A chronic illness in adolescence complicates the developmental problems faced by adolescents and makes it difficult for parents to give up their parental role. Illness may jeopardize adolescents’ autonomous development and may place them in danger of becoming fixed in the role of the child. Diabetic Adolescents and Their Families presents an innovative approach to the study of coping with chronic illness by focusing on the developmental context in its description of a longitudinal study of families with a diabetic or a healthy adolescent. Inge Seiffge-Krenke considers perspectives of the ill adolescents, their parents, and the physicians treating them. Highlighted topics include typical stressors, individual and family coping strategies, and psychosocial consequences associated with diabetes. The author also examines the changes that occur in adolescents’ self-concept and body image and analyzes their relationships with parents, physicians, friends, and romantic partners as sources of support and of stress. Numerous case studies illustrate the difficulty of balancing normative development and adherence to the therapeutic regimen. By integrating clinical concerns with fundamental findings of developmental psychology, this book provides a significant contribution to the study of adolescent health psychology.
CAMBRIDGE STUDIES ON CHILD AND ADOLESCENT HEALTH

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Diabetic Adolescents and Their Families

Stress, Coping, and Adaptation

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Several years ago, I was astonished and delighted to discover a European colleague directing a research project which had striking parallels with our longitudinal study of adolescents with a chronic illness. Since the mid-1970s, our research group had been tracking intersections between insulin-dependent diabetes mellitus and adolescent development (Hauser et al., 1997). Begun within the context of a Diabetes Research and Training Center at the Joslin Diabetes Center, we were examining how adolescents and their families coped with the onset and continued presence of this most common adolescent metabolic illness.

Besides the similar questions being asked by both groups, there were the shared assumptions. We assumed it was improbable that all teenagers with diabetes coped in the same ways. Nor did we expect to find that adolescents with diabetes took the same pathway through the complex teenage years. Dr. Seiffge-Krenke’s project and ours also recognized that the lives of these adolescents could not be properly studied unless adolescents’ contexts – family, school, medical setting – were also included. When we first started, most studies in this area had been based on special samples, those children and adolescents who were having serious difficulties adjusting to their illness. Consequently, prominent findings in these earlier studies pointed to psychiatric symptoms and disorders. To consider the possibility of multiple developmental pathways, reflecting varied coping processes, we designed our longitudinal studies to include all boys and girls with adolescent-onset diabetes, assessing competence and dysfunction of the adolescents and their families.

The importance of understanding how individual adolescents and their families are first touched and then “shaped” by the onset of an unexpected
chronic illness cannot be underestimated. Studies of chronic illness from a developmental and psychosocial perspective are so urgently needed because: 1. health care providers cannot offer optimal services to chronically ill children and their families unless they know as much as possible about the experience of similar adolescents and families dealing with a serious chronic illness in one of their children; 2. along similar lines, preventive efforts for those families and children at risk for becoming impaired must rely on understanding when, where, and how the chronic illness and psychopathology become linked; 3. the unfolding of a chronic illness in the life of an adolescent and his or her family provides an incredibly strong opportunity for observing the spectrum of coping processes, family processes, and parent-to-child communications that emerge as a new illness strikes a younger family member; 4. intensive contextual studies of developing adolescents simultaneously experiencing chronic illness can lead to new insights about other adolescent-relevant contexts – school, peer, and close relationship ones; and, 5. the doctor-patient relationship is yet another context that likely influences the coping and meaning of chronic illness for adolescents and their families. Further understanding of this relationship, from a developmental perspective, can spark significant alterations in the treatment of adolescent patients.

Over the past 25 years we have witnessed an increasing number of thoughtful and rigorous studies in this area. In her remarkably comprehensive and well written book, Inge Seiffge-Krenke has given the fields of pediatrics, developmental psychology, and family psychology a major gift. She deftly reports on her own longitudinal study of German adolescents with diabetes, which has consistently included a control group of nondiabetic patients and their families. Preceding reports of her findings, and often woven into discussions of their meaning, she draws upon previous relevant studies of other adolescent chronic illness as well as research targeting specific adolescent dimensions of diabetes. The scholarliness of her work is clear from the book’s bibliography of over 500 entries. She correctly recognizes one can only with caution generalize from diabetes to other chronic illness. She is thus careful to point out the ways in which diabetes resembles and differs from other adolescent chronic illness. Prominent amongst its unique aspects is the fact that diabetes is an almost “silent” illness, making it almost possible for teenagers to completely mask its presence in their lives. Other key features of diabetes, shared with chronic adolescent illnesses, are its need for regular attention to regulating self-care, thereby intensifying central adolescent conflicts surrounding independence, peer relationships, and intimacy.
Embedded in this thoughtful and gracefully written book are several major themes weaving through most chapters, providing important continuity from beginning to end of this rich and inclusive volume.

1. **Categorical and generic views of chronic medical illness.** Many medical colleagues, and perhaps many afflicted families, will be understandably cautious about thinking of all childhood or adolescent chronic illnesses as being comparable. Dr. Seiffge-Krenke expresses a balanced perspective about this issue from the very start of the book. As I allude to above, there are ways in which adolescent medical chronic illnesses can be grouped together, and special characteristics that separate a chronic blood illness from a life-threatening tumor from asthma, seizure disorders, and diabetes. One welcome strength of the book is its excellent recognition and use of multiple contexts in presenting diabetes findings. Discussion of adolescents with diabetes are always preceded by considerations of what is known about a given dimension (for example, adolescent coping) and then by what is known about the dimension with respect to other chronic illnesses.

2. **The importance of a developmental perspective when thinking about adolescent illness.** Many studies of psychosocial aspects of diabetes and other chronic illnesses have been taken from either a psychopathology framework or in terms of behavior management (often assessing and modifying the compliance of family or child in treating the illness). Dr. Seiffge-Krenke convincingly argues for the importance of needing to know the age and other developmental characteristics of a child when trying to make sense of his or her experience, responses, and overall illness management. Across all of the chapters, developmental considerations abound, whether it be about knowledge of the illness, coping with diabetes, or the very complicated question of psychopathology versus successful adaptation.

3. **The place of context.** Beside development, a second theme pervading nearly every chapter is the multifaceted significance of social context. Developmental psychologists, particularly those studying developmental psychopathology, recognize how vital it is to view development “within a continuously unfolding, dynamic, and everchanging context. Increased recognition of the effects of social contexts not only on psychological but also on biological structures and processes has emerged.” Through these comments Dante Cicchetti recently introduced *Developmental Psychopathology and Family Process* (2000), a book targeting many issues dealt with in this volume.
Dr. Cicchetti also recognizes what a challenging endeavor it is to fully incorporate contextual considerations into empirical research concentrating on families and child development. It is to Dr. Seiffge-Krenke’s credit that she steadily maintains an eye on contexts – family, peer, medical – throughout all of the chapters. Context is an especially important idea in her reflections, in the final chapter, on implications of her work for prevention and intervention initiatives. Although the primary context addressed throughout the book is the family, no context is left untouched. Most ambitious is the fact that peer relations ranging from peers to close friends to romantic relationships are considered from conceptual and empirical perspectives.

4. Person-centered versus variable-centered analyses. When collecting and analyzing longitudinal data, a persistent dilemma is whether to organize data around individual people and their unfolding lives (person-centered) or through aggregates of many individuals with respect to one or more dimensions (for instance, coping, friendship formation, characteristics of friendships). Posing this question in such an either-or way is clearly oversimplifying and runs the risk of losing the benefits of each approach. Once again, it is a credit to Dr. Seiffge-Krenke’s balanced approach that we see strong examples of both approaches. To the clinically minded individual, it is almost reflexive to focus on one individual over time – the trajectory of his or her overall adjustment, strengths, self-esteem, peer network indices. Yet, from a social science perspective, even with longitudinal data, there is often a strong inclination to aggregate many individuals together comparing them with contrasting individuals (for example, nondiabetic adolescents versus diabetic adolescents, boys and girls) in terms of a single key variable, such as romantic relationship development or body image. Almost all of the chapters present and discuss analyses based on both approaches. The significance of using a person-centered approach, and the challenge of carrying out such analyses, are well illustrated in two ways in this book. First, we see poignant case examples, summarizing observed specific changes in individuals (and at times their families too). These examples are very informative, as they include interviewer perceptions together with other assessments. Second, Chapter 10 presents interesting and provocative discussions about “pathways” that individual adolescents and their families used as they faced conflicts between having a chronic illness and progressing in their development.

Viewing the problem of psychopathology and competence in terms of developmental pathways rather than psychopathology versus no psychopathology at a given moment of time is a far more enlightening
way to pursue the problematic fundamental question that has lingered over the years in psychiatric and clinical studies of children with diabetes mellitus: Does the onset of diabetes and/or its course lead to psychopathology for all or most children with diabetes? Posed in such a bald and global way, this question has not been readily resolvable. Not surprisingly, answers depend on measurement approaches and samples. Different studies have provided different answers to the question. Through the organizing idea of multiple pathways and contexts, it becomes easier to think about patterns of events (and mechanisms) that can lead to psychopathology, and then think about prevention interventions that may reduce the incidence of unfavorable outcomes.

5. Internal narratives and external observations. Not surprisingly, we view a spectrum of approaches to observing adolescents during the four-year longitudinal study. There are semistructured interviews through which Dr. Seiffge-Krenke obtains internal narrative data about the experience of individual patients and their families. In addition, the research team watched and analyzed families and children communicating with one another. Finally, through repeated use of psychometrically rigorous observations, the research group collected evidence of specific psychological and social processes and their change over a four-year interval. Given the multifaceted nature of diabetes mellitus, individual development, and contextual processes, it was surely a wise decision to use such a theoretically-driven and demanding measurement plan. The reader is helped in all instances by careful diagrams and summaries in each of the chapters.

One more overarching theme characterizes this remarkable book, integrating a vast array of knowledge about chronic illness and adolescent development. Dr. Seiffge-Krenke reminds us, throughout the chapters, of the resilient adolescents – those showing unmistakable signs of competent development, despite the many “anti-adolescent” challenges posed by diabetes. The self-care demands of diabetes often run directly counter to the experiences of adolescence: new autonomy striving, coming to grips with bodily changes of puberty, an expanding social life of parties, outings, and spontaneous adventures. Norman Garmezy (1982) underlines the tremendous benefits associated with understanding resilient children:

... These “invulnerable” children remain the “keepers of the dream.” Were we to study the forces that move such children to survival and to adaptation, the long-range benefits to our society might be far more significant than are the many efforts to construct models of primary prevention to curtail the incidents of vulnerability.
This important volume, through its dual focus on adaptation and problematic adjustment, will take us a long way toward providing more outstanding care, and to informing families of how they may care for their vulnerable adolescents. The most rewarding benefit may be to adolescents carrying a new illness burden, through the conveying of a message about their agency (Bandura, 2001) – that they can construct pathways to well-being despite the challenge of a new vulnerability that has arisen within their own bodies.

References

From a statistical standpoint, chronic illness is uncommon in adolescence. According to German, other European, and other international overviews, only about 10% of all adolescents are afflicted with a chronic illness. In the individual case, however, the onset of a chronic illness in adolescence can become a major stressor, which requires extraordinary coping efforts on the part of the adolescent. Similarly, the additional responsibilities involved in caring for a chronically ill adolescent may become a burden for the parents. Epidemiological surveys have shown that adolescents with a chronic illness are at significantly greater risk than their healthy peers for developing behavioral and emotional problems. Indeed, the onset and progression of a chronic illness exert many negative effects on the developmental processes occurring in adolescence. For example, chronic illness may jeopardize an adolescent’s autonomous development, often to the point that he or she becomes fixed in the role of a child. All adolescents afflicted with a chronic illness, irrespective of severity and duration of the illness, must negotiate a delicate balance between adhering to the medical treatment regimen and following the normal course of developmental progression.

This book is largely based on the results of a longitudinal study of coping processes in chronically ill adolescents that I initiated and led at the University of Bonn, Germany. Although the study focused on one particular illness, juvenile diabetes, the findings are applicable to other chronic illnesses showing similar characteristics and long-term stress. This has been borne out in our efforts to discover which parallels and contrasts might exist between our findings and those obtained through research on other chronic illnesses. In this research, great emphasis was placed on assessing important information about the psychologically relevant aspects of coping.
processes as garnered from the perspectives of those individuals most involved in or affected by the adolescent’s management of the illness, that is, those of the adolescents themselves as well as of their parents, siblings, and physicians. Furthermore, we endeavored to compare these perspectives with those of healthy controls and their families. Consequently, not only do our findings yield much insight into normative development but they also may be considered as paradigmatic for describing adolescent development under illness conditions or even for coping with any severe chronic stressor.

This longitudinal study is ongoing. Here I report the results obtained from four surveys conducted during the adolescent years of our sample, starting in 1991, when the participants were about 13.9 years old, and continuing until 1994, when they were about 16.9 years old.

This intensive research project was supported for over 4 years, from 1991 to 1995, by a grant from the Bundesminister für Forschung und Technologie (BFT Grant No. 0706567) and for 2 years, from 1995 to 1997, by the Deutsche Forschungsgemeinschaft (DFG Grant No. Se 408/10-1). The adolescents belonging to the original sample are currently being investigated as they make the transition to young adulthood (DFG Grant No. Se 408/10-4). It is my pleasure to thank my former research team in Bonn, Annette Boeger, Frank Kollmar, Sonja Fentner, Judith Hanl, Carina Schmidt, and Marcus Roth, who worked with me on this project from 1991 to 1997. They interviewed and tested the adolescents and their families, and Frank Kollmar was particularly helpful in analyzing the rich longitudinal data. During this time, Anette Floss helped greatly with the organization of the study and the management of data. On assuming a new academic position at the University of Mainz, Gerd Nummer helped in completing data collection on the attachment styles of the participants as young adults. Markus Sonntag, Carola Kirchheim, and Martina Hertel helped us to code and analyze the attachment and family coping interviews. Falk Berger, of the Sigmund Freud Institute in Frankfurt, advised us on all clinical and therapeutic matters. Rachel Bond competently assisted me in translating the manuscript, and Linda S. Lewis corrected this updated revision. Hiltrud Kirsch and Tanja Nieder worked through the final version and checked the references. Nicole Wollmerstedt prepared the figures.

Above all, thanks are due to all of the adolescents and their families who gave us so much of their time and energy. Their intensive and continuous cooperation made this research project possible and gave us valuable insight into the processes not only of coping with illness but also into parent-adolescent relationships and developmental processes in general. The low dropout rate indicates that our study offered the participants valuable
The project was an arduous yet extraordinarily worthwhile undertaking, and I am glad we were able to guide so many families through one stretch of their journey. With my new research team in Mainz, I have continued this project and hope to accompany our subjects during their transition to young adulthood.

Inge Seiffge-Krenke
Mainz, March, 2001