

# UNCERTAIN FUTURES



COMMUNICATION AND CULTURE  
IN CHILDHOOD CANCER TREATMENT

IGNASI CLEMENTE

WILEY Blackwell



## Uncertain Futures

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# **Uncertain Futures**

## **Communication and Culture in Childhood Cancer Treatment**

**Ignasi Clemente**

**WILEY Blackwell**

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

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





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## Series Preface

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

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

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

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

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

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

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

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

James M. Wilce, series editor

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

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

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

# Preface

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

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

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

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

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



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

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

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



# Children: Contributions to Communication and Illness

## Key Issues

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

### Alternatives to Speaking

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

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

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

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

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

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



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

### *Disclosure as a Dynamic and Heterogeneous Process*

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

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

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