of the pre-treatment and treatment. During remission, the most significant difference is a change in the regulation of negative emotions: mothers discuss their fears and overall uncertainties with the doctors in front of their children, as illustrated by the cases of Marc and Quique. During relapse, the main difference is that the new cancer diagnosis and the start of second line treatment are not accompanied by a concerted effort by parents and doctors to deceive children or to conceal all information from them. Parents and doctors are well aware that relapsing children know what a cancer diagnosis and treatment involve. Instead of deception and complete non-disclosure, the bad and uncertain news of a relapse are met with a renewed—even redoubled—commitment to optimistic talk and positive emotions, as exemplified in Dani's case and in my analysis of Toni's question "is the day of the autotransplant going to be delayed," at the end of this chapter. Finally, repeated treatment failure and looming death involve a return to strategies of deception, complete non-disclosure, and concealment of negative emotions in public and official communication in the child's presence, as illustrated by the deaths of Felipe and Eli (see the later section titled "Negotiating Death"). The redoubled commitment to optimism during periods of relapse becomes optimistic collusion when death approaches so as to maintain the social pretense that the child is not dying. Eli's death also highlights the contradiction between public and private discourses: while Eli's mother talks about death with doctors and Eli separately, explicit or implicit references to death disappear when they all come together.

Remission

The end of the long chemotherapy treatment was a reason for celebration. When Marc, a 6-year-old boy with Ewing's sarcoma, finished his treatment, Marc's mother brought champagne and pastries for the other cancer patients and the hospital staff. Other parents brought bouquets of flowers for the nurses, as a way of expressing their gratitude for the treatment received.

A few weeks after the end of treatment, patients and parents were scheduled for the first outpatient routine follow-up visit. These routine follow-up visits

would become the main form of contact with the hospital, as long as the patient stayed in remission. The objective of these visits was to monitor the long list of potential post-treatment side effect problems (such as growth and development problems, problems with the immune system and the nervous system, as well as pulmonary, hormonal, renal, urinary, and post surgical problems) and prevent the reoccurrence of cancer. During the first year of remission, parents and children had monthly appointments. During the second year, visits were reduced to every other month. After the second year, visits were reduced progressively until the fifth year of remission, at which point follow-up visits ended altogether.

Numerous post-treatment diagnostic tests to detect any cancer activity were conducted on a regular basis. Test results were given to parents and patients during the outpatient follow-up visits. For this reason, many parents and patients were terrified of these appointments, especially during the immediate period following the end of treatment. The anxiety of waiting for the test results to see if the cancer had returned was only partially mitigated by the doctor's efforts to create an atmosphere of normality and routineness. Doctors' approach of "business-as-usual" was met with a greater display of anxiety and resistance than during the treatment itself. Parents had less contact with doctors during the post-treatment, and brought up all their concerns at follow-up visits. Unlike during treatment medical rounds in the pediatric unit, there were no hallway conversations either before or after the visits. Parents could still talk on the phone with doctors if they wanted to talk to them privately without their children being present, but as long as patients stayed in remission, these private conversations were kept to a minimum.

The first outpatient visits were moments of great anticipation for parents and patients. For many of them, it was the first time that they returned to the hospital after the end of chemotherapy. They were now considered "healed" cancer patients, officially sanctioned as being in post-treatment remission. However, remission also involved waiting vigilantly to see if their status as "healed" would continue or if the cancer would return. The waiting became almost unbearable when test results were due. It often took a week for test results to be delivered to parents. Imaging technicians were not allowed to tell them anything, despite their anguished pleading. Mothers used words such as "*nerviosa*," "*agonía*," "*intranquilidad*," and "*angoixa*" (nervousness, agony, uneasiness, and anguish) to describe how they felt. They also talked about always having "*el ay*" as in the expressions "*vivir con el ay en el corazón*" in Spanish and "*viure amb l'ai al cor*" in Catalan. The expressive interjection "*ai*" is very common in Catalan (Cuenca 2002), but difficult to translate. It is used for pain, similar to the English "ouch," "ow," or "oh," for a sudden and startling fright, shock, or surprise similar to the English "ah," and also for sorrowful lamentations and expressions of grief. Immersed in the suffering of uncertainty, mothers continued to live in constant fear and anguish.

Communication in these visits displayed both continuities and striking differences from the interactions during pre-treatment and treatment. Three aspects of cancer communication continued as before: the word "cancer" was rarely used, a strong sense of uncertainty remained—though for different reasons than during

the pre-treatment and treatment—and the mandate to be optimistic and hopeful persisted—though it seemed less noticeable because the child's health was indeed good, and so being optimistic required less of an effort. Two other aspects were quite different: mothers and doctors started to talk more openly about negative emotions and overall uncertainties, and moreover, they did so in front of the children during medical visits. Doctors still tried to limit talk to the here and now and avoid talk about the uncertain future. They also persistently reassured mothers that everything would turn out fine, but seemed to be more open to talk about uncertainties. However, all could change rapidly with one test. When test results were inconclusive, took too long to be delivered, or contained something unexpected (see Quique and Marc later in the chapter), the open talk about uncertainty was out, and optimistic talk limited to the present situation was back in.

Children, who continued to avoid talking about their fears and anxieties, were included by doctors and parents for the first time in these conversations during medical visits. It is possible that children were included because the setup of the outpatient clinic was different from that of the pediatric ward. In the pediatric ward, mothers and doctors could simply walk out of the room and talk in the hallway while the patient remained in bed. At the outpatient clinic, the mother would need to leave her son/daughter alone in the waiting room. However, it is also possible that, now that the worst was over, they did not feel the need to “protect” children and control what they disclosed to them.

Quique's mother and Marc's mother asked tough questions now that their sons were in remission. Both sons had long and difficult treatments. Quique was a 13-year-old boy recovering from bone cancer in his left leg. From the start of chemotherapy, Quique did not tolerate it well, was often too immunosuppressed to continue with the treatment, and required some form of preventive isolation care. In addition, he was prone to developing fever and infections. Consequently, chemotherapy administration was recurrently delayed. In addition, he was not able to walk for a long time after his femur surgery. He had two serious falls and had become afraid of walking. Quique and his mother seemed to have an emotional division of labor. Quique kept a laid-back demeanor and rarely displayed his anxiety, whereas his mother talked and displayed her anxiety openly.

When Quique and his mother came through the door for their first outpatient follow-up visit, Quique's mother said that just walking through the door of the doctor's office made her “*nerviosa*” (nervous). It was not only anxiety about seeing the doctor again, but about the culmination of a long-awaited, wished-for remission. As Quique's mother expressed it, “I'm nervous because it's such a big step.” During this visit, she asked questions dealing with the overall uncertainties of why her son had cancer. Referring to Quique's initial cancer as “this problem,” she wanted to know how long he might have had it before he was diagnosed. Quique did not experience pain at that time, and therefore the first sign of trouble was his knee inflammation. Her mention of Quique's initial cancer had implications for how she was approaching his remission. She was worried that if the cancer returned, they would not know before it was too late. Santi's mother

expressed the same fear during her son's second remission. Santi, who was also 13 like Quique, had his left leg amputated during his first line treatment. Santi's mother told the doctor that when she looked at her son, he seemed fine, but she always had "*aquel ay*" ("that ay"), a sense of anguished fear. The fact that Santi seemed fine was no longer an indication that he was. She had been though this once already, when Santi seemed to be fine but relapsed with lung metastases just after being in remission for one month. Santi's mother's departing words to the doctor were "at some point we have to have some luck" with a resigned and somewhat incredulous tone.

During Quique's second follow-up visit, three months after the end of chemotherapy, Quique's mother told the doctor she had spent the previous week cramped up with anxiety, waiting for the scan results that would test if Quique had lung metastasis. Unfortunately, the scan results were not ready, and Quique's mother expressed her resignation to "continue with the anxiety." Nine months after the end of chemotherapy, Núria, a 15-year-old girl recovering from bone cancer, and her parents were still concerned if chemotherapy would be effective after so much time. Núria's mother, herself recovering from breast cancer, also expressed the anxiety she felt every time she was told that further tests were needed.

Marc's mother also had a rough ride during her son's treatment. Marc, a 6-year-old boy, had Ewing's sarcoma in his right femur. In addition to his share of post-chemotherapy immunosuppressions and infections, Marc had problems after his surgery. Like Quique, he was unable to walk for a long time. The bone graft was not stable. Marc could not sit still for a second, and the inability to walk became torture for Marc and his mother. Marc's energy and fiery temper wore his mother out, and there were a few moments when she asked for help because she could not control Marc any longer. Nine months after his first surgery and one month after the end of his first line treatment, Marc underwent a second surgery to stabilize the bone graft with a metal plate. To add to Marc's mother's distress, he had a serious fall after the second surgery, which made it unclear whether they would be able to salvage Marc's right leg.

Three months into remission, Marc's mother had other problems to worry about. After the end of chemotherapy, Marc's latest thoracic tomographies showed a small mass in his lungs. The mass was one millimeter in size and was not growing, and they did not know whether it could indicate lung metastasis. Marc's mother was deeply worried because Marc was not receiving chemotherapy any longer, and therefore there was nothing stopping the growth of the mass, if indeed, it was a metastasis. Marc was scheduled to have another thoracic tomography right after his first follow-up visit during remission.

In this first follow-up visit, Marc's mother brought up the topic of the mass in his lungs in the context of talk about removing Marc's port-a-catheter via minor surgery. The doctor wanted to remove it because Marc had struggled with infections in his port. However, its removal also indicated implicitly that the patient was completely cured, i.e., the patient would not need the port because there

would be no more chemotherapy. Marc's mother did not share the doctor's optimism, and in fact she resisted many times the doctor's emphatic assertions that everything would be okay. Marc's mother asked whether the "millimeter" was the same, which was a reference to the size of the lung mass and an implicit reference to the potential metastasis. Despite Marc's mother's persistent "what if" questions, the doctor refused to talk about the possibility of the return of the cancer. Marc's mother changed her strategy and asked the doctor about when she would get the results of the thoracic tomography that was scheduled a few hours later. When the doctor responded with a contingent "it depends on whether ..." response, Marc's mother openly talked about her anguish and anxiety. She refused to accept the doctor's differing arguments that she needed to remain optimistic and hopeful.

There were multiple rounds of optimistic remarks and reassurances, and Marc's mother resisted each one of them explicitly or implicitly. The doctor told her emphatically not to worry, and she responded that that was very difficult to do. The doctor stated that was no other option but to be optimistic, and she just gave a noncommittal "sure sure." The doctor said she needed to think every test would come back okay because worrying endlessly was no way to live, and Marc's mother did not say anything. After the doctor advised her to look at how well her son was doing whenever she needed confirmation that he was okay, she said, "yes but..." The back-and-forth exchanges only ended when the doctor promised to call her as soon as she found out the results of the tomography. As the visit was coming to an end and Marc's mother gave the doctor two different cell phone numbers, the doctor emphasized that if she did not call her right away, it did not mean that there was bad news, or that she was holding information from her. It simply meant that everything was fine, or that she did not have the results. As a peculiar form of final reassurance, the doctor told her something that I am not quite sure was reassuring. She told Marc's mother that she would be the first person to know if the tomography revealed anything, and if it was visible in the tomography. In other words, the doctor implicitly left open the possibility that there might be something—good or bad—that may or may not be visible in the tomography.

Outpatient follow-up visits were not just about waiting for test results, but also represented moments to rejoice and share the happiness that chemotherapy was over. Children had gained weight, grown a few inches, and regained their hair. Their faces had changed with the return of their eyebrows, and their skin was tan for the first time in years. These outpatient visits became social events. Outpatient follow-up visits were scheduled together with appointments for diagnostic imaging and blood tests, physical therapy, psychological therapy, and the monthly port cleanup maintenance. Some patients in remission continued to receive orthopedic or plastic surgery treatment because of post-surgical complications.

Between appointments, patients and parents would congregate in the pediatric outpatient clinic, even when their appointment was in a completely different area

of the hospital. The pediatric outpatient clinic waiting area and playroom served as information centers. Parents and patients came to the playroom area to find out from hospital staff and other patients who else had appointments on that day, who had been hospitalized, who continued to do well, and who had relapsed. Patients saw each other again, and were delighted to be reunited with the people with whom they had spent long days together during treatment. They exchanged battle stories about overcoming additional surgeries, scars, and infections. They also talked about their transition to normal life, sharing notes about hairstyles, experiences at school, dating, the latest videogames, and all the other things they were finally able to do, now that they were neither sick nor receiving treatment.

Even parents of children who had died came to the outpatient clinic from time to time to talk to the hospital staff and volunteers. The nurses made sure that these parents had a chance to talk to as many people as possible while they waited to talk to the doctors. Parents cried, reminisced, and talked with the nurses, the schoolteachers, the social worker, the psychologist, the volunteers, and other parents and patients who happened to be at the clinic at that time. Nurses were aware of the importance of remembering the children; the walls of the nurses' station were full of drawings and pictures of both patients who had been cured and patients who had died. Some of the cured patients became volunteers, visiting the hospital on a weekly basis. Thus, social relations with the hospital staff and other parents and patients were often maintained beyond death and cure. The hospital came to be regarded as a safe haven where both parents and patients could come to talk about something to which they felt people "outside" could not relate.

Relapse

Time in remission also varied greatly from patient to patient. Some patients did not have much of a break in terms of remission. Santi was back for a second line of chemotherapy less than two months after the end of his first line chemotherapy. During a visit to Catalonia Hospital in 2003, two years after the end of my fieldwork, I learned that Dani, a 16-year-old boy with a rhabdomyosarcoma (see Chapter 5), relapsed after two years in remission. Relapse involved a new occurrence of cancer in the same place that it had occurred, metastases in other parts of their bodies, or both. When patients relapsed, they started a new process of pre-treatment, treatment, and post-treatment periods.

Unlike the periods of first line treatment, when the patient was initially diagnosed with cancer, second line pre-treatment and treatment periods were shorter. With respect to the shorter second line pre-treatment period, new occurrences of cancer were detected earlier, and patients and parents did not have to wait several weeks for a confirmed diagnosis. Patients in remission had a battery of tests conducted on a regular basis that were then reviewed by the doctor during

routine outpatient follow-up visits. In terms of second line treatment periods, doctors used different, more aggressive combinations of chemotherapy drugs. After a few months of second line treatment, doctors assessed if the new combination of drugs was effective. If treatment proved to be effective, doctors might either extend it for some more time, or discontinue it and start post-treatment outpatient follow-up visits. If the patient relapsed again, there would be multiple lines of treatment, as long as there were active chemotherapy drugs or new combinations of drugs that justified further rounds of treatment. When the disadvantages of chemotherapy outweighed the benefits, chemotherapy could still be administered for palliative purposes to relieve pain and other symptoms. With the palliative end-of-life care, the goal of treatment shifted from curative to symptom control.

Relapse was very difficult for patients and parents for numerous reasons, whether it was a few months after the end of the first line chemotherapy or years later. First of all, patients and parents were aware that with each relapse, the chances of a permanent cure slipped further away. If the chemotherapy had not worked the first time, there was no guarantee it would work at all during the second line of treatment. The faith in the treatment that parents and patients displayed at the start of the first line chemotherapy was replaced by a numbing sense of fear. Faith in the success of treatment seemed more of a desire than a reality. Second, they knew what was ahead of them and what chemotherapy treatment involved. They had a vivid recollection of how long it would take, and how they would have to deal with the side effects. Third, because the first line of chemotherapy did not succeed in completely preventing cancer activity, second line treatment was usually more aggressive. Fourth, patients were more experienced, and they seemed to handle the biotechnical details of treatment better than novice patients. However, having to postpone their hopes and dreams for the future once again was difficult. They knew what life was in the hospital, and they had had a taste of what life was like after the hospital.

As Dani's mother explained, all their plans vanished when they were told Dani had relapsed. Dani had lost one year of high school because of the first treatment. After it ended, he went back to high school, and now was preparing to go to college. They had moved from an apartment to a new house in a different town. They were starting to furnish the house, and Dani's mother was working to help with the expenses.

With the relapse, Dani's mother had to quit her job again and take care of Dani. Dani did not feel like studying, and his parents were concerned he would lose another year. Dani's parents were not only worried about their son's physical health, but were also worried about his emotional health. They felt helpless at not being able to protect their son from any suffering. The first time Dani was diagnosed with cancer, his parents had tried to conceal the cancer diagnosis as much as they could (see Chapter 5). Even though they had failed to conceal it, they were convinced they had done the right thing by protecting him from the bad news at least for a few weeks before treatment started. This second time around,

Dani's mother said they could not protect him at all. He was older, had been through it already, and could identify everything that was happening even during the diagnostic phase. According to Dani's parents, the fact that this was the second time Dani knew what was coming made it even worse. In Dani's mother's account, he had worried less the first time because he did not know what was coming. Dani remained silent while his mother told me all of this. He shrugged his shoulders as a display of indifference, but did not say anything. When I talked to him alone, he simply said "*son cosas de mi madre*" (this is my mother's stuff).

Finally, parents and patients who relapsed may or may not have found the social support of earlier friendships. After remission, parents and patients saw each other from time to time at hospital appointments and social events. When a patient relapsed, friendships between patients in remission and relapsed patients were strained. In some cases, parents and relapsed patients found it too difficult to stay in contact with patients who were in remission. When Dani relapsed, neither he nor his mother wanted to have contact with anybody, whether they were first-time diagnosed cancer patients, other relapsed patients who he already knew from when he first received treatment, or patients in remission. Most patients, however, formed new friendships with other patients. For instance, Gemma, a 15-year-old girl who relapsed with a lung metastasis after nine months in remission, made new friends during her second line chemotherapy treatment. She had lost contact with all her friends from her first line of chemotherapy. Most had moved on with their lives, and a few had died. Santi relapsed less than two months after the end of his first line of treatment. Not much had changed in the hospital when he returned: most of his friends were still undergoing treatment. That was also the case for Toni, who relapsed less than four months after going into remission. Toni still knew most patients, and quickly formed new friendships.

Negotiating Death

With every relapse, the prognosis became worse, and the time between remissions shorter. Eventually, when all available treatments were deemed ineffective or the damage of the side effects outweighed the benefits of treatment, curative care was discontinued and only palliative care remained. The dying process of any patient was an extremely stressful period for the entire pediatric unit. The hallway became quieter; the waiting room where patients usually hung out became filled with unfamiliar faces. Relatives of the dying patient came to the hospital and waited. Cancer patients stayed in their rooms. The daily reports that parents offered each other about their children's health became more frequent, because the health of a dying patient could rapidly change at any time. Patients and parents did not hang out in the dying patient's room. The dying patient's room door was closed, in front of which relatives and parents congregated. Other parents continued to have contact with the parents of the dying patient, but at a distance, due perhaps

to a combination of avoidance and the sheer busyness of the dying child's parents. Everyone talked less with each other and spent less time together. For many of them, the death of a cancer patient and friend was too close of a reminder that one's own child could be next. While there was plenty of activity around the dying child's room with parents talking on the phone and relatives coming and going, the entire pediatric unit seemed to be waiting.

This was the case when Felipe died. Felipe was an 18-year-old with papillary thyroid carcinoma and metastases. At the time he began participating in this study, he had already been in treatment for six years. I first met him when he was receiving outpatient palliative, non-curative treatment to manage the symptoms of his thyroid cancer. Unlike other types of cancers, Felipe's papillary thyroid carcinoma had been treated mainly with surgeries and iodine radiation. His lung metastases were the most urgent problem: they were spreading quickly and he was losing his ability to breathe. In order to improve his breathing, the doctors and his parents had agreed that Felipe would be hospitalized for a series of chemotherapy sessions.

Felipe was terrified of chemotherapy. He had never had it, but knew well its side effects from the many fellow patients he had met over the years. In fact, Felipe had already managed to avoid palliative chemotherapy a number of times. He was an anxious child, often took medication, and saw a homeopathic psychologist regularly. When the prospect of chemotherapy was discussed, Felipe would become so agitated that his doctors and parents desisted, particularly because the goal of the chemotherapy was to alleviate his symptoms, not to cure him.

By early June 2001, Felipe could hardly breathe, and walking became almost impossible. After some meetings between his doctors and parents, Felipe was brought to Catalonia Hospital to be hospitalized and start chemotherapy. In a similar fashion to the initial treatment interview examined in Chapter 5, Felipe was informed he was about to start chemotherapy immediately. During the interview, Felipe sobbed and was very upset about the loss of his hair. He was also angry because he did not know he was going to start chemotherapy, and accused his mother of bringing him to Catalonia Hospital by deceiving him. His mother replied that she did not deceive him because she was packing his clothes for an overnight stay in front of him. In this heated exchange, Felipe contended that he was being deceived, whereas his mother contended that her implicit communication was sufficient: because outpatient visits do not require them to bring overnight clothes, packing clothes "communicates" that there will be an overnight stay, and an overnight stay "communicates" that Felipe will start chemotherapy. The reason why Felipe needed chemotherapy (i.e., to alleviate his symptoms as he died) was absent in Felipe's mother's chain of implicitly communicated news.

Felipe resisted every attempt at convincing him that chemotherapy was necessary. In the face of so much resistance, the doctor told him: "But what we know for sure is that if we don't do medication, this will continue to get worse and there will come a time when you won't be able to get out of bed." This was the only reference to dreadful events in Felipe's future during the interview.

Although I did not have a chance to talk to Felipe about these events, I was struck by how Felipe's mother described the night before his interview and immediate chemotherapy. Felipe's mother told the doctor that Felipe said he felt like Jesus during the last supper. He wanted his parents to take him out to a restaurant, rather than going to his cousin's house as they had originally planned. Also like Jesus before he was handed over to be crucified, Felipe did not sleep during the night. Eli, another cancer patient approaching death, made similar references to Jesus' crucifixion (described later in the chapter).

Less than three months after his first chemotherapy, Felipe was hospitalized as he approached death. His parents had taken him to another hospital to undergo experimental treatment, which had failed to bring about any improvements. Now, back at Catalonia Hospital, he was very weak, and could only breathe with the support of an oxygen pump. As young persons and former hospital roommates, Felipe and Robert had become good friends. Felipe's mother had developed a strong friendship with Robert's mother. However, neither Robert nor his mother could support Felipe and his parents much when Felipe was dying. Robert's mother could not sleep at night thinking about why Felipe was dying and her son was not. She felt guilty for thinking that she was lucky that her son was doing fine at that moment. She also strongly felt that there was nothing in her power to prevent her son from being the next patient to die. The Russian roulette of who would survive and who would die made no sense. Felipe, when he was very close to dying, asked Robert to continue coming to his room to hang out. In Robert's last visit to Felipe, Robert became depressed. Robert's mother was concerned about how Felipe's state was affecting Robert. Eventually Robert, his mother and his doctor agreed that Robert should not go to Felipe's room and instead should wait until Felipe's health improved. Felipe never recovered, and they all knew it was very unlikely that he would. A few days later, Felipe was taken home so that he could die there. Felipe's death was discussed in hushed tones around the hospital and never openly addressed in front of patients. With the passage of time, Felipe also disappeared from the talk between patients and doctors. Although all patients sooner or later found out that Felipe had died, parents and hospital staff minimized any reference to him and his death. Patients did not die but "went home."

Eli, a 5-year-old girl with a kidney tumor who had come with her mother from Colombia to Catalonia Hospital for treatment, also went home to die. Eli's mother decided she wanted to take her daughter back to Colombia so she could die surrounded by her father, grandparents, uncles, aunts, and cousins. Eli was a strong girl both physically and mentally. She had a strong will and was not easily tricked by adults to do something she did not want to do. She was also strong physically. Even after a painful and long stem cell autotransplant that could have easily killed her, Eli recovered fully in less than two months. She gained weight, grew a few inches, and had enough energy to wear out both her parents.

Eli's last two years of life had been marked by cancer. In spring 2000, Eli's right kidney was removed in Colombia. Her prognosis was complicated because of the

advanced stage of her tumor. She began radiation therapy, but had developed lung metastases by late 2000. Eli's uncle lived in Barcelona, and Eli's parents decided to take her to Barcelona. She came with her mother, and her father stayed behind in Colombia.

In early 2001, Eli began chemotherapy at Catalonia Hospital, which was abandoned for a new chemotherapy protocol. In mid-July, she began the autotransplant. Eli was hospitalized continuously for a month, spending two weeks in strict preventive isolation care in the pediatric intensive care unit. Eli could see people through her window, but very few people were allowed to come into her room. Eli's mother was with her day and night. She would only leave to take a shower and change clothes. On occasion, she would also leave to buy food and walk around. Often, she would wear sterilized hospital clothes instead of her own. Whenever I spent time with Eli, I wore a hair cap, a mouth mask, a gown over my clothes, and shoe covers. Any object (toys, DVDs, or my computer) was thoroughly cleaned. Nothing alive (flowers or fruit) was allowed.

The autotransplant was extremely hard for both Eli and her mother. Eli's physical strength was remarkable, but she became greatly dependent on her mother. Particularly at the beginning of preventive isolation care, Eli would cry inconsolably whenever her mother was not in sight. Eli's mother's attitude also changed. She wanted to talk about dying. She cried when she talked to me about her husband and about Eli. One afternoon in August, she explained to me that Eli had asked about another patient who had recently died. She told her that he was now a little angel in heaven. Although the treatment plan was for Eli to undergo a second autotransplant after she recovered from the first one, Eli's mother told me that she would not subject Eli to the second one if the first was not effective.

As mentioned before, Eli's recovery after the autotransplant was remarkable. Things looked good. There was no more chemotherapy for now, and Eli and her mother were able to enjoy Barcelona, without being constantly at Catalonia Hospital. At the end of the summer, Eli's father joined them. The abdominal tomographies were promising, showing a reduction in the number of lung metastases. Eli's hair was growing back, and she was delighted that she had eyebrows again.

Everything changed on October 3, 2001. The latest abdominal tomography showed that the cancer had returned with a vengeance. The doctor described the situation by saying the cancer had exploded. Two days later, Eli's parents were asked to come to a meeting to discuss Eli's future. Eli's mother came alone to the meeting, which surprised the doctors and nurses. Of course, nobody expected Eli to be present, but they expected Eli's father. Eli's mother said that he stayed behind because their daughter wanted him to stay with her. The doctor used humor to question Eli's father's reason for not coming. Teasingly, she wondered whether he could not come or did not have the courage to come. Without explicitly asking if Eli's father had made the decision, the doctor expressed her doubts that Eli's mother was the one who made the decision to stop all treatment and take Eli back to Colombia. The doctor commented that he had been left

alone in Colombia without his beloved wife and daughter for over eight months, and she expressed a desire to talk to him directly, perhaps hoping that she could change his mind about taking Eli back to Colombia.

I suspect that Eli's mother was the one to be persuaded if the doctor hoped to change the course of events. On the basis of my conversations with her, I believe Eli's mother chose to come alone and had made up her mind about how she wanted to proceed. She had been in charge of Eli's daily care throughout her treatment in Colombia and in Barcelona and had made clear to me months earlier that she did not plan to try new treatments if the autotransplant did not work. I also suspect that she was trying to stay in charge and protect her husband.

The meeting lasted for half an hour. On the basis of how resilient Eli was, the doctors suggested two possibilities. The first one, which is the one they supported, was to do a few rounds of chemotherapy with new drugs or experimental protocols to stabilize the lung metastases. At that point, they would do an assessment, and decide whether to go on to a second autotransplant or to move to non-curative care. The second one was to stop all forms of curative treatment. Although the head doctor made it clear that the likelihood of cure was less than 10%, she believed that Eli could live much longer if her metastases were stabilized. She also believed that Eli could have an acceptable quality of life, because she had not experienced significant side effects during previous chemotherapies. The head doctor emphasized that there was no return once they switched to palliative care. The doctor was open to it, but not yet. In line with the trope of leaving no stone unturned, analyzed by Bluebond-Langner and colleagues (2007) in their examination of parents' sense of obligation and responsibilities in making decisions when standard care had failed, the head doctor wanted to ensure that when such a decision was made, that "you were absolutely sure that there was not any one drug (left to try) that could help her (Eli)."

Eli's mother quietly resisted doctors' attempts to try new chemotherapy drugs, but never openly rejected their medical advice. Eli's mother cried when the doctor told her she (the doctor) was not ready to give up, throw in the towel, and accept defeat. Eli's mother listened and asked questions about the treatment the head doctor was proposing, but she also started to ask questions about what might happen in the absence of any treatment, how long Eli might live, and how she would eventually die. The head doctor, still arguing that she believed that the time had not come yet to consider stopping treatment, began to explore with Eli's mother the possibility of palliative and end-of-life care in Colombia, including the logistics of a long flight and the availability of pain medication in their hometown. The meeting ended with a last appeal by the doctor to be given one more opportunity. The head doctor told her that she respected and understood whatever decision they made. Eli's mother agreed to think more about it, and said she would come back with Eli to the hospital on the day that doctors had set for the new treatment to start. When the day came, no one came to the hospital.

It was clear to the doctors that Eli's mother had made up her mind, and had decided she was not willing to stay in Barcelona for further treatment and separate Eli from her father once again. They had decided they would all return to Colombia together. The hospital nurses did not call Eli's mother to remind her she had missed her appointment. A few days later, Eli's parents came to the hospital to talk about the medical treatment Eli would need to receive until she died. The pediatric oncology team wrote numerous reports for them, just in case Eli needed to go to a hospital. In addition they gave Eli's parents training, drugs, and equipment so they could take care of her at home. Eli's parents were biochemists who ran a medical lab, and quickly learned the training that they received from the pediatric oncology team.

Both Eli and her mother were aware that Eli was dying. They talked repeatedly about Jesus' passion and death, and about angels and heaven. As a bedtime story, Eli would ask her mother to tell her the story of how Jesus died, asking her mother all kinds of details about how they placed the crown of thorns on Jesus' head and how he was crucified. Eli told her mother that Jesus did not cry because he knew he was going to heaven. However, Eli also puzzled her mother with questions about why Jesus did not do anything to save himself. At first, Eli's mother found these bedtime stories very painful and disturbing. As she wept when she was telling me about their bedtime storytelling, Eli's mother recounted that she was not able to sleep, and cried all night long. Eli, nevertheless, kept asking for stories about Jesus, and from time to time, told her mother she was a little angel. Seeing that this storytelling about Jesus' passion and crucifixion calmed Eli and helped her fall asleep, Eli's mother came to find these stories comforting, being as she was a woman with a strong faith in God. Eli was so serene and happy that her mother started to find peace in these stories.

Eli also "talked" to me about her death implicitly in our private conversations, although I did not realize it at the time. During an appointment between Eli's mother and the head doctor, Eli stayed with me in the outpatient clinic playroom. We drew, played on the computer, and Eli asked me to read to her. I do not remember if she picked the book or if I did, but I began to read a tale of a prince who wants to kill his brother and become the new king as their father is dying. When I realized how morbid the tale was, I tried four or five times to pick another book and read another story to her. Eli, determined as she was, would not let me. She insisted that I read her the story of the moribund king and the murderer prince. I conceded, kept reading, and a few minutes later, Eli leaned against my shoulder and fell asleep. When she woke up, Eli went on to do something that I had seen her do a number of times before: she went to find out who was crying and why. She would stand next to the nurses and watched attentively how they conducted minor medical procedures, such as needle injections, blood drawing, cleaning small wounds, or starting chemotherapy for outpatients.

Eli and her mother had trusted me enough to be part of Eli's dying process. However, the official and public story at the hospital was that Eli was simply

going home. The hospital schoolteachers prepared presents and cards for Eli, and the hospital staff and other patients and families said their good wishes and farewells. One day at the outpatient clinic, one of the schoolteachers went to congratulate Eli on her return home. While she was telling Eli how happy she was to hear that Eli was finally done with treatment, the schoolteacher looked up at Eli's parents and saw their sad silent smiles. The schoolteacher realized then that Eli was not going to be cured. Months after this awkward moment, the schoolteacher would still become infuriated every time she told me the story. She felt embarrassed and outraged that she made such a fool of herself in front of Eli and her parents, and that the pediatric oncology team did not take the time to tell her the truth about Eli's return home.

Furthermore, the pretense was not only enacted for other families and hospital staff, but Eli's parents and doctors also collaborated to maintain it during medical visits when Eli was present. Eli was hospitalized for an infection a few days before they were scheduled to fly back to Colombia. During the medical round, doctors talked to Eli about the excitement of returning home and seeing her cousins. Eli, however, did not display much enthusiasm, and simply went along with the doctors' talk. Most of the time, Eli did not say anything, and Eli's mother felt compelled to answer the doctors' comments on Eli's behalf.

Eli's mother also seemed to want to protect other parents from the saddening news that Eli was not going home because she was cured. When Eli's mother met Laia's mother, the mother of a 3-year-old girl who had recently been diagnosed with the same type of kidney tumor as Eli's, Eli's mother never mentioned her daughter's condition. She listened with great tenderness to Laia's mother. Eli's mother's smiling face was warm and undecipherable at the same time; she was neither encouraging nor discouraging.

On the day Eli's mother came alone to the hospital to discuss the end of Eli's treatment, she waited for the doctors in the waiting room. While she waited, Toni's mother stormed into the waiting room crying that she could not take it any longer. Toni's health had recently deteriorated rapidly, and doctors were about to conduct some highly invasive diagnostic testing in their efforts to stop the deterioration of Toni's health. Eli's mother tried to comfort Toni's mother, telling her she needed to have a positive attitude, and to not communicate her own anxiety to her son. Toni's mother responded angrily, as if Eli's mother were scolding her for not being a good mother. Toni's mother said she had held up for a long time. Eli's mother told her that she herself had been "holding up" for one year and five months. Screaming over Eli's mother's voice, Toni's mother angrily replied that she had been holding up for one year and *nine* months. Realizing that there was no point in engaging in an argument about what mother had held up for longer, Eli's mother sat next to Toni's mother in silence. A few moments later, Eli's mother was called into the doctor's office in order to discuss the end of Eli's treatment so Eli could die at home. After being back in Colombia for 18 days, Eli passed away surrounded by her parents and relatives.

“Is the Day of the Autotransplant Going to Be Delayed?”

In this section, I examine two questions that Toni, a 15-year-old boy with Hodgkin's disease, asked his doctors during a medical interaction that took place in early October 2001, only a few days after the dramatic encounter between Eli's mother and Toni's mother that I recounted earlier. Toni's mother had her own reasons to be very worried. Toni's future was highly uncertain at best and ominous at worst. Two months before the interaction that I will now examine, Toni had ended his second line of chemotherapy treatment. In 2000, he was diagnosed and treated for Hodgkin's disease for the first time. He relapsed less than four months after his first line of chemotherapy in early 2001. He underwent a second line of chemotherapy for six months until August 2001. In early October 2001, he was not receiving chemotherapy treatment in order to allow his body to recover for an autotransplant, which was scheduled for some time in the fall and which constituted the end of his second-line chemotherapy treatment. Then, Toni had to be hospitalized unexpectedly. He developed a fever, coughing, a runny nose, mucus in his lungs, night sweats, lack of appetite, and sometimes abdominal pain and diarrhea. A cold became bronchitis, and then pneumonia. Doctors did not know exactly what was causing the infection, and their different courses of treatment were not effective. Toni continued to have mucus in his lungs and random fevers that came and went every day without apparent reason.

Toni was hospitalized for almost three weeks. With each passing day of fever, of undiagnosed cause for the infection, and of ineffective treatments, Toni's prognosis worsened. Although Toni did not present painless swelling or lump masses in the head or neck area, which are the most common symptoms of Hodgkin's disease, he presented many symptoms that were similar to other symptoms of Hodgkin's disease (Pizzo and Poplack 2011), such as high fever without a cause, drenching night sweats, loss of body weight, and nonspecific symptoms, including lack of appetite and fatigue. Many of these symptoms could be explained by Toni's pneumonia, but doctors did not know exactly what was causing them or how to treat them.

Both Toni and his mother started to worry that he had relapsed again. Doctors conducted a myriad of tests, some of which were part of the preliminary tests regularly conducted before an autotransplant, and some of which were not. Doctors did not know what was happening. Even though pneumonia was a serious condition for a cancer patient like Toni with a compromised immune system, it was nevertheless a better diagnosis than a second Hodgkin's disease relapse. Toni's local uncertainties became too close to overall uncertainties for comfort. Although Toni's questions remain within the limits of local uncertainties, Toni's highly uncertain, if not poor, prognosis brought together local and overall uncertainties. Toni's dangerous and persistent fever seemed to erase the line separating local uncertainties (i.e., his fever was related to an infection and to

the immunosuppression caused by the last chemotherapy session) and overall uncertainties (i.e., he was too sick to continue with treatment, perhaps too debilitated by the successive courses of treatment or by a yet-to-be-determined second occurrence of Hodgkin's disease).

In this ominous context, Toni asked two questions that, although they inquired about local uncertainties of the present course of treatment, had strong implications for overall uncertainties concerning his future. The force of the doctors' rejection of Toni's questions made it highly unlikely that Toni, or any other patient, would dare raise such questions regarding overall uncertainties. Doctors were reluctant to talk about these matters, and the patients did not openly challenge the doctors. In Toni's case, the amount of interactional work that the doctors and Toni's mother carried out in order to remove even the smallest implicit allusion to overall uncertainties from Toni's questions was indicative that these questions, or for that matter, questions that could potentially lead to the discussion of overall uncertainties, were strongly discouraged.

Toni did not ask explicitly: "Am I going to die?" "Am I going to be cured?" or the more gentle "Are things going okay?" As noted in Chapters 2 and 4, from the 500 patients' questions analyzed for the present study distributed over 104 medical interactions, not a single patient asked these questions. In Toni's case, he did not ask these unspeakable questions either. His questions were topically and sequentially an expansion of what the doctors and Toni's mother were discussing. He just happened to be a pediatric cancer patient who was in a delicate situation—having relapsed once and now on the verge of what could be a third relapse—and who was asking questions that the doctors interpreted as embodying a pessimistic outlook on the treatment. The doctors could handle the treatment not going well, Toni's parents could also handle the treatment was not going well, but Toni could not even entertain the thought that treatment was not going well, or even that his treatment was not going as planned.

Like Robert, Toni asked questions about his future autotransplant (see Chapter 6 for a detailed description of the medical procedure). However, unlike Robert, things were not going well for Toni. In this context, Toni asked the doctors a perfectly reasonable question: "is the day of the autotransplant going to be delayed,". The autotransplant had been scheduled for some time from October to November, and it was clear it was not going to happen during that time. Toni's infection was not under control, and even if it were brought under control, he would need to take a course of medication that usually lasted for a few weeks. Then, he would need to recover completely before the autotransplant chemotherapy started. His question targeted a local uncertainty, the scheduled day for the autotransplant. This question embodied the presupposition that matters were not going as planned, with the word selection of "delayed" and its preference for a "yes" answer, as opposed to a negatively formulated yes/no question. The fact that Toni's question might have implicitly suggested that there was bad news was not a risk that the doctors were willing to take. Although the doctors eventually answered Toni's questions, the answers came only after they repeatedly attacked the basis upon which

Toni had formulated his question. Whatever implicit pessimistic outlook was embedded in Toni's questions was removed from the doctors' answers.

In the following transcribed excerpt, the four doctors are about to conclude Toni's medical visit, and are standing at the door with Toni's mother and a nurse. Toni remains in bed, attentively watching the doctors, the nurse, and his mother talk. The doctors have tried to close the interaction several times; the first time, Toni starts a new series of multiple questions with his initial question: "What is better, a cold or pneumonia?" when the doctors are already walking out of the room. Although at a surface level this question is about diagnosis, it has strong prognostic implications. To define a cold as better or worse than pneumonia requires an implicit assessment of how well or how poorly the patient is doing, and more importantly, how well or how poorly the patient may do in the future.

The doctors come back to Toni's bedside and try to respond to Toni's questions without alarming him. After the doctors finish with Toni's questions, they start walking out of the room again. This time, Toni's mother walks out with the

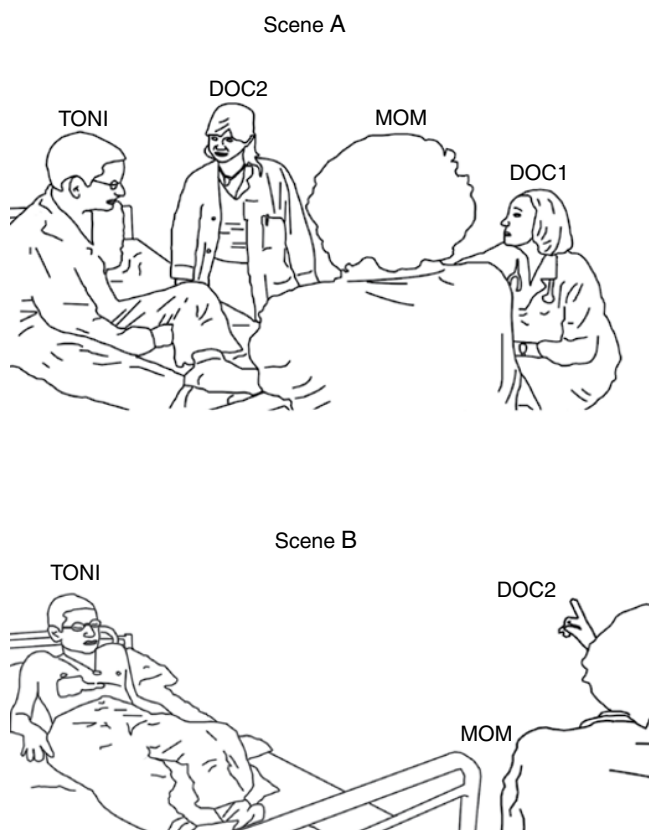


Figure 7.1 Toni talking to the doctors during the visit (Scene A) and as the doctors and his mother leave the room (Scene B).

doctors, while the nurse finishes adjusting the I.V. for Toni's latest medication. As the doctors stand by the door on their way to visit their next patient, Toni's mother and the doctors start talking about Toni's CAT and nuclear medicine test scans that were scheduled before Toni developed an infection and which are part of the preparations for Toni's autotransplant. Doctor 2 tells Toni's mother that there is no rush to carry out the preliminary tests because Toni still has a few weeks of antibiotic treatment ahead of him. The autotransplant is so taxing for the patient that it can only take place when the patient's health is optimal. When Toni asks his initial question "is the day of the autotransplant going to be delayed," the doctors, the nurse, and Toni's mother do not return to Toni's bedside, but remain at the door and turn around to face Toni (see Figure 7.1).

Excerpt 7.1

- 1 MOM: *no no no no. no (és:) sí no, millor. amb òptimes*
no no no no. no (iss:) yes no, better. in optimal
- 2 *condicions. (°no cal cal) [córrer.°*
conditions. (°no need need) [to rush.°
- 3 DOC2: *[e:ɔ ((addressed to Toni))*
[e:ɔ ((addressed to Toni))
- 4 TONI: → *el del trasplantament es retrassará,*
is the day of the autotransplant going to be delayed,
- 5 (0.9)
- 6 DOC2: *a vere no es que es retrassi ni s'adelanti.*
let's see it's not that it is delayed or moved up.
- 7 (.)
- 8 DOC2: *no tenim data encara.*
we still don't have a date.
- 9 (0.3)
- 10 DOC2: *perquè, (.) hem d'esperar primer de tot, a que et*
because, (.) we have to wait first of all, for you to
- 11 *recu[peris.*
re[cover.
- 12 DOC1: *[quines preguntes [fa:s,*
[what kind of questions do you [a:sk,
- 13 DOC2: *[llavors, el [dia del=*
[then, on the [day of=
- 14 MOM: *[shsss:*
[shsss:
- 15 DOC2: *=trasplantament? és quan tu estiguis pe[rfecte.=*
=the autotransplant? it's when you're pe[rfect.=
- 16 DOC1: *[bé.*
[well.

- 17 DOC2: =*[se- no no s'ha no de re[trassar, tranquil.*
 =*[it- no no it doesn't have to be [delayed, relax.*
- 18 DOC1: *[no_ [no per- però escolta, i*
[no_ [no bu- but listen, and
- 19 *dus s'ha retrassat. si encara no sabem quin*
you say it's been delayed. if we still don't know what
- 20 *día[: , [com es pot retrassar.*
day[: , [how can it be delayed.
- 21 DOC2: *[cla [:r,*
[of cou[:rse,
- 22 MOM: *[ssh h*
[ssh h
- 23 DOC2: *e e:stà programat per quan [tu estiguis bé.*
e it's scheduled for when [you are well:.:
- 24 DOC1: *[(clar).*
[(of course).
- 25 DOC2: *imagi[na't.*
imagi[ne that.
- 26 DOC1: *[està programat per qua::n (.) qua:n [sigui=*
[it's scheduled for whe::n (.) whe:n [it is=
- 27 DOC2: *[(mira.)*
[(look.)
- 28 DOC1: *=el mo[ment [més ade[quat.*
=the mo[ment [m o s t su[itible.
- 29 TONI: → *[però [quant més [d'hora millor:r [no?*
[but [the sooner [the bette:r [no?
- 30 DOC2: *[e:xacte,*
[e:xactly,
- 31 MOM: *[no no no.=*
[no no no.=
- 32 *[quan esti[guis, bé.*
[when you [re, well.
- 33 DOC2: *[no. [no. quant més d'hora millor no. [quan=*
[no. [no. the sooner the better no. [when=
- 34 MOM: *[ntx ntx*
[ntx ntx
- 35 DOC2: *=estigu[is bé, és el moment millor per fer-lo.*
=you a[re well, that is the best moment to do it.
- 36 MOM: *[(mira el que et dic).*
[(look at what I tell you).
- 37 DOC2: (0.4)
- 38 TONI: ☺a::[: ,☺ ((Toni smiles))
 ☺oh::[: ,☺ ((Toni smiles))

- 39 MOM: *[que no estem per bromes e:,*
 [we are not up for kidding around e:,
- 40 (0.4)
- 41 DOC2: *[vale?*
 [okay?
- 42 TONI: *[vale,*
 [okay,
- 43 MOM: *.hh a:- e: de plaquetes,*
 .hh a:- e: about platelets,
- 44 MOM?: *mk mk h-*
 mk mk h-
- 45 DOC1: *e:scolta. tu*
 li:sten. you
- 46 DOC2: *esta[va a vint a: vint-i-sis més o menys. en:=*
 he was [at twenty a: twenty-six more or less. when=
- 47 DOC1: *[tu quan toqui per nadal? per nadal estaràs=*
 [you when Christmas comes? by Christmas you'll=
- 48 DOC2: *=[acabat faré un [control.*
 =[I finish I'll run a [control ((test)).
- 49 DOC1: *=[a casa. [ja està.*
 =[be home. [that's it.

I would like to make a number of observations about Toni's initial question, his subsequent question "but the sooner the better no?" and the doctors' responses. First, the number of responses is substantial. Toni's question at line 4 is responded to separately by doctor 1 and doctor 2. By the time Toni asks his second question (line 29), 25 turns of talk have passed, and the response that is closest to a straightforward answer is doctor 2's "it- no no it doesn't have to be delayed, relax." (line 17). Toni's second question is also responded to separately by doctor 1, doctor 2, and Toni's mother as well. Doctor 1 continues responding, even after doctor 2 and Toni's mother are talking about Toni's platelet levels (lines 47, 49), and even though Toni has not said anything else that either pursues the question about the autotransplant or rejects what the doctors have told him.

Second, these responses contain a striking number of nos. Doctor 2 says the day of the transplant is not delayed or moved up (line 6), there is no date for it (line 8), it does not have to be delayed (line 17), the very explicit rejection "no. no. the sooner the better no." (line 33); and doctor 1's "if we still don't know what day:, how can it be delayed." (lines 19–20); and Toni's mother's triple no (line 31). Third, most of the excerpts I have presented so far contain a great amount of overlap. Excerpt 7.1 is unusual because Toni and his mother hardly say anything. Toni speaks four times: his two questions, "☺oh::, ☺" and "okay," (lines 4, 29, 38, 42). His mother does not say much either: two small attempts of a mixture between closed-mouth laughter and the sibilant "s" sound (lines 14, 22), an answer

in full support of the doctor's position (lines 31–32), a double sound of negation (line 34), and two reprimands to Toni (lines 36, 39). Most of the overlap takes place between doctor 1 and doctor 2, who are not waiting for the other to complete their own response, but instead they are both responding to Toni's question at the same time.

What kind of responses are doctor 1 and doctor 2 producing? If we take into account that Toni's questions are both yes/no questions, we can observe that most of the doctors' responses are non-conforming. Doctors clearly reject the terms of Toni's question. Saying "yes" or "no" would mean that they have contemplated the idea that there might be a delay, or more importantly, that things are not going as planned. The closest attempt to answer Toni's first question is non-conforming to some degree, since doctor 2 adds to her "no" in her rejection turn, the clause "it does not have to be delayed," (line 17). Even doctor 2's unmitigated rejection of Toni's second question is to some degree non-conforming (line 32 and 33). The several negation particles "no" are also accompanied by the negatively formulated repetition of "the sooner the better no?" and a parallel alternative to the terms expressed in Toni's question: "no. no. the sooner the better no. when you're well, that is the best moment to do it."

As doctor 1 directly attacks the propositional content of Toni's question, doctor 2 is trying to provide some kind of an answer. Analyzing the doctors' responses sequentially, doctor 2's first turns deal with the rejection of the terms of Toni's question, which comes after a considerable delay (line 5). Next, she makes a quite interesting maneuver. By stating that they do not have a date, she implies that not scheduling a specific day is a better choice than scheduling and having to delay it. She then gives an explanation why this may be the case. Starting with her "because" turn (line 10), she pauses, and gives Toni a contingent response. Before a day can be set, Toni has to recover (lines 10–11).

The degree of uncertainty of doctor 2's contingent response is high. First, Toni has to complete two recoveries before the autotransplant. He has to recover from the chemotherapy and the infection. Second, she is not proposing a list of dependent temporal events that need to happen, such as first we need to complete test X, and then, depending on the test results, Y will be carried out. Instead, she proposes a series of health conditions that need to be reached sequentially. We wait for you to recover, and then the autotransplant (lines 10, 11, 13, 15, 17). Third, her use of "first of all" (line 10) seems to project a list. The following "then," (line 13) seems to confirm that a second item is coming. She does give a second item, but it comes with more conditions. She does not say "first of all the recovery, and then, the autotransplant," but "we have to wait first of all, for you to recover. then on the day of the autotransplant? it's when you're perfect." Fourth, her use of a subordinate clause "when" seems to be another attempt to answer under the grammatical illusion of certainty and definiteness, as she is about to give a temporal reference: a day, a month, or even some temporal reference such as "when you do X." She does not provide more specific temporal information about the autotransplant, but returns to the highly subjective (and uncertain)

“when you’re perfect.” (line 15). Doctor 2 uses a “when” subordinate clause (line 23) again, which is somehow different the second time around from the first “when” at line 15.

Finally, and after all this delicate meandering, doctor 2 eventually concludes with an answer that directly addresses Toni’s question, “it– no no it doesn’t have to be delayed,” and an invitation to Toni to “relax” (line 17). Notice that doctor 2 does not say, “No, it won’t be delayed” which would specifically match Toni’s question, but she chooses a more theoretical and general “it doesn’t have to be delayed.” This latter “it doesn’t have to be delayed,” reintroduces a degree of uncertainty. It does not *have* to be delayed, but it *may* be.

Doctor 1’s response to Toni’s question is more direct. Using a half-humorous, half-complaining undertone, which elicits some laughter from Toni’s mother (lines 14, 22), doctor 1 rejects directly Toni’s question at line 12. Doctor 1’s “what kind of questions do you a:sk,” dismisses the terms of Toni’s question. As with Robert’s questions earlier, the dismissal of Toni’s question may be motivated by doctor 1’s efforts to make light of the situation, and dismiss the fear and anxiety that lie behind Toni’s question. By dismissing jokingly the grounds for Toni’s question, the doctor also dismisses Toni’s action of asking questions. Later, doctor 1 comes in overlap in an attempt to complete doctor 2’s turn (line 16), and launches a second rejection of the propositional content of Toni’s question. Prefacing her rejection with the contrastive “but” she argues that Toni’s question is unfounded because something that does not have a date cannot be delayed.

It is significant that doctor 1 quotes Toni’s question not as a question, but as a statement. Doctor 1 uses the verb “say” and not the verb “ask”: “no_ no bu- but listen, and you say it’s been delayed. if we still don’t know what day:, how can it be delayed.” (lines 18–20). Doctor 1’s “you say” underscores the fact that questions not only ask about something, but also put forward a state of affairs with varying degrees of explicitness (Boyd and Heritage 2006; Clayman and Heritage 2002: 203–208). Toni’s question “is the day of the autotransplant going to be delayed,” does not request information about whether there will be a transplant at all, but assumes there will be one which may be delayed. If doctor 1’s first rejection seems to target Toni’s activity of asking questions (“what kind of questions do you a:sk,”) doctor 1’s second rejection targets the unfounded presupposition embedded in Toni’s question.

Doctor 2 joins in after doctor 1’s second rejection and displays her agreement with doctor 1’s unqualified “of cou:se,” (line 21), which is mirrored by her reciprocal display of support for the “(of course).” in line 24. In line 23, doctor 2 uses again a “when” subordinate clause structure, which she used earlier in line 15. However, doctor 2’s second “when” introduces a contradictory proposition. Toni’s autotransplant is scheduled for whenever Toni is well. The certainty of the verb “scheduled” turns to uncertainty in the syntactic place where a specific temporal reference may be expected: it is scheduled for October, it is scheduled for Christmas, or it is scheduled for November 1st. The verb “schedule,” which is

used later by doctor 1, allows the doctors to answer to some degree, to state that what is happening to Toni is within the realm of the planned and the good. Toni's autotransplant is not going to be delayed because it does not have a date. However, even if it were delayed, it would still not be bad news.

Besides the choice of "scheduled," doctor 2's selection of "when" in line 23 is interesting in its own right. "When" allows doctor 2 to propose a highly uncertain plan for the future that is contingent upon a number of conditions. "When" also allows doctor 2 to present these uncertain conditions as indisputable. It is not a question of the transplant being scheduled *if* Toni recovers, but *when* Toni recovers. Doctor 1 also repeats one more time the structure of "it's scheduled for whe::n" used by doctor 2. She gives it a final twist: she replaces doctor 2's "well" with "the moment most suitable." as if to separate the time to schedule Toni's autotransplant from a subjective and uncertain assessment of Toni's health. It is not "When Toni is well" or "When Toni is perfect," but the more technical, objective, and exact "the moment most suitable." (line 28). The doctors may not have a certain day for the autotransplant, but they are certain that it will happen. In this manner, the message is reinforced that there may be unexpected complications in the treatment, but Toni's overall treatment trajectory is going well and is under control.

In overlap with doctor 1's "it's scheduled for whe::n (.) whe::n it is the moment most suitable." Toni asks his second question, "but the sooner the better no?" (line 29). Toni's second question returns to three basic assumptions that are deeply embedded in his first question, and which are independent from the doctor 1's line of argumentation that the autotransplant cannot be delayed because there is no date for it. First, it is reasonable for Toni to assume the general principle that the sooner the treatment is administered, the sooner the treatment is finished and the sooner he will go home (presumably cured). Second, it is reasonable for Toni to assume that there may be unplanned changes and delays in future courses of treatment, because he has already experienced both during his previous 20 months of treatment. Third, it is reasonable to assume that if what will happen in the future is not known, bad things may happen.

Both Toni's questions and the doctors' responses deal with varying degrees of explicitness with prognostic assessments of good and bad health. Bad health, being sick, or not being cured are not used explicitly. However, whenever there is talk about "being well," "recovering," "being perfect," "the most suitable moment," or "the best time," being well is contrastive to not being well. Moreover, to what degree is all this talk about recovering and being well strictly limited to the local uncertainty of the autotransplant? It is not known at this point how good or poor Toni's health is.

All these lurking assumptions seem to be implicitly stirred up by Toni's second question, if they have not already been stirred by his first one. Quite strikingly, Toni's "but the sooner the better" is exactly the same comparative phrase that doctor 1 used to argue that the sooner Pedro started treatment, the better it would be for him (see Chapter 5). But what is better in Toni's case? Because the

autotransplant is so taxing, it would be disastrous for Toni to start it not having fully recovered from the infection and the previous line of chemotherapy. For this reason, it is better for Toni to wait and finish treatment a few months later, rather than starting the autotransplant when it was originally scheduled and risk dying because of it.

The doctors do not answer Toni's question explicitly. They use most of their talk to reject categorically Toni's second question and to reiterate what they have already said. First, doctor 2's "e:xactly," (line 30) is not occasioned by Toni's question, but is still a display of alignment with what doctor 1 is saying at lines 26 and 29. Toni's mother is the first to categorically reject Toni's suggestion that the sooner the transplant takes place, the better it is for Toni (and that the opposite is true). She returns to the doctors' pseudo-temporal structure "when you're, well." (line 32). In overlap with Toni's mother, doctor 2 starts with her series of nos. Her negatively formulated repeat "no. the sooner the better no." is very effective, because it takes Toni's question "the sooner the better no?" with a final rising intonation, and turns it into a categorical rejection with a final falling intonation: "no. the sooner the better no." She continues not with an account for her rejection, but with an alternative scenario to Toni's formulation. She tells him that the best moment is when he is well, implicitly saying that (1) the start of autotransplant needs to be formulated in terms of the best moment and not of the earliest moment and (2) that he is currently in poor health (i.e., if he is already well, the doctor's "when you're well" makes little sense).

Toni's proposition "the sooner the better" has clearly been rejected. After a 0.4 silence (line 37), Toni simply smiles and says "☺oh:::, ☺" indicating a change of state in his knowledge (line 38): what he had previously assumed was not correct. His mother reprimands him (line 39), and Toni lets slip another opportunity to pursue the topic of the autotransplant, to reject openly the answers and responses that the doctors have given him, and to contest his mother's reprimand. When doctor 2 requests his alignment to close the sequence, Toni aligns with doctor 2, but does so with a minimal token that will not raise suspicions (lines 41–42). Doctor 2 says "okay?" and Toni answers "okay," nothing more, nothing less. Then Toni's mother initiates a new sequence by introducing a new topic in the form of a question "about platelets," and doctor 2 answers it. However, doctor 1 does not entirely align herself with the new sequence about the platelets. With the summons call "li:sten. you" (line 45), she continues with the topic of the autotransplant. Doctor 1 finally uses the "when" formulation to give a real temporal reference: "when Christmas comes? by Christmas you'll be home." With her "that's it." (line 49), she marks her reference to Christmas as the absolute and final point in the discussion. She skillfully avoids any reference to unexpected complications in the treatment, or to a delay. The assumption that Toni will be home and healthy after successfully completing the autotransplant is implied in doctor 1's answer that Toni will be home for Christmas.

The doctors were finally able to treat Toni's pneumonia. After numerous tests, the possibility of a relapse was ruled out. However, it took several months for

Toni's pneumonia to be cured. After the pneumonia, he had other complications that further delayed the autotransplant. He eventually underwent the autotransplant, but not in time to spend Christmas at home.

Optimistic Collusion

Using ethnographic and situated analyses of talk, I have illustrated how communication strategies are adjusted to the changing circumstances of remission, relapse, and death during the period following the end of first line treatment. As a rule of thumb, the more uncertain and ominous the child's future is at a particular point of his or her cancer trajectory, the tighter the control that is placed on *what* is talked about and *how* it is talked about in the child's presence during medical interactions. When the child is in remission, as illustrated by Marc and Quique, parents and doctors are more willing to talk about fears, anxieties, and the future. However, the strong commitments to optimism and to focusing on the present that characterize the treatment period persist during remission. When the child relapses, as in the case of Dani and Toni, the commitment to optimism can become absolute and categorical. When the child is dying, as in the cases of Felipe and Eli, parents and doctors resort to deception and complete non-disclosure during medical interactions with the child.

The detailed analysis of Toni's questions illustrates how optimism may become categorical when a child's future is highly uncertain. Whether Toni was on his question-by-question way to linking local uncertainties of the treatment with the overall uncertainties of yet another relapse is something I cannot establish. However, my analysis shows the significant amount of interactional work that doctors carry out to maintain an optimistic outlook and to discourage any communication that may implicitly allude to or explicitly refer to the uncertain and negative aspects of cancer.

A public and official optimistic outlook becomes even more absolute in medical interactions with a dying child. Optimism becomes optimistic collusion when deception and complete and planned non-disclosure are used to maintain the social pretense that the child is not dying. Everybody defines the patient as dying, but acts otherwise (Bluebond-Langner 1978: 260; Glaser and Strauss 1965: 10–11). Felipe and Eli went along with doctors' optimistic collusion—at least, publicly and during medical interactions. In private conversations, however, Felipe and Eli talked about Jesus' death with their parents. Felipe told his mother that he felt like Jesus during the last supper, and Eli asked her mother to tell her the story of how Jesus died and was crucified. In these circumstances, Bluebond-Langner's (1978: 210) argument for why mutual pretense is practiced is fitting: "The leukemic children, their parents and the staff that attended them, I argue, practiced mutual pretense because it offered each of them a way to fulfill the social roles and responsibilities necessary for maintaining membership in the

society, in the face of that which threatened the fulfillment of social obligations and continued membership.”

The untimely deaths of Eli and Felipe illustrate the end of the cancer trajectories for some of the children in this study. My longitudinal and situated analyses of the variation of six communicative strategies used to live and deal with cancer and its uncertainties show that cancer trajectories may end as they start: with complete non-disclosure and collusion, which were qualified explicitly by Felipe and Robert as deception. Whether they are receiving treatment or in remission, for patients like Toni, Quique, Marc, or Dani, their cancer trajectories and their futures remain open-ended.

Conclusion

Key Issues

- *Communication is central to how children, parents, and their healthcare professionals constitute, influence, and make sense of the social worlds they inhabit—or that they want to inhabit.*
- *The regulation of communication is one of four interrelated ways of living and dealing with the multiple unpredictabilities of cancer and its treatment.*
- *Communication regulation creates obstacles to children's participation in conversations about their own treatment.*
- *There is not a unified, stable, or cohesive strategy of communication, but several strategies that co-occur, often contradict each other, and are constantly adjusted according to children's changing circumstances.*
- *Children's questions can indicate to parents and doctors their desired degree of involvement in treatment conversations, according to their individual needs for information and involvement.*
- *Increasing children's participation contributes to their ability to take responsibility for their own healthcare as they grow up. But policies must also take into account the sociocultural conditions of childhood and the consequences that increasing responsibility can have for the well-being of each child.*

I have examined the communicative strategies of a group of children with cancer, their parents, and caregivers at a hospital in Barcelona, Catalonia (Spain). For an extensive period of time that was full of uncertainties, these children dealt with cancer and its treatment in the confined space of a hospital pediatric cancer unit. As a community with a high frequency of interaction between its members, children, parents, and hospital professionals shared specific ways and understandings of what they were doing, communicating, and feeling. Although I speak of doing, communicating, and feeling separately, I do not consider these as independent. As other linguistic anthropologists and conversation analysts, I consider talk as action, and emotion as emerging in action intersubjectively. To analyze talk and emotions

means to analyze action in situations organized by talk and situations where talk is ancillary. Among their ways of doing, communicating, and feeling, I pay particular attention to *not talking* as a culturally sanctioned alternative to talking, and as part of the communicative economy of the said and the unsaid in this community.

The first argument that I presented is that *not talking* constitutes one among several strategies of communication regulation, which includes communicating implicitly and avoiding some words, topics, and displays of negative emotions such as crying and anger outbursts, as well as talking about some aspects of cancer in hopeful and optimistic terms and favoring the display of positive emotions. The regulation of communication can be considered one of the ways in which this community dealt with the multiple and overlapping uncertainties of a cancer diagnosis, treatment, and prognosis over entire cancer trajectories.

Children and parents develop other ways to help them deal with the local uncertainties associated with treatment and create a sense of normalcy and control. Rather than being consumed by overall uncertainties (e.g., Why cancer? Will the treatment lead to a cure, more treatment, or death?), parents and children keep them at bay by staying busy and focusing on the present course of treatment. Children with bone tumors and their parents settle into a repetitive alternation of chemotherapy hospitalizations and home recovery periods over approximately 12 months. Underlying this routine, however, are many uncertainties. Cancer treatment involves aggressive biomedical therapies that may cause children to become too ill to continue treatment. These unexpected difficulties delay and alter the administration of treatment, such as when a child is too immunosuppressed to start a new course of chemotherapy, or develops a fever because of an infection. Children and parents keep busy by focusing on the present course of treatment, making guesses about different aspects of children's health, being together and caring for each other as a community, and concealing information and emotions from some people and revealing them to others privately. These activities give parents and children an opportunity to fight cancer and to fulfill societal roles (i.e., parents protect children, and children grow up) as they come to inhabit new cancer-defined identities.

The second argument of this book is that all parties, including children, collaborate to keep uncertainty and the negative aspects of the illness and treatment out of their talk, yet do not entirely agree on what to leave out and what to include. They engage in a constant but implicit negotiation and reaffirmation of the limits of how to talk about cancer and what can be said. In doing so, they are also producing, negotiating, and managing locally, turn by turn, which aspects of their experiences are uncertain and require non-disclosure, and which are certain and can be talked about. What may be uncertain for some participants may not be so for others. Accordingly, the constant negotiation of communication reveals that (1) what is delicate and needs to be avoided for one participant may not necessarily be so for another; (2) sensitive domains of psychological, social, and cultural experience may be intrinsically delicate, but are socially

constructed as such; and (3) the interactional “infrastructure” used to constitute something as delicate may still be present in participants’ talk even when the delicate item is absent, having been avoided altogether through the use of implicit and indirect talk.

The third argument this book makes is that disagreements over the limits of cancer talk are observable in the lengthy “cat-and-mouse game” negotiations of what constitutes a sufficient answer. Children exert pressure with persistent questions in order to obtain information and assert their place in the social organization of cancer treatment without challenging their parents’ or doctors’ authority. Doctors, on the other hand, struggle to reach a balance between disclosing information to the children and sparing them the unnecessary anxiety and suffering that they believe information will cause. Parents sometimes align with the doctors in their attempts to protect the children but also sometimes align with their children in attempts to obtain information from doctors. For these reasons, doctors use a number of communicative strategies to withhold information that they perceive to be potentially distressing. However, withholding information has its own risks, because any withholding of information can be easily equated with the concealment of bad and uncertain news. Thus, and in order to avoid alarming the patients, doctors frequently *do* answer, but patients may find these answers insufficient nonetheless and continue to ask questions.

The fourth argument I set forward is that children’s inability to obtain information with their questions exposes the limits of their participation in the daily management of cancer. Children’s questions constitute an essential way through which they obtain information, and are evidence of the medical expertise and experience they accumulate over many months of treatment. However, protecting them becomes more important than allowing them to deal with their cancer treatment on their own terms. As illustrated by Pedro’s, Toni’s, and Robert’s questions, I do not have evidence that withholding information from children necessarily spares them anxiety and suffering. Particularly in Robert’s case, doctors’ reassurances appear to do little to dispel his fears, because immediately after the reassurances, he often returns to the original, unanswered questions. Withholding information may have some success in keeping uncertainty and bad news out of everyday interactions, but appears to do little to reduce children’s anxiety about their uncertain futures.

My book problematizes the three concepts that form its theoretical framework: non-disclosure, uncertainty, and participation. To begin, the term non-disclosure is problematic because it sets up an opposition between disclosure and non-disclosure, whereas the data examined here show that six different communicative strategies coexist within a non-disclosure and disclosure spectrum: deception, official and planned complete non-disclosure, unofficial leakage and gathering of information, improvised partial disclosure, and official and planned partial disclosure. Even within official and planned partial disclosure, one encounters a range of practices, some of which could be considered disclosure and others

non-disclosure. The reader may recall Pedro's question about when he will be cured, Robert's pursuit of information about the combined chemotherapy drugs of his autotransplant, or Toni's pursuit of information about his autotransplant date. To these questions, doctors responded with piecemeal information given only after repeated pressure from patients, inconclusive contingent answers, narrow answers that provide no new information, responses that hardly address the topic of the question, reassurances and teasing that provide no information at all, or with refutations of questions.

The six coexisting communicative strategies are often contradictory. Robert and Dani found out they had cancer because some physicians talked openly with them, but other physicians did not. Pedro did not use the word "cancer" with his doctors, but as soon as they left the room, he asked his parents for confirmation that he had cancer. Later on, the word "cancer" disappeared from Pedro's conversations. Eli and her mother talked about the death and crucifixion of Jesus in their private conversations, but engaged in mutual pretense with doctors in medical interactions and in conversations with the mothers of Toni and Laia. During parental asides, Pedro's and Dani's mothers made it clear that they were strongly opposed to their children being informed, while simultaneously talking among themselves about death, their fears, and anxieties.

The diversity of coexisting communicative strategies is not particular to Catalonia Hospital, but reflects larger sociocultural changes in cancer communication practices and preferences taking place in Catalonia and Spain over the last 25 years. In the absence of empirical studies of pediatric cancer communication in Spain, I relied on studies about cancer communication with adults, media representations of pediatric cancer, and pediatric cancer advocacy groups to show that preferences for more cancer information and more open and visible practices of having and talking about cancer have not replaced practices and preferences for less openness and visibility. Although they may be seen as contradicting each other, these different practices and preferences co-occur, influence each other, and continue to evolve. These diverse communication preferences and practices that transcend the binary of simply *talking* or *not talking* are not just identifiable in my ethnographic study of Catalonia Hospital, but also in Catalan society at large.

A dichotomous division between *talking* and *not talking* is based on a referential theory of communication (Tyler 1978; Wilce 1998, 2009a), in which talk about cancer is equated with disclosure, and silence is equated with non-disclosure. Communication plays a more complex role in how speakers constitute, influence, and make sense of the world they inhabit. Negotiations of the limits of uncertainty and non-disclosure require substantial amounts of talk. Indeed, much of this talk is designed to avoid silence, which is accomplished through strategies such as responding partially or tangentially, and preventing sensitive questions from being asked at all. Real and potential breaks in the conversation and silences are actively avoided in the non-disclosure of cancer information. Silence is thus a rare phenomenon.

Patients, parents, and doctors at Catalonia Hospital are constantly talking about cancer both implicitly and explicitly. One should not assume that just because participants avoid the word “cancer,” they are not talking about it. They stay within the limits of safe and known aspects of cancer, i.e., the present course of treatment, and avoid the unknown aspects of it, such as “Why do I have cancer?” and “Will I be cured?” However, they are nevertheless talking about cancer by choosing to talk about some aspects of their experience and avoiding others. Furthermore, one should not assume that just because patients, parents, and doctors are not explicitly talking about uncertainty, it is not a pervasive and pressing concern for them. A situated analysis of their communication strategies reveals that they are collaboratively working to ensure that uncertainty does not become a central focus of their talk, and that it is neither communicated implicitly nor explicitly.

Participants use talk to impede specific implicit and explicit meanings. My analysis of the activity of communicating, rather than an analysis focusing on words in isolation, shows a complex network of interactive, dynamic, and mutually influencing interrelations between the individual and the social. Social interaction operates on a primordial dialectic in which participants’ experiences shape interaction, and the interaction shapes participants’ experiences. In order for an interaction to occur, individual subjectivities have to come to some kind of shared understanding of what is happening. Hence, the interaction itself becomes more than the sum of private subjectivities. In interaction, participants constitute and give meaning to what they are doing, experiencing, saying, and not saying.

Because children’s cancer trajectories are full of overlapping and hierarchically organized uncertainties, communicative strategies vary according to the changing circumstances of a child’s specific cancer trajectory. In the pre-treatment phase, complete and official non-disclosure predominates over a very chaotic information situation, which is then followed by the official and planned partial disclosure of the treatment interview with young people. Partial disclosure continues during treatment, as long as local uncertainties associated with the present course of treatment and overall prognostic uncertainties are kept separate. Partial disclosure predominates as long as nothing bad happens and as long as conversations do not venture too far into the future. During post-treatment, the predominant communicative strategies depend on whether or not the child is in remission, relapse, or approaching death. In remission, mothers and doctors begin to talk about overall uncertainties and display negative emotions in the presence of the children. However, remission is not a stable situation, and if the child relapses, parents and doctors return to a tighter control of communication. The more uncertain and ominous the child’s future, the more constricting the communicative strategies are about it, which often involves relying on optimistic deception and complete non-disclosure.

To avoid potentially distressing news, the constant regulation of communication occurs throughout the entire cancer trajectory, beyond the relatively rare deliveries of bad news such as the initial delivery of a cancer diagnosis or the final delivery of a poor cancer prognosis. Although the suffering of uncertainty may be

less intense and less visible, it is nevertheless more pervasive than the suffering precipitated by bad news. Whereas the delivery of bad news is episodic, the effects of indeterminacy and uncertainty are long lasting. Because much of the doctors' avoidance of information disclosure is directly related to uncertainty and not necessarily to bad news, I respond to Maynard's (2003: 248) call to go beyond analyses of the delivery of bad and good news by examining uncertain news over entire cancer trajectories. Furthermore, my study extends Maynard's analysis of the delivery of bad news to parents by exploring in a detailed and situated manner how bad and uncertain news is actually delivered, or not delivered, to the pediatric patients themselves.

In addition to illustrating that there is not one uncertainty but changing and overlapping uncertainties, I underscore the social dimension of uncertainty, and more generally, the social dimension of experience. The experience of uncertainty is subjective, but it is also intersubjectively shaped and socially constituted. This is clearly manifested in how concerned doctors, parents, and children are about controlling and shaping communication. When she tells Pedro an optimistic and eventful story about his future treatment rather than answering his question about his cure, the doctor tries to influence and shape his current and future experiences of cancer treatment. When they dismantle Toni's question about the possible delay of his autotransplant, doctors work hard to create a sense of certainty and confidence that everything is okay: the autotransplant cannot be delayed because a date has not been set yet. By manipulating communication toward some aspects of cancer and away from others, doctors, parents, and children try to influence each other's experiences and understanding of what is happening. They work constantly and intensively to regulate, control, and shape communication and ultimately social reality, while at the same time pretending that they are not doing so.

In highlighting the social dimension of the experience of uncertainty, I have also drawn attention to the institutional politics of children's participation in the regulation of cancer communication, and more broadly, children's place in their own treatment. Keeping uncertainty out of medical conversations and maintaining certainty, hope, and optimism requires interactional work and the collaboration of participants. Sustaining hope and optimism is personal (in families and communities) and institutional work (Beach 2001b, 2003, 2009; Mattingly 2010; Peräkylä 1991). Because my work focuses on the regulation of communication at Catalonia Hospital, my examination of hope is limited to institutional hope and does not address the personal and familial aspects of hope (Beach 2009; Mattingly 2010). I have shown that doctors lead the effort in sustaining hope and optimism, even if it comes at the price of withholding information from children and optimistic deception. Using clinical narratives to instill hope is a well-studied phenomenon (Good 1991, 1995; Good et al. 1990; Mattingly 2010; Mattingly and Garro 2000). Hope is intimately tied to information disclosure (Good 1991; Good et al. 1990, 1993). Physicians are deeply concerned about how they administer hope and information in this economic system (Byrne et al. 2002; Fallowfield

et al. 2002; The et al. 2000). Too much hope and too little information can foster unrealistic patient expectations, and too little hope and too much information can result in patients giving up hope. Parents of children with cancer also feel a strong moral imperative to be hopeful, optimistic, and strong (Young et al. 2002a), and welcome doctors' role in sustaining hope (Salmon et al. 2012). Under asymmetrical conditions that place children at the bottom of communication and decision-making, to what degree do optimism and hope become the only way children can talk about cancer?

In concluding her analysis of children's participation in mutual pretense Bluebond-Langer (1978: 235) argues as follows:

The children know what their parents know and want to hear. They are more concerned with having parents around than with telling them the prognosis. Children will do whatever is necessary to keep their parents near, but they would often like to share their knowledge with someone else as well.

To challenge the social and moral order means to risk exclusion and abandonment, "a fate worse than death itself" (Bluebond-Langer 1978: 230). It is not far-fetched then to assume that, almost 40 years later, children at Catalonia Hospital are also more concerned with having parents and doctors around than with obtaining information and talking about the negative and uncertain aspects of cancer. Children in my study do not explicitly challenge medical authority, the regulation of communication, and the mandate to be hopeful and optimistic. However, in the questions they ask and the answers that they pursue, some young people reveal that they may not be so willing to go along. With these small acts, some young people—and I underscore *some*, because there were others who did not ask many questions or pursue them—establish their own topic and action agendas, as opposed to doctors' agendas of what they want to talk about and how they want to talk about it. Like Robert in Chapters 4 and 6, and Toni in Chapters 4 and 7, some young people are willing to prevent doctors from closing the medical interaction and walking out until their questions about topics doctors are reluctant to talk about are dealt with. Robert and Toni pursue answers in a non-challenging but dogged manner. Pedro, on the other hand, makes known his unwillingness to go along with how the doctor is conducting the visit by refusing to look at the doctor and by crying. After obtaining a tangential answer to his question about his cure, Pedro not only refuses to align himself with the doctor's optimistic narrative of his future treatment, but also refuses to align himself with her move to close down the interaction. The doctor eventually gives up and seeks Pedro's parents' alignment before continuing with the interaction.

Small acts contradicting doctors' agendas are significant accomplishments, especially because they go against the grain of medical communication (Frankel 1990; Robinson 2001a, 2001b, 2006). Physicians are in charge of the opening and

closing activities and the phases of medical interactions. They ask the questions, and patients answer, not the other way around. Furthermore, pursuits of answers show that some children hold doctors accountable for answering, and view themselves as individuals who need to be accounted to. Children's actions reveal that they understand themselves as members of society who matter and as individuals whose actions matter. At the same time, children's actions reveal that they understand their social positioning and their limited agency. Sometimes, they ask questions and pursue answers; at other times, they can only look away and refuse to be the recipient of doctors' reassurances.

When patients, especially young people, ask questions, they display their medical expertise through the kinds of questions they ask, and also display their desire to be informed and to be heard. Moreover, they are making public that they want to be involved and be taken into account in conversations about their own treatment. There are evident ethical and legal dilemmas regarding how much responsibility pediatric cancer patients can take on and should take on. At the same time, most pediatric cancer patients will survive cancer and become young adults who must be autonomous, well informed, and fully able to take responsibility for their own healthcare, including treatment-related late side effects (Bashore 2004; Gianinazzi et al. 2014; Kadan-Lottick et al. 2002). The questions children ask about their own treatment may be an indication to parents and doctors of the degree of involvement children seek.

Children's participation in conversations about their own cancer treatment is full of paradoxes for scholars and policy makers. To dismiss their actions because they may only have a local impact and may not affect treatment decisions is to render children invisible and to take from them what little agency they do have. To highlight their actions without taking into account the sociocultural, political, institutional, and legal constraints that limit their participation is to render them as incomplete human beings by naturalizing the conditions of childhood. To romanticize children and promote uncritically increased participation is to overlook the fact that more participation often entails more responsibility (Clemente et al. 2012; Klein and Goodwin 2013; Ochs and Kremer-Sadlik 2013; Ochs and Izquierdo 2009), that some children may not want or be able to assume increased responsibility because of their age and maturity level, and that it may not necessarily be in the child's best interest (Bluebond-Langner et al. 2005). In examining the paradoxes of children's participation in medical conversations, one encounters the paradoxes of human agency and the human condition (Ahearn 2001; Duranti 2004). These are not children's issues, but issues of marginal social actors, young and adult, abled and disabled, who may have limited power to influence the worlds in which they live.

I have set forward an ethnography of small acts by marginal actors in everyday dramas. My ethnography of communication combines the conversation analytic examination of ephemeral moments and ethnographic analyses that contextualize those moments longitudinally, communicatively, and contrastively within

children's specific cancer trajectories. In my attempt to capture the commonalities without sacrificing the diversity of the experiences of children with cancer, the ethnographic and conversation analytic approaches have allowed me to examine aspects of children's lives that otherwise would go unnoticed. We must seek to analyze and understand what children do, no matter how big or small, so we may ensure that the inclusion of children's actions and perspectives in research and policy involving them becomes the norm rather than the exception.

Appendix A

Profiles of Patients

Children (ages 3–6)

Carmen. Three-year-old girl with osteosarcoma (bone tumor). Participation in the study: 8th to 12th month of first line chemotherapy, and during five additional months of follow-up post-treatment. Carmen was a monolingual Spanish speaker. Although she was born and lived in Catalonia, she and her family spoke only Spanish. Her parents could understand Catalan, but rarely used it.

Eli. Five-year-old girl with Wilms' tumor (type of kidney tumor) with lung metastases. Eli's parents brought Eli from a hospital in Colombia, where she was first diagnosed with cancer, to Catalonia Hospital and continued first line chemotherapy. A few months after Eli's arrival, her first line chemotherapy was abandoned and substituted with second line chemotherapy to treat Eli's lung metastases. Her second line chemotherapy concluded with an autotransplant. Eli's lung metastases remained stable for some time after the autotransplant, but eventually started to increase again. She died a few weeks after returning to her home in Colombia. Participation in the study: 10th to 12th month of first line chemotherapy, 1st to 4th month of second line chemotherapy, and during two additional months of post-treatment palliative care. Eli was a monolingual Spanish speaker who could not understand Catalan. She was born and lived in Colombia, and only came to Catalonia Hospital for treatment. Eli's parents could neither speak nor understand Catalan.

Judit. Five-year-old girl with acute lymphoblastic leukemia. Participation in the study: 1st month of follow-up post-treatment. Judit was a Spanish-Catalan bilingual speaker. She spoke Catalan with her family and alternated Spanish and Catalan with most people. Judit's parents spoke Catalan and Spanish.

Laia. Three-year-old girl with nephroblastoma (kidney tumor). Participation in the study: 1st to 3rd month of first line chemotherapy. Laia was a Spanish-Catalan bilingual

speaker. She spoke Catalan with her family and alternated Spanish and Catalan with most people. Laia's parents spoke Catalan and Spanish.

Marc. Six-year-old boy with Ewing's sarcoma (second most common type of bone tumor in children and young adults). Participation in the study: 7th to 12th month of first line chemotherapy, and four additional months of follow-up post-treatment. Marc was a Catalan-Spanish bilingual speaker. Although he could understand Spanish, he never used it. Marc's parents spoke Catalan and Spanish.

Young people (ages 11–18)

Anna. Sixteen-year-old girl with osteosarcoma. Participation in the study: 5th to 12th month of first line chemotherapy, and during two additional months of follow-up post-treatment. Anna was a Spanish-Catalan bilingual speaker. She spoke Spanish and Catalan with her family and also alternated Spanish and Catalan with most people. Her father spoke only Spanish, and her mother spoke Spanish and Catalan.

Bruno. Eleven-year-old boy with acute lymphoblastic leukemia. Participation in the study: 7th to 15th month of first line chemotherapy, and during three additional months of follow-up post-treatment. Bruno was a Spanish-Catalan bilingual speaker. He had no problem understanding Catalan, but rarely spoke it. He spoke Spanish with his family and used Spanish with most people. Bruno's father spoke Spanish and Catalan, and his mother spoke only Spanish.

Dani. Sixteen-year-old boy with rhabdomyosarcoma (soft tissue sarcoma). Participation in the study: 1st to 3rd month of first line chemotherapy. I also interviewed Dani and his parents when he relapsed after two years in remission. Dani was a Spanish-Catalan bilingual speaker. He had no problem understanding Catalan, but rarely spoke it. He spoke Spanish with his family and used Spanish with most people. Dani's father spoke Spanish and Catalan, and his mother spoke only Spanish.

Felipe. Eighteen-year-old boy with papillary thyroid carcinoma (cancer of the thyroid gland), with ganglionic and lung metastases. For six years, Felipe continued to relapse. At the time of the study, he was undergoing chemotherapy for palliative purposes, in order to slow down the growth of the metastases and to help him breathe. After starting palliative chemotherapy, his parents took him to a different hospital. They returned to Catalonia Hospital a few weeks before Felipe died. Participation in the study: 1st month of palliative chemotherapy. Felipe was a Spanish-Catalan bilingual speaker. He had no problem understanding Catalan, but rarely spoke it. He spoke Spanish with his family and with most people. Felipe's parents spoke only Spanish.

Gemma. Fifteen-year-old girl with osteosarcoma and lung metastases. At the time of the study, she had relapsed. She also developed a massive infection in the area of her leg from which the primary bone tumor had been removed surgically. Despite the mega prosthesis and the bone graft, Gemma was never able to use her leg again. At the start of her second line chemotherapy, her leg was amputated. Participation in the study: 1st to 7th month of second line chemotherapy, and during three additional months of follow-up post-treatment. Gemma was a Catalan-Spanish bilingual speaker. She had no problem understanding Spanish, but rarely spoke it. She spoke Catalan with her family and used Catalan with most people. Gemma's parents spoke Catalan and Spanish.

Núria. Fifteen-year-old girl with osteosarcoma. Participation in the study: 3rd to 9th month of follow-up post-treatment. Núria was a Catalan-Spanish bilingual speaker. She had no problem understanding Spanish, but rarely spoke it. She spoke Catalan with her family and used Catalan with most people. Núria's parents spoke Catalan and Spanish.

Oriol. Sixteen-year-old boy with osteosarcoma. Participation in the study: 8th to 13th month of first line chemotherapy, and during four additional months of follow-up post-treatment. Oriol was a Catalan-Spanish bilingual speaker. Oriol spoke in Catalan exclusively with his father, spoke in Spanish exclusively with his mother, and alternated between Catalan and Spanish with most people. Oriol's father spoke Catalan and Spanish, and his mother spoke only Spanish.

Pedro. Fifteen-year-old boy with osteosarcoma. Participation in the study: 1st to 5th month of first line chemotherapy. Pedro was a Spanish monolingual speaker who could not understand Catalan. He was born and lived in Northern Spain, and only came to Catalonia Hospital for treatment. His parents could neither speak nor understand Catalan.

Quique. Thirteen-year-old boy with osteosarcoma. Participation in the study: 6th to 12th month of first line chemotherapy, and during three additional months of follow-up post-treatment. Quique was a Spanish-Catalan bilingual speaker. He spoke Spanish with his family and alternated Spanish and Catalan with most people. Quique's parents spoke only Spanish.

Robert. Seventeen-year-old boy with metastatic osteosarcoma and lung metastases. Participation in the study: 1st to 8th month of first line chemotherapy treatment. Robert was a Spanish-Catalan bilingual speaker. He spoke Spanish and Catalan with his family and also alternated between Spanish and Catalan with most people. Robert's parents spoke Catalan and Spanish.

Santi. Thirteen-year-old boy with osteosarcoma with lung metastases. At the start of the study, Santi was finishing his first line of chemotherapy. One month after the end of the treatment, doctors found he had developed lung metastases. In less than two months, he had finished his first line of chemotherapy and started his second. Participation in the study: 11th and last month of first line

chemotherapy, two months of follow-up post-treatment, 1st to 5th month of second line chemotherapy, and three additional months during follow-up post-treatment. Santi was a Spanish-Catalan bilingual speaker. He had no problem understanding Catalan, but rarely spoke it. Santi's parents spoke Catalan and Spanish.

Toni. Fifteen-year-old boy with Hodgkin's disease (cancer of the lymph nodes). He had previously relapsed and was receiving second line chemotherapy at the time of the study. Participation in the study: two months of follow-up post-treatment after his first line chemotherapy, and from the 1st to 8th month of second line chemotherapy treatment. Toni was a Catalan-Spanish bilingual speaker. Toni spoke in Spanish exclusively with his father, spoke in Catalan exclusively with his mother, and predominantly used Catalan with most people. Toni's father spoke only Spanish, and his mother spoke Spanish and Catalan.

Appendix B

Transcription Conventions

1. Temporal and Sequential Relationships

- [
- [
-]
-]
- =
- (0.5)
- A. Overlapping or simultaneous talk is indicated in a variety of ways. Separate left square brackets, one above the other on two successive lines with utterances by different speakers, indicate a point of overlap onset, whether at the start of an utterance or later.
- Separate right square brackets, one above the other on two successive lines with utterances by different speakers, indicate 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 two things:
- 1) If the two lines connected by the equal signs are by the same speaker, then there was a single, continuous utterance with no break or pause, which was broken up in order to accommodate the placement of overlapping talk.
 - 2) If the lines connected by two equal signs are by different speakers, then the second followed the first with no discernible silence between them, or was “latched” to it.
- C. Numbers in parentheses indicate silence, represented in tenths of a second; what is given here in the left margin indicates 5/10th of a second of silence. Silences may be marked either within an utterance or between utterances.

- (.) D. A dot in parentheses indicates a “micropause,” audible but not readily measurable, and ordinarily less than 2/10th of a second.

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 a rising intonation, not necessarily a question, |
| , | | and a comma indicates a “continuing” intonation, not necessarily a clause boundary. |
| ¿ | | An inverted question mark indicates a rise stronger than a comma but weaker than a question mark. |
| — | | An underscore following a unit of talk indicates a level intonation. |
| ; | | The semicolon indicates that the intonation is equivocal between final and “continuing.” |
| :: | B. | Colons are used to indicate the prolongation or stretching of the sound just preceding them. The greater the number of colons, the longer the stretching. |
| - | C. | A hyphen after a word or part of a word indicates a cut-off or self-interruption. |
| <u>word</u> | D. | Underlining is used to indicate some form of stress or emphasis, either by increased loudness or higher pitch. The more the underlining, the greater the emphasis. |
| ° | E. | 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. |
| ° ° | | |
| ↑ ↓ | F. | The up and down arrows mark sharp rises or falls in pitch, or may mark a whole shift, or resetting, of the pitch register at which the talk is being produced. |
| > < | G. | 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., it sounds as though it starts with a rush. |
| < > | | |
| < | | |

hhh	H. Audible aspiration is shown where it occurs in the talk by the letter h—the greater the number of h's, the more the aspiration. The aspiration may represent breathing, laughter, etc.
(hh)	If it occurs inside the boundaries of a word, it may be enclosed in parentheses in order to set it apart from the sounds of the word.
.hh	If the aspiration is an inhalation, it is shown with a dot before it.
#	I. The pound, or number symbol, indicates a gravelly voice quality in the sound(s) that follow or that are between two pound/number symbols.
☺	J. This sign indicates “smile voice.”

3. Other Markings

(())	A. Double parentheses are used to mark the transcriber's descriptions of events rather than representations of them, for example, ((cough)), ((sniff)), ((telephone rings)), ((footsteps)), ((whispered)), ((pause)), and the like.
(word)	B. When all or part of an utterance, or the speaker identification, is in parentheses, this indicates uncertainty on the transcriber's part, but represents a likely possibility.
()	C. Empty parentheses indicate that something is being said, but what is said is not audible (or, in some cases, the speaker cannot be identified).
xxx	D. A combination of x's is used to indicate that the transcriber has identified the presence of a consonant or vowel sound, but no specific identification of the sound can be achieved. Each x represents one sound, and the number of x's is an approximate representation of the syllable length.

4. Crying (from Hepburn (2004))

°°help°°	Whispering—enclosed by double degree signs
.shih	Wet sniff
.skuh	Snorty sniff

~grandson~

Huhh .hhih

Hhuyuhh

>hhuh<

Wobbly voice—enclosed by tildes

Sobbing—combinations of multiple h's, some with full stops before them to indicate inhalation rather than exhalation, many have voiced vowels, some voiced consonants; if sharply inhaled or exhaled—enclosed in the “greater than/less than” symbols (> <)

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