

Through the Looking Glass: Children's Perceptions of Growing Up with Cystic Fibrosis

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Cette étude qualitative, menée selon une approche théorique fondée, examine la vie quotidienne de jeunes en période intermédiaire de l'enfance, qui sont atteints d'une maladie chronique. Un échantillon de 20 enfants atteints de fibrose kystique (âgés de 6 à 12 ans) fut constitué et des entrevues ont été menées auprès de ceux-ci. De ces entrevues s'est dégagé un thème central : les enfants atteints de fibrose kystique au cours de l'enfance moyenne font l'expérience de la différence. À partir de leurs témoignages, quatre éléments communs ont été identifiés : (a) les problèmes de compréhension du diagnostique, (b) les taquineries et le harcèlement auxquels ils sont confrontés, (c) la difficulté d'en parler et (d) la capacité de suivre les autres enfants dans leur fonctionnement. L'étude a conclu qu'il faut axer les interventions auprès des enfants atteints de fibrose kystique sur les exigences psychosociales auxquelles ils sont confrontés tout au long de leur croissance. En orchestrant ces interventions autour des événements significatifs de leur vie quotidienne, nous aiderons les enfants atteints de fibrose kystique à se sentir normaux, dans un contexte où ils doivent se soumettre à une série de traitements. Nous contribuerons ainsi à améliorer leur qualité de vie.

This qualitative study used a grounded theory approach to explore the unfolding of the chronic illness experience for children during middle childhood. A purposive sample of 20 children (6-12 years) with cystic fibrosis (CF) were interviewed. Discovering a sense of difference was found to be the central phenomenon that described the experience of having CF during the middle childhood years. Four central themes emerged in the stories of these children: (a) puzzling out the diagnosis, (b) being teased and picked on, (c) telling others, and (d) keeping up. The study concluded that interventions must focus on the psychosocial demands made on children with CF along their course of development. By designing interventions around meaningful outcomes in their daily lives, we will help children with CF find ways to feel normal while adhering to treatment regimens, thereby helping to improve the quality of their lives.

Over the past two decades, technological advances have dramatically changed survival rates among children with chronic illnesses. Global trends indicate that cystic fibrosis (CF) is the disease for which the change has been most dramatic (Suris, 1995). The median age of sur-

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vival in CF has risen from 14 years in 1969 to slightly over 30 years in 1995 (Cystic Fibrosis Foundation [CFF], 1996). This transformation in the course of CF challenges nurses to identify supportive strategies to facilitate the adjustment of children with CF as they move through childhood and adolescence into adulthood.

CF is the most common (1:3,100) hereditary disease in Caucasian children (CFF, 1996). Its primary manifestations are chronic progressive obstructive pulmonary disease, pancreatic insufficiency, and sweat-gland dysfunction (Ewig, 1997). Lung involvement is evidenced in 90% of children with CF and is the leading cause of morbidity and mortality in the disease. Typically, children with CF have a chronic cough with mucus production, shortness of breath on exertion, diminished exercise tolerance, and such chronic physical characteristics as barrel chest and digital clubbing. There is great variation, according to the severity and progression of the disease, in the intensity and frequency of treatment regimens. An intensive daily regimen involving chest physical therapy and pharmacologic and nutritional management is vital to the maintenance of health.

In two earlier qualitative studies, Christian and D'Auria (1993, 1997) used a grounded theory approach to explore how adolescents and young adults perceived growing up with CF and managed their disease. The youths identified three critical transitions, during childhood and adolescence, in adjusting to CF: (a) the transition from home to elementary school, during which they first experienced the social consequences of having a chronic illness; (b) the transition to early adolescence, when many experienced acute exacerbations of the disease; and (c) the transition to mid- or late adolescence, when they realized that their management of self-care had a direct bearing on the course of their illness. Findings across these two studies identified middle childhood (6–12 years) as a particularly vulnerable period in adjusting to CF. Therefore, the purpose of this study was to explore in further detail the unfolding of the chronic illness experience for children with CF during middle childhood.

Theoretical Perspective

Social ecological theory focuses on the role of settings and contexts in determining children's responses to disease and treatment. Bronfenbrenner's (1989) ecological model of development places the child at the centre of a series of nested rings, and focuses on relationships between the developing child and the environment in which these interactions occur. Children play an active role in determining the responses of

others, and these reciprocal interactions help shape their behaviour and their understanding. Consequently, researchers must address the interplay between contextual influences and children's developing perspectives of chronic illness and treatment (Eiser, 1993).

Middle childhood (6–12 years) is the developmental period in which children enter elementary school and progress through middle school into pre-adolescence. During these years children make significant advances in both cognitive ability and social understanding. However, although their ability to think logically and systematically has increased, during this period children still lack a broad base of knowledge and have had little time to practise new ways of thinking in real-life situations (Sroufe, Cooper, & DeHart, 1996). Nevertheless, by approximately six years of age children are able to use cognition, including memory, to effectively solve problems, begin to put together their "histories of experience" in ways that shape and guide how they relate to others, and begin to consolidate a self-image (Sroufe et al.).

Methods

Design

A grounded theory approach was used to capture children's memories of the chronic illness experience and related life events (Strauss & Corbin, 1990). Subjects were recruited from a regional CF centre in the southeastern United States. Purposeful sampling continued until data saturation or redundancy was achieved, to ensure appropriateness and adequacy of the data (Lincoln & Guba, 1985). Interviews were conducted with 20 children between the ages of six and 12 (mean age 9.1 years; median age 9 years). All 20 of the children were Caucasian; 12 were male and eight were female. All participants had been diagnosed with CF by the age of three years. Informed consent was obtained from parents. The children agreed to participate.

Interview

Children as young as age six are valid and reliable informants when reporting their experiences of daily life stressors and coping ability (Faux, Walsh, & Deatrck, 1988). Therefore, the children in this study were considered experts on what it is like to grow up with CF. It is important to recognize that children's interpretations of what they do differ qualitatively from the interpretations of their parents (Bigelow, Tasson, & Lewko, 1996). The children were asked to visualize what it is like to grow up with CF. We began the interview by having them focus

on their earliest memory, which was explored in depth: the children were asked to describe the memory by telling us what happened, when it happened, why it was important, and how it made them feel. Finally, they were asked what advice about growing up with CF they would give a child newly diagnosed with the disease. Reflection on and paraphrasing of critical events was used to check for data inconsistencies, clarify meaning, and confirm accuracy and credibility of the data (Lincoln & Guba, 1985). Probes were constructed to suggest that other children might feel the same way; questions progressed from concrete to abstract concepts, to accommodate the range of cognitive ability in the sample and minimize social desirability (Faux et al.).

Interviews were conducted by experienced, advanced-practice pediatric nurses who were not members of the CF team. Each interview, which was coordinated to coincide with a clinic appointment, was held in a private room. It ranged from 30 to 60 minutes in duration and was audiotaped for verbatim transcription. At the end of the interview, a life-event line was used to visually represent and validate the children's perceptions of their chronic illness experience. The anchors of the line corresponded to the child's age at the time of the earliest memory of CF and the child's present age. Children under eight years required assistance with spelling, marking, and labelling of critical events along the time line. Field notes were recorded to document personal characteristics, emotional responses, and the conditions for data collection.

Data Analysis

Transcribed interview data were systematically analyzed using the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Investigators checked each transcription against the audiotape to ensure accuracy. Each interview was read several times and a summary of themes for each child was prepared. A process of reviewing major themes; open, axial, and selective coding; and theoretical memos was established for each interview. Codes were compared and contrasted across all interviews and categorized hierarchically. Open coding was used to identify and name major categories, properties, and dimensions of the core category. Axial coding was used to put data back together in a new way by making connections between categories. Selective coding was used to identify the core category and systematically relate it to all subcategories. Textbase Alpha (Tesch, 1993), a qualitative data analysis program, was used for data management and cross-comparative analysis.

Findings

Discovering a sense of difference was the central phenomenon that described children's memories of growing up with CF during middle childhood. Four central themes emerged in the stories of the children: (a) puzzling out the meaning, (b) being teased and picked on, (c) telling others, and (d) keeping up. These stories highlighted the children's struggles to understand CF, deal with teasing, explain CF to peers, and compete on an equal basis with peers throughout the elementary school years. They attempted to integrate others' views of them into their developing views of who they were and who they were to become. The children tried to appear normal in the face of mounting evidence that they were different from their peers.

Puzzling Out the Meaning

Many of the children remembered being told by their mothers at approximately four to five years of age that they had "cystic fibrosis." Because of the cognitive constraints of early childhood, they were puzzled by this new information and were surprised to find that they were not like everyone else.

My mom just took me and sat down on my bed and said, "Son, you got cystic fibrosis. It's this thing that they can't get off of you now, and you're just as good as anybody else. It's just that you got this disease, and you're not like other people." I just thought she must be insane ... because I always thought I was just like everybody else.

These experiences introduced into their lives the idea of a standard and the inherent contradiction that they were normal yet "not like" other children.

Since the majority of the children were diagnosed in infancy, they did not experience a diagnostic period as a beginning point for becoming chronically ill. For these children, entering the world of peers and school marked the beginning of their chronic illness experience. In peer society, they discovered they had perceptible differences. They were confused by the responses of peers to their differences and did not understand the meaning their CF symptoms had for others.

The attempts of the children to puzzle out the meaning of CF were further constrained by their limited understanding of illness causation. The visibility of the CF cough suggested to peers that they were sick and had something contagious. As a result, the CF symptoms jeopardized their social interactions. Younger children (six to nine years) did not understand they were born with CF and thought peers avoided

them because they were afraid of "catching" CF. Although older children understood they were born with CF and that they were not contagious, their peers continued to ask questions about the CF cough and contagion.

Being Teased and Picked On

During middle childhood, children begin to define themselves by the groups to which they belong and to assess their personal ability by making peer comparisons. Children begin to make judgements about their competence in different domains and construct a view of their general self-worth (Harter, 1982). They strive for acceptance by seeking the approval of peers and conforming to group norms, and they come to view themselves in terms of how others view them, which Cooley (1902) refers to as the "looking-glass self."

Learning to cope with negative peer responses to their visible differences was found to be the most stressful event in the daily lives of the children. Their experiences of being teased and picked on evoked painful feelings of embarrassment, sadness, hurt, and anger.

They're picking on me because I have cystic fibrosis, and every time I have to go into the back and spit it out in the toilet they always follow me.... They think I am a weird girl.

They developed fears and anxieties as they anticipated events and the potential reactions of other children to their differences. They were afraid peers would spread rumours about them and not want to befriend or play with them. To make friends, most of the children learned to hide their visible differences by using a "public cough," not taking medications in front of other children, and pacing themselves during physical activities. Some had good friends who knew about CF and accepted their differences, supporting them and protecting them from teasing. However, at times even the good friends "worried about" the children with CF and helped them "too much," which emphasized their differences and resulted in even more teasing.

The children began to realize that others may not always accept them for who they were. Being teased and picked on told them they did not measure up to the standards of peer culture. The children with CF began to incorporate the standards of peer society into their developing identities. They began to view themselves as others viewed them — as different. Over time, they learned to reject the "looking-glass self" created by peer culture and see themselves as normal:

People sometimes don't take you for who you are...knowing that he's a little bit different from other people. That might make him a little bit sad or angry.... He might be worried about kids making fun of him and stuff like that.... Us cystic fibrosis people have the same feelings as everybody else, but other people don't think that.... We're really not different than anybody else because we just have a little problem just like everybody else does.

Telling Others

Coughing and taking medications were the two characteristics of CF that called most attention to their differences. The children remembered being stared at by other children when they had to cough or take medications. Frequently their coughing interrupted class and embarrassed them. Leaving the classroom to take medication made them miss school activities or playground time, or arrive late in the lunchroom. More important, it precipitated questions from peers about why they had left class. Having to explain these differences introduced the need to control information about their illness in the context of school and peers. They changed health behaviours, such as developing a public cough and skipping medications, to avoid having to tell others about CF and thus minimizing the social consequences of being seen as different.

The children were uncertain about how others would identify them and receive information about CF. Moreover, they did not understand CF and had difficulty explaining it to peers, who had the same cognitive and verbal limitations. The dilemma of telling others about CF and the fear of the negative social consequences of the disclosure threatened their ability to form friendships. They worried that peers would spread rumours about them and think they were contagious. To find trustworthy friends, they watched children in the playground: those who played without fighting or teasing were viewed as potential friends. If they became a "good friend," they could be trusted with the secret of CF. However, disclosure involved the risk that the friend might tell others.

I like to tell the people who I really think are trustful. I got some kids at school that you can't really trust. I mean you can tell them, but you don't want no one spreading it — anybody who'll go around telling anybody what you said and everything.

Instead of telling others, they kept secrets, to control how others viewed them. Indeed, when we asked them what they would tell younger children with CF about growing up, they said they would advise them to keep secrets about their chronic illness.

Keeping Up

Being able to participate in activities and being energetic are important to children's developing views of health (Natahoff, 1978). During middle childhood, developing physical competence is the basis for peer comparison (Damon & Hart, 1992). The functional limitations of CF threatened the ability of the children in the study to compete with peers and created new challenges to fit in. The CF symptoms — coughing, shortness of breath, and limited energy and exercise tolerance — highlighted their physical differences. At a time in their lives when athletic performance is used as a standard for comparison and evaluation, these CF differences were magnified and took on added importance. For example, the CF cough drew unwanted attention to them when they tried to participate in sports. However, the most restrictive problem associated with CF was lacking the energy to run as fast as their friends.

In response to their symptoms, many children were teased and began to withdraw and isolate themselves, thereby reducing their opportunity to participate in peer activities. Others learned to pace themselves to control their symptoms and minimize their differences, so peers would be less likely to notice they were different. Children who were able to participate in sports were proud of their physical capabilities. Being physically active allowed them to be viewed as normal, by themselves and others.

Well, nobody really believes that I have CF. 'Cause I don't act like it! But some of them are real sick and they can't run and things and they get out of breath a lot and stuff.... I'll cough and stuff, then I just get back up and just do all these fun things.

Discussion

Although a great deal of research has focused on the adjustment of the parents and families of children with chronic illness, few studies have focused on the children's own perspectives of the illness, and even fewer have addressed adaptation issues relevant to peer society (Eiser, 1993; Kazak, 1992; Thompson & Gustafson, 1996; Wallander & Varni, 1992). The interpretations of children's own perspectives provide a window onto the significance and meaning of events from their point of view (Bigelow et al., 1996).

The children showed tremendous insight as they told their stories of living with CF during middle childhood. Four themes emerged from their stories of discovering a sense of difference: (a) puzzling out the meaning, (b) being teased and picked on, (c) telling others, and

(d) keeping up. Interactions with peers introduced them to the social implications of having a chronic illness. Peers labelled their CF-related behaviours as different, which challenged their views of normality. It is noteworthy that these children focused on their personal experiences in peer society, rarely mentioning other aspects of their lives (i.e., home and family).

Entry into the world of peers and school introduced the children to the social and functional implications of having a chronic illness (Turner-Henson & Holaday, 1995). The first challenge for learning to live with a chronic disease was puzzling out the meaning of the diagnosis. They were uncertain about what the term "cystic fibrosis" means and how it could account for their differences. In addition, their constant cough supported the idea that CF is a contagious disease. The children began to worry about their peers' inaccurate perceptions of their symptoms and inability to accept anyone who appeared different from the norm. They were caught in the difficult position of learning about standards while simultaneously coming to a realization that they did not meet these standards. The distinctions between normal and abnormal depicted the unfolding of stigmatization for the children with CF (Goffman, 1963; Sigelman & Singleton, 1986). The interpretation of other people's responses to a chronic illness is an important component of coming to terms with it (Radley, 1994; Thorne, 1993). For these children, puzzling out the meaning of peer responses was a great challenge, because of their limitations in memory formation, cognitive maturity, verbal dexterity, understanding of illness causation, and social experiences.

The type of social input children receive during middle childhood may affect the quality of their future interpersonal relationships (Buhrmester & Prager, 1995). In this study, negative gossip and teasing threatened the children's ability to form friendships and be effective members of a peer group. Because they were at the same life stage as their peers — experiencing the same insecurities — they began to hide their differences, to obtain social approval and control their self-image. The children were embarrassed about being different and did not know how to deal with teasing and name calling. Thompson (1990) notes that the long-term effects of being teased as children include dissatisfaction with body image, low self-esteem, and depression.

The children worried about being found out and struggled with how and to whom to tell their secret. These data support Eiser's (1993) contention that disclosure of the diagnosis is a difficult issue during childhood and controlling who knows about the diagnosis may help

minimize the impact of the disease. Gallo, Breitmayer, Knafl, and Zoeller (1991) found that siblings of children with chronic illness used similar strategies for concealing and disclosing information. For these children with CF, it was even more difficult to disclose information to peers, who had the same limitations in cognitive ability and social experiences.

Self-disclosure to friends is a self-presentation strategy, to control the image children offer to peers. Early adolescence is a time of heightened concern about self-disclosure (Buhrmester & Prager, 1995). In a recent qualitative study of 10 adolescents and young adults with CF (16–25 years), Admi (1995) found that stigmatizing information was first managed by participants during early adolescence (10–13 years) in an effort to minimize negative reactions. The findings of this study and our two earlier studies with adolescents and young adults with CF (Christian & D'Auria, 1993, 1997) indicate that children as young as six are concerned about negative gossip and disclosure of the CF label; as a result, managing information is a source of intense concern beginning in middle childhood.

Children with chronic illness must cope with stressful situations related to their disease and treatments as well as the interpersonal situations related to managing their illness (Eiser, 1993; Thompson & Gustafson, 1996). Sources of stress for such children include physical and functional limitations, difficulty adhering to treatment regimens, absences from school, social isolation, difficulty making close friends, and limited opportunities to interact with peers (Bennett, 1994; La Greca et al., 1995; Noll et al., 1996; Patton, Ventura, & Savedra, 1986). The children with CF were further set apart by their inability to fully participate in physical activities. They frequently had less energy and became short of breath, or the activity was interrupted by coughing. Each symptom was a visible marker differentiating them from their peers. Indeed, as Loutzenhiser and Clark (1993) found, for children and adolescents with CF exercise is social activity; and because, during middle childhood, physical activity is also a measure of social competence (Harter, 1985) these children had difficulty maintaining peer relationships.

Numerous studies have demonstrated that social competence with peers is a major problem for children growing up with a chronic illness (Breitmayer, Gallo, Knafl, & Zoeller, 1992; Cadman, Boyle, Szatmari, & Offord, 1987; La Greca, 1990). In a review of adherence behaviours across groups of chronically ill children, La Greca (1988) found that treatment regimens that included medications were a major barrier to

adherence. With adherence rates at about 50% for children with chronic illnesses, treatments that interfere with peer activities or disrupt developmental processes are at risk (Thompson & Gustafson, 1996). This study found that being seen taking medications presented a major barrier to adherence. In an effort to minimize their visible differences, many children began to skip taking their medications when at school, thus increasing their chances of social acceptability.

Buhrmester and Prager (1995) note that close friendships protect children from self-presentational concerns and provide a secure context for self-disclosure. During middle childhood, friends provide a way to share similarities as well as differences, to gain peer approval. For these children, finding friends who could be trusted with the secret of the CF diagnosis was critical to their adjustment to chronic illness. The children had difficulty finding peers who shared their differences. They formed friendships by hiding their CF-related differences and pretending to be just like the other children. By focusing on the similarities, they achieved a sense of solidarity with friends (Dunn, 1993), which protected them when they decided to disclose the diagnosis. Thus good friends helped them find a way through the looking-glass of peer society.

Implications

To understand how children with CF think and feel about having a chronic illness, we must understand the developmental constraints of middle childhood and the social demands of peer culture. Children with CF are faced with trying to understand their illness and deal with a complicated treatment regimen at a time in their lives when they are most concerned about being the same as their peers. No child wants to be different, yet the CF symptoms of these children created a sense of difference in their daily lives. They coped by concealing aspects of themselves to project the right image in peer society.

Interventions must focus on the psychosocial demands made on children with CF during their developing years. Interventions should not only promote adherence to treatment regimens, but also facilitate understanding and management of feelings associated with having a chronic illness. Children should be given developmentally appropriate information about CF, including its diagnosis and management, to help them construct their own personal history of CF and the meaning of CF for their lives. Because they have limited social experience in peer society, they need to learn problem-solving strategies and to acquire the social skills necessary to explain CF-related differences to peers, deal

with the differences on a daily basis, and cope with gossip and teasing. Finally, these children require information on how to participate, to the fullest extent possible, in physical activities, so they can form supportive peer relationships and develop a positive self-image. By designing interventions around meaningful outcomes in their daily lives, we will help children with CF find ways to feel normal while adhering to treatment regimens, thereby improving the quality of their lives.

References

- Admi, H. (1995). "Nothing to hide and nothing to advertise": Managing disease-related information. *Western Journal of Nursing Research*, 17(5), 484-501.
- Bennett, D.S. (1994). Depression among children with chronic medical problems: A meta-analysis. *Journal of Pediatric Psychology*, 19(2), 149-169.
- Bigelow, B.J., Tesson, G., & Lewko, J.H. (1996). *Learning the rules: The anatomy of children's relationships*. New York: Guilford.
- Breitmayer, B.J., Gallo, A.M., Knafl, K.A., & Zoeller, L.H. (1992). Social competence of school-aged children with chronic illnesses. *Journal of Pediatric Nursing*, 7, 181-188.
- Bronfenbrenner, U. (1989). Ecological systems theory. *Annals of Child Development*, 6, 187-249.
- Buhrmester, D., & Prager, K. (1995). Patterns and functions of self-disclosure during childhood and adolescence. In K.J. Rotenberg (Ed.), *Disclosure processes in children and adolescents* (pp. 10-56). New York: Cambridge University Press.
- Cadman D., Boyle, M., Szatmari, P., & Offord, D.R. (1987). Chronic illness, disability, and mental and social well-being: Findings of the Ontario child-health study. *Pediatrics*, 79, 805-813.
- Christian, B.J., & D'Auria, J.P. (1993). *Looking back: Perceptions of growing up with chronic illness*. University Research Council Grant. Chapel Hill, NC: University of North Carolina at Chapel Hill.
- Christian, B.J., & D'Auria, J.P. (1997). The child's eye: Memories of growing up with cystic fibrosis. *Journal of Pediatric Nursing*, 12, 3-11.
- Cooley, C.H. (1902). *Human nature and the social order*. New York: Charles Scribner's Sons.
- Cystic Fibrosis Foundation (1996). *Cystic Fibrosis Foundation National CF Patient Registry 1995 Annual Data Report*. Bethesda, MD: Author.
- Damon, W., & Hart, D. (1992). Self-Understanding and its role in social and moral development. In M.H. Bornstein & M.E. Lamb (Eds.), *Developmental psychology: An advanced textbook* (pp. 421-464). Hillsdale, NJ: Lawrence Erlbaum.
- Dunn, J. (1993). *Young children's close relationships: Beyond attachment*. Newbury Park, CA: Sage.

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- Eiser, C. (1993). *Growing up with a chronic disease: The impact on children and their families*. London: Jessica Kingsley.
- Ewig, J.M. (1997). Cystic fibrosis. In R.A. Hoekelman, S.B. Friedman, N.M. Nelson, & H.M. Seidel (Eds.), *Pediatric primary care* (2nd ed.) (pp. 416-422). St. Louis: Mosby.
- Faux, S.A., Walsh, M., & Deatrck, J.A. (1988). Intensive interviewing with children and adolescents. *Western Journal of Nursing Research*, 10, 180-194.
- Gallo, A.M., Breitmayer, B.J., Knafl, K.A., & Zoeller, L.H. (1991). Stigma in childhood chronic illness: A well-sibling perspective. *Pediatric Nursing*, 17, 21-25.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Goffman, E. (1963). *Stigma: Notes on management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Harter, S. (1982). The perceived competence scale for children. *Child Development*, 53, 87-97.
- Harter, S. (1985). *Manual for the self-perception profile for children*. Denver: University of Denver.
- Kazak, A.E. (1992). Social context of coping with childhood chronic illness. In A.M. La Greca, L.J. Siegel, J.L. Wallander, & C.E. Walker (Eds.), *Stress and coping in child health* (pp. 262-278). New York: Guilford.
- La Greca, A.M. (1988). Adherence to prescribed medical regimens. In D.K. Routh (Ed.), *Handbook of pediatric psychology* (pp. 299-320). New York: Guilford.
- La Greca, A.M. (1990). Social consequences of pediatric conditions: Fertile area for future investigation and intervention? *Journal of Pediatric Psychology*, 15, 285-307.
- La Greca, A.M., Auslander, W.F., Greco, P., Spetter, D., Fisher, E.B., & Santiago, J.V. (1995). I get by with a little help from my family and friends: Adolescents' support for diabetes care. *Journal of Pediatric Psychology*, 20, 449-476.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Loutzenhiser, J.K., & Clark, R. (1993). Physical activity and exercise in children with cystic fibrosis. *Journal of Pediatric Nursing*, 8, 112-119.
- Natapoff, J.N. (1978). Children's views of health: A developmental study. *American Journal of Public Health*, 68, 995-1000.
- Noll, R.B., Vannatta, K., Koontz, K., Kalinyak, K., Bukowski, W.M., & Davies, W.H. (1996). Peer relationships and emotional well-being of youngsters with sickle cell disease. *Child Development*, 67, 423-436.
- Patton, A.C., Ventura, J.N., & Savedra, M. (1986). Stress and coping responses of adolescents with cystic fibrosis. *Children's Health Care*, 14, 153-156.
- Radley, A. (1994). *Making sense of illness: The social psychology of health and disease*. London: Sage.
- Sigelman, C.K., & Singleton, L.C. (1986). Stigmatization in childhood: A survey of developmental trends and issues. In S.C. Ainslay, G. Becker, & L.M.

- Coleman (Eds.), *The dilemma of difference: Multidisciplinary views of stigma* (pp. 185–208). New York: Plenum.
- Sroufe, L.A., Cooper, R.G., & DeHart, G.B. (1996). *Child development: Its nature and course* (3rd ed.). New York: McGraw-Hill.
- Strauss, A., & Corbin, J.M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Suris, J.C. (1995). Global trends of young people with chronic and disabling conditions. *Journal of Adolescent Health, 17*, 17–22.
- Tesch, R. (1993). *Textbase alpha manual*. Desert Hot Springs, CA: Qualitative Research Management.
- Thompson, R.A. (1990). Vulnerability in research: A developmental perspective on research risk. *Child Development, 61*, 1–16.
- Thompson, R.J., & Gustafson, K.E. (1996). *Adaptation to chronic childhood illness*. Washington: American Psychological Association.
- Thorne, S.E. (1993). *Negotiating health care: The social context of chronic illness*. Newbury Park, CA: Sage.
- Turner-Henson, A., & Holaday, B. (1995). Daily life experiences for the chronically ill: A life-span perspective. *Family Community Health, 17*(4), 1–11.
- Wallander, J.L., & Varni, J.W. (1992). Adjustment in children with chronic physical disorders: Programmatic research on a disability-stress-coping model. In A.M. La Greca, L.J. Siegel, J.L. Wallander, & C.E. Walker (Eds.), *Stress and coping in child health* (pp. 279–298). New York: Guilford.

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