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Children: Contributions to Communication and Illness

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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

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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 micropolitical 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). Intracultural 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 non-disclosing 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 though 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 places 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; Tates and Meeuwesen 2000; Tates 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; Tates and Meeuwesen 2001; Tates 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 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' 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 adjuvant[2] 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.