CONSTRUCTING AND MAKING SENSE OF DIFFERENCE:
NARRATIVES OF THE EXPERIENCE OF GROWING UP WITH A CHRONIC
ILLNESS OR PHYSICAL DISABILITY

DISSERTATION

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The purpose of this qualitative study was to gain insight into how those who have grown up through adolescence with chronic illness or physical disability make sense of their experiences of difference in reference to the communication that has surrounded and defined these experiences. The interest was in coming to a deeper understanding, from the perspective of those with chronic conditions, of the holistic, lived experience of difference in life-long chronic illness and disability and its intersection with communicative practices, particularly during adolescence. The data for the study consisted of autobiographies, published as books, of persons who grew up with chronic illness or disability.

Chronic conditions (chronic illnesses and disabilities) among adolescents are a significant and growing health concern. With dramatic advances in medical knowledge and technology, more and more children survive traumatic births, congenital anomalies, and serious childhood illnesses. Typically these young people face numerous profound and often stigmatizing physical and social challenges that persist into adulthood, require ongoing attention, care, and coping strategies, and that result in their experiencing themselves as different—that is, in some way deviant from that which has been culturally constructed as normal.
The ways in which health care providers, parents, peers, teachers, and others communicate with those growing up with chronic health conditions are significant not only for the physical health of these adolescents, but also—and most importantly for this study—in terms of impacts on their long-term holistic health and well-being. Understanding the significance of communication in the context of adolescent chronic conditions calls for an examination of the constitutive role that communication plays in shaping the lived experience of illness or disability.

A qualitative, grounded theory investigation was utilized. Eight autobiographies, written by persons who grew up with five different physical disabilities or chronic illnesses, were analyzed to discover recurring themes in how their authors made sense of their experiences of difference in reference to the communication that surrounded that difference during their adolescence. The authors range in age from early 20s to over 70, and come from varying economic and family backgrounds. The grounded theory analysis of the data involved: immersion in the texts, theoretical questioning, and making constant comparisons; the analysis resulted in the emergence of dominant themes and an overall conceptual schema.

A grounded theory of shifting re-constructions of different self is offered. Authors of the autobiographies analyzed in this study struggled to make sense of their differences, with their narratives serving as means for both articulating and constructing their shifting definitions and understandings of their experiences of difference. These shifting re-constructions of self were in response, and often in opposition, to communication of parents, health care providers, peers, teachers, and others. All authors describe communication that ranges from rejecting, dehumanizing, or abusive, at one end of the
spectrum, to supportive, empowering, and affirming, at the other. Analysis of the
autobiographies revealed four major themes, which surfaced and recurred across all of
the differing narratives, characterizing the experience of difference in reference to the
communication that surrounded it: difference as devaluation, difference as hard reality,
difference as oppression, and difference integrated.

The insights revealed through this study can have a positive impact on the lives of
those growing up with chronic illness and disability. A deeper understanding and
appreciation of the experience of difference for those growing up with chronic conditions
and greater awareness of the constitutive role that communication plays in shaping their
reality could lead to more sensitive, respectful, and empowering communication on the
part of health care providers, parents, teachers, and others.
Dedicated to my son, Mike, with love.
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be lost.

God beyond all names, you have made us in your image;
We are like you, we reflect you, we are woman, we are man.
God, beyond all words, all creation tells your story;
You have shaken with our laughter, you have trembled with our tears.
All around us we have known you, all creation lives to hold you.
In our living and our dying we are bringing you to birth.
~Bernadette Farrell, 1990

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Communicative Construction of Different Self
CHAPTER 1

INTRODUCTION

My son, Mike, was born on September 9, 1979. When he began to make clear that he intended to enter the world a bit earlier than expected, I worried: What if he was too small, too immature? Would he have trouble breathing? Would his vital organs be underdeveloped? Might I lose him? He didn’t keep me wondering for too long. Much as I desperately longed (and tried) to keep him within me a while longer, safe from all the dangers with which his premature entry into the world might confront him, I could not protect him. My body pushed Mike out into a world that was not ready for him.

When the doctor whisked him away from me and began to check him out, my first real indication that all was not well were the doctor’s words: “We have a problem here.” Mike had not just one problem but a whole collection of them—multiple congenital anomalies is the medical term—problems that would require intensive and extensive medical treatment, beginning with life-saving major surgery the following day. I learned that, among other things, Mike had an imperforate anus (necessitating a colostomy for the first year of his life and years of complications, pain, and frustration later); severe congenital scoliosis and other assorted vertebral anomalies (requiring him to spend several of his early years strapped into a rigid body brace and to have major spinal
surgery at the age of thirteen); a malformed right ear (leading to a series of reconstructive surgeries); hemifacial microsomia (meaning that his face was significantly asymmetrical, necessitating, to date, over a decade of orthodontics and more extensive reconstructive surgeries); permanent severe hearing loss in his right ear and repeated ear infections and associated temporary hearing losses in his left ear (requiring more surgeries); a kidney reflux (leading to an endless string of infections and many painful diagnostic tests); and lung abnormalities (resulting in numerous bouts with pneumonia and asthma in his early years). These were the major health issues; other “small” problems were diagnosed as well.

My family was suddenly thrown into an overwhelming world of doctors, hospitals, surgeries, painful and frightening treatments, and uncertain diagnoses and prognoses. I learned quickly that, for all its expert knowledge, there are often no clear answers in the medical world—a world that I found both torturous and miraculous and that dominated Mike’s and all of our lives for a long time and in many ways.

For his physical problems, Mike received largely excellent care, for which I was tremendously grateful. Yet, while the medical community served him well in terms of his physical problems, it seemed clear to me that, while well-intentioned, medicine for the most part ignored what ultimately mattered the most: How all of this would impact Mike’s sense of himself and the world, his sense of bodily integrity, and his psychological and spiritual health and well-being. For example, there was the problem of the communication that took place among Mike’s health care providers, Mike, and me. From his earliest days (and, of course, more and more as he grew older and more cognizant of what was being said), I cringed at the casual indictments so often
 impersonally pronounced over him in medical-ese during histories collected at his frequent clinic visits and hospital admissions. And I cringed at my own necessary participation in these conversations.

What would Mike make of these characterizations of him—these litanies of all the things “wrong” with him—as he grew older? What would his self-concept be? Would he think of himself as lovable, attractive, good, and capable with all his differences or as defective, unacceptable, limited, and in constant need of correction? What would he think about himself in relation to other people and the world generally? Would he find the world around him to be a benevolent place, peopled with individuals who are fundamentally trustworthy and caring, or would he see the world and its inhabitants, including those (like his mother) whom he should have been able to trust to protect and care for and cherish him, as hurtful, cold, condemning, and judgmental? How would his ability to enter into trusting relationships with others be affected by the repeated betrayals of those who professed to care for and about him? And why did the great majority of doctors (there were some notable and saintly exceptions) seem so oblivious to what seemed to me to be such a brutal affront to their patient’s self-esteem?

I expressed my views to various medical and administrative powers-that-be, but the demands for a smooth-running system seemed to outweigh the emotional, psychosocial, and spiritual needs of children. I did what I could, fighting the system when necessary, grateful when the system would accommodate Mike’s needs. For example, during a period that seemed to me to be most sensitive for Mike, I insisted that, whenever possible, arrangements be made for lengthy histories (the litanies of his “defects”) to be given out of Mike’s hearing. But then I worried about the possible effects of what might
be considered over protectiveness and paternalism and perhaps even what could be seen as a secretive and deceptive cover-up and denial to Mike of some of the essential facts of his being. I felt strongly that these facts should not be any source of shame, but was I constructing them as shameful by my shielding him from overexposure to these realities? I also worried about denying Mike what might be an important and beneficial opportunity to exercise some degree of control over these interactions.

During his many, many doctor’s appointments, tests, procedures, and hospital stays, I did everything I could to stay with Mike at all times, and I found a good deal of support for this, especially in children’s hospitals. But then I worried about the degree to which my remaining with him, often joining with his health care providers to elicit his cooperation—or helping to physically hold him down—during scary and painful procedures (and countless times myself necessarily administering these procedures, whether in medical facilities or in the “safety” of our own home) made me, in his eyes, complicit with his torturers, rather than an ally and protector. I agonized over the sense of abandonment and betrayal he must feel at those times when I was ultimately forced to hand him over to strangers just when things were the scariest and most painful.

As Mike’s mother, I was constantly brought face to face with society’s—and my family’s and my own—casual, unthinking prejudices, restrictive stereotypes, and devastating judgments. I hated and raged against the cultural ideology of physical perfection that caused many people to stigmatize Mike and others with any kind of bodily difference, and I agonized over the ways in which this ideology was embedded in and played out through me and my family and the ways in which Mike surely would internalize this same ideology. I became acutely aware of the countless everyday ways in
which virtually all people constantly and unthinkingly sort and classify people into acceptable and unacceptable, normal and discredited or discreditable (Goffman, 1963), and I railed against the assumptions underlying such classifications. Still, I knew that this was the culture within which Mike was going to need to survive and, hopefully, thrive.

So, for example, as the time approached for Mike to begin the series of surgeries, planned by his doctors since his birth, to have his low-set little flap of an ear reconstructed (the medically and psychologically optimal time, I had learned, was between ages four and five), the decision and how to approach it were not easy or obvious for me. I knew the surgeries would mean more pain and trauma for Mike, yet, unlike much of what he had been through up to that point, this was not a medically necessary procedure. Here was a situation in which physicians were motivated primarily by concern for Mike’s long-term psychosocial well being. Undoubtedly, Mike’s “funny” ear drew stares from older children and adults, and soon he and his little peers would become uncomfortably aware of this physical abnormality. The harsh reality of life in our society was that his physical difference was unacceptable and would have life-long consequences. I knew that, as a child, he most likely would be stigmatized and teased. As a teen and young adult, his formation of social interactions and romantic and intimate relationships could be hampered. He could have difficulties getting jobs. His whole self-image would be affected. What responsible, loving mother would even think of allowing all this suffering for her child when the miracle of modern medicine could alleviate it? Given the undeniable realities of time and place, I believed and still believe that going ahead with the surgeries was the right decision. Yet, proceeding meant participating in and perpetuating all that was so wrong, all the attitudes that made these medically
unnecessary surgeries necessary. It meant sitting Mike in my lap in front of a mirror and gently and matter of factly pointing out to him what he had never noticed—that his ears didn’t match like mine or other people’s. I had to explain to him that, even though I loved his little ear and thought it was absolutely fine, lots of other people he would meet along the way who did not know better might think he looked different and weird, so the doctors were going to do an operation to make his ears match. Yes, it would hurt for awhile, but soon it would be fine. I did the best I could—in this situation and countless others like it, without any guidance or advice from the medical profession—to talk with Mike about his body and its trouble in a way that would not do violence to his self-esteem or his basic beliefs about the world. But I knew that, at some level, the message was that difference is unacceptable defect that demands correction. Only then might the person carrying the defect be accepted by others.

As Mike entered adolescence, new issues and concerns surfaced. In our culture, adolescence is a period characterized by many important changes as young people move toward adulthood, greater autonomy, and interdependent rather than dependent relationships with their parents and other family members. One growing concern I had during this period was over the level of involvement and control that Mike should be given in his health care interactions and decisions. I knew it was healthy for him to have greater and greater control over his interactions with his health care providers and to have more and more of a say in decisions about his health care, and I worked hard to gradually shift that control to Mike. I had tried, throughout his life, to give him choices and control whenever I realistically could do so, depending on his age and the circumstances. When Mike was four, I did not judge it appropriate or fair or helpful to him to frame the
reconstructive surgery for his ear as a choice for him to make. When he was thirteen and needed back surgery to arrest the rapid and life-threatening progression of his scoliosis and Mike at first told me there was no way he was going to have that surgery, ever, the conversations that ensued between the two of us were more collaborative—or at least I tried to make them so. In fact, had he continued to resist in the face of the compelling reasons for the surgery that I (and, to a lesser extent, his doctor) presented for his consideration, the communication between us would have had to become less collaborative, and I would have had to be more persuasive, directive, and definite. While I felt strongly that it would be best for Mike to make the choice—or at least to feel he was making the choice—to have the surgery, I knew that, in fact, choosing otherwise was not a viable option.

Statement of the Problem

Mike’s experiences of growing up with a chronic health condition—shaped by all the communication surrounding them—were by no means unique or even particularly unusual. Chronic illness and disability among adolescents are increasingly prevalent, as more and more children survive traumatic births, congenital anomalies, and serious childhood illnesses and injuries. (Gortmaker, Walker, Weitzman, & Sobol, 1990; Hoffman, Rice, & Sung, 1996; Newacheck & Taylor, 1992). Often, however, these young people face profound and stigmatizing challenges that persist into adulthood and that require ongoing attention, care, and coping strategies (Barnard, 1987; Eiser, 1990, 1993; Garrison & McQuiston, 1989). These challenges are important not only in terms of physical health, but also—and more important for this study—in terms of impacts on holistic health, which includes psychological, social, and spiritual health and functioning.
To live with a chronic illness or disability, especially as a child or adolescent, is to experience oneself as different. The experience of growing up with a chronic illness or disability is comparable to other experiences of difference, in which a person who is in some way outside of what is defined as “normal” is often set apart, seen as, and comes to see oneself as “Other.” (The terms Other, Others, and Othering, deliberately capitalized, have become standard terms in critical and cultural literatures that reflexively and critically call attention to the often oppressive political and ethical consequences of practices and processes by which individuals in positions of authority and privilege separate and differentiate and distance Others from ourselves) (See Fine, 1994; Visweswaran, 1994; and West, 1993).

Research Question

The central research question guiding this study is: How is the relationship between communication and the experience of difference portrayed in autobiographical narratives of individuals growing up with chronic illness or disability? Are there common themes in autobiographical narratives of these individuals that provide insight into some of the possible ways that these individuals construct and make sense of their experience of difference in and through their autobiographies in reference to the communication that has surrounded it during their adolescence? The aim of this study is to come to a deeper understanding of the holistic, lived experience of adolescent chronic illness and disability and its intersection with communicative practices. To explore my research questions, I used grounded theory to systematically and interpretively code and analyze autobiographical memoirs by persons with chronic health illnesses or disabilities.
Definition of Terms

*Chronic Illness and Disability*

Chronic illness and disability are related but differing concepts whose definitions are subject to considerable slippage and contentious debate both within and outside of the medical community. The terms are often used casually, but there are extremely complex political, historical, economic, social, medical, and psychological perspectives on these definitions with far-reaching consequences at all levels (Linton, 1998; Wendell, 1996).

Within the medical community, chronic illness and disability are sometimes lumped together, using the term *chronic illness* to encompass both concepts. Many theorists within disability studies strenuously object to this, arguing that disability and chronic illness are quite distinct, with disability being primarily a political and not a medical category (e.g., Linton, 1998). Sometimes, and more accurately, the more comprehensive (and, it might be argued, less pejorative) term *chronic conditions* (e.g., Thomas, 1987) is used when referring to either or both chronic illness and disability. Some theorists see the common defining characteristic as a long-standing physical impairment or disease state that is not amenable to “cure” or “correction” and that necessitates ongoing medical attention for the individual.

Thomas (1987), who writes from a nursing perspective and emphasizes the important role of communication in the context of chronic conditions, provides what seems to me to be a helpful, sensitive, and balanced perspective on chronic conditions. Focusing on the common concerns of children with disabilities and chronic illnesses and wishing to avoid the strictly medical bias that accompanies the term *chronic illness*, Thomas (1987) defines a chronic condition as “any anatomical or physiological
impairment that interferes with the individual’s ability to function fully in the environment” (p. 5). Thomas emphasizes that this definition focuses not on the medical aspects of chronicity but on its consequences for the individual’s life as a whole, including psychological, emotional, social, spiritual, economic, as well as physical consequences (Thomas, 1987; see also Eiser, 1993; Hymovich & Hagopian, 1992; Livneh & Antonak, 1997). Furthermore, she notes that the impediments to normal functioning may be internal but also may be because of any number of social, structural, cultural, political, or economic factors—factors external to the individual.

While I generally embrace Thomas’ definition of chronic conditions and its underlying assumptions, and I share her inclination to examine disability and chronic illness together, unlike Thomas, I most often refer to chronic illness and disability separately. This is to call attention to the fact that, while I do see much overlap in the concepts and the communication issues affecting both, there are also significant differences (including those noted by the disability rights movement) that I do not want to erase.

_Difference_

Difference is defined as a perceived deviation from that which has been culturally constructed as normal (Davis, 1997). Difference is both constructed through communication and negotiated and coped with through communication. Difference is neither fixed nor primarily a trait of the individual; rather, individuals or groups—including those with chronic illnesses or disabilities—are differentiated and set apart through a complex web of intrapersonal, interpersonal, and cultural communicative processes. Difference is a value-neutral concept, as those who are different, while often
stigmatized, in other cases may be the subjects of appreciation and positive interest (Coleman, 1997; Goffman, 1963; Wendell, 1996). Difference is often, but not always, a source of isolation, discomfort, shame, and lowered self-esteem (Marshak, Seligman, & Prezant, 1999; Wehmeyer, 2003). Difference may also be experienced or reclaimed as a source of individual or shared identity and pride as in the case of Deaf culture, for example.

Adolescence

Adolescence is defined as the developmental period during which individuals make the transition from childhood to adulthood and establish an increased sense of autonomy and self-identity, while maintaining close, albeit differently-defined, relationships with parents and other family members (Eiser, 1993). This move of the young person toward individual identity “is generally bound up with attempts to loosen familial ties in terms of both emotional attachments and parental authority” (Marshak, Seligman, & Prezant, 1999, p. 122). The transition occurs approximately between the ages of twelve and twenty years, and encompasses physiological, cognitive, emotional, social, and spiritual changes (Davis, Berger, Anderson, Feinstein, &, Linkowski, 1991; Marshak, Seligman, & Prezant, 1999; Rinehart, 1991; Seiffge-Krenke, 1998).

Communication

Communication is defined broadly and within a transactional, constitutive, social constructivist perspective as a dynamic process by which humans intersubjectively produce and reproduce individual and social representations and understandings of reality through symbolic interaction and social behavior (Berger & Luckmann, 1966; Craig, 1999; Sharf & Vanderford, 2003). Within this perspective, communicative interactions
and behaviors include but are not limited to the intentionally meaningful, face-to-face verbal and nonverbal exchange of messages. For example, without anyone intending to send this message, an inaccessible and unwelcoming physical and social environment in a school may clearly communicate to a child with a disability that her physical difference makes her unwelcome, abnormal, a burden, and someone without the same rights as others to an education or acceptance among peers. Thus, communicative behaviors and interactions and the meanings created by them are situated within a social context that both shapes and reflects them.

Significance of the Study

Given the connections between chronic health conditions and the experience of difference and stigma, the communicative processes by which those with chronic illness and disability are differentiated and stigmatized (or normalized) are of central importance. This is especially so in the context of the long-term care of adolescents with chronic illnesses or disabilities in which the developmental tasks of adolescents and issues of power and control are crucial factors that must be taken into consideration. In this context, even more so than is generally the case, the psychosocial aspects of illness are at least as important as the bodily aspects. In fact, the two clearly cannot be separated; body and mind and heart and spirit make up a whole person, and it is the whole person that is (or should be) our concern.

Yet the model of health upon which the health care system rests and within which health communication research has largely situated itself emphasizes the body while mostly ignoring the ways in which illness or disability impact an individual’s entire life. Within this model, when psychosocial aspects of illness are attended to, it is most often in
terms of how these factors may affect medical outcomes (e.g., how does an adolescent patient’s drive for greater control affect compliance, and with what consequences for physical health?), rather than also looking at psychosocial factors as critical outcomes of physiological health challenges and the communication surrounding them (e.g., how does the experience of chronic illness or disability, its treatment, and the communication surrounding these experiences affect an adolescent’s fundamental views of and feelings about her self and her world and the ways in which she will relate to that world?). In health care generally, but especially in the care of people with chronic illnesses and disabilities, the medical system often fails to provide the kind of care that is most urgently needed by patients: care for the whole person, care that seeks to understand and address the ways in which the experience of illness and its treatment are bound up with the individual’s life as a whole.

Critical studies scholars in communication and disability scholars helpfully call attention to the far-reaching, identity-shaping, whole-life consequences of cultural discourses and practices surrounding illness and health and the ways in which these practices can stigmatize those with chronic illness or disability. These communicative practices include health care provider-patient (and parent) communication, parent-child communication, the communication of peers and strangers, and narratives of the experience of illness and disability constructed by and about persons with chronic health conditions.

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1 An example of a recent exception in health communication research is a study of the everyday life experiences of revival, known as the Lazarus Syndrome, in AIDS patients responding well to new treatments, and the role of communication in the management of uncertainty in this context, by Brashers, Neidig, Haas, Cardillo, Dobbs, & Russell, 2000.
The perspectives of critical studies and disability studies too often are missing in health care communication scholarship, though, which most often has focused on short-term, adult health care contexts and on physiological health outcomes of doctor-patient communication. Thus, while research in health communication primarily has been interested in examining this instrumental role of provider-patient communication, understanding the broad significance of health communication in the context of adolescent chronic conditions calls for an examination of the constitutive role of communication and its role in adolescents’ lived experience of difference within the context of illness or disability. In my examination of the relationship between health care communication and chronically ill or disabled adolescents’ experience of difference, it is the powerful constitutive role of communication that is my focus.

The insights that result from the study ultimately will have a positive impact on the lives of persons dealing with chronic illness or disability by giving voice to and honoring their perspectives and experiences; by providing to health care providers, parents, teachers, and others a deeper understanding and appreciation of the experience of difference and its relationship to communication; and through more sensitive, respectful, and empowering communication that should result from these insights. In addition, such research should be useful in other related communication contexts, such as that involving communication among health care providers, geriatric patients (as their ability to exercise control over their own care diminishes), and the adult children of these patients who often act in the role of advocate or surrogate in a manner similar to parents of young patients.
Limitations

This investigation is limited to the study of the experience of difference of those growing up with physical (as opposed to cognitive) disabilities and illnesses. The experience of difference of those with cognitive disabilities and illnesses, while relevant and comparable in many ways, is not represented in this study.

Second, my reliance on texts written by those with illness or disability excludes the firsthand accounts of those without these skills or inclinations. The perspectives of those who are able to or who choose to write memoirs or produce videos about their experiences may not be representative of the perspectives of those who cannot or do not choose to do so.

Third, since I relied in this study on pre-existing data not generated specifically to answer my research question, the data may not yield in-depth information in areas in which I am most interested.

Outline of the Dissertation

The dissertation is organized as follows:

In Chapter 1 I begin by acknowledging my standpoint and what brings me to this research. I provide a brief statement of the problem, delineate my research question, discuss the study’s significance, state the limitations of the study, and provide an outline of the dissertation.

Chapter 2 provides a review of the literature. Bodies of literature reviewed are as follows: chronic illness and disability as difference; adolescence and chronic health conditions; and communication in the context of adolescent chronic illness or disability.
In Chapter 3, I discuss theoretical perspectives underpinning my method, the data, my criteria for the selection of the data, a description of the method, and a justification for this method given my assumptions and my research question.

In Chapter 4, I provide a discussion of the findings in terms of a conceptual schema constructed from the data.

In Chapter 5, I discuss and draw conclusions based on the findings, propose a theory of the communicative construction and meaning of the experience of difference for those growing up with chronic illness or disability, discuss the practical applications of the research, explain the limitations of the study, suggest areas for further research, and offer final remarks.
CHAPTER 2

REVIEW OF THE LITERATURE

My study of the construction and meaning-making of the experience of growing up with a disability or chronic illness is informed by and primarily draws upon four bodies of literature: the literature of disability studies and the disability rights movement, health communication literature, pediatric nursing literature, and literature explicating autobiographical narrative. The literature review includes the following four general substantive areas: chronic illness and disability as difference, adolescence and chronic health conditions, communication in the context of adolescent chronic illness, and illness and disability narratives.

Zook (1994), Frank (1995), Couser (1997), Kleinman (1988), and others have critiqued the dominance of the biomedical model of health that emphasizes bodily health while paying little attention to the role of health or illness within people’s whole-life experiences, and the consequences of this model for communication related to health. Zook argues that by situating itself within this biomedical framework, health communication scholarship too often has missed an important opportunity and unique responsibility to attend to the pervasive role that communication plays within a holistic view of health that focuses attention not only on the physiological, but also on the
psychological, emotional, social, spiritual, and societal meanings of health and illness. In my study of adolescent chronic illness and disability and the communication that surrounds it, it is this constitutive role of communication in shaping the holistic meaning of illness and disability for adolescents’ lives that interests me the most. It is here that I have found communication scholarship most lacking (research within the fields of nursing and psychology have attended to psychosocial aspects of illness much more extensively, but without attending explicitly and deeply to the role of communication), and this is where I will focus most of my attention.

Chronic Illness and Disability as Difference

Defining Chronic Illness and Disability

In Chapter 1, I briefly delineated the definition of chronic illness and disability I am using for this study. Although I generally refer to chronic illness and disability separately to avoid implying that there is no difference between the concepts, I rely upon Thomas’s (1987) useful definition of a chronic condition as “any anatomical or physiological impairment that interferes with the individual’s ability to function fully in the environment” (p. 5). Thomas emphasizes, and I agree, that it is important to define chronic illness and disability in a way that calls attention to the holistic impacts of impairments and the multiple (internal, physiological, and psychological, but also external, social, structural, cultural, political, economic) impediments to full function, rather than focusing primarily on a medical, pathological, and individualistic view of chronic conditions as definitions from within the medical literature tend to do. This is an important definitional distinction that warrants further discussion.
Unlike definitions from the medical community that tend to focus on chronic illness and disability primarily as individual pathology, the social sciences and the nursing profession helpfully offer definitions that call attention to the ways in which chronic illness and disability affect people not only (or not primarily) medically, but also psychologically, emotionally, socially, spiritually, and economically (Eiser, 1993; Hymovich & Hagopian, 1992; Livneh & Antonak, 1997; Royer, 1998; Thomas, 1987). Such definitions also attend to the support that is needed for persons with chronic illnesses or disabilities from a wide array of social systems in addition to the medical community.

Curtin and Lubkin (1995) and Lubkin and Larsen (2002), offering a nursing perspective, explain the difficulties involved in defining chronicity or chronic illness, and they discuss the strengths and weaknesses of several existing definitions. Definitions they discuss differ in terms of their comprehensiveness; flexibility; the degree of emphasis that is placed on medical versus holistic aspects of chronic illness; and how much attention is given to the role of caregivers, including the wider social structures. However, while these authors move away from definitions that are overly medical or individualized, they still focus on chronicity as disease pathology, and they are among those who consider disability as only a subset of, or the medical, bodily aspect or result of, chronicity.

Many theorists within disability studies, coming from a minority or socio-cultural perspective on definitions of disability and chronic illness, object to this, arguing that disability is a socially constructed concept and an experience quite apart from chronic illness. Disability is seen as a socio-political and not a medical category (Linton, 1998; Stone, 1984; Wendell, 1996). Disability studies and the disability rights movement have
called attention to the many problems arising from the medicalization of disability. As Linton (1998) points out, “the disability studies’ and disability rights movement’s position is critical of the domination of the medical definition and views it as a major stumbling block to the reinterpretation of disability as a political category and to the social changes that could follow such a shift” (p. 11). By treating disability as pathology, bodily difference becomes deviant, aberrant, defective, and in absolute need of correction or cure in order to restore health and normalcy and acceptability, and the ways in which disability is the result of disabling social structures and attitudes and lack of accommodation are ignored.

Yet, as adamant as Linton (1998) is in her call for the de-medicalization of disability, she does acknowledge that:

One clear benefit [of medicalization of disability] has been the medical treatments that have increased the well being and vitality of many disabled people, indeed have saved people’s lives. Ongoing attention by the medical profession to the health and well-being of people with disabilities and to prevention of disease and impairments is critical. (p. 11)

Still, although Linton recognizes the important role of medicine in the lives of people with disabilities, her firm insistence on viewing disability primarily as a social construction and a political category and her rejection of the medical model seem to mostly trivialize and dismiss the very real physical and medical (not socially constructed) challenges faced by people with disabilities (and those with chronic illnesses), and ignore the important role that medicine should and will continue to play in the lives of people with disabilities. I agree with Susan Wendell (1996), another disability rights activist, when she argues,
I think it would be cruel, as well as a distortion of people’s lives, to erase or ignore the everyday, practical, experienced limitations of people’s disabilities simply because we recognize that human bodies and their varied conditions are both changeable and highly interpreted. . . . We need to acknowledge that social justice and cultural change can eliminate a great deal of disability while recognizing that there may be much suffering and limitation that they cannot fix. (pp. 44-45)

Williams and Busby (2000) agree with Wendell’s stance, stating that “it is not possible, we suggest, to encompass all experiences of chronic illness and impairment within a social model that sometimes seems to deny the relevance to disability of bodily damage and decay” (p. 169).

More satisfying and less simplistic than Linton’s stance, I believe, are Couser’s (1997), Frank’s (1995), and Kleinman's (1988) treatments of illness, disability, and medical discourse. These theorists do not vilify, dismiss, or ignore medicine altogether, but, rather, each clear-headedly challenges and critiques medical discourse while searching for alternatives for how that discourse might more helpfully proceed.

However chronic illness and disability are defined and situated, issues of holistic health are very much at stake in any discussions of disability or chronic illness. Therefore, communication surrounding chronic conditions, including communication in health care settings, is of great significance. Many disabilities are not based in illness, although many are (e.g., orthopedic congenital anomalies vs. cystic fibrosis). And many chronic illnesses are not disabling—but many are (e.g., mild osteoarthritis vs. multiple sclerosis). Although it is true that disabling conditions—whether considered illnesses or disabilities—do not always require more than usual medical intervention, very often they do. Furthermore, such conditions, for complex reasons, do very often have significant emotional, psychological and social aspects (Corbin & Strauss, 1988; Hymovich &
Hagopian, 1993; Livneh & Antonak, 1997; Lubkin, 1995; Lubkin & Larsen, 2002; Royer, 1998). This may be especially true for adolescents with chronic illness or disability.

The Construction of Difference

In Chapter 1, I defined difference as a perceived deviation from that which has been culturally constructed as normal. Given the intersections of the physiological realities of chronic conditions, historical perceptions and cultural treatments of chronic illness and disability, and communication surrounding persons with chronic health conditions, experiencing oneself as different—whether this experience is negative, positive, neutral, or, more likely, some combination of these—is most often a fact of life (and perhaps a defining fact of life) for persons with chronic illness or disability.

Historically, and persisting today, cultural attitudes have equated disability and chronic illness with pathology, defect, aberration, otherness. Disability studies turns our attention to the ways in which communication intersects with the embodied experience of disability or illness, and with what consequences for identity and self-concept. However conceptualized, though, it is clear that disability and chronic illness are generally perceived and experienced as outside of the norm.

Davis (1997) asserts that “we live in a world of norms. Each of us endeavors to be normal or else deliberately tries to avoid that state . . . . To understand the disabled body, one must return to the concept of the norm, the normal body” (p. 23). Davis explores the concept of and the construction of normalcy. He argues that the concept of normalcy is a relatively recent construct, captured in the bell-curve (normal distribution), which “became in its own way a symbol of the tyranny of the norm” (p. 29). In societies in
which the concept of a norm dominates (as opposed to the concept of an ideal), there is a strong expectation that members of the society will fit within the norm. Those outside of the norm—the outliers—are *abnormal* and, thus, deviant; *different*, as measured against the standard of normality. Davis (1997) argues that “with the concept of the norm comes the concept of deviations or extremes. When we think of bodies, in a society where the concept of the norm is operative, then people with disabilities will be thought of as deviants” (p. 29). While *difference, abnormality*, and even *deviance* are not inherently negatively or positively value-laden concepts (and, in fact, *difference* especially may be positively valued and is often claimed and celebrated, as noted earlier), Goffman’s (1963) stigma theory call attention to the sociological and psychological processes by which these terms have become loaded with mostly negative meanings and by which persons deviating from the bell curve of normalcy are so often marginalized.

Thus, many of our pervasive cultural conceptions and our everyday talk about disability and chronic illness communicate the idea that a person with a chronic condition is an unacceptably deviant individual with a physical defect that must be corrected (ideally) or that requires that the individual submit to some sort of rehabilitation in order to adjust to his or her defective state and function as “normally” (and as unobtrusively) as possible within an able-bodied society. Disability is an individual problem, to be addressed at an individual level. The defect is an inherent—and unacceptable—part of the individual, and ultimately the responsibility of that person (Linton, 1998; Wendell, 1996).

Not only is the person with a chronic condition seen as having the responsibility to correct or adapt to his or her problem in an independent way, but often is also held
responsible for causing or for having the unacceptable defect or illness. This might be explicitly and consciously stated or believed (AIDS is a now-classic example) or might be unconsciously assumed and implied (e.g., people disabled as a result of accidents or lung cancer).

Wendell (1996) discusses the myth of control that is inherent in the prevailing view of disability and illness. There is a powerful presumption within this perspective that all defects and illnesses are subject to prevention, control, repair, and cure by the medical community and by individuals themselves. Disability and chronic illness, though, are by definition out of control, to a large extent, as noted by Couser (1997), Frank (1995), and Kleinman (1988). In the case of chronic illness and disability, neither physicians nor disabled or ill individuals can “fix” the “problem.” Implicit in this statement, in the context of disability and chronic illness, is the damning but intolerable conclusion that the medical expert and the disabled or ill individual (along with his or her parents, in the case of children) are failures. Thus, there is enormous pressure on both physicians and individuals with chronic illness or disability to persist in the quest for correction and normalization—or, increasingly, prevention—via medical intervention.

Medicine, in our culture, is a site of enormous cultural power and authority. Medical science is given not only the power to define what counts as health and normalcy, but also the power and authority over individuals’ bodies. The “well-adjusted disabled person,” the “good patient,” bows respectfully to this authority, complying with doctor’s orders, often submitting to medical treatments and examinations that have more to do with the physician’s pursuit of scientific knowledge than with the patients’ physical or emotional well-being. Many disability rights activists have strenuously protested what
they see as blatant exploitation of disabled persons in this regard. For example, Lisa Blumberg (1994) discusses and critiques the abusive and degrading “public stripping” that disabled persons too often have been subjected to in the name of the advance of medical knowledge. Blumberg describes the experience of a woman with spina bifida who was required throughout her childhood and adolescence to be examined (and videotaped) twice a year, wearing only her underpants, with more than twenty physicians and other health care providers present. As Blumberg explains, “Anne grew up thinking that what she called ‘public stripping,’ a crude phrase to describe a crude practice, was a periodic humiliation inflicted upon her because she was, as one young doctor called her, ‘significantly deformed and handicapped’” (Blumberg, 1994, pp. 73-74). Blumberg argues that the experiences of Anne and others who have endured this practice powerfully attest to the far-reaching and devastating effects of what amounts to a colonization of disability.

*The Experience of Difference*

People growing up with chronic illness or disability are constructed as and often view themselves as different relative to what is socially accepted as the normal range of wellness, bodily configuration, or functionality (Davis, 1997). This experience of difference may be magnified during adolescence, a time of life when young people typically are obsessed with conforming, with not being different, and especially with not being physically different (Davis et al., 1991; Marshak, Seligman, Prezant, 1999). Davis et al. (1991) state that “the early adolescent wants to avoid being ‘different’ at all costs, particularly because physical appearance, body image, and peer-group conformity are important derivatives of self-esteem” (p. 71).
Chronic illness and disability can result in the perception and experience of difference in many ways. Different physical appearance that comes with many illnesses and disabilities is one major site of difference. Such differences can include delayed physical development, disfigurement, obvious impairment, illness symptoms, or differences resulting from treatment, all of which may negatively affect the body image of adolescents already preoccupied with appearance. Chronic illness and disability also can affect daily routines (e.g., personal hygiene, special dietary needs, etc.), school attendance and performance, social interaction with peers, and participation in sports (Garrison & McQuiston, 1989; Schultz & Liptak, 1998). Any and all of these can be a source of extreme self-consciousness for adolescents with chronic conditions, and may lead to their being teased and ostracized by others, especially their all-important peers.

Marshak, Seligman, and Prezant (1999) argue that while research indicates that adults with disabilities “do not necessarily internalize distorted images others often hold of them . . . distorted projections are more powerful for the adolescent because the sense of self is not cohesive” (p. 127). They point out that outsiders to the experience of illness or disability tend to exaggerate the degree and consequences of physical difference associated with chronic conditions. Furthermore, the perceptual process of spread leads outsiders to infer multiple impairments and differences from the presence of one impairment or difference (Marshak, Seligman, & Prezant, 1999), and to stigmatize the person with the difference.
Stigma

A person who is stigmatized is one who is identified as having some kind of discrediting flaw that leads others to set him or her apart as different, abnormal, devalued, and not quite fully human (Goffman, 1963; Crocker & Quinn, 2000). Stigmas may be observable or hidden. According to Goffman (1963), those with observable stigmas are “discredited,” while those with stigmas that are hidden or less apparent are “discreditable.” Goffman’s (1963) stigma theory holds that those possessing such a flaw internalize the stereotypes and negative evaluations of the society of which they are a part, resulting in shame and lowered self-esteem. According to Sadowski (2003), “the fact that disability is associated with stigma . . . greatly impacts the construction of self for these youth” (p. 128).

Others question the taken-for-granted assumption that stigma leads to lowered self-esteem, however. Crocker and Quinn (2000) describe several studies indicating that self-esteem is situational rather than fixed and that persons with disabilities are not by any means universally scarred by the experience of difference. Admi (1996), in her research on adolescents with cystic fibrosis, cites numerous studies that found that “the psychosocial development of adolescents and young adults with CF was essentially normative; their self-esteem, anxiety level, health locus of control, independence level, schoolwork, and vocational career were age appropriate” (p. 166). Marshak, Seligman, and Prezant (1999) point out that assumptions of outsiders about the experience of living with a chronic condition are notoriously distorted, leading them to infer incorrectly that disabled or chronically ill persons are commonly maladjusted and unhappy:
Because (as outsiders to a situation) those of us who do not have disabilities cannot imagine how we could cope with a severe disability, we project our feelings onto others and tend to assume that they also would feel inferior, bitter, perpetually frustrated, and the like. This assumption is pervasive despite evidence to the contrary. Research studies largely conclude that these inferences are inaccurate. (Marshak, Seligman, & Prezant, 1999)

Marshak, Seligman, and Prezant (1999) note that research indicates that those with severe disabilities often integrate their disabilities into their identities more comfortably and with fewer psychological difficulties than those with mild disabilities, who may be more inclined to attempt to avoid disclosing their disability to others and avoid coming to terms with what it means to be different. In addition, persons growing up with chronic illness or disability are faced with and are able to accomplish—much earlier than most people—the important psychological task of “subordinating physique relative to other factors. This requires the individual to accept that nonphysical attributes are genuinely more important than physical ones” (Marshak, Seligman, & Prezant, 1999, p. 128).

However real stigma may be, though, much empirical research also exists that challenges its power in people’s lives. Wendell (1996) argues that Goffman’s work on stigma, while providing some useful insights into the experience and construction of chronic conditions, also leads to harmful overgeneralization about illness and disability. In addition, Wendell (1996) asserts that, “because [Goffman] does not question the social ‘norms’ that stigmatize people with disabilities, he tends to adopt a patronizing tone in speaking of people who do not meet them, and to belittle and underestimate their efforts to live by different ‘norms’” (p. 57). Goffman assumes, for example, that when people with disabilities value and take pride in their difference (as in the Deaf community), it can only be their resorting to defense mechanisms to protect their damaged identity.
Wendell (1996) contends that “inability or unwillingness to imagine taking real (as opposed to defensive, self-deceptive) pride in a difference that is stigmatized by the majority indicates a failure to question the values of the majority” (p. 60).

Whether one views his or her illness or disability as stigmatizing, shameful, and burdensome; a source of pride; or simply a fairly neutral “fact of life,” it is clear that the experience is an essential part of one’s identity and self-concept. Massie (1985), in his account of growing up with a chronic illness, explains:

“Having a chronic illness” is sometimes an elusive concept because one’s illness becomes melded into one’s identity. To ask what I would be like without hemophilia is an impossible question to answer, like asking who Abraham Lincoln would have been if he had been a midget. Clearly there is a me distinct from hemophilia, but it is hard to say sometimes where the boundaries to that me are. Who would Helen Keller have been if she had been a sighted and hearing little girl? (Massie, 1985, p. 14)

Adolescence and Chronic Health Conditions

**Prevalence and Significance of Adolescent Chronic Illness and Disability**

Chronic illnesses and disabilities among children and adolescents are a significant and growing health concern (Gortmaker, Walker, Weitzman, & Sobol, 1990; Hoffman, Rice, & Sung, 1996; Newacheck & Taylor, 1992). Welcome advances in medical knowledge, technology, diagnosis, and treatments have led to more and more children surviving traumatic births, previously fatal congenital anomalies, and serious childhood illnesses and injuries; often, however, these children and adolescents require ongoing medical attention and are faced with many psychosocial challenges that come with their chronic health conditions (Barnard, 1987; Eiser, 1993; Garrison & McQuiston, 1989; Seiffge-Krenke, 1998).
Estimates of the prevalence of chronic conditions among children range from 10-40% of all children, depending upon the inclusiveness of the definition being used (Hoffman et al., 1996; Hymovich & Hagopian, 1992; Newacheck & Taylor, 1992; Thomas, 1987). Pediatric chronic illness and physical disability include a wide range of conditions, including asthma, diabetes, cancer, hemophilia, HIV/AIDS, cystic fibrosis, muscular dystrophy, spina bifida, arthritis, heart disease, visual impairment, hearing impairment, congenital orthopedic conditions, disability resulting from traumatic injury, and many more. Chronic illnesses and disabilities may be congenital or may be acquired at any time as a result of traumatic injury or disease. Some are serious and life threatening, while others do not pose a serious threat of death. Some result in significant impairment, while others may interfere minimally with everyday physical functioning, yet may be disabling primarily by virtue of the social stigma attached to them. Some are apparent, some are hidden. Whatever the particular nature of the chronic condition, however, all such conditions necessitate intermittent or continuous interactions with the health care system and/or ongoing treatment regimens, and they in some way limit the child’s ability to function fully in the environment (Thomas, 1987).

Adolescent Development in the Context of Chronic Illness or Disability

Many important changes characterize adolescence in our culture, as the young person moves toward adulthood and an interdependent rather than a dependent relationship with his or her parents and other family members. Erikson (1959), in his psychosocial developmental theory, proposes that the crucial task of adolescence is achieving a clear sense of personal identity. This is accomplished by emulating role models and peers, experimenting with different identities and roles, and gaining
independence from family. Achieving a sense of personal identity is foundational for the next developmental stage, developing a sense of intimacy. However, the adolescent’s cognitive development and healthy drive to master these crucial developmental tasks intersect in a complex manner with the experience of growing up with a disability and chronic illness (Eiser, 1993; Garrison & McQuiston, 1989; Hymovich & Hagopian, 1992; Marshak, Seligman, & Prezant, 1999; Rinehart, 1991; Schultz & Liptak, 1998; Seiffge-Krenke, 1998; Wehmeyer, 2003).

In their discussion of adolescence in the context of disability, Marshak, Seligman, and Prezant (1999) comment that in addition to standard (and disruptive) developmental changes that occur during adolescence, such as “pubertal changes, increased peer pressures, heightened sexual impulses, and a questioning of basic values and assumptions, [a] host of additional factors converge in families that have a son or daughter with a disability” (p. 123). This is true in the context of chronic illness, as well. As Eiser (1993) points out:

It has only recently been acknowledged that adolescents with chronic disease face very special difficulties in their attempts to attain independence and autonomy. Successful separation from the nuclear family, career choices, marriage and parenting are difficult for all adolescents and young adults, but especially so for those with chronic disease. The occurrence of chronic disease during adolescence is likely to exaggerate further the challenges of the adolescent period (p. 71)

The healthy and successful achievement of separation, individuation, self-mastery, and transition into adulthood with a strong and positive self-concept can be threatened on several fronts by chronic illness and disability. This is partly attributable to factors such as the physical constraints of the chronic condition itself as well as the
resulting dependency on parents and others for assistance with tasks of daily living and medical treatments (Schultz & Liptak, 1998; Williams, 2002). For example, Schultz and Liptak (1998) explain:

> Activities such as catheterizing their child, ensuring that medications are taken in a timely fashion, and ensuring that numerous visits to health care providers are attended create dependency relationships between parents and their children not typically found with children who are not disabled. (p. 190)

Often, though, difficulties for adolescents with chronic conditions are primarily a result of the clash of societal assumptions, judgments, and stereotypes with the physiological realities of illness or disability (Eiser, 1993; Marshak, Seligman, and Prezant, 1999; Sadowski, 2003; Schultz & Liptak, 1998).

For example, teens in our culture typically begin focusing more on their future educational and career goals, but for adolescents with chronic conditions, such future plans may be threatened or impeded by physical impairment—or impairment that is not fully accepted or adequately accommodated in their society—or even by a history of serious illness (Eiser, 1993; Sadowski, 2003; Schultz & Liptak, 1998). Eiser (1993) cites numerous studies demonstrating job discrimination experienced by persons with diabetes, epilepsy, and long-term survivors of childhood and adolescent cancers (p. 72). Changes in social attitudes and the actual enactment of structural changes in education and the workplace continue to lag behind legislative changes mandated by the Americans with Disabilities Act (ADA) of 1990 (Davis, 1995).

Achievement of career and educational goals are but one area in which chronic health conditions can complicate adolescent development. Adolescents commonly begin visualizing themselves in the future as spouses and parents, but disabled or ill teens,
absorbing the messages of the culture around them, may feel (correctly or incorrectly) that their prospects for finding a mate and bearing children are dim. Peer relationships, both romantic relationships and friendships, are generally extremely important to adolescents, and the acceptance (or the scathing rejections) of peers takes on a whole new, burning significance for an adolescent who is stigmatized because of an illness or disability that is an integral and permanent part of her very identity. Young people grappling with their rapidly and awkwardly changing bodies and budding sexuality often struggle with body image and a preoccupation with their appearance amidst a culture that is obsessed with “perfect” bodies; but the physical development of adolescents with chronic conditions may be delayed or their bodies’ shapes, sizes, configurations, or functionality may be far outside of the norm (and far from acceptable to their peers or themselves), either because of the condition itself or because of medical treatments (Eiser, 1993; Garrison & McQuiston, 1989; Nemeth, 2000).

All of this has the potential to hamper significantly the psychosocial growth and development and health of adolescents with chronic illness or disability. However, it is by no means universally the case that healthy psychosocial development is impeded by chronic conditions. One useful illustration of this is provided by Hanna Admi (1996) in her study of the experience of growing up with cystic fibrosis, a lethal and debilitating genetic disease. Admi’s (1996) analysis revealed what she terms an ordinary lifestyle model:

The way in which the informants worked the disease into their lives over the years followed a normative schedule of psychosocial development. The informants’ self-definition was basically one of ordinary active children and young people. . . . The chronic health condition was basically of little centrality and relevance to
self-image, identity, everyday life, and future plans. The individuals with CF did not view themselves as deviant, sick, or handicapped, or as victims. (pp. 177-178)

Admi, concurring with many disability studies theorists, argues that outsiders—those without illness or disability themselves—incorrectly tend to assume that chronic conditions dominate the lives of disabled or ill persons, perhaps because “disability evokes feelings of vulnerability and loss of control among nondisabled people who project those feelings on people with chronic illness or disabilities” (p. 179).

Admi (1996) compares the ordinary lifestyle model that emerged from her study with three major theoretical views of chronic health conditions and their basic assumptions. The traditional clinical view, including the medical and psychoanalytic models, assumes that persons with chronic conditions are victims of their physiological impairments and resulting psychopathology. Research driven by these assumptions is flawed and misleading, argues Admi, because researchers focus on abnormality in individuals with chronic conditions, rather than being open to the ways in which the experiences of these persons are typical and shaped by the environment (Admi, 1996, pp. 165-166).

The deviance model, based on Goffman’s (1963) stigma theory, assumes that individuals with chronic conditions struggle to avoid being stigmatized by concealing or deemphasizing their discrediting abnormality. Admi’s findings also did not support this model. She explains that “the basic attitude of the young individuals with CF was not shame or pride. They adopted the philosophy that there is nothing to hide and nothing to advertise about their condition” (Admi, 1996, p. 179).
Admi suggests that her findings support the social-psychological view (minority group) model. In this view, difficulties that chronically ill or disabled persons may encounter arise primarily from discriminatory social attitudes and physical restrictions resulting from a lack of accommodation in the environment. As she explains, “Past research focused on characteristics of the individual with the chronic health conditions such as: personality traits, identity, defense mechanisms, and maturity level. The minority group model shifts the focus from the individual with the disability to the physical and attitudinal environment” (Admi, 1996, p. 167).

Communication in the Context of Adolescent Chronic Illness or Disability

*Health Care Communication*

The communication that occurs in any adolescent health care context (as in pediatrics generally) involves a number of special issues, including adolescent development, questions of shifting power and control, and the need for parents’ involvement in health care decisions, that set it apart in some significant ways from that which occurs between adult patients and their health care providers. A further layer of complexity is added when the focus is on communication involving adolescents with chronic illnesses or disabilities as compared to communication that occurs in the well-child or short-term (acute illness) pediatric health care context. Adolescents with chronic illnesses or disabilities are therefore a special concern for health communication researchers for several reasons.

Children and adolescents with chronic health conditions are at risk for short- and/or long-term psychosocial difficulties (Gortmaker et al., 1990; Livneh & Antonak, 1997; Sloper, Larcombe, & Charlton, 1994; Weiland, Pless, & Roghmann, 1992). The
psychosocial difficulties (as well as the physical difficulties) that can be associated with chronic illness and disability may be alleviated or exacerbated by the communication that surrounds them, including that which takes place in health care settings. As Couser (1997) points out, “Increasingly, people—inside as well as outside the medical establishment—are acknowledging that medical discourse, ostensibly and ideally the language of healing, may be at times counterproductive—that it may contribute to patients’ suffering even as it purports to ease it” (p. 19). This is especially true for children and adolescents, for several reasons, and, therefore, should be an issue of pressing importance for those interested in promoting holistic health for adolescents: health care providers, parents of chronically ill or disabled adolescents, adolescents themselves, and health communication scholars.

*Special Issues in Health Care Provider-Patient-Parent Communication*

The holistic care of the adolescent with a chronic illness or disability requires especially close cooperation among the health care provider, the parent, and the young patient, as well as constant awareness of and responsiveness to the pressing developmental tasks uniquely affecting the long-term care of adolescent patients (Eiser, 1993; Garrison & McQuiston, 1989; Rinehart, 1991). As in all health care contexts, communication is a crucial factor in the context of adolescent health care. In the doctor-patient relationship, communication has been demonstrated as affecting a variety of outcomes including patient satisfaction (Evans, Stanley, & Burrows, 1992; Street & Wiemann, 1987)—and, in the pediatric context, parent satisfaction (Howell-Koren & Tinsley, 1990)—and compliance with (or adherence to) treatment recommendations (J. K Burgoon et al., 1987; M. Burgoon et al., 1990; DiMatteo, Reiter, & Gambone, 1994;
Klingle, 1993; Parrott, Burgoon, & Ross, 1992). The communication that occurs in the long-term pediatric health care context, though, involves a number of issues that set it apart in some significant ways from communication in the well-child or short-term pediatric health care context, as well as from adult patient-doctor communication.

In any pediatric health care situation, and certainly in the care of a child or adolescent with a chronic health condition, an important consideration is the degree to which the patient’s ability to speak, make decisions, or implement treatments for him- or herself is restricted, requiring the presence of a surrogate or advocate (usually the parent) who often speaks and acts on behalf of the child (Ault, Rinehart, & Samenfeld, 1991; Rinehart, 1991; Rinehart & Samenfeld, 1991). In a very real sense, the pediatric patient’s well being depends upon the parent balancing dual roles as both parent and patient. Thus, depending on the age and condition of the young patient, doctor-patient communication in this context is very often actually doctor-parent communication, with the physician’s diagnosis and treatment recommendations and compliance-gaining efforts necessarily directed, to varying degrees, toward the parent as well as (or rather than) to the child (Todres, 1993).

A fundamental concern is the effect of the illness experience and the communication interactions involved in dealing with the illness on the young patient’s psychological, emotional, spiritual, and social well being, in addition to effects on physical health. Although the issue of psychosocial consequences of illness is certainly a concern for all patients, developmental factors and power issues make it an especially relevant consideration for the pediatric patient with a chronic health condition (Ault, Rinehart, & Samenfeld, 1991; Rinehart, 1991; Rinehart & Samenfeld, 1991). This is
because the psychological self and social skills largely are formed and established during childhood, changing and evolving and profoundly affected by environmental factors, especially by traumatic experiences. In the case of childhood cancer, for example, research has shown that “patients, despite successful treatment, often carry a conscious or subliminal awareness that a substantial risk—much like the sword of Damocles—hangs over their futures. Thus early severe physical illness involves experiences of anxiety and potential disruption of important developmental stages during childhood” (Boman & Bodegard, 1995). The important social and psychological developmental tasks that adolescents are typically struggling with during this time may be complicated and constrained in a number of ways by chronic illness or disability, including losses of or impediments to control and power that chronic conditions often mean in a person’s life.

In fact, both of these issues—the culturally inscribed developmental tasks confronting all adolescents, and control and power affecting the adolescent patient—intersect and overlap and are profoundly affected by the communication that surrounds them, including health care provider-patient-parent communication in health care settings, with significant consequences for adolescents’ physical and psychosocial health.

Power, Control, and Autonomy

Power is an important consideration in all health care situations. In her examination of patient power in doctor-patient communication, Beisecker (1990) offers the following definitional discussion of power:

Power has been defined as the probability that persons within a social relationship will be able to carry out their will despite resistance and the capacity of individuals to modify the conduct of others in the manner desired and to prevent their own conduct from being modified in an undesirable manner. By supplying
services others demand, a person establishes power over them, and the most prevalent way to attain power is to provide needed benefits that others cannot easily do without. (Beisecker, 1990, pp. 105-106)

In health care situations, physicians and other health care providers hold significant power over patients. They are clearly are in a position to provide needed benefits; patients, in a vulnerable position physically and emotionally, hope to gain from their health care providers expert medical advice and relief from suffering that they may be unable to obtain by other means. Furthermore, at an ideological level, physicians are granted a high level of power and authority. Thus, the relationship between health care provider and patient is asymmetrical. Patients do have other options: they may research their conditions on their own; they may use home remedies, or turn to alternative therapies; they may change physicians. Increasingly, patients are taking more active, assertive roles in their interactions with health care providers. Often, though, they are then labeled as “demanding,” “difficult,” “oppositional,” or “resistant” patients. This is especially likely when the patient is a child or adolescent—someone for whom assertions of power are considered particularly unacceptable, both within and outside of health care situations.

The power and personal control (self-efficacy, self-regulation) over their lives that patients have or are denied are important considerations in health communication research, most often being correlated with health compliance (also conceptualized less paternalistically as adherence) and related physical health outcomes, but also important for patient satisfaction and, most significant for my interests, for holistic health and well being. In research on communication between adult patients and physicians, Beisecker (1990) notes that patients have been assuming a more active role as medical consumers,
seeking more power and control in the management of their health care. She points to increased interest among communication researchers in regard to “the power relationship between patients and doctors and patients’ attempts to equalize the balance of power or gain and maintain control over aspects of their health care” (p. 105).

Beisecker argues that patient compliance may be substantially influenced by patient input and sense of control; in addition, information-seeking behavior has been shown to positively affect patients’ medical outcomes. Beisecker cites research that indicates that “lack of compliance with doctors’ recommendations may be an active coping strategy for a patient to restore a lost sense of control, especially if the doctor has used expert or coercive power and told the patient that he or she must eliminate pleasurable activities” (1990, p. 111).

Ballard-Reisch (1990) supports the notion that active participation on the part of the patient is desirable and yields beneficial outcomes, asserting that “patients actively involved in therapeutic decision making emerged from therapy in better health” (p. 95). O’Hair (1989) cites research demonstrating the benefits of relational control by the patient. Physicians, however, often seek to maintain power, employing numerous communication strategies to control the doctor-patient interactions (Beisecker, 1990). In addition, many patients’ perceptions of their physicians’ dominance and control differs from the physicians’ perceptions, with patients leaving medical interviews believing that their physicians exercised a high (and undesirable) degree of control, resulting in the patient feeling unheard and disempowered (Street & Wiemann, 1988).

As significant as the issue of power and control has been shown to be in health care provider-adult patient communication and related outcomes, the issue is magnified
and complicated in the context of the adolescent patient-parent-health care provider relationship. In this context, power and control must be balanced and negotiated among at least three key participants. The effects of a sense of self-control and power and autonomy on the young person’s physical and psychological health must be taken into account, just as for the adult patient. However, the adolescent’s level of cognitive and emotional development and psychosocial growth and development needs, as well as his or her medical condition, clearly affect judgments regarding the level of control he or she can or should be given. In addition, the simple fact that the child or adolescent is a legal minor affects the balance of power and authority among the young patient, the parent, and the physician, and affects the structure and content of the communication that takes place.

Todres (1993) argues that in a pediatric critical care situation, although the child is obviously the focus of treatment, the parent is, in a sense, the patient. This conceptualization of the relationship is seen in and perpetuated by the communication that takes place among the health care provider, the parent, and the young patient. Todres notes that, although “one should never overlook the opportunity to communicate directly with the patient when appropriate” (p. S383), the parent is the one with whom the doctor primarily communicates in this context. Patient satisfaction becomes parental satisfaction; patient compliance becomes dependent upon parental compliance. Parental satisfaction with the interaction (and, at times, parental/patient compliance) depends not only on how the physician communicates with the parent, but also hinges on the parent’s observations of the doctor’s communication with the child. The parent is typically
extremely sensitive to the manner in which the physician talks with the child, looking for “indications that the physician cares for the child as a person and not as a specific disease” (Todres, 1993, p. S383).

This communication pattern often carries over into adolescence, with health care providers and parents talking about and making decisions for the young person with only token efforts to encourage or allow meaningful involvement of the adolescent patient in his or her own health care decisions. However, the importance, at any age, of children’s maintaining some sense of control and power over their health and health care should not be minimized.

For example, Crittendon (1990) asserts that “for all adolescents, issues of autonomy and independence become central, for adolescents with a disability, the resolution of these issues presents special challenges” (p. 162). She urges health care providers to recognize the importance of helping disabled adolescents to develop a sense of autonomy and independence through assuming greater responsibility for their health-related behaviors and making decisions regarding their health care. Christian, D’Auria, and Fox (1999) agree with this perspective. They learned through in-depth interviews with adolescents that gaining freedom was the primary phenomenon explaining the process of gaining self-responsibility. The research indicated that a prerequisite to adolescents’ gaining this freedom was their active involvement in decisions about their health care and the day-to-day management of their diabetes. The themes emerging from the interviews were supported by theories of adolescent development. Christian, D’Auria, and Fox (1999) argue that health care providers must consider the implications of adolescent development for the illness experience, and must adopt a more collaborative
approach in their interactions with their adolescent patients, including talking directly with adolescents about their experiences, needs, and preferences.

Several studies (mostly involving young children, but certainly relevant for adolescents) investigating strategies to alleviate adverse reactions, stress, or pain of children experiencing hospitalization, surgery, or difficult medical procedures demonstrate the crucial importance of providing the child with age-appropriate information to reduce uncertainty and of assisting the child in gaining a sense of control by providing choices; methods the child can use for stress- and pain-reduction; and decision-making power whenever possible (Hunsberger, Love, & Byrne, 1984; Lambert, 1984; McGrath & DeVeber, 1986; Naber, Halstead, Broome, & Rehwaldt, 1995). Hunsberger et al. (1984) also cite research demonstrating the significance of the concept of control in children, arguing that “a perceived lack of control over events is a factor in elevating anxiety. . . . Having control or perceived control of aversive events reduces anxiety and fear. . . . From a sense of control comes a sense of pride and autonomy. This implies that having some control can assist children in feeling positive about themselves” (p. 156).

Lambert (1984) and Naber et al. (1995) note the significance of the child’s developmental level in its effect on his/her perception of experiences, processing of information, and preferred coping mechanisms; strategies employed to prepare the child for hospitalization and surgery must therefore be responsive to the child’s developmental level, as well as his or her previous experience in the hospital environment. Hunsberger et al. (1984) agree, asserting that “while giving information is generally viewed as
benefiting children and parents, it is [an approach] that must be practiced with some caution as well as understanding of its potential to affect individuals differently” (p. 147).

Hunsberger et al. (1984), Lambert (1984), and Naber et al. (1995) discuss the importance of parental presence during hospitalization and medical procedures. In a dramatic and positive change over the past 30 years, pediatric health care professionals now generally welcome and invite parents’ presence with their ill children, having recognized that children typically experience less stress and a greater sense of control when parents are present to support the child through the unfamiliar, frightening, and often painful experiences associated with hospitalization. This makes parental preparation for the hospital experience, as well as child preparation, especially important, since the uncertainty, fear, and anxiety of unprepared parents can hinder rather than help children’s ability to cope successfully. In addition, parental preparation can help to sensitize parents to those times when their presence or what they intend as supportive communication might actually serve to stifle the older child’s needed independence and control and sense of dignity.

As important as the young person’s ability to exercise some control and decision-making in regard to his or her health care is, though, his or her condition and age must dictate, to a large degree, the level of power that the parent and the doctor should responsibly relinquish. The complexities of these decisions are alluded to by Rushton (1993), who discusses some of the ethical concerns that can arise for health care providers and parents in caring for the ill child. Health care providers must balance a desire to honor the preferences and decisions of parents with the need to sometimes overrule parental decisions in order to protect the child. In addition, “ethical concerns
surrounding the process of informing children or surrogates about diagnosis, treatment, and prognosis may . . . arise. Many question whether consent can truly be informed when one is confronted with critical illness or injury” (Rushton, 1993, p. S387). The younger the child, of course, the more clear are such judgments; as the child grows to adolescence and to young adulthood, though, parents and physicians gradually—and often painfully—must shift control to the patient. At this point, concerns and questions about compliance (or noncompliance) and its health consequences loom especially large for health care providers and parents of adolescents with chronic conditions.

The chronically ill or disabled adolescent’s healthy drive to achieve autonomy (a drive that, when constantly thwarted, has both immediate and long-term significant consequences for the individual’s healthy and happy functioning), can lead to a notoriously high level of noncompliance, potentially posing a significant threat to his or her physical health (Krasnegor, Epstein, Johnson, & Yaffe, 1992). Fundamentally, as discussed above, adolescence is a time when young people become focused on the crucial task of exploring and establishing their identities, separating from their parents, and becoming self-sufficient and self-directed. To accomplish this task, young people typically battle for more independence, more freedom from restrictions and rules, more decision-making power, more control over their own lives, more chances to make mistakes, to fall and pick themselves up and learn from their mistakes (Eiser, 1993; Garrison & McQuiston, 1989; Rinehart, 1991). Parents who are wise and strong and brave recognize this as a crucial and fundamentally healthy (albeit frightening) process,
and they gradually shift from the close guidance and protection and structure they have appropriately given to their young children to offering greater and greater freedom, responsibility, and choice.

This process is complicated and may be compromised, though, in the context of adolescent chronic illness or disability, when the consequences of health-related decisions (whether involving self-care and risk avoidance, or accepting physicians’ medical treatments) may be immense and sobering (Eiser, 1993; Garrison & McQuiston, 1989; Hymovich & Hagopian, 1992). Health care providers and parents of adolescents with chronic conditions are faced with a constant dilemma, knowing the crucial psychosocial importance of the adolescent’s successfully gaining autonomy and control over his or her decisions and actions (including those that are health related), yet knowing that a teen’s refusal to agree to or adhere to treatment recommendations or to engage in healthy behaviors may jeopardize his or her health or life itself.

*Adolescent Patient, Parent, and Provider Communication*

Very little research exists exploring the dynamic interactions among the child or adolescent patient, the parent, and the physician or other health care provider (Eaton & Tinsley, 1999). The complex communication that occurs among the key participants in the pediatric health care context, though, appears to hold the potential of having a significant impact on the child’s well being, above and beyond the effects of the separate dyadic interactions most often studied. Two interesting studies illustrate some of these complex potential effects.
Using a qualitative ethological approach, Naber et al. (1995) studied communication among caregivers, parents, and children undergoing painful medical procedures for the diagnosis or treatment of cancer. The purposes of the study were to examine how the interactions of health care providers influence both parent and child during painful medical procedures; to investigate how parental behavior influences the child’s response to painful procedures; and to learn whether or not the interactions of health care providers influence parents’ and children’s responses to various interventions as well as to the procedures themselves. Typical of children with cancer, the children in this study experienced lengthy treatment periods during which they had to undergo many painful procedures.

The authors indicate that several variables influence how children will respond to painful procedures. Child variables include age (younger children evidence more distress), previous experience (children with previous painful experiences exhibit more distress), and fear (children who are more fearful in anticipation of the procedure evidence more distress). Parent variables include parent presence, parent anxiety, and parent behavior (including relinquishing control to the child, reassurance, distraction, ignoring, and humor). The effects of these parent variables often depend on other factors such as the age of the child.

Analysis of the interactions among parents, children, and health care providers in this study revealed varying predictable interactions associated with different stages in the procedures. Patterns and content of the interactions were identified. Four major patterns of interaction that emerged included talking with, talking at, talking around, and talking to the child. These different patterns resulted in varying responses from the children; for
example, parents and staff talking with the child tended to quiet the child, lower the child’s distress level, and facilitate the completion of the procedure; on the other hand, talking to the child and parents by caregivers—engaging in social small talk intended to distract—tended to increase the child’s distress and agitation. In every case, the talking to pattern was “initiated by the physician, and once this conversation pattern started, less and less attention was directed to the child as physician-to-parent conversation became predominant. When attention was refocused it was the parent who attempted to redirect attention to the child” in response to the child’s increased restlessness (Naber et al., 1995, pp. 86-87). In one case, a young girl exerted considerable influence on her environment and the communication among the adults in the room by playing her pain control/relaxation tapes aloud in the room. Extraneous conversation (such as the talking around and talking to patterns) among the adults in the room was reduced to a minimum, and activity and conversation in the room remained focused on the girl.

Additional findings of the study indicated that physical closeness of the parent was associated with more focused parent-child interaction and less child distress. The authors conclude by asserting that “making health care professionals aware of the various patterns of child-caregiver-parent interactions and the implications of these for the child’s comfort is . . . essential” (Naber et al., 1995, p. 89).

Another unusual study, although designed primarily to study physicians’ communication, reveals interesting and significant features of the dynamics of doctor-parent-adolescent patient communication. Raimbault, Cachin, Limal, Eliacheff, and Rappaport (1975) analyzed transcripts of interviews between doctors, pediatric patients, and parents. The 17 patients in the study were all girls with Turner’s Syndrome, a genetic
disorder that results in a collection of physical abnormalities including severe growth retardation and gonadal dysgenesis. Interviews took place between 1968 and 1972. All the interviews reviewed involve girls aged 15-19.

Several issues become apparent in reviewing the interviews. One is the tentativeness, indirectness, and anxiety, in varying degrees, of all participants in discussing the patients’ conditions. In an often quite indirect and tentative manner (although there were some instances of almost brutally direct questions from the parents in the presence of their daughters), the patients and the parents sought information regarding the level of “normalcy” the girls might expect to achieve in terms of height and sexual development and associated lifestyle potential. These were clearly important concerns, under laid with uncertainty and anxiety, and yet often they were approached in a decidedly roundabout way or, whether direct or indirect, were quickly dropped when no clear response was forthcoming.

Similarly, the physicians in the interviews seemed to avoid directly addressing or answering the concerns alluded to or expressed, often interrupting or changing the subject just as the parents’ or patients’ concerns were voiced. At other times, the physicians did provide answers, but often seemed to fall back on obscure scientific, medical terminology or highly qualified, ambiguous responses.

In reading the excerpts from the interviews, one has the impression that all parties were extremely ambivalent about the desire for clear answers versus the tendency to avoid truly coming to terms with or openly articulating the difficult facts of the girls’ conditions and prognoses, at least in the presence of the other conversation participants. The participants together seemed unable to discuss clearly and openly, yet sensitively, the
girls’ conditions. There seemed to be little middle ground between confusing indirectness and ambiguity on the one hand, and insensitive, potentially damaging directness (which seemed to elicit an indirect, possibly protective response from the other participants) on the other.

One wonders how the content and structure of the conversations would have been altered if either parents or patients were absent. In fact, two transcripts reviewed are of interviews involving only the physician and the parent; in these conversations, both physicians and parents were somewhat more open and clear. This, though, recalls concerns over issues of child (especially adolescent) patient rights to information, control, and autonomy in regard to their own health care.

Adolescent Chronic Conditions and the Communication of Others

The communication that takes place in health care settings, while clearly significant for its impacts on those with chronic illness and disability and an important focus of this study, does not exist in a vacuum and is by no means the only type of communication affecting the experiences of persons growing up with chronic illness or disability. Everyday communication of family members (particularly mothers), peers, and others (teachers, acquaintances, strangers, etc.) have been shown to play an important role in the experiences of persons with chronic illness or disability.

Parents

Parents, especially mothers, have a powerful influence in the lives of their children, an influence that is complicated and intensified in the context of adolescent chronic conditions (Hillyer, 1993; Wendell, 1996; Williams, 2002). Persons who have grown up with a disability or chronic illness frequently attest to their lives having been
profoundly affected, for good or for ill, by their mothers, including the care-giving and the messages they received from their mothers relating to their chronic health conditions. It is mothers who most often take on the critical and sometimes massive job of coordinating their children’s health care and of communicating with health care providers on behalf of and/or alongside their children. Mothers generally play the key role in the socialization of their disabled or chronically ill children within a culture that is overwhelmingly able-bodied. Most importantly, mothers typically have a strong influence in the formation of their children’s identities as capable, normal, and lovable, or as handicapped, defective, ill, and unlovable.

Williams (2002) points out that the “responsibility/autonomy dilemma,” commonly faced by mothers of all adolescents, is exacerbated when the adolescent has a chronic health condition. She cites research showing that “mothers were expected to encourage independent self-management of conditions by their teenage children, whilst they were still held responsible if problems in illness management arose” (p. 115). Williams’ analysis shows that mothers are blamed both for caring too much and caring too little for their children with chronic conditions.

Wendell (1996) comments on the ways in which high expectations for mothers to selflessly care for their disabled or chronically ill children can serve to divert attention from injustice or oppression. She argues that “mothers are often the scapegoats of a society that fails to provide adequate resources for people with disabilities but increasingly holds them to a high ideal of ‘independence.’ Such a society exploits mothers’ caregiving, demands unlimited sacrifice from them, and then blames them for giving too much care” (p. 141).
Marshak, Seligman, and Prezant (1999) comment on this, as well, and make the point that the emphasis on disabled or chronically ill adolescents making a transition to an independent and autonomous adult life is recent, leaving parents with little in the way of historical precedent or role models. Furthermore, parents desiring to move their adolescents toward independence as they approach the age of emancipation (and the loss of educational entitlement and transition to an inadequate system of adult services) are faced with a paradox. “Just as there is a developmental need to let go, external reality demands that parents become very involved to help their child obtain appropriate services and carve a good-sized niche in society for himself of herself” (Marsha, Seligman, & Prezant, 1999, p. 135).

In terms of their communication with their chronically ill or disabled adolescents, both mothers and fathers too often participate with the surrounding culture in sending the message that they see them as perpetual, helpless children, as asexual “holy innocents” who are not expected to live independently, have sexual relationships, marry, or have children (Nemeth, 2000; Sadowski, 2003). Consciously or unconsciously, parents may avoid or omit conversations they routinely have (or would have) with their able-bodied children about future educational and career goals, dating, sexuality, marriage, childbearing, etc. Parents may send this message more subtly by persisting in “helpfully” providing undue assistance or exercising inappropriate levels of control over their adolescent.

While parents may explicitly echo and reinforce the stigmatizing messages of the wider culture in their communication with their children, leading their children to see themselves as devalued and deficient, sometimes parents go to great lengths to avoid
acknowledging their child’s difference. This may indicate that the parent is in denial of their child’s chronic condition and its consequences, or it may demonstrate the parent’s awareness of and sensitivity to the social construction of illness and disability. Marshak, Seligman, and Prezant (1999) argue that this silence is not helpful:

If the differences are not acknowledged, families lose the opportunity to help adolescents place these differences into perspective and contain them. The position of ‘no difference’ generally contrasts with the adolescents’ actual experiences. . . . Adolescents may feel that parental avoidance of the disability indicates that it is so awful to them that it cannot even be talked about. (p. 129).

Parents who acknowledge their adolescent’s difference and talk openly, matter-of-factly, and affirmingly with them about the realities and ramifications of their chronic conditions send the message that they know their child is different, and that being different is okay.

**Siblings**

While numerous studies have examined the effects on nondisabled siblings of living with an ill or disabled child or adolescent, little research has been done to study the impact on disabled or chronically ill children or adolescents of their siblings’ communication. However, Fitzpatrick and Badzinski (1994) cite research demonstrating that “the interactions that children have with their siblings have a profound influence on the personal happiness that they experience in the family growing up” (p. 744), and are an important part of peer socialization. Caro and Derevensky (1997) agree, and argue that when one of the siblings has a disability, the sibling relationship is of even greater importance.

Findings of research on the influence and impact of relationships between siblings with and without disabilities are mixed. Caro and Derevensky (1997) discuss several
studies, some of which indicate that disability of one sibling has little effect on the quality of sibling relationships, while others demonstrate significant positive or negative impacts.

Peers

Peers relationships are of great importance to adolescents. As noted by Eiser (1993), peers can be a strong source of social support for children and adolescents. On the other hand, adolescents are notoriously sensitive to the judgments of their peers. Clarke and Kirton (2003) note that “children learn to perceive themselves through their interaction with others. Children with special needs often experience negative social relationships as indicated by a rejected or isolated social status” (p. 137). As noted above, the desire to fit in, to not be seen as different from their peers, is powerful among adolescents. For adolescents with chronic illness or disability, then, the communication between themselves and their peers looms large.

Teasing and bullying can powerfully affect self-esteem. Adolescents with disability or chronic illness are often subjected to teasing and bullying from their peers (Eiser, 1990, 1993). In their research on the relationship between difference and teasing, Sweeting and West (2001) cite numerous studies demonstrating that children with disabilities are at significantly increased risk of being teased and bullied. Those with conditions affecting appearance are twice as likely to be teased and bullied as those with non-visible conditions (Dawkins, 1996).

Children with physical disabilities affecting their speech, such as cerebral palsy, are often impeded in their communication, social interaction and school participation. This is especially the case when their speech deficits are severe, despite advances in augmentative and alternative communication (AAC) systems. In their study of the
communication between children with physical disabilities using AAC and their peers, Clarke and Kirton (2003) observe that “barriers to the development of positive relationships [for speech-impaired children] include classmates’ attitudes towards and expectations of children using AAC and limited knowledge and skills in building interactions” (p. 145). Arguing that much more research in this area is needed, Clarke and Kirton (2003) suggest that professionals working with children with physical disabilities need more guidance in how to help to facilitate strong peer relationships between disabled and nondisabled youth, including more information about how AAC systems influence these relationships.

Summary

In this chapter, I provided a review of the literature relevant to the study. Bodies of literature I reviewed include: chronic illness and disability as difference; adolescence and chronic health conditions, and communication in the context of adolescent chronic illness or disability. The review of the literature supports the need for further research into the impact of communication on those growing up with chronic illness or disability.

In the following chapter, I discuss my methodology. I include an explication of theoretical perspectives underpinning my method, the data for the study, the criteria I used for selecting these data, a description of the grounded theory method, and a justification for this method given my assumptions and my research questions.
CHAPTER 3

METHOD

Postmodern and feminist sensibilities demand of scholars that they self-reflexively locate themselves in their research. The possibility or desirability of the “objective” and “detached” study and representation of Others has been laid to rest by those who insist that we always and inevitably come to research from a particular standpoint and with personal biases (Alcoff, 1991; Berg, 1998; Denzin, 1994; Fine, 1994; Hertz, 1997; Oleson, 1994). Researchers are flesh and blood humans with identities, life experiences, values, and perspectives that shape our research interests, our stances toward and relationships with those we research, our interpretations of our observations, our conclusions, and our representations of what we believe we have learned through and about Others. As a result, insist critics of the positivist paradigm, we who call ourselves scholars have no choice, ethically or epistemologically, but to acknowledge up front our subjectivities—not as a way of taking ourselves off the hook or expunging our guilt, but as a way of humbling our selves and our knowledge by explicitly and self-reflexively situating what we have observed and learned, acknowledging our biases, and recognizing and honoring the inherent dignity and value and wisdom of those we presume to research and their perspectives—perspectives that may different from and must inform our own.
To me, such a stance seems instinctive. As an academic, I have found it nearly impossible (even when I was doing my best to adhere to a more traditional model of objective academic writing) to separate the personal me from the academic me. Not only do such attempts feel strained and slightly surreal, but they also feel false, dishonest, and deceptive. I often have had a strong and uncomfortable sense of concealing something vital when I have attempted to bracket out my self from the ideas I am trying to articulate or the people I am attempting to represent. The closer to my heart the subject matter, the more the discomfort intrudes, and the farther along I have come in academia, the more compelled I have felt to dedicate myself to learning about those things closest to my heart. So, for me, the growing calls for self-reflexivity within the academy have, in a sense, given me permission to do what comes naturally.

So, how shall I situate myself within my research context of disability studies and health communication? What story shall I tell of illness, disability, difference, and communication? I am an academic with intellectual, scholarly interests in communication, chronic illness, and disability and in qualitative, interpretive approaches to the study of these issues. Equally important, I am a woman in relationship with family and friends, aware of the ways I am defined in and through those relationships and in and through the communication through which, in turn, these relationships are established and maintained and nurtured. And I see that those around me—the people I love and care for the most—are so defined as well.

My research interests and my methodological choices for this study are very much tied to all that I have experienced, observed, and learned as the mother of Mike, my son who is a person with chronic health conditions, and as a communication scholar. All of
these experiences, observations, and accumulated knowledge lead me to a critical and emancipatory perspective on the broad area of health communication, informed by disability studies, and to a commitment to a methodological approach to the study of health communication that is ethically and epistemologically satisfying. Specifically, I am interested in gaining insight into the experience of difference in those growing up with chronic illness and/or disability and the ways in which communicative practices surrounding chronic illness and disability shape the experiences of those with chronic conditions.

My perspective leads me to a commitment to furthering health communication scholarship that responds to calls (Braithwaite & Thompson, 2000; Zook, 1994) to go beyond what have been dominant trends in the field (e.g., Burgoon, Parrott, Burgoon, Coker, Pfau, & Birk, 1990; Holloway & Rogers, 1992; Parrott, Burgoon, & Ross, 1992; Schneider & Beaubien, 1996; and Street, 1991), both substantively and methodologically. My commitment is to health communication research that is critical and emancipatory rather than administrative and that privileges an insider rather than an outsider perspective as a basis for reliable data and theory building.² I am disturbed by the fact that health communication research (especially that involving children and adolescents and their experiences), however well intended and useful, historically has tended to ignore the complex relationship between communication and disability (Braithwaite & Thompson, 2000), and too often continues to reflect an authoritative, superior, paternalistic, system-oriented perspective—a perspective that aims at maintaining control

² Thorne & Paterson, in their 1998 meta-analysis, provide a helpful discussion of a gradual movement toward inclusion of an insider perspective of chronic illness within qualitative nursing literature over the past two decades)
and order and gaining compliance while making judgments about what patients in general need in the absence of any genuine consideration and valuing of individuals’ health-related experiences and perspectives and their significance in terms of their holistic meaning for these patients. In so doing, research practices mirror and reinforce seriously problematic health care practices. I find this approach, both in health care practices and in the research that re-enacts and perpetuates those practices, to be disrespectfully dismissive of patients who have grown up with chronic conditions. I also see this approach as potentially harmful, especially in light of adolescents’ crucial developmental tasks of self-definition and of gaining and asserting independence, autonomy, and a greater degree of control over their lives—a process that is already radically threatened and disrupted in the context of chronic illness or disability (Eiser, 1993; Garrison & McQuiston, 1989).

Further informing my concerns about the absence of the perspective of patients themselves in much of the health communication literature are fundamental and crucial challenges increasingly raised by postmodern, postcolonial, and feminist critiques in discussions of methodology and ethics in ethnography and in qualitative research generally. These challenges probe issues involving the ethics of the treatment and representation of research subjects—those whom we presume to set apart and study as Others (Alcoff, 1991-92; Fine, 1994; Sullivan, 1996). For example, as a researcher attempts to understand and describe any group, as well as to help her audience to gain an understanding of the researched group, what role is given to the Other in relation to the researcher and in relation to dominant social structures and discourses? Are we, as researchers and readers, willing to trust the sense that Others make of their lives, or do we
persist in imposing our own “expert” perspectives and agendas throughout the research process? To what degree are we willing to assume that Others can speak with understanding, insight, and “accuracy” about their experiences and their social worlds? What credibility do we grant to an individual member of a group? To what extent can the voice of one representative of a group or culture speak for the collective? All of these challenges have important methodological implications for all research, including research of health communication and the lived experience of health and illness.

My emphasis on drawing upon and interpretively understanding the experience of difference for those with chronic illness or disability flows both from these ethical concerns and from my perspective that it is the holistic life meaning of chronic illness and disability and the resulting experience of difference—with bodily struggles being but one part of that experience—that is of ultimate interest and importance. This meaning, however, most often has been ignored or diminished in health communication scholarship that so often focuses primarily on physiological health outcomes and that seeks to quantify, predict, and control patients’ responses to the communication surrounding illness. For example, drawing a distinction between disease and illness and calling for a shift in how we think about and talk about chronic health conditions, Frank (1991) explains:

Illness is the experience of living through the disease. . . . Illness begins where medicine leaves off, where I recognize that what is happening to my body is not some set of measures. What happens to my body happens to my life. My life consists of temperature and circulation, but also of hopes and disappointments, joys and sorrows, none of which can be measured. . . . Ill persons need talk that recognizes all that they are experiencing. They need to talk not only for themselves, but also for those who are not yet ill. (pp. 13, 15)
My perspective on health and health communication research thus leads me to a qualitative, interpretive research methodology that privileges and closely attends to rich narratives of the experiences and meanings of chronically ill and disabled persons in the theory-building process.

Health Communication Research, the Biomedical Model, and the Experience of Chronic Illness or Disability

Exploring health and health communication by focusing qualitatively on firsthand accounts of the experience of those facing chronic illness or disability brings a different lens to the inquiry than is usually the case. Such a move rests upon a fundamental reconceptualization of health itself, urged by Zook (1994), from the biomedical conception that is dominant in both health care practice and in health communication research to a holistic or “ontological” conception of health in which the “meaning of being” is the central concern (p. 363).

In a culture in which scientific knowledge still holds sway, health and illness most often are conceptualized within a biomedical model, in which the focus is primarily on diagnosing and treating physiological, biological conditions and on efforts at prevention of physical illness (Zook, 1994). Bodily difference (deviation from the statistical norm) is seen as pathology demanding cure or correction. Health is equated with absence of physical pathology. The physician’s task is to apply his or her expert knowledge and skills to heal or correct the patient’s deviant body and to promote normal bodily functioning, and the challenge for the physician is to find ways to accomplish these goals in spite of often resistant, stubborn, lazy, ignorant, or forgetful patients. The patient’s role is to listen carefully to and to comply obediently with doctors’ orders so as to restore or
protect bodily function. Thus, in the biomedical model, “the politics of medical discourse . . . favors the professional; doctors exercise their medical authority through their privileged place in a specialized discourse” (Couser, 1997, p. 19).

Within the biomedical model, the immediate, everyday, lived experience of the very real, inevitable, and pervasive psychological, emotional, social, and spiritual aspects of physical illness (particularly chronic illness) or disability are most often brushed aside by physicians. If they are attended to, it is generally in terms of how they impact the promotion of optimal bodily function or the correction of physical pathology. The body remains the primary, and often the only, consideration (Zook, 1994).

Scholars looking critically at disability and illness, including Linton (1998), Frank (1995), Wendell (1996), Kleinman (1988), Couser (1997), and Davis (1995), have argued that the biomedical model of health, in which disability and illness have been conceptualized as primarily medical problems, has enormous and damaging consequences for disabled and ill persons’ lives. These consequences include an inattention to holistic conceptualizations of health, wherein bodily troubles are just one among many aspects; an inattention to the role of communication, including medical discourse, in defining and stigmatizing disability and illness (a result of the fundamental conceptualization of disability and illness as unacceptable, stigmatizing pathology); and the locating of disability and illness within the individual, with insufficient attention to the social, cultural, structural factors that construct disability.
In this vein, Zook (1994) argues that, while some scholars have advanced a biopsychosocial model as a corrective to the biomedical model, even within the “new and improved” biopsychosocial model,

> the biomedical commitment to biology remains the foundation of health care; *psychosocial* merely replaces *mind*, and dualism remains. . . . This allows for—even leads us to—fall short of a truly holistic conception of ourselves, wherein concern for biological health and longevity is effectively tempered by concern for the *meaningfulness* of life. (pp. 358-359)

Still, medical outcomes are obviously not unimportant; people suffer greatly as a result of their bodily struggles, and efforts to alleviate such suffering are undeniably laudable and crucial. The problem, though, is in the primacy given to the physiological without attention to the fundamental truth that body, mind, emotions, and spirit are an inseparable whole, a human person moving through time and space with a history and a future, searching for meaning, existing within and through and shaped by and shaping the relationships and the culture within which he or she exists.

Furthermore, within the biomedical model’s conceptualization of humans as the carriers of the enemy (disease and disability) and the commensurate necessity of the medical practitioner’s bringing to bear expert knowledge and exercising authority and control over the patient, the dominant perspective and voice in both medical interactions and in research remains that of the practitioner. The patient’s perspective in health care interactions is limited to the medical community’s definition of an “accurate” account of physical symptoms and medical history, designed to equip the physician with only that information necessary to diagnose and treat physical problems. Patients’ accounts of their rich and complex lived experiences of illness or disability are irrelevant at best and a distracting and time-consuming impediment to knowledge and health at worst. As
Kleinman (1988) notes, “illness experience is not legitimated by the biomedical specialist, for whom it obscures the traces of morbid physiological change; yet for the care giver of the chronically ill who would be an effective healer, it is the very stuff of care” (p. 17). Kleinman poses an elemental but vital question and offers what many would consider a revolutionary answer:

What is the purpose of medicine? . . . There is a moral core to healing in all societies that I take to be the central purpose of medicine. . . . The purpose of medicine is both control of disease processes and care for the illness experience. Nowhere is this clearer than in the relationship of the chronically ill to their medical system: for them, the control of disease is by definition limited; care for the life problems created by disorder is the chief issue. When viewed from the human situations of chronic illness, neither the interpretation of illness meanings nor the handling of deeply felt emotions within intimate personal relationships can be dismissed as peripheral tasks. *They constitute, rather, the point of medicine* [italics added]. (Kleinman, 1998, p. 253)

Kleinman argues that fundamental changes in health care interactions are needed to enact this perspective. Such changes, in Kleinman’s view, necessarily would include an entirely new emphasis on patients’ narratives of their experiences of illness—what Kleinman calls *mini-ethnographies*—to gain a deep and essential understanding of the whole-life meanings and impacts of illness in their lives.

Zook’s (1994) call for a reconceptualization of health communication research, reflecting and promoting a holistic understanding of health (or, to use Zook’s term, *ontological health*) rather than a biomedical model of health and health care, fits well with Kleinman’s perspective. Health communication research, largely situated within the biomedical model, has tended to focus on the physiological outcomes of communication practices, emphasizing especially patterns of communication between health care providers and patients and associated medical outcomes. Most often, the patient’s
perspective is sought only for the purpose of identifying factors that can clearly contribute to “better” physical health outcomes, rather than also looking, at a minimum, at psychosocial factors as critical outcomes of physiological health challenges and the communication surrounding them.

Again, I am not suggesting here that physical health outcomes are unimportant. Anyone who has faced chronic illness or disability will attest to the enormous role that physical suffering and impairment play in their lived experience, and health communication researchers can and should make a difference in physical health outcomes by focusing on communication practices. This is an important part of the health communication research agenda and should continue to be so. Among other achievements, health communication scholars have contributed much to an understanding of the value of more humane communication practices on the part of health care providers and more assertive, informed, and knowledgeable communication practices on the part of patients. However, it is problematic that the ultimate and narrow goals of such improvements, the desired outcomes, have remained largely unquestioned, with emphasis too often on instrumental communication practices aimed at improving only bodily health, while ignoring the monumental significance of communication in the holistic life experience of illness or disability (Zook, 1994).

Within the biomedical context, much health communication research also is focused on identifying demographic factors and fixed personality traits (such as locus of control) that are associated with various health-related behaviors. Increasing patient compliance (and, less often, increasing patient satisfaction) often become goals unto themselves for health communication researchers. For example, in their discussion of the
relationship of locus of control to compliance, Burgoon and her colleagues (1990) begin with a startling, unequivocal statement of presumed fact, asserting that “the ultimate objective of physician-patient interaction is a patient’s compliance with a physician’s recommendations. How physicians attempt to secure compliance and how patients regard those attempts is, therefore, of the utmost importance” (p. 30). As Zook (1994) argues:

[The] uncritical acceptance [by health communication scholars] of the biomedical vision of health commits us to a similar acceptance of its traditional ends (i.e., maintaining and/or restoring bodily function). However much we have applied communication theory and process toward the goal of “rehumanizing” and enhancing effectiveness of medical practice, we have questioned neither the presumption of biological primacy nor the scientific knowledge upon which such practice is founded. As such, we have effectively “medicalized” the field of health communication. (p. 347)

Zook (1994) argues for a reconceptualization of health in health communication research that “balances the concern of biological survival with concerns of personal and social, as well as societal, well-being . . . [and] wherein instrumental interests are balanced by emancipatory interests. This tandem action emphasizes the need for a concept of health (and health care) that answers to the human quest for meaningful rather than mere existence” (p. 345). Zook defines ontological health as “the meaningful (i.e., authentic) embodiment of biological, psychological, and social experience” and argues that, “in such a conception, communication is recognized as the means whereby we consciously understand, assess, and pursue authentic integration” (p. 364). In this view, health communication research has a central, essential role, rather than an ancillary one, bringing to light not only the instrumental power of communication, but, more importantly, the constitutive power of communication in health (Zook, 1994). I agree
with Zook that the first and overriding concern of health communication research generally should be for how communication constitutes experiences of health and illness and for how communication scholarship can contribute to the holistic health of patients. This is especially important, I argue, for research involving adolescent chronic illness and disability and the communication that surrounds this experience.

In pursuing such an agenda, I believe that health communication researchers in this context have a special responsibility to attend to issues of power, control and autonomy and the complicated role these play in the communication for adolescent patients. Furthermore, given the lack of attention in health communication research to adolescents’ own firsthand accounts of their experiences (a telling indication of the lack of power and control afforded to adolescents in health care settings and elsewhere), I propose that research in this context should bridge this gap by privileging the perspectives and voices of chronically ill or disabled adolescents.

Methodological Implications

I believe that a methodological approach to health communication research that focuses on a close reading and analysis of individuals’ own accounts of the meanings of their experiences of chronic illness or disability and the communication surrounding, shaping, and reflecting these experiences can provide especially enlightening insights. One especially rich source for such accounts is in the life-writing of those with chronic illness or disability in their autobiographical narratives, and this is the body of work to which I turned in this study.
Exploring the experience of difference for those with chronic illness or disability through their own narratives is especially important because characterizations, conceptualizations, and definitions of disability and illness most often have been controlled by those without illness or disability and particularly by those in the medical community. As Geist-Martin, Ray, and Sharf (2003) point out, illness narratives give voice to the concerns of persons who are usually not heard because of the stigma of their spoiled identities. More often than not, our society privileges those with undamaged bodies and minds to speak with a stronger voice than the voice of ‘others’” (p. 42).

In writing about their experiences of illness and disability, individuals seize the power to claim and name their experiences and the sense they have made of their lives. They tell the stories they wish to tell—those that have significance to them. They frame their narratives in ways that are meaningful to them (Couster, 2002).

As Couser (2001) notes, autobiography historically has been used by marginalized groups, including African Americans, Native Americans, and women, both because it is especially accessible as “a threshold genre” (p. 78) to those who have been excluded by lack of experience or expertise from other literary genres and because it involves, by definition, self-representation. Bjorklund (1998) agrees, pointing out that, beginning especially in the early 19th century, average, everyday people, and not just the rich and famous, found in autobiography an opportunity to tell their stories to the public. “It was possible, for example, for someone obscure but with an interesting story . . . to
publish an autobiography. . . . Furthermore, an autobiographer need not be well-educated; an editor or acquaintance could correct the grammatical and spelling errors if this was required” (p. 10).

This makes autobiography an especially useful and important vehicle for chronically ill or disabled persons to tell their stories: “If marginalization is in part a function of discourse that excludes and/or objectifies, autobiography has considerable potential to counter stigmatizing or patronizing portrayals of disability because it is a medium in which disabled people may have a high degree of control over their own images” (Couser, 2001, p. 78). Atkinson (1997) argues that “autobiographies have the potential to provide an insider view of people’s real lives; to give us an holistic view of people; to provide a counterbalance to other views; and to form the basis of a political document for understanding and change” (p. 21).

Critics question the value of autobiography and memoir for gaining insight into the experience of disability and chronic illness. Some point to the fact that autobiographers do not constitute a random sample of the population from which they are drawn. Others question whether the emotion, imagination, and subjectivity of autobiographies renders them unreliable data (Bjorklund, 1998). Some argue that personal life stories keep the focus on the individual and sentimentalize difference rather than shifting attention to the ways that difference is culturally inscribed and challenging, for example, the social construction of disability (Davis, 1995). Autobiographies of disability and illness may be constrained by strong cultural expectations that the narrative be one of inspiration and the triumph of an exceptional person over his or her (unacceptable) disability. As Couser (2001) points out, this type of rhetoric of triumph “is
entirely congruous with the medical paradigm, which locates disability entirely within a ‘defective’ or ‘abnormal’ body; . . . overcoming [disability] is a matter of individual will and determination rather than of social and cultural accommodation” (p. 80). In spite of these reservations, though, Couser (2001) argues that narratives that make use of what he calls a “rhetoric of emancipation” have “counterhegemonic potential. . . . In their consciousness of their own condition as culturally constructed and as shared by others, their authors may move beyond the familiar formulas of disability memoir and point the way to broader critiques of the construction of disability in America today” (p. 89).

While the critiques of autobiography are important, I agree with Berube (1996), Couser (1997, 2001, 2002, 2004), Frank (1991, 2000, 2002), and Mairs (1996), all of whom insist that a necessary element in challenging oppressive cultural narratives and practices is through the individual’s personal life story. Whether emancipatory or sentimentally heroic, autobiographies of illness and disability are vitally important because, as long as issues can be held at arm’s length, out there in the more theoretical and abstract realm, the real impacts of cultural constraints on countless real people’s lives (and, of course, it is the real individual people, both those within and outside of the group, that ultimately concern us) may never be recognized or dealt with. As Mitchell and Snyder (1997) argue, “the autobiographical narrator . . . provides a glimpse at a unique subjectivity that evolves out of the experience of disability as a physical, cognitive, and social phenomenon” (p. 9). In their discussion of the importance of attending to illness narratives in health communication scholarship, Sharf and Vanderford (2003) argue:
Narratives not only serve as a means to assert agency for persons whose control has been diminished but also provide “wounded” storytellers with a means to reshape their identities, either in functional, enabling ways or, alternatively, with an emphasis on loss, trauma, or impairment. (p. 21)

By claiming and telling their own personal stories, people with illness or disability can take back the illness or disability narrative from those who have framed the experience for them. Speaking from their own irrefutable experiences, they can set straight the “facts” and the “truth” of these experiences in a way that no theoretical treatise can do, thereby benefiting both others with illness or disability and those who, probably unwittingly, have participated in oppressive and marginalizing practices.

Yet, the “truths” that are represented in the autobiographical narratives analyzed here I assume to be truths that are constructed, multiple, culturally and socially situated, and in flux (Bjorklund, 1998; Frank, 1995). As Frank (1995) explains:

The ill body’s articulation in stories is a personal task, but the stories told by the ill are also social. The obvious social aspect of stories is that they are told to someone, whether that other person is immediately present or not. Even messages in a bottle imply a potential reader. The less evident social aspect of stories is that people do not make up their stories by themselves. The shape of the telling is molded by all the rhetorical expectations that the storyteller has [internalized]. . . . Whenever a new story is told, these rhetorical expectations are reinforced in some ways, changed in others, and passed on to affect others’ stories. (p. 3)

Bjorklund (1998) notes that autobiographies are shaped not only by authors’ responsiveness to perceived audience expectations, but also by demands of editors and publishers, who are interested in stories that are understandable, interesting, and meaningful to readers. Therefore, “although autobiographies do not represent a random sample of the population, their stories do teach us about the available vocabularies of the self” (pp. 10-11).
Analysis of autobiographies does not yield objective, verifiable facts. Rather, it gives us insight into the meanings and truths that individuals have chosen to construct for their lives and present to their readers. Autobiography is both a means of expressing and of constructing truths and meanings and selves, all of which are fluid and context-bound. Frank (1995) explains that

. . . the stories we tell about our lives are not necessarily those lives as they were lived, but these stories become our experience of those lives. A published narrative of an illness is not the illness itself, but it can become the experience of the illness. The social scientific notion of reliability—getting the same answer to the same question at different times—does not fit here. Life moves on, stories change with that movement, and experience changes. Stories are true to the flux of experience, and the story affects the direction of that flux. (p. 22)

One of the authors included in this study, Lisa Roney (1999), makes this point eloquently in the prologue to her autobiography:

As we all know by now, memory is not absolute, and I make no claims that this book represents any objective truth. Others will certainly remember some things differently. Others . . . will have had experiences very unlike mine. It is my hope that these variations in memory and experience may become not nasty quibbles, but part of the world’s dialogue about the meanings of illness, health, family, friendship, love, and language. For we must be forever starting over with talking, telling our truths, and listening to each other in order to make sense of our lives. No one else can do it for us. (p. xx)

Data

My data set consists of eight first-hand, autobiographical accounts of those who have grown up with a chronic illness or disability. Five criteria guided my selection of the texts: (1) The texts must be accounts of those with long-term physical disability or illness; (2) The texts must make reference to communication in the context of chronic illness or disability; (3) The texts must include recollections and accounts of experiences during adolescence; (4) The texts must be truly first-hand accounts, as opposed to stories
of illness or disability as narrated by family members, friends, physicians, or others, although the level of disability may necessitate the assistance of a collaborator to interpret, mediate, and/or record the disabled person’s ideas; and, (5) The texts must be focused primarily on how the life-long experience of disability or illness has affected the individual and the way the individual has made sense of his or her life.

Beyond these criteria, I deliberately refrained from restricting the texts to accounts of persons with one specific disability or illness, persons with similarly severe/disabling chronic conditions, or persons who are comparable demographically (i.e., age, socioeconomic class, race, ethnicity, gender, etc.). While cognizant that there may well be significant and noteworthy differences within the difference of chronic illness or disability, my interest was in gaining insight into the experience of difference as it cuts across varied chronic conditions and life circumstances.

The texts were collected through exhaustive searches of OhioLINK, a comprehensive public network of academic library catalogs in the state of Ohio, and Amazon.com, an internet shopping website that includes a very extensive, fully searchable database of the most current publications as well as out-of-print and used books. I used several search terms in various combinations, including disabled, disability, physical disability, handicapped, chronic illness, chronic conditions, narrative, autobiography, memoir, first-hand account, childhood, children, child, adolescence, adolescents, and adolescent. Applying the above criteria eliminated the great majority of the hundreds of extant disability and illness memoirs I discovered, most of which are focused on adult-onset conditions or, if about those with congenital or childhood
conditions, are written by parents or others rather than the individuals with those conditions.

Several texts that at first appeared to fit my criteria were, upon closer inspection, later eliminated. For example, one book I originally included in my sample was the autobiography, *How I Became a Human Being: A Disabled Man’s Quest for Independence*, written by Mark O’Brien with Gillian Kendall. The abstracts and reviews of the book described it as O’Brien’s own account of his lifelong struggle to gain independence, including struggling through rehabilitation, institutionalization, and interactions with the medical community throughout his adolescence after becoming permanently paralyzed at age six as a result of polio. O’Brien’s story appeared to be a perfect fit for my analysis. However, as I began to read the book, it became clear that Kendall’s collaborative role was considerably larger than that of a scribe or mediator. As she explains in the preface,

> As coauthor, my job has been to slow down and expand the stories behind Mark’s poetic, journalistic style. . . . When Mark died, in 1999, we had a complete draft of a book but not a fully developed story. . . . I have tried to fill in some spaces and to provide transitions and clarifications. (2003, p. xiii)

However true she may have attempted to be to the story she thought O’Brien would have told, the fact that it was Kendall who developed and completed O’Brien’s story—and especially since she did so after his death—makes the book more biographical than autobiographical.

In contrast, in the introduction to *I Raise My Eyes to Say Yes* (1989) written by Ruth Sienkiewicz-Mercer with Steven B. Kaplan, Kaplan explains that while Ruth “has never spoken a word, never written or typed a sentence” (p. vii) due to her very severe
impairment as a result of cerebral palsy, the book is truly and completely her own account of her life. As he says, “This book tells the life story of Ruth Sienkiewicz-Mercer, as recounted by her. It is her autobiography, written with my assistance” (p. viii). Kaplan provides a detailed account of the arduous collaborative process by which the book was produced, with Ruth communicating via facial expressions and a limited repertoire of sounds and the use of a set of word boards containing some 1800 entries. Kaplan explains: “Throughout the narrative, I have attempted to present events from my source’s perspective. In every instance, Ruth and I painstakingly reviewed the written account, sometimes through four or five drafts. Each time, Ruth approved, or edited, or altered, or added to her original account and my rendering of it” (Sienkiewicz-Mercer, 1989, p. xi). Elaborating on the process, Kaplan describes his own concerns and Ruth’s dogged insistence that the book truly be her own story:

Every time I attempted to provide words for Ruth’s thoughts, I questioned whether the written product accurately represented her commentary or unwittingly embodied too many of my own projections . . . . My skepticism diminished as I got to know her better. In particular, there were several times in those first few months when we floundered over an obscure detail in a story and Ruth insisted that we get it just right. This made me realize that once she begins to tell someone something on her word boards, she never willingly permits that person to misconstrue the message. I had discovered the one absolute rule of Ruth’s approach to conversation: once she begins to express a thought, she is as obstinate as the proverbial dog with a bone. Her correspondent either perceives her message accurately or tears his or her hair out trying. (1989, p. xv).

Thus, while Sienkiewicz-Mercer’s story, like O’Brien’s, involved a collaborator in the writing process, Sienkiewicz-Mercer’s book met my requirement that the texts be truly firsthand accounts, while O’Brien’s did not.
Another text that was originally part of my sample was Cass Irvin’s *Homebound: Growing Up with a Disability in America* (2004). While marginally fitting within the autobiographical genre, this book is most clearly intended as a powerful political statement, with Irvin’s experiences providing concrete but peripheral illustrations of her true subject matter. Illuminating and provocative as it is, I eventually eliminated Irvin’s book from my sample because her focus is primarily on the disability rights movement and disability issues rather than on making sense of and articulating an account of her own life experiences as a disabled woman.

*Texts for Analysis*

The following is a list of the autobiographical books that are included in my data:


*Alive at 25: How I’m Beating Cystic Fibrosis* (2001), is Andy Lipman’s account of growing up with this chronic, debilitating, and ultimately fatal congenital disease.

*From Where I Sit: Making My Way with Cerebral Palsy* (1999), by Shelley Nixon, is Nixon’s story of her life with quadriplegic cerebral palsy, a complication of her extremely premature birth.

*The Me in the Mirror* (1994), by Connie Panzarino, is Panzarino’s memoir of her life with a rare and life-threatening congenital condition called Spinal Muscular Atrophy Type III (formerly known as Amytonia Congenital).

*Sweet Invisible Body: Reflections on a Life with Diabetes* (1999), by Lisa Roney, is Roney’s account of growing up with juvenile (Type I) diabetes.

I Raise My Eyes to Say Yes (1989) is Ruth Sienkiewicz-Mercer’s autobiography, mediated by Steven B. Kaplan, telling her story of her life growing up with severely disabling cerebral palsy.

Journey into Personhood (1994), by Ruth Cameron Webb, is Webb’s memoir of growing up with cerebral palsy resulting from a difficult delivery.

In order to situate the authors’ accounts of their experiences, additional contextual information about the authors, their circumstances, and their narratives is provided in Chapter 4. A summary description of the authors/subjects included in the study, including a brief profile of their families as they describe them and/or as I gleaned from their autobiographies, is provided in Table 3.1.

Analysis

I used the grounded theory method to analyze the selected texts. As defined by Strauss and Corbin (1990), “the grounded theory approach is a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon” (p. 24). In this approach, theory is generated through a research method that entails “a balance among the attributes of creativity, rigor, persistence, and, above all, theoretical sensitivity” (Strauss & Corbin, 1990, p. 58).

Grounded theory was first explicated by Glaser and Strauss in their book, The Discovery of Grounded Theory (1967). Initially developed and most heavily utilized by sociologists, the methodology rapidly became well known and widely used for diverse areas of study, especially among qualitative researchers throughout the United States and
<table>
<thead>
<tr>
<th>Author</th>
<th>Illness/Disability; Effects</th>
<th>Age at onset</th>
<th>Born</th>
<th>Pub.</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grealy, Lucy</td>
<td>Ewing’s Sarcoma; Treatment led to severe facial disfigurement</td>
<td>9</td>
<td>c. 1965</td>
<td>1994</td>
<td>Somewhat dysfunctional; middle or upper-middle class</td>
</tr>
<tr>
<td>Lipman, Andy</td>
<td>Cystic Fibrosis; life-threatening chronic illness; periods of severe illness, daily respiratory therapy, medications, bowel and lung obstructions</td>
<td>Birth</td>
<td>1973</td>
<td>2001</td>
<td>Protective, loving, supportive; upper-middle class</td>
</tr>
<tr>
<td>Nixon, Shelley</td>
<td>Cerebral Palsy; Limited use of hands, walks with assistance, slow but understandable speech</td>
<td>Birth</td>
<td>1977</td>
<td>1999</td>
<td>Resourceful, loving; upper-middle class</td>
</tr>
<tr>
<td>Panzarino, Connie</td>
<td>Spinal Muscular Atrophy; unable to walk or care for any of her physical needs, must be on a respirator for periods each day</td>
<td>Birth</td>
<td>1947</td>
<td>1994</td>
<td>Often dysfunctional, chaotic, overburdened; working class; abusive mother</td>
</tr>
<tr>
<td>Roney, Lisa</td>
<td>Type I Diabetes; “Invisible disability”; life-threatening chronic illness; requires constant monitoring, dietary control, insulin shots; frequent episodes of severe hypoglycemia, infections</td>
<td>11</td>
<td>1960</td>
<td>1999</td>
<td>Supportive, loving; upper-middle class</td>
</tr>
<tr>
<td>Rothenberg, Laura</td>
<td>Cystic Fibrosis; extensive and progressive damage to her lungs and other organs, leading her to have a double lung transplant</td>
<td>Birth</td>
<td>1981</td>
<td>2003</td>
<td>Supportive, loving, knowledgeable; upper-middle class</td>
</tr>
<tr>
<td>Sienkiewicz-Mercer, Ruth</td>
<td>Cerebral Palsy; no speech, very little voluntary movement, communicates only through eye movements, a limited repertoire of about ten sounds, and word boards</td>
<td>5 weeks</td>
<td>1950</td>
<td>1989</td>
<td>Nurturing, loving, but sacrificed her for the sake of the rest of the family; working class</td>
</tr>
<tr>
<td>Webb, Ruth</td>
<td>Cerebral Palsy; impaired speech, reliant on wheelchair (walks with significant difficulty)</td>
<td>Birth</td>
<td>1923</td>
<td>1993</td>
<td>Supportive, resourceful, progressive; upper-middle class</td>
</tr>
</tbody>
</table>

Table 3.1: Autobiographers: Contextual Information
England (Bernard, 2000; Strauss & Corbin, 1994). Denzin (1994) asserts that “the grounded theory perspective is the most widely used qualitative interpretive framework in the social sciences today” (p. 508), with its greatest presence in education, health sciences, and communication.

Grounded theory is an interpretive research method whereby data are closely analyzed by means of a primarily inductive and iterative process of systematic coding through constant comparison and questioning of the data, resulting in the discovery of themes, conceptual categories, and emergent theory based on the relationships among concepts (Bernard, 2000; Charmaz, 2003; Glaser, 1998; Glaser & Strauss, 1967; Lewis, 1992; Lincoln & Guba, 1985; Strauss & Corbin, 1990, 1998). Grounded theory does not begin with hypotheses or propositions, nor does it set out to test already established theory. Rather, it is an open, process-oriented method that deliberately avoids approaching data with pre-existing theorizing so as to ensure that the researcher remains tied closely to the data and open to the conceptual schema that emerge from them.

Thus, in order to move from raw data to themes, propositions, and theorizing, grounded theory methodology relies upon and demands theoretical sensitivity on the part of the researcher. As Strauss and Corbin (1990) explain, “theoretical sensitivity refers to the attribute of having insight, the ability to give meaning to data, the capacity to understand, and capability to separate the pertinent from that which isn’t” (p. 42). Theoretical sensitivity is developed through a combination of the researcher’s professional and personal experience and the actual interaction with the data (collecting,
questioning, making comparisons, further questioning and reflection, developing conceptual frameworks, etc.) throughout the analytic process (Strauss & Corbin, 1990, p. 43).

Given my research question and assumptions and the perspectives on health care communication and health communication research and scholarship that I have explicated, grounded theory was a particularly useful and appropriate method for this investigation. My goal was to gain insight into and a qualitative understanding of the holistic experience of difference among those growing up with a chronic illness or disability. I framed my research question in a deliberately broad and open-ended manner because I wished to avoid making (and imposing) assumptions about the meaning of difference for those growing up with chronic illness or disability. My goal was not to test existing theories but to develop theory as it evolved from the data.

Also fitting well with my research perspective is grounded theory’s insistence that “interpretations must include the perspectives and voices of the people whom we study. . . . They have perspectives on and interpretations of their own and other actors’ actions. As researchers, we are required to learn what we can of their interpretations and perspectives” (Strauss & Corbin, 1994, pp. 274, 280). Charmaz (2003) agrees, arguing that “we must try to find what research participants define as real and where their definitions of reality take them” (p. 272). This important assumption supports my commitment to research that privileges and relies upon an insider rather than an outsider perspective on the experience of chronic illness and disability.

While grounded theory privileges insider perspectives and emphasizes the importance of constantly remaining tied to the data in seeking insights and formulating
theory, the approach also assumes a synthesis between the data and the researcher’s theoretically sensitized interpretive framework (Coffey & Atkinson, 1996; Strauss & Corbin, 1994, 1998). This assumption of grounded theory fits well with my perspective on the researcher’s role and the ethical and epistemological responsibility of researchers to self-reflexively locate themselves in their research. As Charmaz (2003) explains, “the grounded theorist’s analysis tells a story about people, social processes, and situations. The researcher composes the story; it does not simply unfold before the eyes of an objective viewer. The story reflects the viewer as well as the viewed” (p. 271). Graue and Walsh (1998) agree, arguing that the researcher is ethically obliged to self-reflexively examine and make explicit her subjectivity in relation to her research context, since “theory does not grow on trees, waiting to be plucked by the careful observer. It does not leap out of one’s data record. It is constructed, and it has its origins in many places” (p. 28).

*Procedures*

Following standard grounded theory procedures (e.g., Bernard, 2000; Charmaz, 2000, 2003; Dey, 1999; Strauss & Corbin, 1990, 1994, 1998) this study involved the following “steps.” Although I describe these steps individually, the steps were enacted not in a linear manner, but in an ongoing, simultaneous, iterative process.

First, I clarified my existing perspectives and assumptions, which provided the foundation for my research question, selection of data to be collected, and interpretive framework. In addition to the perspectives and assumptions previously explicated in this and in the first chapter, three additional specific assumptions underlie this study and the method of investigation. First, I assume that chronically ill or disabled persons’
experience of difference is not unitary or fixed, either within or among individuals; rather, my assumption is that this experience is multidimensional and fluid and shaped by a variety of complex and changing factors both within and outside of individuals. A second assumption is that the recollections and stories of individuals’ experiences and the meanings they assign to their experiences constitute primary, essential, and reliable data. I assume that their perspectives and insights are significant, valuable, and revealing and that common themes and concepts that emerge from their stories have validity and provide a reliable basis for emergent theory. A third assumption is that many of the experiences of difference in chronically ill and disabled individuals cut across various types of chronic illnesses and disabilities. Therefore, although I limited my study to physical as opposed to cognitive illnesses and disabilities (because a number of different issues and variables are involved in disabilities and illnesses primarily affecting cognitive functioning), I included the perspectives of persons with a variety of conditions, both congenital and acquired.

Second, I specified my broad research questions and definition of key terms. For this study, as previously stated, the research questions I posed are as follows: How is the relationship between communication and the experience of difference portrayed in autobiographical narratives of individuals growing up with chronic illness or disability? Are there common themes in autobiographical narratives of these individuals that provide insight into some of the possible ways that these individuals, in and through their autobiographies, construct and make sense of their experience of difference in reference to the communication that has surrounded it during their adolescence? Key terms related to this study are chronic conditions, difference, and adolescence. As discussed
previously, *chronic condition* is defined as “any anatomical or physiological impairment that interferes with the individual’s ability to function fully in the environment” (Thomas, 1987, p. 5). *Difference* is defined as a perceived deviation from that which has been culturally constructed as normal (Davis, 1997). *Adolescence* is defined as the developmental period during which individuals make the transition from childhood to adulthood and establish an increased sense of autonomy and self-identity, while maintaining close relationships with parents and other family members (Eiser, 1993). *Communication* is defined broadly as a dynamic process by which humans intersubjectively produce and reproduce individual and social representations and understandings of reality through symbolic interaction and social behavior (Berger & Luckmann, 1966; Craig, 1999; Sharf & Vanderford, 2003).

Third, guided by my research question, appropriate data were collected and reviewed. As explained above, the data for this study were gathered through an exhaustive search of library and commercial databases for autobiographical books and essays meeting these criteria: the texts are accounts of those with long-term physical disability or illness; the texts make reference to instances of interpersonal communication in the context of chronic illness or disability; the texts include recollections and accounts of experiences during adolescence; the texts are first-hand accounts; and the texts focus on the impact on the individual of his or her experience of disability or chronic illness. Since my interest was in gaining insight into commonalities in the experiences of difference for persons growing up with varying types and degrees of disability and with various life circumstances, I did not limit my data set to texts written by persons with similar chronic conditions, level of impairment, age, socioeconomic status, race, etc.
Once the texts were selected, I immersed myself in the authors’ stories, reading and re-reading the narratives to become closely familiar with and sensitive to the authors’ accounts of their lives and begin to gain a general sense of themes and meanings and formulate new questions. In order to truly enter into and listen carefully to the stories my subjects had to tell, I resisted the temptation to begin coding and analyzing the texts as I went along during this deep listening stage. Instead, I used “sticky notes” to quickly flag passages that I might want to return to later, so as not to interrupt the flow of the writers’ stories.

Fourth, the data were coded through an ongoing process of questioning and constant comparative analysis, resulting in the identification of theoretically relevant conceptual themes, characteristics, and categories (open coding). While the asking of questions and making of comparisons are fundamental to the grounded theory method and constants throughout the entire process, during open coding these operations are brought to bear in a more intensive and systematic manner. As Strauss and Corbin (1998) explain,

during open coding, data are broken down into discrete parts, closely examined, and compared for similarities and differences. Events, happenings, objects, and actions/interactions that are found to be conceptually similar in nature or related in meaning are grouped under more abstract concepts termed “categories.” Closely examining data for both differences and similarities allows for fine discrimination and differentiation among categories. (p. 102)

Given my research questions, the coding at this stage consisted of recording references in the texts to communication of others during the individuals’ childhood and adolescence, in various contexts (for example, communication of parents, health-care providers, siblings, and peers; and communication in health-care settings, home, and
schools), in regard to disability, illness, or difference; mentions of self-definition or self-concept, especially references to experiencing or observing the disabled or ill self as different from or similar to others; and references to the physical experience of disability or illness, particularly during childhood and adolescence, and what the individuals say about how they and others communicate about this experience. I went back through each book, noting the flagged sections and typing up sections that included these references. In the early stages of this process, I typed up every reference that seemed possibly relevant; later, as I observed emerging themes and categories, I became more selective in choosing the passages that I typed up. This resulted in some 700 individual passages or “data segments.” In the open coding process, these data segments were closely re-examined, questioned, and compared, both individually and within the context of the authors’ larger narratives, and the events or actions were defined and conceptualized through grounded theory’s process of naming or labeling (Strauss & Corbin, 1998). References were coded based on frequency and intensity. The individual data segments were examined, sorted, and categorized and re-categorized according to prevalent themes and characteristics that emerged. The theoretical sensitivity that is central to grounded theory led to an ongoing adjustment of themes, concepts, categories, and characteristics. For example, many types of references that initially had been coded because of their intensity or frequency were later eliminated because of a lack of relevance to this study. Some categories/themes were subsumed within other larger categories; some categories were combined, forming a new and different theme; still others were eliminated entirely as lacking significance. Through this process, I moved from twelve initial categories to eight, and then to five.
Fifth, in the axial coding process, further in-depth, interpretive comparison and questioning of categories and subcategories revealed significant relationships, linkages, and integration among them (Dey, 1999; Strauss & Corbin, 1990, 1998). At this stage of the grounded theory method, “data are put back together in new ways after open coding, by making connections between the categories” (Strauss & Corbin, 1990, p. 96). This process allowed for further revision of the categories, moving from five categories to four, and the development of a number of propositions, supported by the data, offering a tentative explanation of the relationships among the themes, categories, and concepts that emerged in open coding.

Finally, the process of selective coding, an interpretive and holistic examination of the propositions and categories (Dey, 1999; Strauss & Corbin, 1990, 1998), led to a conceptual framework that provides a partial, theoretical response to my research questions and suggests areas of further research. In selective coding, categories and propositions that emerged earlier were further questioned and, gradually, were refined and integrated. The findings and conclusions are discussed in the following chapters.

Table 3.2 provides a summary of the “steps” I took in this research. As the grounded theory method demands, these steps demanded theoretical sensitivity throughout, took place in an iterative rather than a sequential process, and involved theoretic notes or “memos” that I wrote to myself as I reflected on my data, findings, and the process itself at various stages.
Table 3.2: Grounded Theory Method in Research of Portrayals of Difference in Autobiographies of Individuals Growing Up with Chronic Illness or Disability

<table>
<thead>
<tr>
<th>Step 1:</th>
<th>Clarify perspectives and assumptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 2:</td>
<td>Specify broad research question; define key terms</td>
</tr>
<tr>
<td>Step 3:</td>
<td>Determine sampling criteria and collect data (autobiographies)</td>
</tr>
<tr>
<td>Step 4:</td>
<td>Immersion in data; closely read and re-read texts, flagging significant passages</td>
</tr>
<tr>
<td>Step 5:</td>
<td>Type up and then cut apart relevant passages from texts (data segments)</td>
</tr>
<tr>
<td>Step 6:</td>
<td>Question, compare, and name/label data segments; sort and categorize into piles according to emerging themes; set aside data segments that represent phenomena or categories that appear infrequently, appear insignificant, or are interesting but not relevant to the research question (open coding)</td>
</tr>
<tr>
<td>Step 7:</td>
<td>Continue questioning and comparing categories and themes to develop tentative propositions explaining relationships, linkages, and integration among them (axial coding)</td>
</tr>
<tr>
<td>Step 8:</td>
<td>Holistically examine and integrate propositions, develop conceptual framework and theoretical response to research question (selective coding)</td>
</tr>
<tr>
<td>Step 9:</td>
<td>Write up discussion of findings and conclusions</td>
</tr>
</tbody>
</table>

Summary

In this chapter, I discussed the qualitative, grounded theory method I used for the study. I clarified the theoretical perspectives underpinning my method, explaining my commitment to an approach to the study of health communication that is critical and emancipatory rather than instrumental and administrative, that privileges an insider rather than outsider perspective as a basis for data and theory building, and that focuses on interpretively understanding the holistic life meaning of chronic illness and disability. I
explained that my methodological perspective is informed by postmodern, postcolonial, and feminist discussions of epistemology and of the ethical issues entailed in the treatment and representation of research subjects. I discussed and critiqued the biomedical model that has driven much health communication research, contrasting this model with a perspective that focuses on exploring the connections between communication and holistic health (rather than only physiological health), and I explained the methodological implications of my position, including a rationale for the use of autobiographical narratives as my data. I described my data (eight autobiographies written by persons who grew up with a chronic illness or disability) and the criteria I used in selecting the texts I analyzed. Finally, I provided an explication of the grounded theory method and the specific grounded theory procedures I used in my study.

In the following chapter, I present the results of my grounded theory analysis of the data, explaining and illustrating the conceptual schema that emerged from the analysis.
CHAPTER 4

FINDINGS

The purpose of this research was to gain insight into some of the possible ways that individuals growing up with chronic illness or disability construct and make sense of their experiences of difference in reference to the communication that has surrounded them during their adolescence. How is the experience of difference for these individuals, as well as the relationship between communication and this experience of difference, portrayed in their autobiographical narratives? In Chapter 4, I present themes that emerged through the grounded theory method of questioning and constant comparative analysis of my data, previously described in Chapter 3. The data thus analyzed consisted of eight autobiographies written by persons who grew up with chronic illnesses or disabilities. Themes were identified based on the clustering of references from the texts that were coded in terms of their frequency, intensity, and relevance to the study.

Understanding this discussion of the stories and voices that are represented in the autobiographies that provide the data for this study requires some additional descriptive information about the authors and their narratives. While it was not my goal in this study to identify, compare, and contrast the diverse experiences of persons with different conditions, different levels of impairment, or different life circumstances (rather, I sought
to discover *commonalities* in the experiences of persons who were in many ways very unlike each other in these ways), an awareness of factors such as the type and extent of physical impairment, family background, birth year and age of the author when he book was written, and significant aspects of the narrative helps to contextualize the authors’ reflections.

**Descriptions of Autobiographers/Autobiographies**

*Lucy Grealy, Autobiography of a Face (1994)*

In her book, which she wrote in her late twenties, Grealy tells her story of dealing with the life-threatening cancer Ewing’s sarcoma, diagnosed at age 9, and the subsequent years of traumatic and disfiguring treatment of the disease and its results. Grealy was born around 1965, and raised in a middle to upper-middle class family. She and her two older brothers, her older sister, and her twin sister all were born in Ireland. Her parents moved the family to the United States when Grealy was four. She describes her parents as being at times warm and loving, but at other times dysfunctional and quite distant and cool, especially in their handling of her illness. Grealy eventually earned a Master of Fine Arts from the University of Iowa.

Grealy’s story is unique within my data set in that she most clearly was handicapped not by her illness or physical impairment but by society’s lack of acceptance of physical difference—the social stigma attached to her because of the severe and lifelong facial disfigurement that resulted from surgery and radiation to treat her cancer and the many, many subsequent attempts to reconstruct her face. While her difficult and debilitating cancer treatment was ultimately successful, with no recurrences, the many complex procedures attempting to reconstruct her face, over the course of some fifteen
years, were not, and her face remains noticeably disfigured. In her story, she explores her life-long struggle to accept and love herself in the face of continual messages from the world around her that she was not only unacceptable, but repugnant.

Grealy’s perspective is primarily a psychological one in which, in spite of all that she recounts about how she has suffered as a result of socially constructed standards of beauty and others' merciless judgments of her, her conclusion seems to be that her own distorted perceptions and self-doubt and lack of self-acceptance and love were the crux of the problem. Still, her story serves as an incisive commentary on a culture that so values physical beauty and external perfection and equates beauty with lovability, while stigmatizing and rejecting those with visible differences.


Andy Lipman is a young man, born in 1973, who tells his story of growing up with this chronic, debilitating, and lethal congenital disease, within a stable, loving, and very protective upper-middle class family environment. He had an older sister who died when she was two weeks old, two years before Lipman was born, of cystic fibrosis—a fact that his parents hid from him until he was 25. This was just one among many examples of Lipman’s parents’ determined efforts to shield him from the reality of his illness. For example, although his doctors recommended it, his parents never allowed him to attend camp for kids with CF, nor did they allow him to associate with other children with CF. His parents’ overprotectiveness and secretiveness about his illness is one of the issues that Lipman explores in his book.
A dominant theme in Lipman’s story is that of an individual-triumphing-over-adversity. He wrote his book partly to prove that he has triumphed and partly to inspire and motivate others. Although he has been fortunate in that, compared to many others with CF, his illness has been relatively moderate and well controlled through much of his life, Lipman has dealt with recurrent periods in his life of severe illness, impairment, and depression, and he describes the agonizing process of gradually realizing that he had a life-threatening illness and coming to terms with himself as different from and often ostracized by his peers. However, he attributes his survival thus far largely to his determination and positive thinking, and ultimately blames only himself for those times when his self-esteem or his physical or social functioning were at their lowest points.

Lipman has a Bachelor’s degree from the University of Georgia.

*Shelley Nixon, From Where I Sit: Making My Way with Cerebral Palsy (1999)*

Shelley Nixon, born in 1977, tells her story of her life with quadriplegic cerebral palsy, a complication of her extremely premature birth. She can walk with assistance, she has limited use of her hands, and her speech is slow but intelligible. She was raised at home in a stable, supportive upper-middle class family. She had the benefit of consistent physical therapy and counseling and participated in numerous programs, and she attended schools where she was either completely mainstreamed or in special education classrooms or “resource rooms” within regular schools. She has one younger brother. She is working on her Bachelor’s degree in human relations at Cabrini College in Pennsylvania, with a career goal of working with disabled children.
Nixon describes her years of struggling to construct a positive self-concept in the face of various barriers and social judgments in a simple, straightforward manner. She speaks frankly about the impact of others’ dismissive, degrading, or condescending messages, and the constant struggle for acceptance and full inclusion. Although her narrative is not explicitly motivational in the way that Lipman’s is, and she does provide a critique of societal attitudes and treatment of disability, Nixon’s story is similar to Lipman’s in that her narrative leans toward locating disability and the responsibility for managing it within the ill/disabled person, not society.


Panzarino’s book is a memoir of her life with a rare and life-threatening congenital condition called Spinal Muscular Atrophy Type III (formerly known as Amytonia Congenital), which has disabled her since infancy. Panzarino was born in 1947 and was raised in an often dysfunctional and sometimes abusive middle class home; in particular, she describes a disturbingly ambivalent and confusing relationship with her mother. Panzarino has never been able to walk, and requires assistance for all of her physical needs. She has a younger sister and brother. Her sister, who is ten years younger, was born with the same condition. Panzarino’s mother cared for these three children, two of whom were severely disabled, with very little assistance, and within a society that at that time made very few accommodations (such as accessibility in education) for disabled people—a burden that Panzarino eventually identifies as contributing to her mother’s abusiveness.

Panzarino’s focus is on tying her story and her experiences to an explication of a wide range of disability rights and identity issues. Of all the autobiographies in my study,
Panzarino’s narrative represents the most explicitly critical stance, situating disability as wholly a social construction and disability issues firmly within a civil rights perspective. Panzarino has a Master’s in art therapy from the University of New York.


Roney provides an introspective and revealing account of growing up with and managing, since age 11, juvenile (Type I) diabetes. She vividly describes the constant and pervasive impacts of diabetes on every aspect of her life. Roney was born in 1960, and raised in an upper-middle class environment. Her parents divorced sometime after she went away to college (an event that Roney attributes at least in part to the stress of dealing with her diabetes) and subsequently both of her parents remarried. She depicts her mother as having been particularly strong, determined, supportive, and resourceful. She has one brother.

Roney is extremely insightful and articulate in making connections between her experiences dealing with her diabetes and cultural assumptions, expectations, and judgments about illness, weight, sexuality, appearance, difference, and mortality. At the time she authored the book, Roney was a graduate student at Penn State, working on her Master of Fine Arts.


Laura Rothenberg’s memoir of living with cystic fibrosis and finally undergoing a double lung transplant is told through journal entries and letters written to friends and family members between January, 2000 and January, 2003. Rothenberg, the youngest of my autobiographers, was born in 1981. Sadly, she died in March of 2003. She grew up in a stable, loving, supportive upper-middle class environment.
Rothenberg’s story of living with cystic fibrosis is different from Andy Lipman’s in several respects. She was not shielded from the reality of her illness or from other children and adolescents with CF. On the contrary, Rothenberg’s story is filled with her honest and head-on grappling with the illness and her mortality over the years and with references to others with CF with whom she bonded (and often lost) through the shared experience of dealing with this debilitating and fatal illness. This may be partly because the serious and progressive nature of Rothenberg’s symptoms made it impossible for her or her parents to deny the pervasive and life-shaping effects of the disease. Rothenberg did not have the luxury, as Lipman does, of being able to hold onto the belief that with a positive attitude and sufficient individual determination and effort she could triumph over her disease. She attended Brown University.


In her autobiography, mediated by Steven B. Kaplan, Sienkiewicz-Mercer tells her story of her life growing up with severely disabling cerebral palsy which renders her unable to speak, walk, or care for her physical needs in any way. Sienkiewicz-Mercer (hereafter, for simplicity, referred to as Mercer) was born in 1950. Her early years were spent with her loving, working class family. When she was 5 years old, two factors led to her being sent to a state school for physically handicapped children: first, in spite of daily physical and speech therapy provided by her mother, her parents felt Mercer was not progressing as well as she should, so her doctors recommended she live in an institution where she could receive professional attention; second, her mother was finding it increasingly difficult to care for both Mercer and her younger sister without help.
Mercer’s father, in particular, determined that it was best for her to be institutionalized. As she came to realize, Mercer’s father made the decision to sacrifice her well being in the interests of the rest of the family.

Mercer spent two disappointing, misdiagnosed, and misunderstood months in the first institution, and three and a half good years at a progressive rehabilitation center. In 1962, at age 11, Mercer began the horrific sixteen years in which she was more or less warehoused at an archaic and appalling state institution called Belchertown. For the first three and a half of these years, she was written off as an “imbecile” who had no thoughts, feelings, or ideas and couldn’t communicate them if she did. She endured shockingly inhumane treatment at the hands of doctors, nurses, and attendants. Only gradually and with great determination did she manage to break through and show those around her that inside her very severely disabled body was an intelligent person who was able to communicate using her eyes—“raising her eyes to say yes.”

In 1973, as a result of a legislative investigation, reforms were implemented at the institution and conditions improved. Eventually, at age 28, with the crucial help of an important advocate and numerous personal care attendants, Mercer and several other Belchertown residents were able to move out of the institution into an apartment building. Two years later, in 1980, she and a man who was part of this group were married.

*Ruth Cameron Webb, Journey into Personhood (1994)*

Framing her story as a spiritual journey toward full “personhood,” Webb writes a memoir of growing up with cerebral palsy, the result of a difficult birth. Born into a loving, stable middle or upper-middle class family in 1923, Webb grew up during a time when society’s obstacles were far more profound and limiting for persons with
Webb writes thoughtfully and clearly about her experiences and feelings growing up disabled, including and the many barriers she encountered and their effects on her. With great effort, extensive physical therapy, and the help of numerous mentors—“spirit guides,” as she calls the key support people throughout her life—Webb was able to function remarkably well within an unaccommodating able-bodied world. However, throughout her life, Webb’s disability affected her appearance, significantly impeded her mobility, speech, and her ability to care for herself, and has been a continual source of stigma and barriers to the independence she worked so hard to achieve.

Writing in the present tense, Webb narrates the unfolding events and emotions of her long life, and she reflects with insight and clarity on the ways that her sense of herself as a full “person” and her ability to strive for and achieve her goal of relative self-sufficiency and independence were shaped by her interactions with those around her, as well as social structures and policies. She earned her PhD in counseling and guidance in 1963 from the University of Illinois, spent twenty years working as a team psychologist at a state institution for the profoundly retarded in Iowa, and fought what ultimately seemed to be a lost battle for legitimacy as a researcher and therapist. With her long-time housekeeper and companion, she entered a retirement community in 1990.
Emergent Themes

My analysis of the autobiographies that constitute the data in this study revealed four dominant themes representing the major ways that these disabled or chronically ill individuals—persons who have in common the experience of growing up with some chronic health condition but who are otherwise very different from one another—portray their experience of difference in reference to the communication that surrounded them as they grew through adolescence into adulthood. These four themes emerged through an inductive analysis of the data, a process that is detailed in Chapter 3. Briefly, the grounded theory process by which the themes that are discussed in this chapter emerged consisted of: deep immersion in the eight autobiographical texts; typing up data segments that appeared relevant to the investigation; naming/labeling and grouping data segments, yielding preliminary themes, characteristics, and categories; and further coding of data segments, re-examination of categories, and integration of categories through continual in-depth questioning and constant comparison of the data. Further questioning and comparison of these themes led to integration of the themes and the development of a theoretical response to the research question, which is proposed in Chapter 5.

The dominant themes that emerged through the analysis are as follows:
(a) *difference as devaluation*, (b) *difference as hard reality*, (c) *difference as oppression*, and, (d) *difference integrated*. For each of these categories, the data analysis revealed significant thematic references that the authors make to their portrayal of the experience of difference; a characteristic stance or orientation of self toward difference and disabling communication about difference; and corresponding characterizations of the different self. The authors include abundant references to communication of those around them,
including health care providers (e.g., physicians, nurses, and allied health professionals), parents, peers, and the wider culture, as well as memories of their feelings and thoughts, and reflections on all of their experiences. The communication they describe is sometimes positive, confirming, and empowering. However, most often the communication that surrounded these individuals, as remembered and described in their narratives, was instead painfully negative and disconfirming. In and through their narratives, the authors work to make sense of this communication and their overall experiences of difference.

While a particular theme is in some cases the dominant story or “moral” in a narrative, none of the authors’ characterizations of illness/disability identities or experiences are fixed or stable. All portray their experiences of difference as in flux. Furthermore, the four themes do not appear in the narratives as discrete, hierarchical, or sequential stages that the authors see themselves progressing through. Rather, these are amorphous and overlapping perspectives, and the authors portray themselves as shifting back and forth among them throughout their stories. The table below (Table 4) provides a summary of the four thematic characterizations of the difference experience that emerged in my analysis of the data.
<table>
<thead>
<tr>
<th>Characterizations of Difference Experience</th>
<th>Stances Toward (Disabling Communication about) Difference</th>
<th>Characterizations of Different Self</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Difference as devaluation</strong>&lt;br&gt;Stigma, unacceptability, rejection, dismissal, pity</td>
<td>Diminished, overcome, defined and devalued by difference</td>
<td>Unacceptable, defective, passively suffering victim; rejected, abandoned, isolated, ashamed, inferior, humiliated, helpless, ugly</td>
</tr>
<tr>
<td><strong>Difference as hard reality</strong>&lt;br&gt;Natural source of inevitable limitation, burden, alienation; unquestionable</td>
<td>Succumbing, submitting, knuckling under; tolerating difference; grin and bear it</td>
<td>Coping, adapting, accommodating abnormal self to society’s taken-for-granted attitudes, rules, prejudices; compliant; burdened</td>
</tr>
<tr>
<td><strong>Difference as oppression</strong>&lt;br&gt;Society’s attitudes about difference as source of unjust treatment; difference as a civil rights issue</td>
<td>Standing up to, battling, defying, wrestling with; challenging cultural definitions of difference</td>
<td>Defiant, critical, angry, strong; confronting injustice; claiming disability/illness identity</td>
</tr>
<tr>
<td><strong>Difference integrated</strong>&lt;br&gt;Difference as integral part of self and life; difference accepted, embraced, normalized, or valued</td>
<td>Surviving, making peace, coming to terms, reconciling; embracing, transcending, overcoming, or reframing difference</td>
<td>Serene, at peace, strong, resilient, survivor; valuable, loveable</td>
</tr>
</tbody>
</table>

Table 4.1: Narrative Constructions of Different Self

To most helpfully and vividly explain and illustrate these four themes, and to remain true to the assumptions of grounded theory method and to my commitment to honor the perspectives and voices of those who have grown up with chronic illness or disability, I present the results of the data analysis primarily through a great many representative sections of the authors’ own accounts, allowing them to speak for themselves and characterize their experiences in their own words as much as possible.
Difference as Devaluation

When I think back . . . I remember a shame about my body—whether silently communicated by my worrying parents or simply something they were powerless to prevent being taught me by other sources, I don’t know. It was a shame based upon a flaw and a need, an inferiority that I could never overcome. (Roney, 1999, p. 271).

I began having overwhelming attacks of shame at unpredictable intervals. The first one came as I was speaking to Hans, my boss at the stable. He was describing how he wanted me to ride a certain horse. I was looking him in the eye as he spoke, and he was looking me in the eye. Out of nowhere came an intense feeling that he shouldn’t be looking at me, that I was too horrible to look at, that I wasn’t worthy of being looked at, that my ugliness was equal to a great personal failure. (Grealy, 1994, p. 185)

The authors in the study describe struggling with frequent and intense experiences of feeling degraded or devalued as persons because of their physical differences. They write of experiencing their different selves as a source of shame, worthlessness, inferiority, alienation, and invisibility. Within this experience of difference, the authors portray their stance toward difference as a helpless and passive one, viewing themselves as overcome, overwhelmed, diminished, and devalued as a result of their different physical selves. They report having absorbed and internalized a barrage of subtle or blatant messages that they were abnormal, defective, helpless, disgusting, repulsive, and that their feelings, needs, and aspirations were less important than those of “normal” people.

Communication in Health Care Settings

The authors provide many accounts of feeling demeaned, overwhelmed, and stigmatized by negative communication that they experienced in health care settings. Given the amount of time the authors had to spend interacting with others in health care
settings, the power and authority granted to medicine, and the emotional intensity associated with such visits, the communication in these settings was especially consequential.

*Health care providers.* Doctors and other health care providers were a frequent source of devaluing messages for the authors. For example, Mercer recalls the events of her first frightening and demoralizing day in 1962 at Belchertown State School, the institution where she was forced to live for sixteen years:

I was taken into an office and examined. . . . Dr. Soong spoke English with a very thick accent. With the nurse’s assistance, he placed me on a table, undressed me, removed my leg and back braces, slapped me into diapers and a hospital Johnny, weighed me, measured my height, and moved my arms and legs around. . . . His method of evaluating me consisted of looking me over during the physical exam and deciding that since I didn’t talk and apparently couldn’t understand what he was saying, I must be an imbecile. Although Mother and Father told Dr. Soong how I communicated before they left, I doubt whether he was aware of my facial signals. It wouldn’t have mattered anyway. When he examined me, he mumbled unintelligibly. I couldn’t tell whether he was talking to me, the nurse, or himself. Since I couldn’t ask him to speak up or repeat what he said, he assumed I was a moron. . . . After Dr. Soong completed the examination, the nurse . . . took me down the hall to a small room with a hospital bed in it. She did not bring along my braces and clothes, or my suitcases. Without saying a word, she put me in the bed, took my wheelchair, and walked out, shutting the door behind her. I was left in the room without one personal item, and with no explanation of what was happening. . . . There I was, alone and flat on my back in a small room with the door shut tight. Although I suspected nothing of what was to follow, I became very apprehensive about Belchertown. To begin with, I didn’t appreciate being placed in diapers and hospital bedclothes. I had been toilet-trained at an early age . . . and needed only physical assistance to and from the bathroom. . . . Later that first day I was treated to yet another surprise when a nurse came in to check my diaper and feed me. Bored and scared, I desperately wanted the woman to talk to me, to tell me what I could expect. Instead she handled me like a sack of flour. She changed and fed me as if I couldn’t even tell what she was doing. . . . After several of these sessions and two days in that room, I was absolutely despondent. It was obvious that the attendants didn’t understand me at all, and they were making little effort to do so. They talked disparagingly about me right to my face, as if I couldn’t understand a word they were saying. They handled me roughly, and they couldn’t get out of that room fast enough. (Mercer, 1989, pp. 40-41).
Through much of her narrative, Mercer vividly portrays the painful effects of the staff’s inhumane treatment on her and other residents at Belchertown. She describes the demeaning language and procedures routinely employed by the nurses and attendants:

“Potty chair” is a familiar term, since it usually refers to those little contraptions used to toilet-train toddlers. It was widely used at the State School to refer to the portable toilets used by the “kids” (the residents, regardless of their age), which gives you some idea about the attitudes of the staff, even in 1974. The term “slab room” was also widely used at Belchertown, as at other state institutions. It was derived from the two huge porcelain sinks, only a few inches deep and about waist high, in the bathroom. The residents were bathed right in these sinks, with a hose that had a showerhead attached to the end—a relatively efficient setup, I guess, but not one that does a lot for your dignity or self-respect. (Sienkiewicz-Mercer, 1989, pp. 162-163)

Mercer also recalls the humiliation of being placed in “The Box,” an odd arrangement the attendants at the State School devised in a feeble attempt to respond to complaints from parents and other advocates about the practice of keeping residents confined to their beds at all times. The Box consisted of a long table with one-foot wooden sides all around and a mattress inside. Three or four girls would be placed inside—generally unwillingly—for what the attendants called “socialization.” The undignified and hazardous arrangement itself, along with the fact that she was forced to submit to a routine that she detested, communicated loudly and clearly to Mercer that she had little worth as a human being:

Since I had just fallen into a depressed state after adjusting to my surroundings on Ward 3, the last thing I needed was to lie around in the Box. Nobody cared to ask my opinion, however, and into the Box I went. . . . I was laid flat on my back in the company of three girls whose behavior ranged from tolerable to downright dangerous. . . . The Box didn’t exactly thrill me. . . . I was able to put up with it, but I would have preferred physical therapy, not to mention the comfortable privacy of my own bed, to the “socialization” of the Box. . . . Being stuck in there got on my nerves. It made me feel like a helpless little baby trapped inside a big, clunky crib with three other babies. As such, the Box magnified the effect of wearing diapers at the age of thirteen. But the worst part of this “therapy” was the timing. It started when I was at a low point in my self-esteem and overall
emotional level. Good old Belchertown! The institution had found yet one more way to strip me of what little dignity and individualism I was struggling to preserve for myself. (Sienkiewicz-Mercer, 1989, p. 98)

While Mercer’s experiences of being devalued and dehumanized at the hands of health care providers within a horrific state institution are particularly abundant, extreme, and shocking, the basic theme is repeated over and over again in the others’ autobiographies. For example, Webb recalls the humiliation of being stripped and displayed as a teaching case at clinic visits:

The physical therapy sessions with Miss Carr make me an unwilling participant in frequent clinics for young doctors in Worcester. At these meetings, patients are paraded before thirty or more strange men in white coats while Dr. White comments upon the individual’s condition. Before going “onstage,” I am completely undressed and clothes in a binder, gown, and robe. The latter two garments are hastily taken off when I am wheeled into the room. Icy chills go up my spine as I sit thus exposed for ten to fifteen minutes. Dr. White at last acknowledges my presence by saying, “Here we have a spastic child with poor speech and involvement of all four extremities. We are teaching her to walk. Stand up, Ruth, and show them how you walk.” He takes my hands and pulls me to my feet and walks me around the room. The doctors watch my naked body perform its awkward movements. (Webb, 1993, p. 37)

Webb’s witnessing a classmate endure the same kind of public stripping was similarly painful and traumatic for her:

One particular clinic stands out in my memory. While I wait my turn, I watch my naked classmate Mildred, a tall lanky girl, badly deformed with arthritis, limp around the circle of doctors. Her face is a dull red with shame and embarrassment. This dehumanizing scene haunts me for many years. (Webb, 1993, p. 37)

In Roney’s account of her visits to the specialist treating her diabetes, she recalls the doctor and his nurse dismissing her as a person, treating her instead as nothing more than a disease with a collection of quantifiable illness indicators that she was expected to control by following his strict orders, regardless of variations in her life or how she might differ from his other patients:
At Dr. Gilbertson’s once every few months, the nurse would draw a tube of blood and test it for an actual blood glucose reading. There was no discussion of how I’d been feeling, what changes in routine or activity I might be dealing with, whether my appetite and weight were stable, how many insulin reactions I’d had, whether I’d had infections or other signs of high blood sugar, or any other aspect of this complicated, life-saturating condition. Once the test result was ready, I would sit across the desk in Dr. Gilbertson’s huge, dim office, and he would bestow on me a harangue about how I needed to do better with my urine tests. That was all. Once I tried to tell him that the lower urine-test results he wanted made me feel terrible, but he waved his hand, narrowed his baby blues, and told me to quit making excuses. In an instant shock, I recognized that he would never believe a word I said. What he cared about were the numbers. (Roney, 1999, p. 39)

Roney recalls another occasion when, after she had suffered an episode of severe insulin shock, she felt diminished and powerless as a result of medical personnel making judgments about her physical condition while dismissing her voiced perceptions about her own body:

I don’t remember much of anything until I was wakened several hours later, still in the emergency room, after I’d been treated with nausea and pain medications and allowed to sleep. According to the nurse who wakened me, I was ready to go home, but I told her I couldn’t get up, that it would make me sick again. I begged for her to let me lie there and sleep some more, but she coaxed and prodded me toward the wheelchair, behind which my father stood ready to roll me out. As soon as I sat up, I puked again. They admitted me to the hospital that night, and by morning I felt better, though I wondered why no one ever seemed to believe me when it came to my disease. (Roney, 1999, p. 43)

Grealy remembers the effects of often being objectified, treated by medical personnel not as a thinking, feeling person, but, at best, as an interesting case. For example, she recalls her hospital experience in the aftermath of a long surgery, one of many efforts to reconstruct her face after her cancer treatment. She woke from her anesthesia to several “surprises” that her doctor had failed, prior to the surgery, to tell her to expect:
Where they’d taken the graft, there was a long row of thirty or forty large metal staples. It looked as if someone had sawed my leg off and then put it back on with an office stapler. That sight upset me, but when I tried to speak, I found they’d given me a tracheotomy, another surprise. . . . At some point in the night I found it difficult to breathe. I wrote out a note to the nurse, who said she would tell the doctor. An hour later it was worse; I had to think about every breath. I wrote another note to the nurse, and finally a doctor arrived to draw an arterial blood sample to check my oxygen level. A long time went by. It was still dark, and there didn’t seem to be any people around. I was frightened. When the doctor returned and started taking another blood sample, I was only dimly aware of him. I couldn’t see very clearly, and his voice sounded muffled as he said hello to another doctor, who walked in and asked, “Didn’t you just do a blood gas a little while ago?” I could hear them talking as if through water. “Yeah,” he replied congenially, “but I didn’t believe anyone’s oxygen level could be that low.” However unable I was to communicate with the outside world, this comment jolted my inside voice awake. Oh my God, I thought to myself, brain damage—I’m going to have brain damage, I’m going to be brain-dead, and as far as I could tell, no one seemed to care very much. (Grealy, 1994, p. 198)

Doctor-parent-child. In the narratives, degrading messages are sometimes seen in descriptions of interactions in doctors’ offices involving the young patients, their parents, and their doctors. For example, Grealy describes the experience of her first chemotherapy treatment, emphasizing her emotional suffering over the physical misery of the procedure. In Grealy’s description of the situation, it is clear that neither her doctor nor her parents had talked with her about what to expect or about her feelings and fears. She recalls the doctor conversing only minimally with her mother and not at all with her during the examination and the chemo treatment. Not only is she not treated with respect or empathy as a person, she is not even really acknowledged. Her mother appears annoyed, tense, and frustrated, but ineffectual:

I went into it completely unprepared. Radiation at that point seemed like a good deal—all that time off from school, no pain, or at least not yet, the meditative drives into the city with my mother. The only thing that really worried me about chemo was the prospect of weekly injections, because that’s all I thought it would be, an injection. If I had been blind to what the original operation would be like, and blind to warnings [from a friend’s father] about chemo, once I entered the
When we were finally in Dr. Woolf’s office, my mother ready to scream from the long wait, we encountered his telephone, apparently a permanent appendage. He could carry on a conversation with my mother, me, his nurse, his secretary down the hall, and someone on the phone simultaneously; he had it down to an art. My mother thought him incredibly rude, and she was right. Dr. Woolf’s manner was gruff and unempathetic. The first time he examined me I could only flinch at his roughness as his large fingers pressed hard into my abdomen, pried open my still stiff mouth. . . . This first examination was more thorough than the ones I would later receive. I was asked to strip down to my underwear, which I did, feeling humiliated and exposed. While the doctor talked to the nurse, my mother, and the person on the phone tucked beneath his chin, he prodded me with his hands, hit me just slightly too hard with his reflex hammer, and spoke far too loudly. . . . He got a tourniquet and wound it tightly around my arm, pinching the skin just like a kid on the playground giving an Indian burn, and despite every ounce of strength I could muster, I began to cry. Not loudly, not even particularly heartily, just a few simple tears, which were as accurate and prophetic as any I’d ever shed. (Grealy, 1994, pp. 72-75)

She recounts her memory of her failed effort, on that occasion and later during her second week of chemo treatment, to adhere to the admonition of the doctors, nurses and her parents to be brave and not cry—a failure that, to her great shame, Grealy would repeat over and over again:

We went through the whole routine again, the endless waiting, Dr. Woolf’s eternal phone call, his strong hands on my body. I tried not to look at the syringes beside me. . . . When I looked down at the floor, I somehow chanced to look at the exact time and the exact spot where Dr. Woolf would send a brief spurt of fluid out of the syringe to clear the needle of air. A graceful, thin arc of liquid would fall directly onto the tile I was concentrating on. I took it as a sign to cry, which I did, ashamed of myself, unable to meet my mother’s eyes as she began telling me not to, to hold it back. The tourniquet went on, and it began all over again, just like the week before, except that this time when I got home I went straight to bed. I didn’t even try to sit up or to eat anything as grotesque as ice cream. I felt that my mother was disappointed with me. I hadn’t gone straight to bed last time—why was I doing it this time? She came to my room and sat on the edge of my bed. She looked tired but beautiful, always beautiful to me, her makeup exact and perfect, the redness of her lips, the faint hue of her power, the distinct, musky smell of her perfume. ‘You can’t let this get you down, you know.
I know it’s hard, but you can’t get depressed by it. Don’t give in to it. You were not so bad last time, so make sure that what you’re feeling isn’t just in your head.” (Grealy, 1994, pp. 82-83)

Grealy remembers her feelings when, time after time, the chemo treatments caused her suffering and reduced her to tears, despite her best efforts:

When the next injection came, the next bout of crying, and I wasn’t able to not suffer I felt I had only myself to blame, felt that I had failed in some unknowable, spiritual way. In my mind I didn’t have what it took: I didn’t deserve to be comforted. (Grealy, 1994, p. 87)

Grealy’s memories of her father’s interactions throughout her illness and rounds of treatments are similarly painful. He seemed unequipped to give her the support that she needed, and apparently unaware of the consequences of his abandonment of her:

My father bought me toys, not because he believed for a second that they would sufficiently compensate me but because it was as close a gesture as he could manage. He didn’t really have the stomach for the treatments, and only on the rare days when my mother was ill or busy would he take me in for chemotherapy. . . . He’d accompany me into the office and exchange greetings with Dr. Woolf, but as soon as I was asked to take off my clothes he’d turn to me and say, ‘Right then, I’ll go get the car.’ Perhaps in part he was embarrassed to see his daughter half naked, but I knew that he did not want to see me suffer. . . . I watched his back as he left and felt relief, because his embarrassment and awkwardness caused me as much pain as they did him. There was no blame in those moments, no regrets, no accusations, not even despair. Those things came later, when I learned to scrutinize and judge the past . . . . As an adult, I wonder how he could have left me alone in there. (Grealy, 1994, pp. 84-85)

Panzarino recalls her frequent experiences of being treated as an object by physicians, with her parents’ acquiescence or participation. Her description of a particular visit to the doctor with her parents provides a painful example of the impact such interactions had on her:

We went into a little booth with a curtain around it. “Please undress her and put her up on the table.” The woman disappeared in a swish of curtains. Dad lifted me onto the table and Mom undressed me silently. She put my clothes on the wheelchair. I laid there naked, getting goosebumps. Dad propped my braces up on
the wheelchair and cleared his throat. He looked at the floor, nervous or embarrassed, I couldn’t tell which. After a long time, the curtains swished wide open and a crowd of doctors appeared. The head doctor smiled at me and nodded to my parents. He then lectured to the doctors for fifteen minutes in language I could not understand while he pointed to various parts of my body and flopped my arms and legs around. “Stick out your tongue, darling. See! See! Take a look.” One by one the doctors peered around him at my tongue, nodding. I felt sick to my stomach. (Panzarino, 1994, pp. 57-58)

Panzarino recalls a hushed and tense conversation between the doctor and her parents at the end of this appointment, not about her health or well-being, but about her parents’ fears of having “this kind of thing” happen to them again:

The doctor started to say goodbye and leave. My father grabbed him by the arm and whispered. “What about . . . other children . . . will they . . . handicapped . . . normal . . . Are there tests . . . ? Should we . . . ?” My mother had stopped dressing me. Her full attention was on the doctor’s face. “There’s no problem. The chances of this kind of thing,” he waved toward me, “happening again is so small. I would go ahead.” I saw my parents breathe a sigh of relief and smile at each other. (Panzarino, 1994, pp. 58-59)

While Panzarino does not explicitly state any emotional reaction she may have had to this conversation at the time, but within the overall context of her narrative, her inclusion of her memory of the conversation makes clear the demeaning effect it had on her.

*Parents’ Communication*

In addition to depictions of communication within health care settings through which the authors experienced difference as devaluation, they also make frequent references to the impact of what they saw as negative, disconfirming communication of their parents in their day-to-day lives. Often, they describe interactions in which they view their parents as well-meaning but inept and hurtful, nonetheless.
For example, Grealy recalls the period at the end of her 6th-grade year, during which she had gradually been returning to school and interaction with her peers after her long absence while going through surgery, chemotherapy, and radiation. With warm weather approaching, her mother presented her with a bag of new clothes:

She took a bright red shirt out of a bag and held it up against my chest. It smelled new and a price tag scratched my neck. “Turtlenecks are very hard to find in short sleeves, so I bought you several.” I was still a tomboy at heart and cared little about what I wore, just so long as it wasn’t a dress. But turtlenecks—why on earth would I want to wear turtlenecks in the spring? I didn’t ask this out loud, but my mother must have known what I was thinking. She looked me straight in the eye: “If you wear something that comes up around your neck, it makes the scar less visible.” Genuinely bewildered, I took the bright-colored pile of shirts down to my room. Wouldn’t I look even more stupid wearing a turtleneck in the summer? Would they really hide my “scar”? I hadn’t taken a good long, objective look at myself since the wig fitting, but that seemed so long ago, almost two years. I remembered feeling upset by it, but I conveniently didn’t remember what I’d seen in that mirror, and I hadn’t allowed myself a close scrutiny since. (Grealy, 1994, pp. 121-122)

The outcome for Grealy of her mother’s attempts to be helpful was that she became acutely aware of what had not occurred to her before: that those around her—including her own mother—must see her as ugly. Grealy recalls another interchange between her and her mother after yet another of her many unsuccessful surgeries:

Once home, my mother, still fuming [about the dismal outcome of the oral surgery] . . . turned to me and said, “You don’t have to go to school tomorrow if you don’t want. I understand that you might not feel very good about the way your teeth look.” We looked straight at each other. Something had just happened, but I wasn’t sure what. . . . She stood over me in the living room . . . and offered me, what, compassion? As I think of it now, I’m certain her offer to let me stay home was an attempt to understand what she must have known instinctively. But it was too late. I’d already given up that fight. I understood my mother’s offer only as barbed verification of what I believed to be the indisputable truth: I was too ugly to go to school. (Grealy, 1994, pp. 147-148)
Grealy acknowledges her mother’s intention may have been to show compassion, yet she is honest about the devastating effect it had on her already rock-bottom self-esteem.

Mercer recalls feeling a sense of rejection, devaluation, and helplessness when she overheard her parents’ deliberations surrounding the decision to send her to Belchertown State School—a decision that her father felt was in the best interest of the rest of the family, in spite of the negative effects he knew it would have on Mercer:

I overheard them arguing about it a couple of times, which was very rare for Mother and Father. Mother was reluctant for me to go there, and she seemed quite upset about it. Father kept saying that it was the best thing for the family. When I heard them arguing about this, I wanted to run away. (Sienkiewicz-Mercer, 1989, p. 35).

Panzarino frequently recalls her troubled and chaotic relationship with her parents, especially her mother, and cites this as a major source of the life-long difficulty she would have in gaining a sense of acceptability, self-esteem, and self-efficacy. She remembers her mother’s volatile emotional reactions to her:

Occasionally, [my mother] turned away from me in shame and despair. It was a sudden turning away; a turning away where her whole body would tense up. Sometimes it would happen when I asked to go to the bathroom or wanted a drink. She’d get gruff with me and I would feel anger in her touch. There were other times when she was gentle with me and very loving, stroking me. Sometimes she was very funny and we would laugh until our eyes filled with tears, and then other times she would grip my body until it hurt, and I would get scared. (Panzarino, 1994, p. 29)

Panzarino frequently recounts examples of her mother’s dismissal of her feelings:

There was an exercise I had to do in the two kitchen sinks. Once sink was filled with very hot water and the other with cold. My mother would sit me on the edge between the two and alternate putting my feet in each sink. First, she plunged them into the hot water for a couple of minutes, then into the cold water, back and forth repeatedly. It was supposed to improve my circulation, but it felt like hell. It shocked my whole body. My mother said it wasn’t painful, and then got mad at me when I cried. (Panzarino, 1994, p. 17)
Panzarino’s memories are of the guilt she felt as she experienced her mother being constantly stressed and burdened by the unremitting demands that Panzarino’s disability placed on her. She recounts many painful occasions when her mother expressed warmth and affection followed quickly and unpredictably by impatience or anger at her as she cared for her needs. For example, she recalls one incident when her mother had instructed her to keep her feet propped up on a book, as the doctor had ordered (a “treatment” that was very difficult and painful for Panzarino because of her disability), and play with a ball while her mother did her chores. Panzarino remembers trying to entertain herself by talking to the “other Connie” in the mirror:

Mom found my ball and put it in my hands saying, “Now don’t drop it, okay? Mommy’s got a lot of work to do.” She kissed me on the cheek and walked out of the room. . . . I threw my ball at the other Connie in the mirror and said, “Catch.” My mother appeared from nowhere saying, “Who were you talking to? Why aren’t your feet on the book? I told you not to throw the ball. Can’t you be good?” She put my feet roughly back on the book and turned to a clean coloring page. “Color,” she said. She put the ball away and brought out three Little Golden books for me to read and put them within my reach. I picked up a book and leafed through three or four pages. “Mom,” I called. “I have to go to the bathroom.” A response came from the other room. “You wait. I was just in there. Why didn’t you tell me then? Now I’m in the middle of something. You wait.” I began rocking to ease the discomfort. My feet were hurting from being up on the book, but I was afraid to wiggle them off. . . . Every few minutes I would stop rocking and call out, “Mom, I can’t wait”. . . . Suddenly in the midst of my rocking, she appeared, snapping, “I know what you’re doing, you stop that business.” She picked me up over her shoulder and carried me into the bathroom. . . . When I was done, she picked me up over her shoulder, wiped me, and pulled my pants up. . . . “Do you want anything else now? I have to go clean the bathroom.” “No,” I said, and smiled up at her. She walked away. (Panzarino, 1994, pp. 19, 21-22)

Panzarino painfully recalls her mother reaching the breaking point on one occasion.

Panzarino had lost her balance while sitting on the couch, where her mother had left her to play with her doll:
“Mom!” I called as loudly as I could from that position. I couldn’t breathe well with my head tipped back and over. Betsy-Wetsy slid to the floor. “Mom, I fell!” Mom came in silently. She was tense and had a far-away look in her eyes. She sat me up abruptly, picked up the doll and slammed it into my lap. I winced, smiled up at her, and whispered, “Thanks, Mom. You look pretty.” She walked out again without a word. . . . I got a tickle in my throat and started coughing. I coughed quietly. I realized I had to go to the bathroom again. Mom came in looking angry and tired. “Are you all right?” “Yes, but I think I have to go to the bathroom.” Something hit me across the face and continued hitting me on my arms and legs. I kept trying to catch my breath. I wanted to run. I wanted to cry, but nothing came out. “Mommy, Mommy,” I cried until I realized it was Mom hitting me. Time seemed to stand still as the blows kept coming. She picked me up and carried me to the bathroom, saying, “You’re so ungrateful. You don’t care about me. I hate you! I hate you! What do you think I am, a slave? You don’t appreciate me. You don’t deserve anything.” She put me on the toilet directing me to “Go!” . . . Yanking me off the toilet, she pulled up my pants and carried me into the bedroom, pinching my legs and my bottom as she went. She put me down hard into my crib and left, slamming the door behind her. “Mommy,” I sobbed. I was terrified. I would die without her. I cried and choked and gurgled on mucus. I had difficulty swallowing. I cried and shouted for her endlessly, “I’m sorry, I’m sorry.” (Panzarino, 1994, p. 30-32)

While Panzarino grapples in her narrative with the devastating effects on her self-esteem of her parents’ failure to cope with her disability, Lipman depicts his struggle with his self-image as being partly the result of his parents’ (especially his mother’s) over-protectiveness coupled with secretiveness regarding his illness. Terrified of the possibility of his suffering or dying from his illness, but determined that he should lead a life untainted by knowledge of or worries about the risks and prognosis for children with cystic fibrosis, Lipman’s mother was exceedingly vigilant in monitoring his symptoms and protecting him from possible threats to his health. At the same time, she did everything she could to keep him from identifying himself as a “CFer,” or even really knowing that he had the disease or understanding what it is. This resulted in his receiving confusing mixed messages about his health. He knew he was seen by his friends as sickly, small, and weak, and he knew he received “special treatment” at school that his
classmates did not. Yet, his parents never discussed his illness with him, leaving him feeling different and stigmatized without knowing why and worried about just what was “wrong” with him:

My mom, though, told me that everything was fine. I didn’t know who or what to believe. My mom had always been there for me, but she had always been so adamant about me taking pills. She would ask me every day after school if I took them. It made me realize that if I didn’t, something negative would happen to me. So I began to believe my friends. I missed a lot of school. Kids get the sniffles and colds a lot, and that’s perfectly normal, but it can be more serious for someone who has cystic fibrosis, so my mom was especially vigilant. I hated it. Sometimes I missed weeks of school. . . . No one every asked me to play. When my mom did let me go outside, it was always with a stern warning to be careful and not overexert myself. My mom wanted me to have a life, but she had a lot of fears. What if something happened to me? What if she couldn’t be there? (Lipman, 2001, pp. 16-17)

Lipman was never allowed to associate with other “CFers,” nor did his parents ever let him read about CF, view informational videos the doctor suggested they watch together, or attend summer camp for children with CF. He finally learned more about CF when he was 7 and, in a moment of terrible shock, read about it in the encyclopedia. More and more, he began to see himself as unspeakably defective and afflicted. Later, at age 12, he saw part of the film *Alex: The Life of a Child*, by Frank Deford, about his daughter who died of CF, before his mother angrily turned off the TV and sent him to bed.

The next morning, everything was “normal.” We didn’t talk about the show or what happened to the girl or why my parents were crying. But I wasn’t stupid. I began to worry that like the girl in the movie, I too would cough up blood and become bed-ridden. No one could live like that, so I knew I would die. Would it be terrible like that? What ever happened to her? Would the same thing happen to me? These questions plagued me for years. I’d be lying if I didn’t admit that sometimes they still haunt me. (Lipman, 2001, p. 33)
Communication of Peers and Others

Another frequent source of painfully degrading, devaluing messages for the authors was the communication of their peers, teachers, acquaintances, and others.

Grealy’s suffering at the hands of peers and strangers was especially acute. For example, she recalls her response to the stares of children and their parents at the parties where she supervised children having pony rides:

As soon as they got over the thrill of being near the ponies, they’d notice me. Half my jaw was missing, which gave my face a strange triangular shape, accentuated by the fact that I was unable to keep my mouth completely closed. When I first started doing pony parties, my hair was still short and wispy, still growing in from the chemo. . . . I was . . . dependent upon my audience. Their approval or disapproval defined everything for me, and I believed with every cell in my body that approval wasn’t written into my particular script. I was fourteen years old. (Grealy, 1994, pp. 3-4)

She recounts many occasions when she endured the merciless teasing of her peers throughout grade school, junior high, and high school. For example, she recalls an incident in the lunchroom on the first day of junior high:

As it happened, I sat down next to a table full of boys. They pointed openly and laughed, calling out loudly enough for me to hear, “What on earth is that?” “That is the ugliest girl I have ever seen.” I knew in my heart that their comments had nothing to do with me, that it was all about them appearing tough and cool to their friends. But these boys were older than the ones in grade school, and for the very first time I realized they were passing judgment on my suitability, or lack of it, as a girlfriend. “I bet David wants to go kiss her, don’t you, David?” “Yeah, right, then I’ll go kiss your mother’s asshole.” “How’ll you know which is which?” My initial tactic was to pretend I didn’t hear them, but this only seemed to spur them on. In the hallways, where I suffered similar attacks of teasing from random attackers, I simply looked down at the floor and walked more quickly, but in the lunchroom I was a sitting duck. . . . After two weeks I broke down and went to my guidance counselor to complain. I thought he would offer to reprimand them, but instead he asked if I’d like to come and eat in the privacy of his office. Surprised, I said yes, and that’s what I did for the rest of the year whenever I was attending school. . . . I felt safe and secure in that office, but I also felt lonely, and for the
very first time I definitely identified the source of my unhappiness as being ugly. A few weeks later I left school to reenter chemotherapy, and for the very first time I was almost glad to go back to it. (Grealy, 1994, pp. 124-126)

This ordeal continued for Grealy at school the following year. Although Grealy remembers trying to find strategies to deal with the teasing, ignoring or rising above her tormenters and refusing to allow them to affect her, as an adolescent girl she was unable to do so, instead internalizing their judgments of her:

At school the gang of boys from last year appeared to have dispersed, and I was free to eat in the lunchroom again. But a new group had formed, and they tracked me down every day. . . . By the time I reached the staircase near my English classroom, nearly everyone else was already there, leaving me to climb the stairs alone. Alone, that is, until that group of six boys discovered they could find me in this stairwell each day at the same time and took to waiting for me. Their teasing was the most hurtful of all because it wasn’t even directed at me but at a boy named Jerry. “Hey, look, it’s Jerry’s girlfriend. Hey, Jerry, go on, ask your girlfriend out.” I heard Jerry meekly protest, but I knew that he was as much at their mercy as I was, and I knew that to have me called his girlfriend was just about the most malicious insult the other boys could level at him. I even felt sorry for Jerry, though I never saw him, for I refused to lift my gaze from the floor. . . . Martin Luther King, one of my heroes, had said, “I will not allow my oppressors to dictate to me the means of my resistance”. . . . I wanted to hate them, but instead I tried to forgive them. I thought that if I could do this, the pain they caused would be extinguished. Though I had genuine glimpses of what charity and transcendence meant, I was shooting for nothing less than sainthood; often, after my daily meeting with them, I only ended up hating myself instead. (Grealy, 1994, pp. 151-152)

Grealy’s sense of rejection and devaluation came not only at the hands of children and adolescents, but from the communication of strangers wherever she encountered them:

If feeling like a freak had been more in my mind than in my face at other times in my life, the visage I saw staring back at me was undeniably repulsive. The feeling was confirmed for me whenever I went out on the street. People would stop dead in their tracks and stare at me. One afternoon a beggar ran up behind me, demanding money. I stopped and turned around to look at him. He stopped in midsentence, looked at me for a second longer, then politely apologized and handed me a dollar bill before turning away, muttering to himself. My self-esteem reached the bottom of the deepest, darkest pit. (Grealy, 1994, p. 200)
While Grealy suffered particularly extreme and ongoing stigma as a result of her facial disfigurement, her experience of rejection by peers and others and its impact were by no means unique. For example, Lipman recalls suffering similar searing pain as a result of his peers’ teasing when he was in elementary school:

Over the years, my classmates learned that I had CF. I doubt any of them knew much about it, but when you’re a kid, any sign of difference is perceived as bad, and you become a target. Some kids taunted me by saying I’d be dead before I ever got to high school. One girl, Julie, used to grab my frail arm and say, “You’re so skinny!” I’d come home many days and cry. (Lipman, 2001, p. 16)

Later, as a college freshman struggling for acceptance by his peers, Lipman was devastated by his friend’s reaction of fear and revulsion upon witnessing him doing his respiratory therapy:

As I was doing therapy, Sally, another girl who I was interested in and one I thought liked me, peeked in the room. She saw me and a wave of what I took to be horror and disgust raced across her pretty face. I froze. “I am leaving! Bye!” I could hear her say. She didn’t say goodbye to me. Was I that revolting? Did I look like an alien with all sorts of freakish tubes attached to its body? I thought people accepted me. I thought people knew me as Andy, not some freak. I was always going to have to use this machine and always have to take medication and always disgust women. I ripped off the vest and pulled the nebulizer from my mouth. “Get out,” I yelled. “Everyone get out!” . . . I slammed the door shut and locked it. I pounded on it until my fist was sore. I hated this stupid machine. I hated this stupid disease. I hated myself. I hated my parents for giving it to me. I hated them all. Why did I hate everyone? I didn’t know. I just felt if one person thought I was different because of my CF, then everyone would think I was a freak. So many insecurities came to the forefront. Were people friends with me because they liked me or because they pitied me? Was I ever going to meet a girl who thought of me as a man? Would I always be thought of as a case study? . . . I threw the vest on the floor and kicked the machine. Why do they have to be so ignorant? I wanted to die. God, just kill me already. I started to cry and jammed my pillow on top of my head. “Damnit. I am a loser.” I grabbed at my hair and pulled it out, strand by strand. “I’ll always be a loser and it’s all because of CF.” I didn’t want to face the
people who thought of me as a freak. Everyone pretended to like me, but they didn’t. They just felt sorry for me. God must have hated me. He must really have hated me to give me CF. (Lipman, 2001, pp. 71-72)

Like Grealy and Lipman, Nixon recalls the damaging effects of being teased by classmates:

The first time I was made fun of because of my CP was in second grade. I heard a boy say mean things because I was in a wheelchair. I came home crying. I was sad and for years I hated even the sound of his name. . . . Being made fun of is not something to be taken lightly. It doesn’t help for parents and teachers to say, “Oh, don’t worry about it. Just ignore it.” It wounds deeply. (Nixon, 1999, p. 48)

Webb, too, writes of the lasting effects of the teasing and rejection of peers and others. She recalls the beginning of the rejection she endured at the boarding school for disabled children she attended, beginning at age 12:

[Miss Crawford] says, “Ruth, come with me and meet the living room girls.” In the living room, she announces to the residents, “This is Ruth Webb, our new girl. Introduce yourself to her.” “I’m Winnie Brant, president of C-4,” says a heavyset girl, standing with crutches and long leg braces. “You’re a spastic! Can you talk at all?” she asks scornfully. Before I can answer, a girl in a high-backed wheelchair says, “My name’s Robert Elgin. You’re the only spastic in the cottage. Most of us are polios.” One by one each of the ten living room girls tells me her name and disability and indicates disdain for “spastics.” (Webb, 1993, p. 31)

She recalls being tormented for three years by several older girls who rejected her because they were jealous of her intelligence and because they judged her disability to be “worse” than theirs, and also by two demeaning housemothers. She remembers her feelings on the day she finally was able to leave the school, and the aftermath of her experiences at the school:

The phone rings and I hear Miss B. call out in her raucous voice, “Ruth Webb going home for good!” It is the cry I have yearned to hear for three long, weary years. This day I leave C-4 and my minority role forever. The first painful steps of my journey, taken with shame and rejection, are over. But they leave shadows.
There are many nights in which the Berry sisters and the big girls haunt my dreams. The three years in which “I never do anything right” bequeath a lasting impression of inferiority. (Webb, 1993, p. 43)

Not all experiences of devaluation recounted by the authors take the form of explicit teasing or rejection. Often, the authors’ experiences of rejection reflect more subtle cultural assumptions relating to disability and illness. For example, Panzarino recalls an incident when two of her girlfriends were “hanging out” with her in her room. The two began chatting about their boyfriends and dating, insensitively ignoring the fact that Panzarino had told them previously of her interest in a boy named Glenn:

My eyes filled up with tears, but I tried to hold them back. “You didn’t tell me you went out with Glenn. I like Glenn.” “Let’s put on another record.” Linda jumped up, ignoring my question. “Yeah,” said Carol. “We shouldn’t be talking about this stuff here.” She nodded at Linda. “You wouldn’t go out with Joey, would you, Linda? You know that Carol likes Joey, so you wouldn’t go out with him if he asked you, would you?” “That’s different, Connie,” responded Carol, and Linda nodded agreement. They changed the record, then changed the subject completely. I realized they thought that since I was physically different, I shouldn’t have a boyfriend or even be interested in boys. They never asked me if I wanted to get married or have babies, although they asked each other questions like that all the time. That night I lay in my bed and wept. (Panzarino, 1994, p. 81)

Rothenberg’s memoir reflects times when she experienced the pain of isolation and rejection resulting from the neglect of peers who seemed at times to be “fair-weather friends.” Her realization is that they’re happy to be friends with those who are not needy and dependent, who are “normal” and healthy and self-sufficient in a way that she never can be:

What worries me the most at this moment, though, is the loneliness. When I go for the transplant it will be weeks in the hospital followed by weeks of rest in an apartment, followed by weeks still of quiet activity. My friends won’t come to me to stay out late and party. I won’t be any fun. I don’t want to be the chore on the list of things to do. I don’t like being alone. I wish that someone would call and offer to come up. I will be here tonight by myself wondering where my friends are. But they don’t wonder what I’m doing. They know I’m here. Fewer hospital
visitors have come by this admission. I’m not so sure my reputation here will stick. My name will probably fade, too, just like this time of day. Gradually, hazily, darker and darker. (Rothenberg, 2003, p. 26)

Roney’s narrative echoes Rothenberg’s experience in this regard. She speaks often of feeling that her friends had no understanding of—and no desire to understand—the real constraints and dangers posed by her illness. Instead, they often dismissed or trivialized her “invisible” illness, and were quick to abandon her when she willingly or unwillingly revealed her illness and the needs and dependency that accompany it. Roney learned that strangers and friends alike preferred that she politely hide her reality by “passing” rather than being honest about this crucial part of her identity:

[Diabetes is] a condition with you forever that will almost certainly limit your life and eventually kill you, but which, if you accept some lifestyle adjustments, allows the appearance of good health and normalcy. It constitutes a tightly balanced catch-22. . . . I only knew that I had to think about diabetes every minute of every day in order to maintain the appearance of not being ill at all. This generally undramatic character of diabetes—hypoglycemic reactions are relatively rare—and its lifelong duration both contribute to people’s mistaken sense that it is no big deal. The greatest compliments to me have always been to the effect that I don’t allow my diabetes to interfere with what I want to do; the greatest hurts have come when someone implies or states outright that I’ve used it as an excuse. These days I long for someone to be impressed with how well I accept the limits. This is a far harder thing to do than struggling against them, but I have never heard anyone praise it. People, perhaps rightly, fear the obligations that my weakness implies for them. (Roney, 1999, pp. 64-65)

She remembers the self-consciousness that accompanies the normal physical changes of adolescence being magnified for her, as her diabetes brought changes in her body that were more dramatic and visible than those of her peers—and all the more stigmatizing if she let the source of the changes be known. While the rejections of her friends were
painful, Roney’s locates the source of her feelings of defectiveness and ugliness not so much in her friends’ responses to her, but in cultural ideologies of gender, beauty, and health:

Already, I had a typical horror of the real, mature female body. . . . Soon, my skin was breaking out from scalp to waist, and within months, I began gaining significant amounts of weight and metamorphosed from skinny to plump. I no longer knew myself. And so, I did what we all do. I covered myself and I hid what all women hide—menstruation, bulges, hair, pimples—and the extra mess of urine tests and injection sites. The women that I wanted to be like were smooth, nice-smelling, and functioned as imperceptibly as the grass grew. I took to wearing high collars and long pants in dark colors, continued to let my hair grow as a veil over my ears, neck, and face, and took to filthy bathroom stalls to take my shots. No one wanted to see the truth, and I wasn’t about to make them. Although in the back of my head I wanted to believe there were more important things than cosmetic beauty, I thought the truth was just as gross as most people did. It was just that because of my diabetes I knew that the ugly truth was me. (Roney, 1999, pp. 33-34)

Often, the authors recall feelings of rejection and devaluation coming at the hands of strangers, rather than peers. Webb recalls being devastated when her hopeful efforts to be admitted to college were repeatedly thwarted:

With the beginning of my last year in high school, I begin to wonder if I will get to go to college. My grade average is B+, high enough for acceptance by most colleges. But when the admissions officers look at my application and see the words cerebral palsy, they reject my application without ever seeing me. After five such refusals from colleges whose names are long forgotten, my spirits sink to suboceanic depths. (Webb, 1993, p. 55)

Nixon remembers being devastated by the reaction of strangers on a trip she took with her parents:

My parents knew it was a difficult time for me, so for my sixteenth birthday they took me to a Club Med in the Dominican Republic. I had never experienced another country’s culture. I am glad I went, but it didn’t turn out to be exactly a happy event. The people in the resort, both staff and tourists, didn’t understand me or my disability. I was the only disabled person there. We had been assured that it would be accessible. Some of the places were, but none of the activities were. I basically got to watch everyone else have fun. . . . I was stared at a lot and
mean things were often said in my presence, as if I couldn’t understand. A woman
came up to us and asked, “Why did you even bring her here?” One day, as my
mom was lifting me up over a doorway, a man asked, “Isn’t she awfully heavy for
you?” There were times when my mom and I were out and we could have used a
little assistance over those doorways and such, but many people looked away.
What was supposed to be a happy experience for me turned into one of the most
distressing events of my life. I sobbed many times that week. (Nixon, 1999, pp.
93-94)

**Difference as Hard Reality**

A second theme that emerged in the authors’ narratives is the characterization of
the experience of physical *difference as hard reality*—an inevitable and unquestionable
fact of life, posing limitations that one must simply accept. Here, the authors’ stance
toward difference and the largely negative way difference has been communicated to
them in their culture is one of submission, tolerance, forbearance. They portray
themselves as accommodating, accepting and adapting to the hard reality of their physical
differences and impairments, as well as to society’s judgments, rules, and structures. In
this perspective, prejudicial attitudes and inaccessible and exclusionary social structures
are not questioned or challenged. Rather, the illness or disability itself is seen as the
natural source of limitation. However, although internalized negative cultural attitudes
about illness and disability are apparent in this perspective, the authors do not portray
themselves as profoundly devalued, diminished, ashamed, or helpless as in the *difference
as devaluation* theme.

**Communication in Health Care Settings**

The authors’ narratives often reveal their experience of health care settings as a
site and source of unquestioned cultural power and authority. When characterizing their
experience of difference as hard reality, doctors’ offices, clinics, and hospitals are often places where their acceptance of and resignation to social definitions and rules surrounding physical difference play out.

**Health care providers.** Within the *difference as hard reality* framework, the authors’ portrayals of their interactions with health care providers are telling. For example, Panzarino recalls her mute acceptance of a doctor’s cool definition of her *as* her disease:

> Basically, according to the tests, she appears to have a neuromuscular disease which affects voluntary muscles. She has amyotonia congenita. . . . With amyotonias, well, we just try to manage their care with therapy and braces to keep them from curving and to keep them from getting stiff.” . . . Now I had a disease. It didn’t seem like I had a disease. It seemed like they were saying I was a disease. I knew I was different. Now I had a name for the difference, like being Italian or Jewish. I was an an Amyotonia. (Panzarino, 1994, p. 40)

Roney recalls fearfully but compliantly tolerating the many, many blood sugar tests that her first hospitalization entailed, and learning to keep her fears to herself:

> What I remember most about that stay in the hospital is needles. My thin arms soon enough were tracked up and down with bruises and punctures, as in those days a full tube of blood was needed just to determine the moment’s blood sugar. . . . Soon, it was discovered that I was cursed with “rolling” veins, so that most samples required that the needle be turned and gouged back and forth, as the lucky seeker sought to catch the vein as it turned evasively in my arm. I dreaded the arrival of the technicians and when one mistakenly told me that I would be “giving blood” every hour all night I wept uncontrollably until a nurse asked me what was wrong. Hysterical, I could hardly tell her, but soon enough she corrected the error and left me lying in a barren pool of white light in the dark room, relieved, but drained, staring at a wall that I did not see. With that I had overstepped my allotment of tears, and I did not cry about my diabetes again in front of people. (Roney, 1999, pp. 24-26)
Roney remembers that first hospitalization as the beginning of her recognition and acceptance that, however much attention her physical health problems were receiving, there was little or no recognition of the way her illness had already begun to alter her entire sense of self:

Would anyone recognize me through all the physical changes? No longer cute, I searched for other ways to assure myself this was actually my own body. Somehow, I wanted affirmation that someone knew me, understood the essence of me, would miss me if I were gone. What I got was a lot of attention to the practical matters of keeping me around, but little acknowledgement of the painfulness of what I knew: that I had a serious illness that would almost certainly shorten my life and which could arbitrarily end it at any time. (Roney, 1999, p. 26)

Roney remembers later submissively enduring the ordeal of periodic doctors’ appointments and unquestioningly tolerating the fumbling efforts of inexperienced nurses who apparently used her to practice drawing blood:

We all pretended that the ordeal was worth the trouble, though I didn’t really believe it. I remember one occasion in particular, when the nurse couldn’t manage to get the blood out of my thin, rolling, collapsible veins. She was new, pert and pretty, and reeked of inexperience, but I resigned myself to her cheeriness and let her seat me in the chair. . . . “The left one is usually best,” I said, pulling my right hand out of her grasp and pointing. “There’s a pretty good one right up there.” Her eyes darkened slightly. “I think I prefer this one,” she said, regaining my right arm and indicating a vague green smudge right in the crease of my elbow. Oh well, I thought, I can carry my books on my left arm for a few days . . . She jabbed. And missed. I turned to look as she pulled back on the plunger and got nothing. Quickly, she pulled the needle out. “You’re right,” she smiled stiffly. “Let’s try that other one.” The second and third tries, both on the left arm, and the fourth, back on the right, went on much longer but yielded the same result. Nothing. . . . I felt as though a molly bolt had been screwed into my arm. Eventually, they would send me across the street to the hospital lab, where an old country woman would sit me down, shake her head over the mangled condition of my arms, and tell me to “milk a cow” for her. Within seconds, a tube of dark blood would glitter in her hand like the world’s largest ruby. But for an eternity, I sat underneath the shadow of Dr. Gilbertson’s nurse as more and more intently she bent over me. I slumped further and further down in the chair, my arms unnaturally upturned like the legs of a played roadkill, trying to remember that this was no big deal. (Roney, 1999, pp. 44-45)
Grealy recalls her first hospitalization and her unquestioning compliance with the daily battery of frightening and painful tests and routines that she endured alone, largely without the presence or support of her parents:

Though it seemed like an eternity, that hospital stay probably lasted only two weeks or so. Every day I’d have some test, and it never occurred to me to ask what was going on, what the tests were for, what the results were. (Grealy, 1994, pp. 42-43)

She also remembers her passivity during a later incident when, as a young woman, she met with her specialist to discuss the ongoing efforts to reconstruct her face:

As sophomore year drew to a close, I went to see Dr. Baker about setting up the next operation. I was full of hope, but as it turned out, Dr. Baker had far too much work right then to do the operation himself. . . . I felt I should be understanding of how much of Dr. Baker’s time it would take, that I should just go along and let these strange doctors take over. “I’m still your doctor,” he assured me, but I felt completely cowed, as if I didn’t have the right to speak up and voice my fears. I wanted to know if this change had anything to do with my being on Medicaid now, but I felt too abashed to ask. (Grealy, 1994, pp. 196-197).

Doctor-parent-child. Characterizations in the narratives of communication involving the individuals, their parents, and their doctors or other health care providers also reveal the *difference as hard reality* theme, with authors recounting incidents in which they recall accepting it as their lot in life to tolerate situations that were frustrating, difficult, or painful. In some cases, the individuals remember their parents being less willing to passively accept the authority of health care providers and so speaking up, but themselves as compliant. For example, Grealy remembers a doctor’s appointment in the early days of her illness:

The doctor, who wasn’t a doctor but a specialized dentist, smiled condescendingly after each inquiry [my mother made]. Nothing infuriated my mother more than this condescension, which even I recognized as endemic in the medical profession. Unfortunately for my mother, I was still a typical nine-year-old, and I
seized upon every opportunity to be embarrassed by her. Why did she have to make such a fuss? Couldn’t she just accept what they said? Not brave enough to actually speak up, I mentally rolled my eyes at each encounter between my mother and the doctor. (Grealy, 1994, p. 25)

At other times, the narratives depict experiences in which the authors recall their parents as allied with the medical community, and themselves as passively accepting the edicts of this united authority. Grealy, for example, recalls submitting to the hard reality of the expectations of doctors, nurses, and especially, her mother, that she should be brave and not cry during her many painful and frightening procedures:

One had to be good. One must never complain or struggle. One must never under any circumstances, show fear and, prime directive above all, one must never, ever cry. . . . The subtleties of my first visit to the emergency room, where I’d been praised as good for being brave, were already arranging themselves into a personal treatise in much the same way that a seemingly inconsequential architectural miscalculation on the ground floor can result in a sweeping chasm in the penthouse. (Grealy, 1994, pp. 29-30).

She remembers her first hospitalization, trying, as always, to be brave and not act “like a baby” in front of her parents, doctors, and nurses. Hopeful that her parents would stay with her for a procedure that she was to undergo, as she had observed the parents of other young patients commonly doing, she remembers feeling shock and panic when they instead prepared to leave for the night. There is nothing in her account of any discussion among the hospital staff, her parents, and/or herself of her parents’ decision to leave their daughter, nor an indication that she objected to this abandonment. Instead, Grealy recalls her panic being quickly followed by a feeling of clear and unquestioning understanding and acceptance of the solitary burden of her illness:

As the day wore on, I began to believe that maybe my parents really were like the other parents after all. . . . Finally, as dinnertime approached, the intern who’d examined me earlier explained to my parents (I listened as he talked about me in the third person) that he was going to do a bone marrow test on me. . . . I don’t
remember whether I was afraid of this test I’d never heard of, but when my parents said, ‘Well then, we’ll be off,’ I looked at them panic-stricken and asked, ‘Aren’t you going to stay with me?’ They looked at each other, then back at me, and said something about the traffic, and besides, I wasn’t scared was I? I felt my face flush. . . . Immediately I regretted all my assumptions. The embarrassment I felt then stays with me still, though of course it wasn’t embarrassment. That feeling was about as different from embarrassment as a patch of soil is from a tree, an egg case from a spider, a lump of stone from a sculpted hand lying heavily on an even stonier lap. It was the moment when I understood unequivocally: I was in this alone. (Grealy, 1994, pp. 36-38)

Roney remembers her family and herself trying and failing to comply with “doctor’s orders” regarding her diet—instructions that often seemed questionable to them, but which, for the most part, they would not think of challenging:

In those days, virtually no one practiced patient-centered medicine. What you were given was a prescription: do this, no protest please. My family habitually had partaken of what Dr. Hawkes indicated were weak, corrupt breakfasts. We always ate in the morning, but usually we quickly downed a bowl of cereal and a small glass of juice, just enough to get the U.S. RDA of vitamin C. Although not guilty of the Pop-Tart sin, horror of horrors, we sometimes resorted to Carnation Instant Breakfast. We were duly chastised, but I continued to have trouble with the change. That much food in the morning grossed me out. Unfortunately, it never occurred to any of us to question Dr. Hawkes’s directions. . . . Dr. Hawkes put me on a 3,000-calorie diet. Nowadays this sounds incredible, and it’s hard to imagine anyone prescribing or trying to follow such a plan, but back then we thought that doctors knew best. (Roney, 1999, p. 36)

Parents’ Communication

The theme of difference as hard reality also emerges in the authors’ recollections of their parents’ communication. For example, while Grealy’s repeated failure to adhere to the insistent urging of her parents that she be brave and not complain or cry as she endured her painful and frightening cancer treatments was the source of a great deal of shame for her, as noted earlier, she also most often did not question or rail against her illness or the unreasonable and hurtful expectations of the adults in her life for such bravery and stoicism on the part of a young girl. Rather, she took to heart the admonition
to be brave, and she continued to do everything she could to accept and comply with the painful and bewildering reality that confronted her. She remembers coming home after her first chemo treatment:

“It wasn’t so bad, was it now, Lucinda Mag?” my father asked. I shook my head no. . . . My stomach rebelled. I stood quickly and made my way over to the sink, where I threw up the now liquid ice cream. . . . For some reason, I started to cry. My mother put her hand on my head and tried to soothe me, and when I was done began to explain that there was no need to cry, that everything would be all right, that I mustn’t cry. How could she know I would take her so seriously? She went on to explain how disappointed she was that I’d cried even before Dr. Woolf had put the needle into me, that crying was only because of fear, that I shouldn’t be afraid, it would be all right. It was one thing to cry afterward, because she knew that it hurt, but why did I cry beforehand? Hadn’t I always been so brave before? . . . Sometimes the briefest moments capture us, force us to take them in, and demand that we live the rest of our lives in reference to them. What did my mother mean? Part of me knew then, and still knows, that she was afraid for me. If somehow she could convince me not to be afraid, we could rally around the truism she had grown up with: there was nothing to fear but fear itself. My mother didn’t know how to conquer what I was afraid of, nor could she even begin to tell me how to do it for myself. Instead, out of her own fear, she offered her own philosophy, which meant in this instance that I should conquer the fear by not crying. It was a single brief sentence, a fleeting thought she probably did not mean and doesn’t even remember saying but I, who would have done anything to find a way out of this pain, would never forget it. As I made my way downstairs to my room, I resolved to never cry again. (Grealy, 1994, pp. 78-79)

Webb’s narrative reveals that, while her parents often encouraged and helped her to strive for her dreams and not allow her disability to stand in her way, their attitudes and communication also often reflected the prejudices of the culture of which they were all a part, and they taught her that she should accept that her sad lot in life would, inevitably, limit her in many ways. For example, Webb recalls an incident during her early college days when her father persuaded her that she should be realistic and accept the social constraints posed by her disability:

I write Dad and ask him to buy me a formal dress for the autumn dance. Dad answers with a very loving and tactful note. He writes, “Your handicap makes it
‘socially impossible’ for you to attend the dance. Your mother and I love you too much to allow you to enter such embarrassing situations. Don’t worry, Pilikia, there will be other affairs at which you will shine.” At first, I am deeply hurt but the longer I think about Dad’s letter, the more I agree that he is right. With my grimacing face and hard-to-understand speech, what business do I have attending a college dance? My parents’ old question—“what will people think?”—pops up again.

While Panzarino’s narrative often recounts the demoralizing effects of her parents’ negative communication, at times she views their callous attitudes and treatment of her with stoicism—just another part of her reality that she needed to find ways to cope with. She also sometimes characterizes their unpredictable communication with her as useful preparation for the hard world she would have to adapt herself to in the future:

There were times when [my parents’] lack of support increased my difficulties to the point where they became insurmountable. My parent’s support was inconsistent. Not knowing when they would be there for me caused me a great deal of anxiety, and forced me to face many problems alone, but it also helped me learn how to get along in a non-caring world. (Panzarino, 1994, pp. 136-137)

*Communication of Peers and Others*

The *difference as hard reality* theme is especially prominent in the authors’ narratives in their accounts of interactions with and/or their responses to peers and others. Their accounts reveal that they often accepted dominant social definitions and expectations for those with chronic illness or disability, and that this acceptance played out in their interactions with peers and others, as well as their interpretations of others behaviors and communication.

For example, in reflecting on the benefits of educational mainstreaming for her, Nixon focuses on how this helped her to understand the hard reality of others’ prejudices and learn how to accommodate herself to this reality:
In retrospect, I believe mainstreaming me into regular classrooms gave me the survival skills to make my way in the world. I learned what was required of me to bridge the gap between the able-bodied and disabled. I became perceptive in recognizing friendship over pity. Sometimes I endured hurtful social lessons, but they only made me stronger in the end. (Nixon, 1999, p. 57)

Similarly, Lipman assumes that because of his illness, the weight of the responsibility for forming and maintaining any friendships he might have lay with him. He accepts that, unlike his healthy friends, he should passively put up with others’ teasing, assuming that this was their natural right in an unequal relationship:

I always felt that because of CF, I’d have to go the extra mile to make friends. I presumed it was tough on them because I was, after all, so different. So I listened to the guys tease me about my geeky wardrobe and non-existent love life. It wasn’t the first time they’d said those things. I had slowly grown used to it. (Lipman, 2001, p. 62)

Grealy, too, remembers feeling that her peers had a right to tease her, however painful it might be for her. What she struggles to work out is how to get used to the inevitable, again placing the responsibility for others’ intolerance and its solution on herself:

At school the taunts were becoming only harder to take. Somehow I had reasoned that if a bad thing happened often enough it would get easier. It worked with pain, so why wasn’t it working with teasing? Every time I was teased, which usually happened several times a day, it seemed incrementally more painful. I was good at not listening, at pretending I hadn’t heard, but I could sense myself changing, becoming more fearful. Before I’d been an outgoing person, and in the right circumstances I still was, but now meeting new people was laced with dread. Except for the one time I went to me guidance counselor to complain, I discussed this with no one. Besides, I reasoned, what could I do about it? I was ugly, so people were going to make fun of me: I thought it was their right to do so because I was so ugly, so I’d just better get used to it. But I couldn’t. (Grealy, 1994, pp. 145-146)

Mercer recalls her disappointment and her sad acceptance when she faced hard reality and abandoned her hopes for ever having a romantic or sexual relationship with a handsome young psychologist at Belchertown—or with anyone:
Shortly after our date, I asked Hans to the prom, and he readily accepted. During one of our conversations about it, he started telling me that he thought I was a beautiful woman with a good mind locked up inside an unfortunate body. He said that he liked me very much as a friend, but he didn’t think we would make a very good match romantically. I understood what he was saying, and I was heartbroken. For the first time in my life, I realized that I would never be able to enjoy a romantic relationship with a “normal” man. It finally dawned on me that no nonhandicapped man would ever be sexually attracted to me—certainly no nonhandicapped man to whom I was attracted, anyway. Since I had never been physically attracted to men with disabilities like mine, I concluded that I would never enjoy a sexual relationship with anyone. This was a bitter pill to swallow. (Sienkiewicz-Mercer, 1989, pp. 190-191)

Nixon recalls similar disappointment when a boy she had a crush on turned down her invitation to her prom, saying he wanted to keep in touch and remain “friends.” Like Mercer, Nixon’s rejection leads her to doubt whether she will ever be able to date or have a sexual relationship. Although she notes that it is societal prejudice that stands in the way, her tone indicates that she sees this prejudice as a hard fact of life that she must accept:

In high school I watched kids pair off into couples. That was hard. I very badly wanted, and still want, a boyfriend. Just to have someone to love, and to be loved back. And to go out on dates and do all the normal stuff that girls my age do. Yes, I also think about sex and what that must be like. . . . I would be happy right now to have someone want to hold my hand, kiss me, and tell me I am pretty. I have terrible doubts at times whether someone will ever want to have a sexual relationship with me. I fear society’s stereotype that disabled people are nonsexual will get in the way. (Nixon, 1999, pp. 116-117)

Panzarino remembers as a teenager sadly coping with the fact that her disability isolated her from her peers and prevented her from engaging in normal social activities. She depicts her and her parents, at that point in her life, as trying to accept and accommodate themselves to (rather than question or challenge) the lack of accessibility for disabled people:
Although I had many friends at school, by the beginning of my freshman year they were beginning to enjoy more and more activities that I could not participate in. Transportation was still a problem, and I found myself dreading the isolation of being homebound on evenings and weekends. My parents planned more and more family outings for us. That helped relieve my boredom, but it increased my feeling of being different from my friends, who went out with their peers. (Panzarino, 1994, p. 85)

Roney reflects on the constant sense of vulnerability and caution that she sees her illness experience having created in her, accepting that her attitude is an inevitable response to the ever-looming rejection of others that she assumes to be a natural fact of life:

When you have a disease that no one can see, you are alone with it in a peculiar way: the more obviously ill and handicapped may be rejected out of hand, but with diabetes you are accepted, to the extent that you can “pass.” And, I might emphasize, only so far as you seem “normal.” What this creates is a division of self, the “abnormal” hidden within the “normal,” the body primed to betray its secrets, the rejections delayed but looming. I have learned over the years to expect them, and many friends have commented on this trait of skittish anticipation of the worst. This attitude, however strange and sad it seems, reflects my reality. I am always a guest in the good graces of others, and, directly or indirectly, it is my body that will turn them away from me. (Roney, 1999, p. 32)

Rothenberg reflects often on her likely early death from cystic fibrosis. Yet she accepts this hard reality, even as she contemplates a lung transplant in hopes of improving the quality of her life: “I’m a typical college student, if there is such a thing. Except that I won’t be able to look back on my life from an old age” (Rothenberg, 2003, p. 2). As she weighs the pros and cons of undergoing the lung transplant, she worries about how the surgery will affect her appearance and, consequently, her “love life,” unquestioningly assuming that as a “super ugly” person, she should expect rejection:

Regardless of how the surgery goes, I am afraid of the appearance changes. I’ll be on steroids ALL the time and anti-rejection medications that will make my face
round and puffy and I’ll probably have extra hair growth. My body might function better on the whole, but I will look like I’ve been sick. I am worried that I will stick out as looking “weird.” I remember one kid when I was growing up whose face was at least the size of a basketball—and I’m NOT exaggerating. His name was Robert. I remember that after he left our room Gina and I just looked at each other and couldn’t believe how much his face had changed. We were afraid of, as bad as it sounds, how ugly he had become. And of course outside appearances don’t matter in the grand scheme of things, but if the point of the surgery is to prolong a good quality of life, that has to include my love life. I certainly don’t want to be single for the rest of my life. And if I look like I have a huge hairy coconut head no one will fall in love with me—no one. I already have enough trouble getting guys to like me. I don’t need to be super ugly, too. (Rothenberg, 2003, pp. 23-24).

As much as Rothenberg grieves and struggles with her many losses as she awaits her transplant, still, her narrative often indicates that she believes her job is to put up a good front, accepting and coping with her losses and accommodating herself to the hard reality of her marginalization from her “normal” friends and a healthy world:

I feel like a pouty child. No, maybe a bitter forty-year-old who is too old to be young. I can’t help but be envious. They are living the college life, flying high at night, sleeping by day. Hiking, singing, drinking, politicking. Maybe even becoming acitivists, or at least they have friends who are. And then, the boyfriends. They’ll graduate from college, go on to grad school, then save the world because they have the smarts and the credentials. Envy. Is it one of the Seven Sins? I’m not sure. Life goes up and down, down and up, up and down. For everyone. And I don’t want any of them to be down, ever. I want them to keep flying, to go abroad junior year, get competitive internships. Wish I could forget about my situation when I’m with my peers, that I could just be with the giddy laughter, brag about living in Brookline. If only I believed it was better. (Rothenberg, 2003, p. 41)

Rothenberg was on the “active” list and waiting alone for lungs for six months before receiving her transplant. During this time, her narrative portrays her growing sense of herself as profoundly different from her peers, separate and distant from them in ways she could not expect them to try to understand:

It pleases me when friends call. However long it’s been, however disconnected I feel, I know that it is an effort for them to pick up the phone, for them to hear
about where my life is, and so it means something to me. After all, there are those who don’t call or e-mail. And yet, a phone call ends by even those I feel closest to saying, “Well, I’ll call next week.” Or, “I’ll be in Boston in the next couple weeks.” And I realize that I am in a different time zone that very few are able to calculate. (Rothenberg, 2003, p. 77)

Roney, too, recalls resigning herself to the unbridgeable gap between her “normal” friends and herself that her illness created:

Even then, I had no interest in being pawed by drunken boys or in throwing up in the weeds at the edge of the trees. Though I enjoyed getting tipsy, I could not imagine anyone intentionally bringing on a stupor or unconsciousness. I had been that way too many unpleasant times from hypoglycemia to embrace drunkenness. From the position of observer, I watched my friends act stupid. . . . One guy I usually liked dribbled beer down my cheek and slurred a few words into my ear. I knew I was supposed to be thrilled, but I just wasn’t. . . . I went home, ever divided from normalcy, with no place to fit, neither a goody-two-shoes nor a partying gal. (Roney, 1999, pp. 54-55)

_Difference as Oppression_

A third prevalent theme that emerged in the analysis is the experience of _difference as oppression_. When speaking from this perspective, the authors characterize themselves as identifying, wrestling with, and challenging the injustices that accompany their different selves. They focus on those times when they were angry at or critical of cultural prejudices and inaccessibility, and they locate the source of their struggles primarily in the social construction and stigmatization of difference. In their reflections and memories of their experiences and the communication around them as they were growing up, they express anger not only at the fact of their physical difference, but especially at the society that stigmatizes that difference. In and through their narratives, they actively confront and resist cultural norms, attitudes, social policies.
Communication in Health Care Settings

Health care providers. Within this theme, the tone of the authors is that of questioning and challenging health care providers and systems, rather than mutely accepting them or seeing themselves as defined and demeaned by them. For example, Rothenberg recalls with pride and satisfaction an incident in which she vocally expressed indignation at what she saw as the rude intrusion of an intern into her territory—her hospital room:

As usual, Laura’s Room is proclaimed on an electric-bed-width-door on 10 South, pictures overwhelm the walls. It was my pre-back-to-college admission in August before returning as a sophomore. . . . My door is open. I like it open. . . . Maybe that year at Brown had given me a confidence I never had before; maybe I was bored and wanted to play. He walked in. Long white coat over scrubs and clogs. I deconstruct the outfit to figure out his seniority. Long coat—important, but he’s in overnight gear, like a resident. Important resident is either a chief resident (but I know them) or a fellow studying in a specialized area of pediatrics. My guess is the latter. “Excuse me, can I help you?” Without even a glance he pushes on the foot pedals for the correct temperature and begins to wash his hands. I said, “Excuse me.” He continues to ignore my attention attempt. “Hello?” Now he squeezes the liquid soap dispenser several times. “Hi, yes, person at the sink, I’m talking to you! Excuse me, are you going to introduce yourself? Aren’t you at least going to ask permission to use my sink? My name’s Laura. I’m nineteen, I have CF, I go to Brown, this is MY room.” Beginning to finish up. “Hey, excuse me, person at the sink!” This time loud and pissy. He turns and gestures confusedly as if I was actually talking to the reflection I glimpsed in the mirror. “Can I help you with something?” I proceed to ask, as if he had just entered the room. He is silent. “Who are you?” “I’m Doctor . . .” (don’t remember his name). “What are you?” Shocked by my blunt question: “I am a Cardiology fellow.” “Well, for future reference, on this floor we don’t just walk into any patient’s room. This is my room!” Dr. Fellow turns around and walks out, faster than I could see his reaction. I retold the story that day over and over, how I valiantly protected my space. (Rothenberg, 2003, pp. 17-19).

Mercer recalls feeling a similar sense of satisfaction and triumph when she was able to express her indignation and exert some control in her dismal health care environment,
joining with another resident in strenuously objecting to the treatment they were receiving from a new attendant:

One day a new attendant came around to feed me. I didn’t like that rough way she was going about it, so I made some hostile faces and growled at her. As a newcomer to the Infirmary, unaccustomed to such modes of expression, the startled attendant was set back on her heels by my outburst. Then Theresa piped up and joined in the assault with a vocal attack of her own. For a few seconds the two of us vented all of our frustrations on this unsuspecting woman. We drove her away in tears. Without a doubt, this was one of my finer moments on Ward 4. The attendant returned later, but with a markedly more cautious and respectful attitude toward Theresa and me. (Sienkiewicz-Mercer, 1989, p. 66)

While Rothenberg’s and Mercer’s accounts depict them as asserting themselves and exercising some power and control in these health care situations, often the narratives reveal the theme of difference as oppression through the authors’ recognition and identification of injustice, even when unable to exert any real influence to alleviate it. Mercer, for example, recalls her growing anger and outrage at how she was treated by her health care providers at the state school:

The facilities at the Infirmary were woefully inadequate and terribly overcrowded, but even so, it was the staff that made my life truly miserable. They viewed me as a helpless little creature whom they were supposed to keep alive, and nothing more. (Sienkiewicz-Mercer, 1989, p. 99)

Mercer increasingly recognized the conditions, procedures, and attitudes at the state school as wrong and unjust. She recounts many examples of treatment she identifies as intolerable. On one occasion, for example, Mercer was hospitalized for treatment of a serious injury to her leg and hip that she suffered as a result of rough handling by a careless attendant. She describes the doctors’ dismissal of her as a person:

As usual, the doctors couldn’t be bothered to let me know what was going on, or even ask me how I was feeling. They just assumed that I was incapable of understanding anything. This has been the story of my life as far as doctors are concerned, and it has usually caused me a lot of grief. This time was no different.
The x-rays told the doctors all they needed to know about my leg, but that didn’t make it any easier to hear them talk about me as if I weren’t even there. It also didn’t tell them about my hip. If the doctors or nurses had only asked me how I was feeling, I would have told them about my hip. A frown and a negative sound would have indicated that I didn’t feel well. Then either my eyes or a few intelligent questions would have led them to my hip. But they never asked, and I couldn’t tell them without some help. (Sienkiewicz-Mercer, 1989, pp. 132-133)

Mercer remembers becoming more and more angry as her pain continued for many months, with the attendants and doctors ignoring her obvious suffering. Finally a new staff member at the state school, a young physical therapist, discovered Mercer’s injury and informed one of the attendants, Wessie:

Her first question to me was why I hadn’t told her before. From my exasperated response, and a few follow-up questions, Wessie finally understood that I had been trying to tell her [about my sore hip] for nearly a year and a half. Within a day or two, the Infirmary doctor examined my hip and pronounced with great authority that it was sore. He ordered no x-rays, and no changes were made in my routine, other than to cancel physical therapy and prop another pillow under my hip when I was in the wheelchair. The extra padding, along with gentler handling, relieved my discomfort a little, and I felt much better emotionally now that my unwanted secret was known. But I was very angry, although not surprised, that the Infirmary doctor didn’t do a thing to help me. The pain didn’t go away as a result of one more pillow and his neglect. (Sienkiewicz-Mercer, 1989, pp. 145-146)

Within the difference as oppression theme, rather than being diminished and defined by this kind of treatment, Mercer recalls becoming critical and angry at the overwhelmingly dehumanizing treatment of the disabled residents at Belchertown:

It didn’t take me long to become hostile toward these people, which I think was understandable under the circumstances. The diapers, the solitary confinement, the weird noises, all rattled my nerves. The callous treatment from the attendants transformed my anxiety into anger. (Sienkiewicz-Mercer, 1989, p. 41)
Mercer remembers with disdain and indignation a particular ward supervisor who earned the nickname of “The Witch”:

[The Witch] was . . . insensitive to the real needs of the residents. Under her command, the attendants provided us with custodial care of the most basic kind, and any attempt to treat us as individuals was severely discouraged. Few residents died on our ward, so in that sense the Witch met her objectives, especially when one considers how she overworked the attendants. But that was no excuse for how she viewed us. We weren’t people with physical and emotional needs; we were objects that had to be fed, cleaned, and changed, fed, cleaned, and changed, and so on. If an attendant took a few minutes out from her chores to talk to me, she risked being yelled at by the Witch. (Sienkiewicz-Mercer, 1989, pp. 99-100)

At other times, Mercer recalls her resentment of treatment that, while not blatantly negligent or callous, she found unjust and discriminatory in its condescension or dismissal of her and other residents’ feelings and preferences. For example, she recalls her frustration with circumstances surrounding trips to a carousel that the residents were taken on. While these outings represented one significant improvement in the treatment of the residents, still, residents had very little influence over plans that were made for them. Mercer remembers feeling both powerless and patronized by attendants who regularly ignored her communication of her wishes and simply assumed they knew what she would enjoy:

An attendant who didn’t know me very well would run up and say, “C’mon, Ruthie, let’s take a ride on the merry-go-round, you’ll love it.” I always responded with my sourest grimace and most negative sounds, my version of “No, anything but that.” Without fail, the attendant would ignore my clearly stated wishes, lift me out of my wheelchair, plunk me down on a hard wooden bench on the carousel, scrunch me up in a terribly uncomfortable, sometimes painful position, and take me for a ride. Then he or she would tell me how much fun we were having. The carousel would turn ‘round and ‘round . . . and I would get sick to my stomach. . . . The more we went there, the more I despised the thing. (Sienkiewicz-Mercer, 1989, p. 178)
Grealy, too, is at times critical of inattentive or dismissive treatment she received from health care providers. Although Grealy’s accounts of her experiences in health care settings often have a tone of resigned acceptance or focus on her memories of feeling demeaned and abandoned, at times she points to the injustices she suffered in overcrowded, understaffed hospitals. For example, she recalls an incident that occurred when she was 11 and hospitalized for a week for the latest of her many intensive chemo treatments:

It was late at night, always a bad time in the hospital, but especially on this ward, which I’d been on before and which was notoriously understaffed. . . . I had to go to the bathroom. I tried to assess if I could walk the few feet unaided and decided I couldn’t. [I pressed] the call button for a nurse. . . . I waited. I waited and waited and even tried calling out, but my voice couldn’t carry that far. . . . How much time passed I don’t know, but I had to make a decision: get up and walk or pee in the bed, as I’d done once before in a similar situation. . . . I called and called for a nurse or an aide, but finally I couldn’t stand it any longer and, with great relief, let go and peed right there in the bed. I had to lie in it until it was cold and had spread through all of the sheets before an aide finally, almost comically, walked in with a bedpan. She looked at me disapprovingly and said she’d send someone to change my sheets. Ten minutes later a woman showed up and looked at me in surprise. She asked me how old I was, and I told her eleven. She shook her head and said that when she heard someone had peed in the bed, she thought it must have been a baby. (Grealy, 1994, pp. 132-134)

Doctor-parent-child. The theme of difference as oppression appears also in the authors’ depictions of interactions involving the individuals, their parents, and their doctors or other health care providers. For example, Mercer points to the lack of clear and effective communication between her parents and the health care providers at Belchertown state school, as well as her parents’ failure to verify with her the facts of her treatment there, as the cause of so much of her unjust suffering. Thinking back to the day one attentive staff member finally recognized that she was able to communicate, Mercer explains how it happened that it took more than three years for anyone to realize this:

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None of the staff at Belchertown had noticed my yes-and-no signals until that day, when Wessie [one of the attendants] discovered them. For more than three years I hadn’t been able to communicate any of my thoughts or feelings to the people on whom I depended for my survival. Back when my parents first brought me to Belchertown, they made a point of telling Dr. Soong and others about my facial signals, but no one paid any attention to what they said. Everyone just assumed that I was a helpless cripple, and with the constant turnover of staff, the very suggestion that I could communicate was soon lost. During visits or vacations, my folks never thought of specifically asking me whether my signals were being used at the Infirmary. They just assumed that they were, so they didn’t follow up with anyone at the State School to make sure. (Sienkiewicz-Mercer, 1989, p. 11)

On the other hand, Roney’s mother was often a helpful ally against the power of the health care system. Roney remembers times when she, together with her mother, refused to comply with the medical system into which they had been thrown and before which they had always been taught to stand in awed obedience. She and her family learned to stand up to a system that they recognized as inadequate, at best, and sometimes bluntly dangerous and emotionally damaging. For example, she recalls an incident surrounding her referral to a new doctor:

Within a couple of visits it became clear that he knew nothing about diabetes and was merely a med school buddy of [the referring physician]. An old man with an unsympathetic style, he was completely uninterested in and at a loss to deal with the issues of my weight, my severe menstrual cramps, and the blood sugar difficulties posed by the unpredictable world of high school. He asked the same questions over and over again at our first appointment, as if trying to catch me out in a lie or an inconsistency, or as if he simply could not comprehend my answers. Menstrual cramps, he said, were just something I’d have to learn to bear. Docile as we were, after a couple of visits my mother and I had had enough. (Roney, 1999, p. 37)

Parents’ Communication

While parents are sometimes characterized, as in the above passage from Roney’s narrative, as providing support and encouragement to their children in the face of social attitudes that the authors perceive as oppressive or unjust, the narratives also sometimes
portray parents as either complicit with or as a primary source of oppression. For example, Mercer remembers her growing realization and difficult acknowledgement that, in sending her to Belchertown State School and keeping her there even as the harm being done to her became undeniable, her parents (mainly, her father) had made a decision to sacrifice her well-being for the good of the rest of the family. She recalls going home for a visit, certain that she would be able to persuade her parents to not send her back:

I knew all along who was the driving force behind my going to and remaining at Belchertown. As that first Christmas vacation came to a close, I could scarcely hide my resentment toward Father. I was angry at him, and he knew it. I felt that I had given the place a long enough try and it had failed miserably. The idea of leaving home wasn’t the issue, either, for I knew from experience that a proper facility could provide me with decent care and take a great strain off my family. I understood why Father wanted me to give Belchertown a fair chance. What I couldn’t accept was that he would allow me to stay there any longer. So far, my parents had avoided any discussion of my leaving Belchertown. But by the end of that first Christmas vacation, my resentment toward Father was so obvious that he was forced to explain his position to me. He talked to me alone. He encouraged me to give the State School more of a chance. I tried to show him from my response that more time wouldn’t do any good; I was miserable there and it was the institution’s fault. When Father repeated his belief that he was doing what he thought was best for everyone in our family, I tried to make him understand that Belchertown was so bad that it couldn’t possibly be good for anyone . . . . I was determined to convince him that I could no longer remain at the State School. Father couldn’t read my mind, and since I could express my emotions only nonverbally, he couldn’t always tell what points raised my anger, despair, anguish, or frustration. But he knew, or sensed, what I was trying to tell him. Our discussion ended in a heart-wrenching stalemate. Father pleaded, “What else can I do?” I responded with tears, overcome by all of my emotions. I returned to Belchertown a confused young girl. I had gone home expecting to convince my parents that the State School was a horrible place and that my stay there must end immediately. I had failed. I had always looked up to Father as a pillar of strength and wisdom, relying on his word as the last word, but now my faith in him was severely shaken. . . . By the end of my second Christmas vacation at home, in 1963, a year and a half after I was first taken to Belchertown, I no longer blamed my continued presence at the State School on my parents’ lack of information or awareness. A few details may have been missing, but the basic picture was painfully clear to both Mother and Father. Father had made the decision, and he was sticking to it. My personal development had been sacrificed for the benefit of the rest of my family. (Sienkiewicz-Mercer, 1989, pp. 72-74)
Mercer recalls that, in the process of writing her autobiography, she had to make a hard decision about how honest to be in exposing what she now recognized as a terrible injustice:

I didn’t want to hurt Father’s feelings when he read my comments about being sent away. But after thinking the whole thing through, I decided not to pull any more punches. It was my father’s decision to send me to Belchertown, as well as to keep me there. He made that decision against Mother’s wishes. He stuck with that decision throughout those awful early years, despite my obvious desire to return home, which I tried to make clear to him every time I saw him. As I have said, Father believed that he had to sacrifice me for the well-being of the rest of the family. Given the combination of our family circumstances and the lack of social programs and support services for families with disabled children, he felt that he had no choice. I disagreed, then and now. We could have gotten help from relatives. Father could have taken a different job, one that didn’t keep him away from home so much. If I couldn’t stay home, my parents could have kept trying to get me into a different place, one more like Crotched Mountain. My parents had a pretty fair idea of what Belchertown was all about when they put me there. And after they saw what the place was doing to me, any illusions they had must have been shattered. I kept trying so hard to talk to them about returning home, and they always avoided it. It couldn’t have been easy for Father; I know it was hell for Mother. I had been angry at Father for seventeen years—not so much for sending me to the State School in the first place as for not bringing me home when he saw what it was doing to me. Although I came to understand that decision as I grew older, I never accepted it or agreed with it. (Sienkiewicz-Mercer, 1989, pp. 211-210).

Roney, too, grapples with anger over her father’s failures, as she thinks back on his lack of involvement in her health care:

My father never went along to my doctors’ appointments, in fact, never really participated in my care beyond giving me juice when my blood sugar went too low and sometimes making a dinner that fulfilled the requirements. To this day, he has never given me an injection. He credits this to my already-formed personality. “You wouldn’t allow me to give you your shot,” he recalled when I asked what he remembered about the year of my diagnosis. “You were always so independent and stubborn.” I was stunned by this conversation, because I’ve considered it one of those signs of familial failure that my father has never in all these years given me a shot. How uninvolved could a parent be? And yet, it came back around to me. I was sure that he was right—it would have been like me to pull away, to reject his attempt to help—but I also found myself angry that the
Roney places the blame for the tense and distant relationship between her and her father during her adolescent years with him and his failure to help in any meaningful way with the health care routines that were such a pervasive part of her life:

The very thing that might have made us closer—his participation in my diabetes regimen, which might have brought him understanding of its wider implications for me—hung beyond our reach. On the other hand, I think he hesitated to discipline me as he might have otherwise. This led to a spiraling frustration on both our parts, which never let up until I went away to college. (Roney, 1999, p. 49)

With some apparent reluctance, Lipman also identifies some of his parents’ secretive and overprotective attitudes about and treatment of his illness as wrong:

In my family, it was next to impossible to get straight answer to tough questions. So after a while, I just stopped asking them. I still thought about them, particularly the mystery of my life expectancy, but I kept them to myself. I thought of my myriad questions like quicksand—they looked safe, but I knew they’d suck me under and suffocate me if I ventured in. I tried not to blame my folks for shunning discussions about CF. I mean, what kind of parent wants to tell their child, “Yes, dear, your life expectancy is 25 so you’d better enjoy life while you can?” And what kid should have to ask, “Mom, how long am I going to live?” In my family, the way we dealt with CF was by not dealing with it. These questions chewed away at my guts, but I knew I couldn’t bring them up with Mom or Dad. (Lipman, 2004, p. 161)

Within the context of his portrayal of a basically healthy and loving relationship with his parents, and believing their intentions to be good, Lipman’s tone is gentle and forgiving but honest as he struggles in his narrative to work out his conflicting feelings about his parents’ handling of his illness and his feelings of confusion, alienation, rejection, and abnormality that resulted, at least partially, from their approach:

My parents tried to shelter me as much as possible from the negative stuff about CF so that I could enjoy my childhood without fearing for my life and obsessing about my health. I remember how my mom would tell me to just ignore the kids
in elementary school who taunted me about dying from CF. I remembered how she refused to enroll me in CF camp because she didn’t want me to be around kids who were sicker than I was and who might get me focused on illness and dying. But I think I would have been better off if I’d known a little more about CF. As a kid, I didn’t know anyone else who had cystic fibrosis. Imagine being African-American and growing up without seeing another black person. Or imagine speaking French and for years never encountering another French speaker. You’d start to think you were not “normal” without realizing there was a universe where you fit right in. You’d assume there must be other people like you. You’d long to meet them just to “compare notes,” to reinforce the idea that you’re part of a group, and to know that the things that you feel, other people feel them too. That was absent from my childhood and teen years. It made those times, which are tough for every kid, even more alienating for me. (Lipman, 2004, p. 34)

**Communication of Peers and Others**

The theme of *difference as oppression* emerges strongly in the authors’ accounts of interactions with peers and others. While at other times the narratives frame others’ disconfirming communication as causing feelings of devaluation or as simply a hard reality to be accepted, within this theme they protest such communication as unjust, wrong, and/or oppressive.

Rothenberg, for example, recounts occasions when she lost patience with her close friends for what she saw as their thoughtlessness and insensitivity when they were forgetful or distant, carrying on with their lives with little thought for her loneliness and isolation and failing to visit, call, or write:

Today’s been lonely. I picked up the phone mid-cry fest. Talked to Genevieve, Julie. Called friends at Brown and left message after message. If you want phone calls, make some yourself, right? I tried not to, but couldn’t help leaving sorry-sounding guilt-trip messages. Anyone paying attention could obviously tell I’d been crying. Someday, when they have lung transplants they’ll see how hard it is to wait, how much one phone call could have done. (Rothenberg, 2003, pp. 46-47)
The authors sometimes express anger at communication of others they encountered that they found dismissive and condescending. Nixon articulates her resentment of and objection to this kind of patronizing communication:

It seems that I fight one of two battles with people who don’t know me well. They assume I am mentally disabled since I’m in a wheelchair and/or they assume I can’t physically do anything at all. This is not true, of course, and I love to do everything I possibly can for myself. But because of people’s attitudes, I feel that I need to work doubly hard to prove myself. Then, once people know me, they discover that I am a hard worker . . . whether at school or at my summer job . . . and the stereotypes disappear. It is just a matter of forcing people to see past my wheelchair. It is an exhausting job. What is her name?” “Can she talk?” “What does she want?” People who don’t know any better come up to my companions and ask questions like that. I’d like to shout at them, “Ask ME! I’ll answer!” Just give me the chance. Another thing that drives me CRAZY is when stranger come up to me and say things like, “My, what a big girl! Aren’t you a big girl!” as if I were a baby or mentally disabled. It is condescending. (Nixon, 1999, pp. 2-3)

Mercer echoes Nixon’s frustration with the condescension of others. For example, she describes the difficulties she constantly encountered in dealing with people who, because of her small stature and physical impairments, assumed that she could not understand them, and she notes that others’ patronizing and dismissive communication was more than a mere annoyance for her:

I was small for my age, and people constantly spoke to me in baby-talk. They even talked about me in my presence as if I couldn’t understand what they were saying. This kind of attitude, whether based on good intentions or sheer ignorance, has always been insulting at best. Many times it has done me serious damage. (Sienkiewicz-Mercer, 1989, p. 7)

Mercer also remembers ultimately feeling both patronized and exploited after she was dressed up to be a part of a film to promote Crotched Mountain, the school for disabled children she attended briefly:

My big scene showed me being taken outside in my chair for a stroll around the grounds. I was dressed for the part in a ruffled pink party dress. The costume consultants topped the Shirley Temple look with pink barrettes, some very cute
pink ankle socks, and a matching necklace and bracelet. All of the kids were thrilled about the project, and we had great fun watching the filming. We saw the finished product several times, but the first time was the best. . . . As a promotional device, the movie was meant to show all the good things that were being accomplished at Crotched Mountain. Even so, when I saw myself in it, I wasn’t very pleased. I looked tiny, almost lost, in my wheelchair, and much younger than I really was, partly because of the cutesy outfit I was wearing. My dress was almost grotesquely humorous in contrast to the thick metal braces on my legs and my cumbersome corrective shoes. This was the first time I’d every seen myself wearing the braces, and it scared me. . . . Thinking about that film now, I’m annoyed that we all were scrubbed up and dressed in costumes for it. The crew filmed me eating, but did not include that segment in the final version; it was probably too messy and unsettling for the idealistic effect they were trying to achieve. . . . The film was sentimental in other ways. Rather than just showing a boy struggling heroically to walk with an artificial leg, or the kids whooping it up in the pool, they might have informed the public about some of the more frustrating aspects of handicapped people’s lives. The center was achieving some remarkable things and there was no need to romanticize it. But I suppose that the general public’s attitudes toward the handicapped in 1959 had a great deal to do with determining the tone of the film. (Sienkiewicz-Mercer, 1989, p. 17)

Mercer recounts a series of events that occurred much later, when she had finally gained freedom from the state school where she had been confined for so long. She had been invited to a friend’s wedding shower and wedding:

About thirty women attended [the shower], mostly friends of Mrs. Boomsma’s [the mother of the groom]. . . . Mrs. Boomsma’s friends were like so many other phony people I had run across. They came up to me and rubbed my arm, stuck their faces close to mine, and remarked to nobody in particular, “Isn’t she sweet, the poor dear.” They went on talking about me for another minute or two as if I had disappeared, and then they ignored me for the rest of the party. . . . Bobbi put one of my big blue paper bibs over my blouse . . . and began to feed me. Right away one of Mrs. Boomsma’s ladies announced quite loudly that she was getting sick from watching me eat. John’s mother thereupon instructed Bobbi to take me into another room to eat. Bobbi said no, and we stayed put. Mrs. Boomsma then explained that it wasn’t for her sake, but out of consideration for one of her guests. Bobbi replied, “Too bad.” I was insulted and angered by both Mrs. Boomsma’s and her guest’s attitude, but Bobbi handled it perfectly and expressed my sentiments exactly. We ran into the same brand of hospitality at the wedding. . . . The [disabled] guys were stuck in the back of the room at the reception, off where nobody would see them. I was part of the wedding party, but Mrs. Boomsma asked that I eat in another room. As an alternative, it was suggested that I be fed after everyone else had finished. After consulting with me, our
program supervisor (who was my companion at the wedding) . . . ignored both requests. I ate dinner along with everybody else at the head table. (Sienkiewicz-Mercer, 1989, p. 215-216)

The authors often express disapproval, resentment, or anger when they are treated unfairly, their opportunities are limited, or their goals or dreams are thwarted because of the prejudice and stereotypes of individuals or the wider culture. For example, Nixon remembers as unjust the punishment she received when, in fourth grade, she was disciplined for the one time she cut class:

As punishment I was not allowed to drive my wheelchair in the building for a week. Someone would have to push me everywhere. That absolutely crushed me. What made it worse was that when anyone pushed me, they rubbed it in: “Oh, Shelley, I sure wish you hadn’t skipped class. This sure makes it difficult for us.” My parents knew they could not condone cutting class so they supported the teacher, as far as I knew. Years later, though, they told me that they admired me for having the spunk to do it. My mom did not agree with the teacher’s punishment, however. She felt I should have been sent to the principal’s office, given after-school detention, or had my recesses taken away just like other kids. No other children were told as a punishment that they couldn’t walk around school for a week. My wheelchair was my mobility and Mom didn’t think it right that it be taken away from me. . . . I guess I learned my lesson but, like my mom, I don’t think the punishment should have been connected to my CP. (Nixon, 1999, pp. 51-52)

Webb recalls the disappointment and anger she felt in 1939 when, after attaining her dream of being admitted to college, she was sent home after less than two days because the dean decided after this “trial period” that she was too handicapped to go to college.

She remembers her father arriving to take her home:

[Father said,] “I’ve just talked with Dean Harding. She’s sorry things didn’t work out. She says you made top scores on your French and English tests, but taking care of you is just too much. . . . She’s also afraid of your falling in these old buildings. She doesn’t want to upset you by saying good-by and asks me to tell you she admires you greatly.” “Humph! I bet!” I snort. I give my college-room-for-a-night one last look and slowly walk out the door. . . . At home there is nothing to do but feed the fires of indignations and anger kindled by my unjust expulsion. . . . Small flames of wrath, ignited and fed over the years by put-
downs, both real and imagined, now gather into a huge conflagration of resentment and perform a searing dance in my chest. (Webb, 1993, pp. 60-61)

Panzarino’s growing recognition of the discrimination and barriers that she and other disabled persons constantly encounter is a central aspect of her narrative. She describes the significance of her awakening activism in response to these injustices. For example, in 1961, when she was fourteen, she joined a support group for disabled young adults. Panzarino recalls that as the members revealed their stories and invited speakers to the group, she became aware that others shared her experience of being treated unfairly, and her resentment turned to determination:

I was devastated when I learned that individuals with disabilities were not covered under the Constitution of the United States or the New York Bill of Rights. It was legal then for people to exclude other people simply because of disability. We got letters from people who had been asked to leave restaurants or hotels because their wheelchairs or bodies made people uncomfortable. I began to make connections between the stories I was hearing and what was happening to me. I started writing letters about it and sending them to newspapers, friends, relatives, legislators and anyone else who might read them. (Panzarino, 1994, p. 89)

Panzarino’s narrative portrays the sense of empowerment she felt as she named and claimed her disability identity in solidarity with other disabled persons and gained the strength to point out and stand up to injustice. She recounts an early example of her activism, a protest she launched in which she ultimately triumphed:

One of the places that the kids often went was the library. Since it was way across town, I couldn’t meet them there unless my parents drove me. When I got word that the town was building a new library just a few blocks from my home, I was ecstatic. I loved to read. If there was a library so close, I could be wheeled there by a friend. Towards the end of my first year at Massapequa High, the new library was completed. To my dismay, there were over a dozen steps at the entrance, making it totally inaccessible to me. My disappointment quickly turned to rage, and I called the library. . . . “I would like to discuss the inaccessibility of the library at [the next board meeting]. Is there anyone I can talk with to get that arranged?” . . . I immediately got on the phone to people from the young adult group, the Muscular Dystrophy Association, a nearby nursing home, and the
Association for Better Conditions for the Disabled (ABCD). I got five adults in wheelchairs to go with me to the board meeting. . . . Then I called the local newspaper and asked them to cover the meeting because it was going to deal with a very important issue. (Panzarino, 1994, pp. 99-100)

Later, Panzarino was admitted to Hofstra University as one of the first five disabled students accepted as part of a new program that openly accepted some disabled students. She recounts her continual struggles with transportation problems and the inaccessibility of the campus, as well as the tension and frustration of still living at home with her parents at a time when she longed for more independence. This led to her investigating the possibility of living in the campus dorms, and an encounter with new barriers:

I thought perhaps I could have a roommate help take care of me. I figured [the Office of Vocational Rehabilitation] might be willing to pay for the dorm instead of transportation. I found out that since I was in a wheelchair and could not walk down the steps independently, I was not allowed to live in the dorms because I was considered a “fire hazard.” This made me angry enough that I decided to try to organize people about issues of disability. I reserved a room and put up flyers saying “Are you a fire hazard? Hofstra University says that disabled students are fire hazards and cannot live in the dorms. If you are concerned about this issue, please come to a meeting” . . . . Five people came to the meeting. Jimmy, my friend who had joined SDS, was one of them. . . . We established a campus organization called People United in Support of the Handicapped (PUSH). A year later we had over one hundred and fifty members (Panzarino, 1994, pp. 121-122)

Mercer reflects on large questions about disability and normalcy in light of her own severe impairment and the conditions of others she encountered at Belchertown. From her unique standpoint, she challenges widely held attitudes and judgments about disability that lie at the heart of the injustices suffered by people with serious chronic illnesses and disabilities:

The arrival of a new girl on the ward in early 1964 disrupted my emotional status quo. She was severely hydrocephalic, with a head as big as a watermelon set atop a tiny body. . . . This poor girl spent three years in the bed across from mine. In all that time, she never exhibited any behavior to indicate that she was aware of anything going on around her. She only made horrible noises and thrashed about,
hurting herself with uncontrolled body movements. . . . Many people would feel that this girl was probably better off dead. Although I can understand this sentiment, I am cautious about forming such opinions. I’m sure that a lot of people would look on me just as I viewed that girl, believing that life couldn’t possibly offer my anything worthwhile on account of my “pathetic” physical condition. I know far too many people who are enjoying their lives fully, yet appear to others as pitiful. . . . When you’ve spent as much time as I have with people who have been totally rejected by society, when you have been written off by nearly everyone around you, it becomes very difficult to draw the line at which life is no longer worthwhile. I choose not to draw that line at all. (Sienkiewicz-Mercer, 1989, pp. 90, 92)

**Difference Integrated**

The fourth theme that emerged in the analysis of the authors’ stories I call *difference integrated*. Throughout their narratives, all of the authors work to sort through and positively integrate their experiences of difference into their identities in a way that makes sense to them. They portray themselves as accepting, normalizing, embracing, and/or valuing the difference of their disability or illness. Within this perspective of difference, the individuals characteristic stance is one of making peace with the reality of their different bodies and different lives within a culture and relationships that are ambivalent, at best, in their communication regarding the difference of illness or disability. Their self-portrayals include depicting themselves as resilient survivors, serene, strong, at peace, valuable, and/or loveable.

Like the previous three themes, the theme of *difference integrated* often emerges in reference to descriptions of the effects of or their reactions to others’ communication. The authors recall supportive or affirming communication of others that aided them in positively integrating difference into their identities. However, the theme is seen most vividly through the authors’ narratives of their internal reflections on the meaning they decide to make of their experiences, physical differences, and their identities, often in
opposition to the negative communication of others. In other words, the integration of
difference is a perspective that most clearly is the result of an assertion of agency, an
active process of narrative self-reconstruction.

Internalizing Affirming Communication

The authors recount many examples of others’ affirming communication that
stand out for them as positively influencing their sense of self and making it possible for
them to hold onto a sense of dignity and worth in the face of sometimes overwhelming
messages to the contrary. For example, Webb remembers the positive impact on her self-
estee and confidence of a summer camp for children with cerebral palsy that she was
able to attend:

One day two tall ladies, friends of Aunt Ethel, visit me and invite me to spend the
summer at Robin Hood’s Barn, a camp for spastic children. I joyfully accept,
since otherwise I would have to spend the entire summer at [the boarding school].
. . . When Dad drives me up to a little Vermont town in early July 1937 and leaves
me at camp, I enter a fairy tale world. Gone are the matrons’ day-long scoldings
and the ceaseless criticisms from the big girls. Gone is the anxious fear that I will
do something wrong. At Robin Hood’s Barn, each camper, as well as each
counselor, lays aside his or her accustomed role and becomes one of Robin
Hood’s merry men. We even wear Lincoln green. This ingenious idea to enable
spastic children to experience life beyond their handicaps was developed by two
special education teachers who called themselves Robin Hood and Little John.
Unknown to either of these ladies or to my parents and Aunt Ethel, living as
Queen Eleanor, or “Queena,” for eight weeks that summer restores my self-
confidence. I am Queen Eleanor not only in name. With my counselor, Maid
Marian, in attendance, I have the power to choose what I want to do. (Webb,
1993, pp. 39-40)

Webb also recalls an incident that occurred during her early college years that stands out
for her as a time when she felt accepted and valued:

At Faulkner House parties, I listen to chatter about what young man is asking
what Faulknerite to the spring prom. I never dream of getting such an invitation.
However . . . a tall, blond preministerial student not only goes through a very
formal ceremony to ask me to the prom but also buys me my first corsage, an
enormous lavender and yellow orchid. I am thrilled! . . . [Mother] buys me a powder blue, silk evening dress with a wide collar and puffed sleeves. Almost as excited as I, she then drives the hundred miles to bring me the wonderful dress. I wear a blue velvet choker, black slippers, and Mother’s pink-flowered Chinese shawl. Bonnie sets my hair and helps me dress. “You’re a real Cinderella! You’ll wow Charles!” She declares. Charles and I have a lovely time. . . . I am on top of the world. This night is never-to-be-forgotten. (Webb, 1993, p. 77)

Lipman recalls how he felt affirmed during his freshman year in college by the acceptance and good-natured humor of a friend who consistently interacted with him as a “normal” guy:

I liked him because he took a real interest in me and because he wasn’t bothered by the fact that I had CF. When people would find out that I had CF and then get that polite, concerned look on their faces, Aaron would interject, “Yeah, he can’t breathe or anything. I think he’s missing a lung. Does anyone see it? I hope he didn’t lose it in the Jello again.” When I’d be doubled over with a coughing attack, other people might nervously ask if I was O.K. Aaron would ask me if he should call the coroner. That might sound cruel, but it was funny to me. I’d lived for so long with CF and dire reports about my health and life expectancy that it was a relief to hear someone joke about it. . . . Aaron helped transform my attitude about CF. I had been so secretive about it for fear that people would think I was odd or sick, but my friendship with him made me realize someone could like me for me. He didn’t care about the fact that I had CF any more than he cared that I was from Atlanta or that I was a Braves fan. It was one fact about me, but it didn’t define me. (Lipman, 2004, p. 67)

Nixon recounts early memories of feeling accepted, valued, and empowered as a result of the recognition and encouragement of her writing abilities that she received from her parents, teachers, and others who looked past her disability and focused instead on her gifts:

My parents and teachers praised my writing. And strangers did, too. For the first time I could express myself without letting people know I had CP. They could see a representation of my voice and thoughts. They could see my intelligence, playfulness, and creativity. They could know me. That felt wonderful. And when people stared at me or made fun of me, I knew I had an ability that I could use to fight back. (Nixon, 1999, pp. 47-58)
The authors recount some examples of affirming communication within health care situations that helped them to see themselves, with their illness or disability, in a more positive and healthy way. Roney recalls the impact that a young hospital volunteer unknowingly had on her. During her first admission to begin treatment of her diabetes, 11-year-old Roney spent days trying to work up the courage to inject herself with insulin for the first time. She remembers the nurses’ growing exasperation and her sense of failure as the days went by. Finally, a kind and sensitive candy striper helped her to overcome her fear and gain the beginnings of a sense of competence, independence, control, and acceptance in regard to her illness:

I still remember her with all the awe and fondness accorded a savior, her bright face and her helpful lies. As part of the encouraging entourage, she had visited me at least once during each of her shifts, always popping her head politely in the door, her eyebrows raised cheerfully and expectantly in a question of whether I had done it yet. She exuded an unusual sincerity, as though she thought it really was her job to help people. . . . I’ve often wondered if my candy striper knew how much she helped me, even had the notion of going on Unsolved Mysteries to see if I could locate and thank her, though it probably wouldn’t merit a segment because she didn’t do anything as dramatic as pull me from a burning or sinking-in-the-water car. What she did was to cut a deal with me: she’d let me try it on her first if I’d go on and do it to myself immediately afterward. She said she wasn’t afraid because it wouldn’t hurt anyway. If I had to do it the rest of my life, she said, she could certainly let me try it on her once. . . . I’m grateful that I was able, with that young woman’s help, to take the first big step toward growing up. Sitting on the hospital bed, with an expectant audience, I performed. In earning others’ relief and approval, I learned that doing for others often is also doing for oneself. Alongside that, however, I encountered my own solitary nature in the heavy responsibility that would never leave me, not for a waking or sleeping instant, though I might rail and rage and plead and despair over it. Staring down at my leg, taking the plunge, swallowing my fear of my body, I learned that I was so much more than just that mass of flesh.

Mercer recalls some interactions and procedures at Belchertown that communicated respect for her—or, at least, an acknowledgement of her humanity—and how strongly
these affected her. For example, she notes one huge improvement that came when some of the more sensitive attendants finally began to believe that there was a thinking person inside Mercer’s impotent body:

The official tag for me was “severely retarded,” yet Wessie and Hazel noticed that I was trying desperately to communicate with them. After several weeks they realized that the label was incorrect. Since I looked like a rather intelligent seven-year-old (I was fifteen at the time), that’s how they treated me. . . . This was a terrific development, and I was thrilled. (Sienkiewicz-Mercer, 1989, p. 108)

This recognition and increasingly humane treatment on the part of some of the attendants boosted Mercer’s self-esteem and renewed her hope that she finally might be able to persuade those around her that she was able to communicate her thoughts, ideas, and feelings purposefully and intelligently through her eye signals. She recalls the positive impact that even the smallest of gestures had on her:

Roseanne spoke to me as if I was more than just a heap of flesh and bones. Whenever I saw her, even if only for a quick “Hi Ruthie” and a smile, Roseanne seemed like a visit from the outside world. (Sienkiewicz-Mercer, 1989, p. 125)

Then came the breakthrough that Mercer had been steadfastly striving to achieve for over three years:

During lunch one day in early December 1965, Wessie said something to me like “Too bad the food at this place is so lousy.” I laughed, and raised my eyes toward the ceiling in an exaggerated way to draw her attention. As she brought the next spoonful of food up to my mouth, she noticed that I was doing something funny with my eyes, obviously in reaction to what she had just said. . . . She put the spoon down and thought for a few seconds, then asked, “Ruthie, are you trying to tell me something?” With a broad grin on my face, I looked at her squarely. Then I raised my eyes up to the ceiling again with such exaggeration that I thought my eyes would pop up through the top of my head. . . . She pondered for a few more seconds . . . then it clicked! A silent conversation flashed between us as loud and clear as any spoken words. Even before she asked me a dozen times over, and before I exuberantly answered a dozen times with my eyes raised skyward, Wessie knew. And I knew that she knew. I was raising my eyes to say yes. We both started laughing. Then I started laughing really hard, and before I knew it I was crying so uncontrollably that I couldn’t see because of the tears. They were
tears of pure joy, the kind of tears a person sheds on being released from prison after serving three years of what she had feared would be a life sentence. (Sienkiewicz-Mercer, 1989, p. 110)

Although the recognition of Mercer’s communication ability on the part of at least some of the staff boosted her self-concept significantly, she continued to struggle with largely demeaning treatment at the institution for thirteen more years. She notes exceptions along the way that helped her to hold onto some sense of dignity. For example, she recalls the impact that two special nurses had on her life, at a time when she was ill and deeply depressed:

My real lifesavers were the two nurses at the Infirmary, Roseanne Wroblicki and Margaret Clark. They gave me the large doses of tender care and pampering that no doctor ever prescribed for me but that were so essential for my survival. . . . It was their job to monitor my physical condition and satisfy my medical needs. . . . They performed this task quite well, but more important—most important—they treated me with respect, consideration, and gentleness, very rare commodities at the State School. Roseanne and Margaret quickly became my closest friends. They recognized my desire to communicate with them and actually gave me the chance to do so. Roseanne read Mother’s letters to me. They were warm, caring letters, and that’s how Roseanne read them, whereas some of the attendants read the letters as if they were grocery lists. Recognizing my strong ties to my family, Roseanne asked me many questions about them. From Mother’s letters and my answers, she developed a good understanding of my background and upbringing. . . . Although I did suffer from severe fits of depression, the damage was limited by the genuine concern of my two nurses. I dread to think what might have happened if Roseanne and Margaret hadn’t been there. (Sienkiewicz-Mercer, 1989, p. 136)

Mercer also recalls feeling affirmed and “normalized” by her interactions with the teenage daughters of two staff members at the state school who began dropping by regularly to visit with her:

I was very impressed with both Gena and Mary Lou. They had been dropping by the State School for about a year, but this was the first time either one had walked onto a ward at the Infirmary. . . . The girls didn’t gawk or stare at anyone; they didn’t act afraid or hesitant; they didn’t giggle nervously. When we were introduced, they said, “Hi, nice to meet you,” and started right in talking to me like I was a classmate. It was the first time I had felt like a “normal” person in
five years... Mary Lou was quiet at first, but after we got to know each other, she gradually opened up and became very outgoing. Mary Lou shared her fantasies with me. We dreamed out loud about romance, movie stars, and all of the wonderful and exciting things we would do when we grew up... Mary Lou was my best friend at the State School in the years after my leg was broken. She was always interested in finding out what was on my mind. Gena, in contrast, was a delightful chatterbox... These two young women provided me with a sense of what “normal” teenage girls thought, said, and did together. I really missed out on being a teenager by living at Belchertown all those years, but my contact with Mary Lou and Gena at least helped me learn what I was missing. (Sienkiewicz-Mercer, 1989, p. 138-139)

Although the authors often point to their parents as the source of negative, disconfirming communication, their narratives also sometimes describe communication of parents that helped these them to develop a positive view of their different selves. Mercer recalls receiving a potent affirmation of her personhood from her parents in the form of a Christmas gift they gave her in 1965, after she had been suffering the indignities and degradation of the state institution for three years:

I received [a very special gift] from my parents: a beautiful powder-blue dress with lace ruffles and satin trim. Even though it was too big for me... and even though I knew that I would never wear that dress at the State School, I loved it... In my parents’ eyes, I deserved a fancy party dress, regardless of how much I actually needed it. It might have been only a gesture but it meant the world to me. I still consider that dress the best Christmas present I’ve ever received. It represented my parents’ unwavering belief that I could and should lead the same kind of life as any “normal” girl. Even when I was spending my days in diapers, in the Box, or in a bed on Ward 3 of the Infirmary, my parents envisioned me wearing a blue satin dress. (Sienkiewicz-Mercer, 1989, p. 117)

Although Lipman at times describes the decidedly negative effects of his parents’ secretive and overprotective attitudes and actions regarding his cystic fibrosis, he also sees the complexity of their decisions and credits them with having a lot to do with his development of a view of himself as a “normal” guy who just happens to have CF. For example, he calls his mother refusing to agree to send her son to CF camp, partly because
of the risk of picking up dangerous lung infections from other children, but also because she didn’t want him to think of himself as sick and different:

My mom considered Dr. Compton’s recommendation. . . . She softly said, “I’d prefer that he didn’t go. I don’t want Andy to become friends with kids he’ll see pass away. I don’t want him to think he’s different from everyone else just because he has CF. I want him to have a normal life. He deserves that opportunity.” That might seem ironic in light of my parents’ support of CF groups, but my mom felt there were some CF children who needed CF camp and others who didn’t. I fell in the latter category. . . . Dr. Compton had told my mom what I couldn’t eat and what I couldn’t do athletically. So many times, Dr. Compton had told my mother and me about the things I could not do. On this day, she was telling him that I could accomplish a lot. She wouldn’t allow CF to define and/or limit me. She wanted me to be a kid like every other kid. (Lipman, 2004, pp. 15-16)

Lipman also recalls the positive influence on his self-image when his father, realizing that his young son was suffering as a result of being sheltered from potential risks and isolated from his peers, insisted against Lipman’s protests that he learn to play baseball. Lipman remembers feeling better and better about himself not only because of his gradually growing athletic ability, but, especially, because of his father’s expressing confidence and pride in him. Lipman recounts an event that stands out for him, when he first successfully caught a fly ball in a Little League game:

All those rigorous practices, scraped knees, bruised elbows, and carpet burns had finally paid off. But the best memory of the day came a second later. I looked into the stand and saw one man stand up and applaud like his kid had hit a home run with the bases loaded in the bottom of the ninth with the score tied. He hollered, “All right, Andy!” so loudly that I had no trouble hearing him on the field. My dad was so proud of me that he proclaimed to everyone that I was his son. . . . I realized that the reason he’d sent me to Little League tryouts two years before was not to humiliate me. Instead he wanted to show me that if I worked hard, I could play well, just like anyone else. He didn’t want me to use CF as an excuse for not trying or excelling. (Lipman, 2004, pp. 26-27)
Even Panzarino, whose relationship with her mother was so tortured, sees her mother’s communication as a primary source of her ability to define her different self as valuable and deserving of respect:

Mom was the one that consoled me when other kids ran off to play without me or when I spilled food on myself while eating. Sometimes she had no patience for me [but at] other times Mom seemed a pillar of strength. At those times I could lean on her and depend on her for comfort. She interpreted the world to me and helped me learn that I had a place in this world, even if I was different. (Panzarino, 1994, p. 50)

Reflecting on Illness/Disability Identities: Making Peace with Difference

In their narratives, the authors tell of their internal struggles to make sense of and come to peace with their different selves. For example, Rothenberg reflects on the reality of her life with cystic fibrosis and the many profound ways this shapes her identity and separates her from others:

CF is about growing up sick, knowing and facing it your whole life, not about being diagnosed as you would cancer or something else. To me, that’s part of it. Granted, some get diagnosed six months after birth or four years old, but that’s pretty much knowing from birth. It’s weird. . . . I don’t think before now that I really understood how much separates me and the rest. I think of forty as old; others say it’s young. I am living on a day-to-day basis now, while a day to most is a matter of where to meet whomever when, and then how to get there. . . . I will never have the realistic hope of being cured. [My illness] is chronic, like a book that goes on and on. . . . I feel now as if I’m watching details more intently. It’s sort of strange: slowing down my speech and movement. (Rothenberg, 2003, p. 67)

As she contemplates the decision of when she should take the step of undergoing the lung transplant that holds the hope of extending her life, she ponders what this would mean in terms of a profound shift not only in her day-to-day reality, but in terms of her very identity:

I have always said that I would never trade my life for one without CF because of all that CF has given me—relations through the hospital, special dying children
and friends I’ve met, eyes into microcosms that I never would’ve been privy to at such a young age. My lungs are just as much a part of my life as my glasses or my hands. I am the coughing girl. . . . I have spent my life fighting, coping, and then accepting. Now I’m being told not to accept, that I should just say my life is so horrible that I would rather not live at all than live like I will have to live eventually. And it’s hard for me to say that, to admit that I’ve been lying to myself over the years. And I’m not sure that it is that bad. (Rothenberg, 2003, pp. 23, 25)

Five months after receiving the double-lung transplant, having endured the physical misery and agonizing uncertainty of ongoing complications, hospitalizations, and treatments, Rothenberg makes peace with the reality that, even with new lungs, CF will always be part of who she is:

I’ve discovered that the waiting will never stop. I will always be waiting for a scan to come back, a new med to start working, a bed to be available in the hospital. Illness is not leaving my life, though I tried so hard to rid myself of it. But the waiting is the hardest part. Always wanting an answer that no one seems capable of finding because medicine just isn’t there yet. Because I am a work in progress, we are learning with me. (Rothenberg, 2003, p. 132)

Lipman, too, struggles to make sense of and come to terms with his CF. In his story, he characterizes his coming to terms with his illness and its impact on his life as resulting from “hitting bottom”—a moment of crisis when he was forced to face the fact that he had been allowing his illness to completely define him and dominate his life. After a painful period of months of self-pity and self-destructive behavior, during which time he had focused on and internalized all the stigmatizing rejection and devaluation that had been communicated to him by his peers, he reached a turning point when he was forced to face up to the damage he had done to himself:

What had happened to me in the last eight months? How had I faded from the cool and athletic “Flip” to someone so self-hating and timid, so pitiful and despairing? I’d always had a steady stream of friends calling to invite me out or stopping by to talk. I’d chased them all away and retreated further into myself, seeking their pity. Was I any happier? No. Had I made my peace with CF? Not
really. What was I doing? Where was I going? . . . Inside my room, all the rage I’d been feeling for months welled up inside of me. “Damnit! Damnit! Damnit!” I screamed. “What the hell have I done to myself?” I was so enraged that I ripped off my shirt. “I hate myself! I hate myself!” But then I said something that I hadn’t said before or even thought in all those months. I don’t know where it came from. It just sort of erupted from within. “I’m going to change! I mean it! I’m going to change!” . . . I looked at myself in the mirror. A pale, nearly gaunt face with red-rimmed eyes and a sad mouth stared back at me. I knew my face so well, yet this seemed like a stranger’s. I examined myself as though I was strange. Who was this person? I felt a rush of compassion and an urge to help him. Not pity him, but help him out of the hole he’d fallen into. No more feeling sorry for myself, I vowed. . . . No more skipping therapy. No more skipping pills. No more skipping meals or classes. (Lipman, 2003, pp. 102-104)

Lipman tells of resolving to turn his life around, putting himself on a personal improvement program during which he regained good control of his CF symptoms, recovered and surpassed his former athletic abilities, re-built friendships, and formed serious romantic relationships. Lipman accepts that his illness will be a part of who he is and will shape his experiences forever. But, for Lipman, the simple key to making peace with his difference is a positive attitude:

Bottom line: For now, CF remains incurable. But I learned that there’s one thing that can defeat this killer: attitude. It took me nearly 28 years to discover that the more positive I am, the better I feel. The more determined I am to feel better, the better I feel. Sure, there are things like infections I can’t control. But rather than seeing them as doorways to my demise, I accept them for what they are—temporary setbacks, that’s all. It’s all about attitude. (Lipman, 2003, pp. 219-220)

Nixon, too, recalls struggling to make peace with her difference, and, like Lipman, identifies a turning point in her struggle:

My psychologist, Dr. Goodwin, helped me with another difficult period in my life. I disowned my CP. Logically, I knew I still had it, and I knew it was a part of my life, but I didn’t want it to be a part of me. I simply was tired of it. I had been wrestling with this for a while, and one day I was insisting that my CP was separate from me. Dr. Goodwin sharply said, “Wrong!” I was shocked. It was so out of character from his soft-spoken ways. My head was spinning. Wait a minute! I thought. I don’t like this! We continued to talk about it but I was determined that my CP was not going to be a part of me! Later at home, after
much introspection, I reluctantly decided that I couldn’t deny it anymore. My CP is part of my life. It is part of me. I told my mom, “My CP runs my life.” She replied, “Yes. You’re right. It does. But just don’t let it ruin your life. Don’t allow the letter i to be in there.” Mom has a way of saying things to make them stick in my head. (Nixon, 1999, pp. 109-111)

Webb situates her “journey into personhood” within a spiritual framework. In the concluding pages of her narrative, Webb describes her struggle to work out the meaning and purpose of her life and God’s plan for her in a world that repeatedly has thwarted her because of her differences and impairment:

Created by countless frustrations throughout my childhood by my physical inability to achieve what my mind desired, I cast my accumulated wrath on the Great Spirit. . . . If my behavior is really caused by brain mechanisms, am I to blame when I lose emotional control? In calm minutes, I assume responsibility for my actions, but in the heat of anger, I blame my birth injury for my misbehavior. For me this is a never-ending argument between the prosecuting and defense attorneys within me. . . . Eventually I solve the puzzle and recognize that my deep fear and anger originate from rejection by the “big girls” at the New England Institute of Learning. I have never forgiven my tormentors, and so over the years, fear has added its paralysis to the terrible anger aroused by my cerebral palsy. I now realize I have suffered from these emotional wounds all through my learning and working careers. . . . A perplexing question persists in my mind. Why am I brain-injured and subject to perseverating thoughts? My “logical” answer to the query goes like this: Every happening has a cause; because my brain did not receive sufficient oxygen during my twenty-nine hour birth, it did not develop in the same way as in an uninjured child. . . . My long birth changed forever the way my brain and body operate. Why was my birth prolonged? Was it because the doctor was late in arriving or was it God’s will? Neither explanation absolves me of any responsibility for my uncontrolled anger. . . . Some nights I lie awake for many hours thinking of this problem. Words without voice begin to reverberate in my mind. They tell me that I am loved as I am and that the Great Spirit has a purpose for me about which he will tell me when I am ready. . . . The next morning as I awake I hear these words, “Ruth, you must give up being angry at the Great Spirit and at yourself as well as at the persons who have wronged you. When you stop pouring vengeance into your body, you will be freed from the bonds of anger. Forgiving yourself also prepares your heart to receive God’s love.” A week later the voice without words speaks again. . . . These words come into my mind. “Ruth, you have a special mission from the Lord, the Great Spirit. Your mission is similar to that of the man born blind about whom John, the gospel writer, wrote. You, too, are asked to reflect God’s glory in your disabled body. Without knowing your assignment, you have faithfully pursued this mission by
helping everyone you met on your journey. To do this, you need to review the battles you have won. Remember, with each victory, you have taken another step on your journey into personhood.’ . . . I now realize my ongoing journey into personhood has led me along the path of faith. My search for integrity as a person has not only brought yeared for opportunities to give and receive love. In that giving and receiving . . . I have come to know the Son of the Great Spirit. (Webb, 1994, pp. 178-182)

Panzarino depicts her long search for self-acceptance as culminating in her increasing involvement in and commitment to the disability rights movement. Thus, while her narrative strongly expresses the theme of difference as oppression, for Panzarino, proudly proclaiming her identity as disabled and lesbian in solidarity with others is the vital path to integrating her difference into a positive sense of self. At the end of her book, she recalls her presentation at a National Lesbian and Gay Pride March, reiterating for the reader the convictions she proclaimed to her audience:

“I’m proud to be here. Proud that I’m a lesbian, proud that I’m disabled, and proud to like my body. I want to talk to you about ableism. Do you know what ableism is? Ableism is the disease that causes us to hate what’s ‘different.’ It’s what homophobia and sexism and racism are about. . . . We need to stop committing ableism amongst ourselves. Each time you look in the mirror and say to yourself, ‘I’m too fat,’ or, ‘I’m too skinny,’ you are committing ableism. Be proud of your difference. What would a forest be like if every single tree and every leaf were identical? I have seen some very beautiful trees with twisted or broken branches. I’m tired of being ashamed. I’m proud of being a lesbian! And I’m proud of being disabled. . . . I love you all, and I want you to love yourselves and each other.” I felt lifted up into the air by the cheering. I did not feel like a performer, or an act in a sideshow. I felt like a treasured member of a great throng, and we all agreed. (Panzarino, 1994, pp. 259-260)

At the end of her autobiography, Grealy, too, describes finally coming to a sense of peace and acceptance of her different self. She had endured for many months a process that was the most complex yet of the many, many attempts to reconstruct her face. The process entailed going about her day-to-day activities for three months with an implanted tissue expander that gradually ballooned her face in preparation for the numerous
surgeries that followed. As her face became more and more grotesquely huge and misshapen, she became more reclusive than ever. In the end, the long process was “successful,” in that her appearance was improved and the repair did not fail as others had. But Grealy still looked “different”—and, after all her years of growing up disfigured, she continued to feel different and unacceptably ugly. She recalls her response:

Something was wrong: was this the face I had waited for through eighteen years and almost thirty operations? I couldn’t make what I saw in the mirror correspond to the person I thought I was. It wasn’t only that I continued to feel ugly; I simply could not conceive of the image as belonging to me. . . . The only solution I could think of was to stop looking. It wasn’t easy. I’d never suspected just how omnipresent our own images are. I became an expert on the reflected image, its numerous tricks and wiles, how it can spring up at you at any moment. . . . I found I could stare straight through a mirror, allowing none of the reflection to get back to me. (Grealy, 1994, pp. 219-221)

Grealy recalls that she managed to totally avoid seeing her reflection for almost a year.

Finally, she says, she began the journey back to herself. She concludes her story:

One evening near the end of my long separation from the mirror, I was sitting in a café talking to a man I found quite attractive when I suddenly wondered what I looked like to him. What was he actually seeing in me? I asked myself this old question, and startlingly, for the first time in my life, I had no ready answer. . . . I studied the man as he spoke; for all those years I’d handed my ugliness over to people and seen only the different ways it was reflected back to me. As reluctant as I was to admit it now, the only indication in my companion’s behavior was positive. And then I experienced a moment of the freedom I’d been practicing for behind my Halloween mask all those years ago. As a child I had expected my liberation to come from getting a new face to put on, but now I saw it came from shedding something, shedding my image. I used to think truth was eternal, that once I knew, once I saw, it would be with me forever, a constant by which everything else could be measured. I know now that this isn’t so, that most truths are inherently unretainable, that we have to work hard all our lives to remember the most basic things. Society is no help. It tells us again and again that we can most be ourselves by acting and looking like someone else, only to leave our original faces behind to turn into ghosts that will inevitably resent and haunt us. As I sat there in the café, it suddenly occurred to me that it is no mistake when sometimes in films and literature the dead know they are dead only after being
offered that most irrefutable proof: they can no longer see themselves in the mirror. Feeling the warmth of the cup against my palm, I felt this small observation as a great revelation. I wanted to tell the man I was with about it, but he was involved in his own thoughts and I did not want to interrupt him, so instead I looked with curiosity at the window behind him, its night-silvered glass reflecting the entire café, to see if I could, now, recognize myself. (Grealy, 1994, pp. 222-223)

Roney is particularly introspective and articulate in her account of working to make sense of and to peacefully integrate her illness into her identity. Roney’s narrative often explores the ways in which she sees her illness experience as profoundly and inevitably shaping her personality, her relationships, her life. For example, she ponders how her efforts during her college years to integrate her illness smoothly and imperceptibly into her life affected her:

My diabetes became my own secret—I behaved fairly responsibly to it, so that others would never see it. My life, my boyfriends, even the general run of my other companions, I often think, might have been very different if I had not tried to live this dual existence. And yet, I don’t know. My doctor seems sometimes to be of the opinion that this has nothing to do with diabetes, that my personality is in this regard independent of my illness. After all, many people with diabetics marry and have ultra-normal love lives. But how can a condition that affects nearly every tissue and substance in one’s body not shape the personality, albeit differently in every individual, in a back and forth or found and round that is much like the dance of lovers themselves? I feel somehow certain that my personality and my disease have mated and produced this difficult offspring, this confused love child. (Roney, 1999, pp. 193-194)

Roney sees her illness as having set her apart from others, giving her a painful but oddly privileged view of the world that she knows her healthy peers cannot share. She portrays herself as reaching a point where she no longer tries to escape this reality:

It’s strange . . . that in this new solitude I also find an odd familiarity . . . . This turn inward, away from sociability, I realize, happened long ago, but has just now captured my fleeing stride. I have only now, perhaps, turned and embraced a shadow running behind me for years, the aftermath of a strange adolescence, the sentence of an untimely death. How fantastical to know what will be the cause of one’s death when one is twelve! Even if that death is not the one that comes, all
manner of unacceptable prescience comes with the named possibility, all kinds of burdens that one’s peers will understand only when they are sixty, and maybe not even then. (Roney, 1999, p. 229)

Roney explains how she eventually reaches a point where she not only accepts her difference, but embraces it as an essential and valued part of who she is and as providing her with a rich and privileged vision of life that few others can share:

Perhaps there is nothing that can make up for the injustice of a child being stricken by a serious illness. However, there is something else which perhaps replaces that—a gleaming, clear light shed on the world. What it illuminates is not always pretty, but it is true, and in the warmth of that light I begin to cease mourning my long-gone innocence. Now, I understand my difference as a reason for living, dark chocolate as richer than milk and unsweetened mole sauce the tangiest of all. (Roney, 1999, p. 259)

In the final pages of her narrative, Roney speaks of her longing to reveal herself and to share the truths that her illness experience has taught her with all those whose good health has allowed them to deny their flawed and vulnerable human existence. She concludes her story with these words:

Writing about [the isolation of my illness experience] is an attempt to change it, an interim way through this lonely time, a way to make myself visible without taking the bullets directly. Here on the page I can be both myself and my disease, without ignoring the latter or being subsumed by it, without subjecting myself to the fear I evoke in others. But I also want this off the page: to live . . . fully, to be . . . completely known. . . . I abide with that hope, though it often seems to be to an empty room that I say, See? Here I am with all my flaws. See? Others are afraid; I am afraid. . . . Many people accelerate, whooshing in a rush by my kudzu-threatened face, my battered existence. Dear fools, I think to those who flee, leaving me alone in this rich and rigorous silence, you, too, are dying. Would it not be better to mark the interval together, looking at what is really here, seeing others, telling the truth about our bodies, neither so perfect as we might hope nor so horrible as we dread? As the blithe healthy stream by, I wave, rooted here, solid and knowing, waiting for them all to come back this way someday soon. It is a fine, inevitable place. See? (Roney, 1999, p. 297)
Summary

In this chapter, I discussed the findings of the study, presenting the results of my grounded theory study of the eight autobiographies that constitute the data for the study in terms of the thematic, conceptual schema that emerged from the analysis. I began the chapter by providing some descriptive information about each of the eight authors and their texts in order to contextualize their stories and their voices. This was followed by an explanation of the four themes that surfaced and recurred across all of the differing narratives: difference as devaluation, difference as hard reality, difference as oppression, and difference integrated.

In my analysis of the texts, I found that the authors portray their experiences of difference in reference to communication of parents, health care providers, peers, teachers, and others that surrounded them as they grew through childhood and adolescence into adulthood. They all describe and work to make sense of communication that ranged from rejecting, dehumanizing, or abusive to supportive, empowering, and affirming. In keeping with my methodological assumptions and perspectives, each of the four dominant themes was elucidated primarily through numerous representative excerpts selected from the vivid, first-hand accounts of illness and disability that I coded in the analysis.

In the following and final chapter, I present conclusions drawn from the preceding data analysis, and I propose a grounded theory of the communicative construction and meaning of the experience of difference for those growing up with chronic illness or disability. I also discuss practical applications of the research and limitations of the study, and suggest areas for further research.
CHAPTER 5

DISCUSSION

In this chapter, I discuss conclusions drawn from the results of the data analysis, previously presented in Chapter 4. Building on these findings, I propose and explicate a grounded theory of shifting re-constructions of different self. I also discuss practical applications, limitations of the study, suggestions for further research, and offer a final concluding note.

Summary of Findings

The purpose of the study was to gain insight into how those who have grown up through adolescence with chronic illness or physical disability make sense of their experiences of difference in reference to the communication that has surrounded and defined these differences. My aim was to come to a deeper understanding, from the perspective of persons who have grown up with chronic conditions, of the holistic, lived experience of difference in life-long chronic illness or disability and its intersection with communicative practices, especially during adolescence.

The autobiographies analyzed in this study do provide rich and compelling insights into the experience of difference resulting from illness or disability and the communication surrounding these experiences. The grounded theory analysis of the
narratives revealed four overarching themes that emerge in all of the stories: difference as devaluation, difference as hard reality, difference as oppression, and difference integrated. All four themes appear with significant frequency and/or intensity within each narrative, with each author providing characterizations of their experience of difference that are not fixed but, rather, that shift and change across time and in response to a number of factors.

The authors frequently portray themselves as feeling fundamentally devalued as persons as a result of their physical differences and the negative communication surrounding them. They recall at times feeling defective, inferior, ashamed, or ugly. Within this characterization of the illness/disability experience, individuals depict themselves as helpless victims of their physical realities and others’ communication with or about them. They see themselves as overwhelmed, negatively defined, or profoundly diminished by their experience of difference. Others’ negative definitions of them, in conjunction with their experiences of physical suffering, incapacity, and perceived difference from “normal” others, determine their negative, devalued sense of self.

At other times, the authors portray difference as a hard reality that they must endure. They depict themselves primarily as compliantly tolerating and accommodating themselves to dominant cultural norms and attitudes regarding illness and disability. Within this theme, the narratives show their authors as, to some extent, reframing others’ negative communication and their bodily experiences of illness or disability, negotiating their identities and finding ways to adapt and fit themselves into an acceptable “place” within a cultural ideology that they largely have internalized and assume to be natural and inevitable.
A third thematic characterization of the illness/disability experience is that of difference as oppression. Here, the authors’ claim their illness/disability identity, often in solidarity with marginalized others, and their narratives focus on those times when they recognized and actively confronted and challenged negative and discriminatory cultural attitudes toward and treatment of the difference of illness or disability. They resist the limitations posed by their impaired bodies within an inaccessible culture, and they seek or demand accommodations to allow them to fully and equitably participate in society. They portray themselves as critical, assertive, confrontational, proud, and/or defiant, resisting and refusing to be defined by others’ negative communication about them and about illness, disability, and difference generally.

The fourth theme that emerged from the analysis is that of difference integrated. The authors all portray themselves as working in a variety of ways to actively reconstruct their experiences and their identities, integrating their illness or disability into a positive, strong sense of self. They depict this work as being aided by positive, supportive, affirming communication of others. Within this perspective, the individuals’ narratives characterize them as resilient, strong survivors, at peace with their different selves. They accept the vicissitudes of their different bodies, without denying the difficulties they often pose or the need to care for them differently than others might. They accept, embrace, transcend, normalize, and/or value their differences as integral parts of valuable and loveable selves.

Thus, these different thematic characterizations of the experience of difference emerge within the context of communication of important others that ranges from negative and disconfirming to positive and confirming. All of the authors recall
frequently enduring communication of parents, health care providers, peers, and/or others that was rejecting, cold, dismissive, demeaning, malicious, or patronizing. On the other hand, all also recount communication of others that was supportive, respectful, sensitive, empathic, and affirming. The communication of others clearly has had a powerful impact on these individuals’ experiences of difference and their identities as persons with illness or disability. However, it is also clear that the relationship between others’ communication and the construction of these different selves is not simple, straightforward, or deterministic. As important and defining as others’ communication is in the lives of persons growing up with chronic conditions, the analysis of these authors’ accounts reveals that other crucial factors are at work here, as well.

A Theory of Shifting Reconstructions of Different Self

Numerous scholars have theorized about the process by which both the self and the wider culture are formed in and through communication and interaction. Berger and Luckmann’s (1966) social construction of reality, symbolic interactionism’s mind/self/society (Blumer, 1969; Mead, 1934), Dewey’s (1927) pragmatism, Buber’s (1965) concept of the between, all call attention to the dynamic, reciprocal, transactional relationship among communication, self, and society. As stated earlier, my approach to this study assumes and is informed by this general philosophical perspective. What I set out to do through this research was to focus attention on the significance of communication, from this broad perspective, in the context of life-long chronic illness and disability.

The stories that the authors in this study tell reflect a complex, multi-faceted, and dynamic process by which ill/disabled (different) selves are constructed, experienced, and
reconstructed. I propose that this process occurs through the interaction of three shifting components: one, chronically ill or disabled individuals’ communication with and exposure to health/illness/disability-related communication of others around them, including health care providers, parents, and peers; two, the embodied, material reality of illness and disability (e.g., physical impairments, symptoms, medical treatments and procedures, etc.); and, three, individuals’ interpretations and representations of these experiences in their self-talk and in the narratives they present to others, including illness or disability narratives such as the autobiographies in this study.

These three shifting components of different selves continuously interact with one another, each shaping and shaped by each of the others in complex ways. Furthermore, all are situated within a wider context that includes factors such as cultural values, beliefs, attitudes and norms; media messages; structural barriers or accommodations; family structure; economic factors; and many others. All of these contextual factors are also constantly in flux and in a mutually influential relationship with the three central components of constructed selves. Thus, the self that emerges at the intersection of the three central components is continuously co-constructed and reconstructed, changing and shifting over time as the embodied reality of illness/disability, communication of and with others, and individual representations of the experience interact and change both individually and in response to each of the other components and contextual factors. Figure 5.1 provides a theoretical model representing this process of communicative construction of ill/disabled selves, at the center of which is what I call shifting reconstructions of different self.
Figure 5.1: Communicative Construction of Different Self
Shifting Context

While not the explicit focus of this study, a multitude of surrounding contextual factors have an ongoing influence on the ways in which individuals communicate with one another; the physical realities of illness and disability; and individuals’ self-talk, personal stories, and narratives. The social context includes factors such as cultural values and norms (e.g., what are common, widely embraced cultural views of illness and disability?), legal institutions that produce social policies and laws (e.g., what are the effects of the Americans with Disabilities Act and its mandate of accessibility?), art and literature (e.g., how are illness and disability commonly portrayed in various artistic and literary genres?), religion (e.g., are illness and disability viewed as punishment for sin, as evil, as curse, as special challenge and calling?), social/cultural discourse and language (e.g., are disabled persons referred to as defective, crippled, special?), educational institutions, family structures, media messages, economic factors, and many others. Just as the three major components of different selves each are continuously in flux and interdependent with one another, so, too, do the surrounding contextual factors continually shift and influence all other contextual factors. Furthermore, these shifting and interdependent contextual factors influence the communication of important others with or about persons with chronic conditions, chronically ill or disabled persons’ embodied realities, and disabled or chronically ill persons’ own portrayals of their experiences and their identities.

Shifting Communication of and with Others

The narratives in this study show that the authors see themselves as becoming who they are partly as a result of how they have experienced the communication of
important others around them, including parents, health care providers, and peers. All of
the narratives portray ways in which the authors see themselves as having been strongly
affected by others’ communication. Sometimes they recall experiencing others’
communication in their direct interactions with them, while other times the accounts are
of the authors’ observations or awareness of others’ communication about them, about
other disabled or ill persons, or about illness or disability generally. They all describe
communication that ranges from rejecting, dehumanizing, or abusive, at one end of the
spectrum, to supportive, respectful, or empowering, at the other. They explain how
others’ disconfirming communication sometimes (but not always) contributes greatly to
their feelings of devaluation and how, on the other hand, others’ confirming
communication often helps them to integrate their difference into a strong and positive
sense of self.

Shifting Embodied, Material Reality of Disability/Illness

While the communication of important others plays a crucial constitutive role in
shaping the realities and identities of those with chronic illness or disability, the physical,
embodied, material reality of disability or chronic illness also is a vital part of how they
are defined by others and how they experience themselves as different. The authors in
this study all describe experiences of difference at times primarily in terms of the raw,
embodied, material reality of their disability or illness. They deal with physical illness
symptoms (e.g., breathing difficulties, severe and/or repeated infections, insulin shock,
etc.), physical impairments (e.g., inability to walk, speak, sit upright unaided, feed
oneself, etc.), and/or visible disfigurement. In addition, to varying degrees, their different
bodies demand ongoing medical attention in the form of tests, procedures, treatments,
surgeries, medications, and/or dietary or activity adjustments. At times, they describe grappling not only with present symptoms and impairments or those they recall experiencing in the past, but also with physical realities that loom in the future, including increasing impairment, declining health, and/or early death.

The physical, material reality of illness or disability (and, thus, individuals’ sense of self) sometimes is shaped by others’ negative or positive communication. For example, Mercer’s physical condition deteriorated dramatically when the barrage of demeaning messages of her caregivers sent her into a deep depression. On the other hand, Webb attributes the gradual improvements in her mobility and speech throughout her childhood and adolescence to the encouraging and affirming messages of family members and other important persons in her life. Still, the stubborn material realities of illness or disability sometimes dominate these individuals’ lives and their identities and negate the positive, supportive, affirming, normalizing communication of others. Roney captures this reality when she explains,

The separateness [of chronic health conditions] is carried by the absolute individuality of the body, its capacities and limits. Both curse and the necessary condition of survival, both self and not-self, the arcane requirements of illness cannot be shared, often even among those with the same illness. In this way, there are differences from other kinds of marginal communities—gay and lesbian, feminist, Rainbow people, and so on. We, the ill, are dictated to by our bodies, not our minds, and each of us handles it differently, finds different boundaries and balances, with nuances making incredible differences in our lives. In other words, even if illness were generally socially acceptable, or if I filled my life with diabetics, I would still need to retreat every now and then, to sleep my extra fill, to regulate my diet and exercise, and to perform the private rituals of my disease. (Roney, 1999, p. 230)
For persons with chronic illness or disability, then, this kind of embodied reality is a pervasive, inescapable, and defining part of the experience of the different self that distinguishes their experience of difference from others in society who also are viewed as different but whose differences are not a result of chronic illness or disability.

*Shifting Personal Stories, Illness/Disability Narratives, Self-Talk*

Although it is clear that, in significant and powerful ways, individuals’ physical realities and the communication of important others construct/define persons with illness or disability and conceptions of difference, this research demonstrates that individuals are active agents in *re*-constructing and *re*-defining themselves in and through their own internal and external communication. The descriptions of the individuals in this study make it clear that they do not passively absorb and internalize the communication of others, nor are their experiences of themselves absolutely determined by their material realities of illness or disability. Rather, the individuals communicate in ways that are in response, but also often in opposition, to communication of parents, health care providers, peers, and others, and which reframe their embodied realities. Their own self-talk (how they interpret and internally construct their experiences) and how they portray themselves, their own illness or disability experiences, or illness or disability generally, serve to mediate and create meaning of others’ communication and their embodied realities. Through their self-talk and their communication to and with others, including their voices in the autobiographies they have written (all of which are inevitably shaped by others’ communication), they assert themselves as active agents in the portrayal and reconstruction of their experiences and their identities—and in the reconstruction of
others’ perceptions of them and of ill or disabled persons generally. Thus, the authors’ narratives serve as means for both articulating and reconstructing their own and others’ shifting definitions and understandings of the experience of the difference of illness or disability.

This is not to minimize the significant constitutive role of the communication of the individuals and the culture surrounding persons with chronic health conditions. Rather, I argue for attention to the ways in which the experience of difference for persons growing up with chronic conditions is co-constructed in and through communication transactions at every level.

Practical Applications

My hope is that the insights revealed through this study ultimately will have a positive impact on the lives of those growing up with and living with chronic illness and disability. A deeper understanding of the experience of difference for those growing up with chronic conditions and greater awareness of the constitutive role that communication plays in shaping their reality could lead to more sensitive, respectful, and empowering communication on the part of health care providers, parents, teachers, and others.

Health care providers, including especially physicians and personal care attendants, are badly in need of consistent education and training that sensitizes them to the crucial importance of respectful, supportive, and affirming communication with their patients, especially those with chronic conditions. Parents of children with chronic illness or disability need to be provided, early on and throughout their children’s lives, with information and guidance regarding the exceptionally pivotal and complex role of their
own communication and parenting skills for their children’s well-being, as well as encouragement and skills to communicate assertively with health care providers as strong advocates for their children. Consciousness-raising for teachers at all levels regarding the experiences of persons growing up with chronic conditions and the connection between these experiences and communication with teachers and peers can lead to improvements in teachers’ interactions with students with disabilities, as well as improvements in the education of non-disabled students in terms of their ethical and responsible communication with persons with disabilities, illnesses, and other differences.

Insights into the experience of difference for those growing up with chronic conditions and the impact of communication on this experience contribute to our understanding and appreciation of the importance of communication in other contexts, as well. For example, individuals with disabilities or chronic illnesses acquired during adulthood (including age-related conditions) grapple with some of the same issues as the individuals in this study. They, too, are challenged by the embodied, material realities of their illnesses or disabilities—in this case, though, with bodies that, once familiar, healthy, dependable, and “normal,” have now changed dramatically and become unfamiliar, ill or impaired, unreliable, and “different.” These persons also now must interact regularly with and rely upon physicians, personal care attendants, and other health care providers, as well as negotiate the health-related communication of significant others in their lives. Individuals with acquired illness or disability must work out their interpretations, framing, and depictions of their experiences of illness or disability to
those around them. In short, like persons growing up with chronic illness or disability, these individuals must reconstruct their now-different selves in reference to the communication surrounding them.

Limitations

While this study provides significant and useful insights into some of the ways that those who have grown up with illness or disability have experienced themselves as different, the experiences described cannot be claimed to be representative of disabled or chronically ill individuals generally. The experiences of the eight individuals represented in the study may not be typical of others who have grown up with chronic conditions who did not choose or were not able to write their autobiographies and have them published. Persons who are do not feel called to write their stories of illness or disability may experience their conditions and the communication surrounding them as less—or more—defining, constraining, or prominent in their lives. Further research is needed to explore the experiences of persons growing up with chronic conditions more broadly.

In addition, the study was deliberately confined to exploring the commonalities of the experience of difference among persons with varied types of chronic conditions and degrees of impairment, and of a wide variety of ages and backgrounds. As such, the study does not provide information about important differences within difference (e.g., how is the experience of an individual with an extremely incapacitating disability such as severe cerebral palsy different from that of an individual with well-controlled diabetes? How do age and the passage of time affect the ways in which individuals remember, interpret, and construct their experiences of disability and illness?).
Suggestions for Future Research

More research is needed to explore the relationship between communication and the experience of growing up with chronic illness and disability. The present study invites further research that would seek to clarify specific communication practices and experiences that are associated with resilience and the formation of strong, integrated identities in those growing up with chronic health conditions. Further research could take into account the effects of variations in type and severity of disability and variations in family backgrounds, age, etc., as noted above. Future studies also could focus on individuals who have grown up with similar types of chronic conditions but who have not chosen to tell their stories publicly. Research in this area could also focus specifically on the effects on persons growing up with chronic conditions of the communication of one particular group (i.e. health care providers, parents, or peers). Another important and understudied area is that of health care provider-patient-parent communication in the context of chronic health conditions, particularly in terms of the relationship to evolving power issues across time. Finally, the findings in this study could be extended by exploring narratives of other marginalized groups to see what similar and differing themes emerge from their firsthand accounts.

A Final Note

When I first began studying health care communication and chronic conditions as an undergrad, my son Mike was 14 years old. Still ahead of him—ahead of us—were more big health-related decisions, more major surgeries, ongoing encounters with the
medical community, and all of the developmental issues and social, personal, and relational milestones of the high school and college years, magnified because of his physical differences.

In recent months, Mike completed his Master’s degree in Social Work and has launched successfully into a career as a counselor and outreach worker, working with troubled and disadvantaged young people and their families. I cannot think of a better person than Mike for this vocation. He is upbeat, smart, energetic, confident, organized, highly motivated and self-disciplined, and committed to patiently nurturing growth in himself as well as in others. He is much more than accepting and tolerant; he deeply respects and values the diversity and differences among people, even as he continues developing his own convictions, ideals, and identity. Moreover, he is thoughtful, self-reflexive, sensitive, supportive, caring, and empathetic in his interactions with others. He knows firsthand what it is to suffer, physically and emotionally, knows that it is an inevitable part of life that can bring with it insight, depth, and compassion.

Mike says that, while he does not recall experiencing a lot of teasing or rejection during his adolescence and does not focus much on his physical differences, he believes that growing up with these differences and experiencing the impact of the varied communication of health care providers, family members, and others around him did lead him to be acutely aware of and vigilant about the power of the communication of individuals and the surrounding culture, for good or for ill. He says he sees this power daily in the lives of the kids he works with and how they are in many ways defined by positive and negative messages from peers, teachers, parents, social workers, and counselors.
He shared with me a couple of months ago an incident that, in these earliest days of his career as a counselor/social worker, he said “made his week”: the mother of one of his young clients told him that since he’s been working with her son, the boy is a “new person.” Mike didn’t make a big deal about this, but he was clearly, and rightfully, pleased and proud. My fervent wish is that he—and all others who play such important roles in the lives of young people who struggle against daunting odds to positively define themselves and their place in the world—will never take for granted the power of their communication within these roles, and will strive always to use that power carefully, responsibly, ethically, and with love.
LIST OF REFERENCES


