Pediatric Self-management: A Framework for Research, Practice, and Policy

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KEY WORDS

adherence, children, family, model, individual, family, community, health care system, influences

ABBREVIATION

SES—socioeconomic status

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abstract

Self-management of chronic pediatric conditions is a formidable challenge for patients, families, and clinicians, with research demonstrating a high prevalence of poor self-management and nonadherence across pediatric conditions. Nevertheless, effective self-management is necessary to maximize treatment efficacy and clinical outcomes and to reduce unnecessary health care utilization and costs. However, this complex behavior is poorly understood as a result of insufficient definitions, reliance on condition-specific and/or adult models of self-management, failure to consider the multitude of factors that influence patient self-management behavior, and lack of synthesis of research, clinical practice, and policy implications. To address this need, we present a comprehensive conceptual model of pediatric self-management that articulates the individual, family, community, and health care system level influences that impact self-management behavior through cognitive, emotional, and social processes. This model further describes the relationship among self-management, adherence, and outcomes at both the patient and system level. Implications for research, clinical practice, and health care policy concerning pediatric chronic care are emphasized with a particular focus on modifiable influences, evidence-based targets for intervention, and the role of clinicians in the provision of self-management support. We anticipate that this unified conceptual approach will equip stakeholders in pediatric health care to (1) develop evidence-based interventions to improve self-management, (2) design programs aimed at preventing the development of poor self-management behaviors, and (3) inform health care policy that will ultimately improve the health and psychosocial outcomes of children with chronic conditions. *Pediatrics* 2012;129:e473–e485

In the past 2 decades, the rate of chronic conditions among children has doubled.[1] It is estimated that 13% to 27% of children in the United States have an existing chronic condition (eg, asthma, diabetes, epilepsy, end-stage renal disease, inflammatory bowel disease) that requires ongoing treatment and, consequently, self-management.[1–5] Advances in pediatric medicine have resulted in medical interventions that effectively treat a wide range of previously intractable conditions. As a result, children with chronic health conditions and their families are responsible for managing multicomponent treatment regimens that can include the administration of medication, dietary prescriptions, obtainment of laboratory work, lifestyle modifications, and attendance at routine clinic appointments with a variety of health care professionals. For example, treatment regimens that were solely provided in hospital settings only a decade ago, such as intravenous antibiotics for cystic fibrosis, are now managed within the home environment by families.[6] These medical treatment regimens, which can be complex, intrusive, and time consuming, place substantial burden on families who are already negotiating the typical activities and developmental challenges of childhood (eg, going to school, developing peer relationships).

Effective management of these treatment regimens is difficult at best. It is well documented that adherence (ie, the extent to which a person's behavior coincides with medical or health advice) to treatment regimens is less than optimal.[7–9] Nonadherence affects 50% to 75% of children and adolescents with chronic conditions.[9] In contrast, self-management is the interaction of health behaviors and related processes that patients and families engage in to care for a chronic condition. Although these are separate constructs, they are interrelated in that nonadherence can be a result of poor self-management. Ineffective self-management behaviors reduce the potential benefits of treatment and increase the likelihood of adverse health outcomes, making interventions to improve self-management a high priority. The advent of new technology and rigorous validation of self-management and adherence measures have facilitated researchers' and clinicians' understanding of self-management and adherence in pediatric and adult populations.[10–13]

The importance of understanding and promoting self-management in the care of pediatric chronic conditions is becoming increasingly apparent, not only through research and clinical efforts, but also through the introduction of new health care policies. California recently instituted a law that requires health maintenance organizations to expand coverage for self-management education programs for children with uncontrolled asthma and children with active asthma symptoms.[14] Such expansion efforts (10%) are expected to require minimal health care expenditures and result in substantial reductions in hospitalizations (21%–22%) and emergency department visits (4%–11%).[14] In addition, the National Institutes of Health and Office of Behavioral and Social Sciences Research[15] have prioritized the need to examine and promote self-management behaviors in pediatric populations through recent Requests for Applications and Program Announcements. These new policies demonstrate an increasing need to develop comprehensive pediatric self-management models that can be used for research, clinical care, and state and national health care policy. To better understand the importance and impact of self-management behavior on health outcomes and to design effective intervention and prevention models for pediatric chronic conditions, a novel conceptual framework is needed that addresses the complex systems within which pediatric self-management occurs.

Our primary objective is to propose a comprehensive pediatric model of self-management. A pediatric self-management model is necessary for several reasons. First, previous models are condition-specific (eg, diabetes[16]) or do not include the multiple systems in which the child lives.[17,18] Second, existing models are further complicated by interchanging critical terms such as self-management and adherence, which are related but not identical. Our model explicitly defines these terms. Third, adult self-management models cannot be effectively translated to pediatrics, because they do not account for the effect of the larger family system, such as caregivers and siblings, on self-management behaviors. For example, the parent-child dyad likely involves a reciprocal process, in which caregiver functioning impacts child functioning and vice versa.[19] Furthermore, developmental factors that impact self-management (eg, ingestion difficulties among young children, children transitioning into adolescence and adulthood) have not been accounted for within a pediatric self-management model.[20] Finally, technological and medical advances, as well as social media,[21] which are increasingly used by pediatric patients, must be considered in a truly contemporary pediatric self-management model. We propose a comprehensive pediatric self-management model that clarifies the mechanisms and processes that influence self-management, adherence, and ultimately children's health outcomes. We provide a coherent, unified conceptual approach that will enable stakeholders in pediatric health care to (1) develop evidence-based interventions to improve self-management, (2) design programs to prevent the

development of poor self-management behaviors, and (3) inform health care policy that will ultimately improve the health and psychosocial outcomes of children with chronic conditions.

DEFINITIONS

The term "self-management" encompasses a broad spectrum of behaviors across a wide variety of patients and conditions. It is often used interchangeably with terms such as "adherence" and "compliance." Consequently, lack of consensus and potential misuse of terminology has led to the development of several definitions of self-management. These definitions range from complex, which specify various types of activities and aspects of health, to parsimonious, which require subjective interpretation.[22–25] These definitions are vague or, conversely, too restrictive to apply across patients, conditions, and settings. Not surprisingly, no 1 definition has been universally accepted and applied in research and/or practice. Furthermore, these definitions have also been primarily conceptualized within an adult health care framework and have very limited applicability within the pediatric health care system. With these issues in mind, we propose a definition of self-management that is straightforward and generalizable, and that accounts for the familial context in which pediatric self-management occurs.

Self-management: The Interaction of Health Behaviors and Related Processes That Patients and Families Engage in to Care for a Chronic Condition

Importantly, this definition presents self-management as a neutral concept. That is, efforts to manage one's condition can either positively or negatively affect health outcomes, which are not always anticipated. This definition is also condition-oriented (ie, it does not apply to general health promotion in the absence of a chronic medical condition, such as exercise and dietary habits in healthy individuals) and is treatment-focused (ie, does not focus on the prevention of negative health events).

Adherence has also been defined in several ways,[26,27] although most definitions are extrapolations of Haynes' definition,[28] which is "the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice." Haynes[28] captures the essential aspects of adherence as defined in behavioral terms and refers to a correspondence between health care providers' recommendations and patient behavior. Moreover, the Haynes definition is broadly applicable to pediatric adherence. The only restrictive component of this definition is the parenthetical reference to medication, diet, and lifestyle changes. We propose a slightly modified version of Haynes' definition of adherence that excludes this component and is more general.

Adherence: The Extent to Which a Person's Behavior Coincides With Medical or Health Advice

This definition suggests that adherence refers to behavioral correspondence with direct prescriptions, medical recommendations, and/or advice from health care providers. This underscores the fact that adherence is socially constructed and would not exist without an interchange between patients and providers, and indicates the degree of correspondence between self-management and medical advice. Thus, qualifying terms are commonly used, such as poor or perfect adherence, as well as nonadherence. We encourage users of these terms to clearly define them in case reports, manuscripts, and grants.

Adherence has been operationalized in several ways, including cutoff scores (eg, >80% = good adherence), an index of overall adherence based on multiple indicators (eg, appointment keeping and medication taking), and adherence frequency for each treatment component prescribed. Because most conditions have not identified optimal levels of adherence needed for the best health outcomes, with the exception of 95% adherence for HIV treatments,[29,30] the use of cutoff scores (eg, 50%, 80%, or 95%) is arbitrary. We advocate for calculating adherence frequency scores for each treatment component prescribed for the child because it facilitates the examination of rates and patterns of adherence with the same individual (ie, diet versus oral medications), between individuals with the same condition, and between individuals within different conditions. Adherence frequency is defined by the number of treatments performed each day divided by the number of treatments prescribed and multiplied by 100 to determine percent adherence (eg, percent of prescribed antiepileptic drugs taken each day) and should be used in clinical and research practice.

COMPONENTS OF SELF-MANAGEMENT

Our conceptualization of self-management contains 3 interdependent parts, represented by the circle in the left part of Fig 1: self-management behaviors (center of circle), the contextual variables across 4 domains (ie, individual, family, health care system, community influences) that impact the execution of those behaviors, and the processes (inner ring of circle) that link influences (outer 2 rings of circle) with self-management behaviors (see Table 1).

Self-management behaviors, which are conducted by a child or family member,

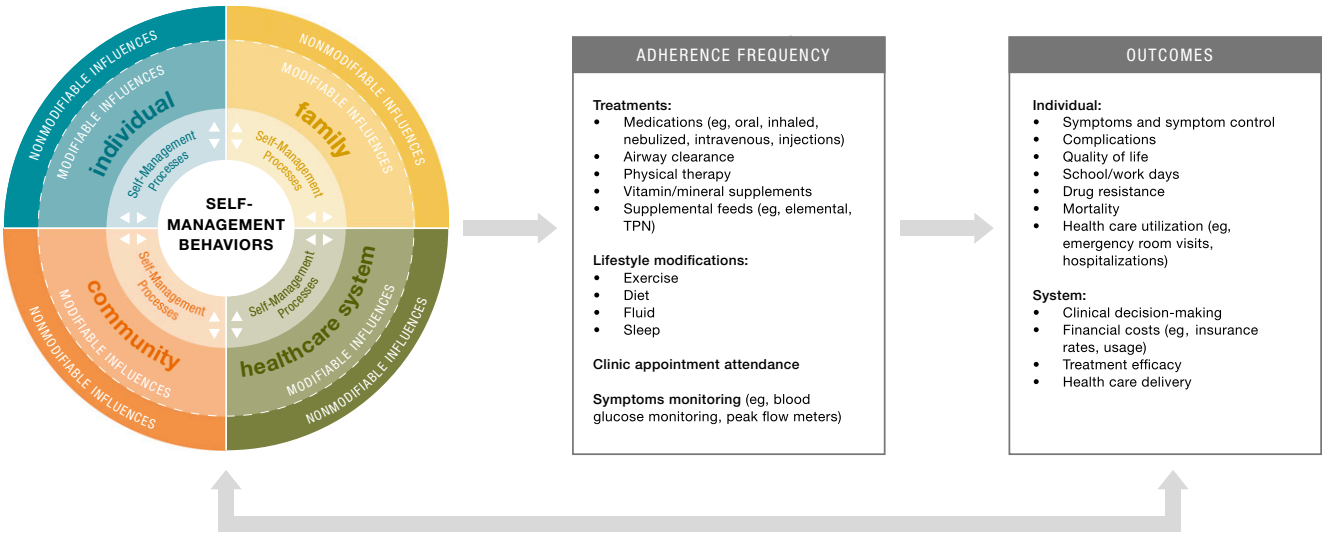

FIGURE 1
In the Pediatric Self-management Model, self-management behaviors (pictured left) operate within individual, family, community, and health care system domains. Modifiable and nonmodifiable domain-specific influences impact self-management through underlying cognitive, emotional, and social processes. The degree to which self-management behaviors affect adherence, and ultimately outcomes, may result in changes in self-management behaviors.

are performed in the context of care for the chronic condition. This does not assume positive or negative impact, only that the behavior was conducted for the purpose of treatment. Self-management behaviors occur across 4 domains: individual, family, community, and health care systems. Examples include an adolescent taking prescribed oral medication to treat type 2 diabetes (individual); a young child with cystic fibrosis and his mother jointly performing chest percussion therapy (family); a young adult using social networking to discuss the "likes and dislikes" of having a particular chronic condition (community); and a parent discussing with his insurance company the possibility of getting a new technology (eg, new blood glucose meter) approved for the child's use (health care system).

As with self-management behaviors, self-management influences and the related processes can occur within each of the 4 domains. In the 2 outer rings of the circle, influences are the contextual variables from those 4 domains that promote or detract from the conduct of health behaviors. Our conceptualization of these influences is in line with Ecological Systems Theory[31] in that the microsystem (individual influences) touches the mesosystem (family and community influences) and is broadly based in the macrosystem (health care system influences). Our model designates influences as modifiable or nonmodifiable, meaning that, with intervention, some can be changed (eg, psychological symptoms, treatment regimens) whereas others (eg, disease duration, age) cannot.

There are critical, related processes linking self-management behaviors and the variables that influence them. In 1 of the first models of processes related to self-management, the Health Belief Model[32] highlighted that health behaviors are influenced by the individual's perception of their appropriateness, utility, and potential impact on health. Individual perceptions, cognitive, emotional, and social processes link influences to self-management behaviors.

Each domain described below provides examples of influences and related processes involved in the ultimate execution (or omission) of a health behavior. Within each domain, the child's developmental level may differentially impact how influences and processes manifest. For example, parental involvement in cystic fibrosis management will differ for a young child (eg, administering daily nebulizer treatments) compared with an adolescent (eg, providing reminders for daily nebulizer treatments).

Individual Domain

Nonmodifiable individual influences include age, gender, and cognitive ability. Notably, self-management tends to deteriorate with increasing age, from childhood through adolescence.[33–37] Gender is less clearly linked with self-management, with approximately equal findings for poorer adherence in each gender.[38–40]

Adherence is compromised when self-management responsibilities outweigh a youth's intellectual capacity or maturity level.[41] These issues likely influence self-management through cognitive processes, such as executive functioning or memory, which can interfere with one's ability to manage and successfully execute complex treatment regimens.[42–45]

TABLE 1 Examples of the Influences, Processes, and Behaviors of Pediatric Self-management

Domains	Influences		Processes	Behaviors
	Nonmodifiable[a]	Modifiable		
Individual	• Age • Gender • Developmental level • Cognitive functioning (eg, IQ) • Sociocultural factors (eg, race/ethnicity, SES, religion)	• Disease and treatment knowledge • Child internalizing/ externalizing symptoms • Coping style • Health beliefs and perceptions (eg, self-efficacy, perceived stigma)	• Determining health care needs • Seeking disease- and treatment-related information • Communication with the medical team	• Taking medications or treatments • Attending clinic appointments • Refilling prescriptions • Self-monitoring of symptoms • Lifestyle modifications • Behavioral compliance with parental instructions and medical procedures • Self-care (eg, dressing changes) • Health care utilization
Family (eg, caregivers, siblings, extended family)	• Parent marital status • Family structure • Cognitive functioning (eg, IQ) • Insurance coverage • Income • Education • Sociocultural factors (eg, race/ethnicity, SES, religion)	• Disease and treatment knowledge • Family internalizing/externalizing symptoms • Family coping style • Health beliefs and perceptions • Family functioning • Relationship quality • Parental monitoring and supervision • Parental involvement	• Determining child's health care needs • Seeking disease- and treatment-related information • Allocation of treatment responsibility • Behavioral management (eg, reinforcement) • Management of stress, physical, and psychological functioning within the family • Communication with the medical team	• Giving medications or treatments • Attending clinic appointments • Refilling prescriptions • Monitoring of symptoms • Supporting lifestyle modifications • Parental support and supervision of treatments • Providing access to recommended therapies (eg, nutrition, physical activity) • Sibling/extended family support and behavioral compliance with parental requests • Respite care • Health care utilization
Community	• Neighborhood • Availability of health and wellness resources within communities and schools	• Peer support • Social stigma • School-based accommodations related to health • Availability of social networking	• Learning about patient's disease and treatments • Degree of social acceptability of disease • Provision of support for treatment regimens • Collective beliefs • School reintegration	• Provision of support for treatment regimens • Engagement in patient's disease-related activities (eg, camps) • Use of social networks • Community support
Health care system	• Availability of health care resources (eg, access, health insurance)	• Patient-provider communication • Frequency of clinic visits • Medical training models	• Modification of communication styles • Shared decision-making	• Patient advocacy • Legislation/health care reform • Health care provider training in sociocultural factors

[a] Nonmodifiable factors are defined as those that are not typically targeted in intervention but may be used to target subgroups for intervention or stratify intervention samples.

Other cognitive processes, including treatment knowledge and literacy, have also been implicated in treatment adherence.[46–48]

Several individual characteristics linked to self-management are modifiable. Psychological and behavioral problems demonstrate robust relations with worse self-management across many chronic conditions.[49–53] Emotional processes associated with ineffective self-management include poor adjustment to the disease and its management and coping with life stressors.[54] For example, depressive symptoms can disrupt self-management via decreased motivation to carry out tasks or diminished attention and concentration skills. Interventions to treat depression in youth with chronic conditions may thus lead to improvements in self-management and health status. On the other hand, positive characteristics such as optimism, hope,[55,56] and better coping skills[57] are related to enhanced adherence and health status. Adaptive health beliefs, including self-efficacy, internal locus of control, and confidence in the utility of treatments, are also associated with better self-management[54,58,59] and are potential targets for intervention.

Family Domain

Single parenthood is a primary nonmodifiable family structure factor consistently associated with poorer self-management.[60–62] These families may have less support or fewer resources to effectively execute the multiple components of chronic condition care.[61,63] In connection with this lack of resources, family socioeconomic status (SES) is often associated with health disparities, with families reporting lower income and public (or no) insurance coverage evidencing poorer adherence and health status than those with higher income and private insurance.[64–67] Racial and ethnic minority status are also associated with poorer health outcomes, which may be confounded with SES.[47,68,69] Other explanations include underutilization of health care services or poorer patient-doctor relationship quality.[70]

Modifiable family influences include caregiver involvement and family interaction variables that support illness management. Increased parental involvement and monitoring are associated with effective self-management[53,71–75] and become increasingly salient during adolescence. Although research typically involves mothers, greater paternal involvement in chronic condition management may also facilitate better self-management outcomes,[76,77] as well as benefits for maternal caregiving.[75,78] Parental psychological symptoms (eg, depression and anxiety[79–81]), parenting stress, and caregiver burden[82–84] can compromise self-management, but factors such as higher health literacy[85] and perceived social support[86] can promote better self-management.

Finally, poorer general family functioning and greater family conflict hinder self-management behaviors and health status,[84,87,88] whereas greater family cohesion, support, efficacy, and flexibility are associated with more effective self-management.[89–93] These family environment influences occur through key interactive processes among family members. For instance, family communication is a critical factor in effectively problem-solving and negotiating disease management tasks. Clear allocation of responsibility for regimen tasks is associated with effective self-management and improved adherence.[94] Interventions to reduce conflict and improve family communication demonstrate improved adherence rates and health outcomes among adolescents with type 1 diabetes,[95,96] and may also be beneficial for other conditions.

Community Domain

Individuals and families manage chronic conditions in the context of broader community domains that include schools, peers, neighborhood organizations, and interpersonal networks that are not geographically constrained. Although children and adolescents spend a great deal of time within these communities, relatively little research has examined their roles in self-management.

School influences, such as school personnel training and policy, require modification on a systemic level. Limited staff/teacher knowledge about the chronic condition, unhealthy food options, and school policies that conflict with management needs are barriers to optimal health care.[97–100] Furthermore, families' unfamiliarity with relevant laws and policies[99] or experience with illness-related stigma[101] can impede self-management efforts at school. For example, families may request 504 plans (accommodations that aid a student with a documented medical condition to perform comparably to same-age peers) to ensure that disease management is adequately supported. Children's negative expectations and perceptions about support from teachers have been linked with worse health outcomes.[102] However, school-based programs to support students' management of chronic conditions can enhance self-management and may lead to symptom improvement.[103] Participation in other community organizations, such as health-promotion summer camps[104] or church and community youth groups, may also positively influence self-management and health outcomes.[105]

Social influences, such as the quality and supportiveness of peer relationships, particularly among adolescents, can play a role in pediatric self-management.[93,106,107] This reflects a developmental shift from parental

influences to peer relationships during adolescence.[108] However, youth may underuse peer support for self-management because they do not wish to draw attention to their illness.[109–111] Moreover, there is some evidence that extreme orientation to peer relationships detracts from adherence.[112] Furthermore, children perceive social interactions differently, and their perception of the acceptability of health behaviors in social situations can influence whether those behaviors are executed appropriately. For example, adolescents with type 1 diabetes may be less likely to check their blood glucose levels around friends if they feel embarrassed or self-conscious. On the other hand, receiving disease-related support from friends can buffer fears of stigma and self-consciousness and promote adherence.[93]

An emerging area of self-management research is online communities and social networking. Online communities and social networking allow patients and their families to connect with others who have a chronic illness but are geographically distant. Cantrell et al[113] have started examining the potential benefits of participating in a virtual mentoring program for adolescent transplant recipients.

Health Care System Domain

Compared with the proximal influences and processes discussed above, macrosystem influences on self-management have received less attention. However, some nonmodifiable health care system level influences have a clear relationship with self-management. Racial and ethnic minorities tend to be underrepresented in clinical research, resulting in fewer culturally tailored, empirically supported treatments and potentially less relevant prescribed care.[114–116] Clinically, non–English-speaking patients who are not provided with professionally trained medical interpreters have poorer understanding of prescribed treatments, which limits their ability to complete self-management tasks accurately.[117] Increased efforts to improve training in sociodemographic and cultural issues, as well as access to medical care and professional interpreters,[118–121] have demonstrated short-term improvements.[122]

Modifiable macrosystem influences may also impact self-management, adherence, and health outcomes. The physical environment in which health care is received (eg, room and medical floor configuration, average bed occupancy) can impact medical staffs' functioning and perception of care quality,[123,124] as well as patient-reported quality of life.[125] The clinical practice environment may be especially important because staff work-related satisfaction is associated with patient-perceived quality of care.[126]

Effective conversations between families and medical staff are critical for the collaborative problem-solving of barriers to self-management and adherence in pediatric chronic conditions. Important variables that impact how families manage chronic conditions include (1) expectations about what is appropriate to discuss, (2) the degree to which the discussion is perceived as a team approach instead of 1-sided instruction, and (3) general fit between the patient and provider.[127] Family-centered rounds are generally defined as interdisciplinary work rounds occurring on an inpatient floor and at patients' bedsides.[128] In pediatrics, the patient as well as his or her parents and family are considered key contributors to the health care process, reflecting the policy set forth by the American Academy of Pediatrics, which recognized the need for collaboration with families as standard care.[129] As such, family-centered rounds may improve communication and shared decision-making between families and providers, while offering new learning for residents and trainees.[130] Families report improved understanding of their child's care and increased feelings of respect and satisfaction with participation in family-centered rounds.[131] Similarly, providers report improved team communication, trainee role modeling, and increased family involvement,[132,133] all factors that could contribute to successful self-management of a pediatric chronic condition. Time constraints are potential barriers to implementing effective family-provider communication. However, 1 study found that family-centered rounds only required an additional 2.7 minutes than conventional rounds.[129] Each of the factors mentioned here may influence how patients and their families perceive health care information and experiences, and thus enhance family-based chronic care and self-management.

Health care system factors are often seen as nonmodifiable. Yet, the above findings highlight that changes to the practice environment and patient-provider communication are both necessary and manageable. The authors' own research and clinical efforts focus on enhancing the health care system by providing psychosocial screening in medical clinics to promote self-management and training for subspecialty providers to improve shared decision-making and adherence at the point of care. Others have even involved children in assisting in the design of pediatric health services.[134]

DISCUSSION

Based on extensive empirical evidence, we developed a comprehensive model of self-management that is clinically relevant and generalizable across a wide range of pediatric chronic conditions. One key feature of this model is the distinction between self-management and treatment adherence as targets

of clinical intervention. This model focuses on self-management processes as targets of intervention, because they influence treatment adherence in clinically relevant ways. For example, self-management processes, such as decision-making, are clinically relevant targets of intervention that influence treatment adherence. Previous models have focused on individual influences on self-management in adults with chronic conditions.[135] Our model focuses on pediatric chronic illness and emphasizes multiple, interlocking influences across individual, family, community, and health care systems that are critical to support and sustain self-management and treatment adherence across multiple developmental transitions.

This model has unique implications for clinical care, research, and policy. With respect to clinical care, our model guides the design, selection, and implementation of targeted interventions that promote adaptive self-management and effective treatment adherence. The proposed model informs strategies of primary prevention to promote adaptive self-management and prevent nonadherence, as well as secondary prevention focused on self-management problems that disrupt treatment adherence and threaten children's health and well-being by causing symptoms and illness-related complications.

This comprehensive self-management model facilitates the design and implementation of clinical interventions in several important ways. First, our model distinguishes between (1) modifiable influences (eg, risk and resilience factors) on self-management that are most amenable to change and are the most clinically relevant targets of intervention, versus (2) nonmodifiable influences (eg, genetic influences, gender, economic status) that are much less responsive to change but moderate the impact of self-management interventions. For example, clarifying the moderating influences of variables such as SES on intervention outcomes can be a more effective strategy than controlling for the effects of SES, which can obscure important influences on self-management. Second, our model emphasizes the importance of multiple evidence-based targets to achieve the most powerful and sustained effects of self-management promotion on treatment adherence and clinically relevant health outcomes. Based on available evidence, individual level self-management promotion will be most effective by targeting clinically relevant emotional processes (eg, depressive affect[136]), cognitive processes (eg, adaptive problem solving and planning[137]), social processes (eg, peer influences[138]), or behaviors (eg, self-monitoring and reward[139]).

Although interventions that focus on individual processes enhance self-management, they may not be sufficiently powerful to support and sustain self-management and positive treatment adherence over the long-term course of chronic illness management.[140] This is because patterns of adaptive self-management are either reinforced or disrupted by powerful, chronic influences that are present in many different situations. For this reason, interventions focused on improving family communication, routines, and involvement have been shown to be effective in promoting effective self-management and treatment adherence.[33,95,140,141] Sociocultural influences also can have an extraordinary impact on patterns of self-management. For example, there is emerging evidence for efficacy of interventions that reduce sociocultural barriers to self-management by improving access to medical care, enhancing family resources, and utilization of medical care.[142,143]

Finally, our model and recent research underscore the importance of health care systems to implement effective pediatric self-management promotion by provider-guided collaborative chronic illness management.[144] The following steps of a provider-based model of self-management are closely aligned with the proposed self-management model.[135,145] These steps include: (1) access (to self-management support), (2) advise (eg, provide information about facilitating self-management by addressing key barriers), (3) agree (eg, establish collaborative provider-family–based goals to enhance self-management), (4) assist (eg, implement support for self-management behavior), and (5) arrange (eg, monitor self-management in follow-up, address salient barriers, and make necessary referrals).

To implement innovative, empirically supported models in pediatric chronic illness care, providers would benefit from new methods of training and support. Programs that train and support providers' listening skills and collaborative goal setting and help them to implement ongoing review and modification of self-management plans have been shown to facilitate self-management across a range of chronic conditions.[144,146,147]

The comprehensive systems-based approach to promote pediatric self-management advocated here should be supported by innovative health care policies. Clinically relevant policies include reorganizing the delivering of pediatric chronic illness care to focus on self-management promotion[148] and enhancing reimbursement for comprehensive self-management.[148,149] Reimbursement for self-management education for diabetes educators under Medicare is an example of 1 such policy.[150] Although such creative financing strategies for chronic illness are unusual, they may have extensive long-term benefits. Promoting access to preventive self-management has

extraordinary potential to save substantial costs to the health care system by reducing preventable health care utilization and illness-related morbidity, especially complications that are directly attributable to problematic self-management and nonadherence.[26,148,149,151]

Our review has indicated a number of critical gaps in scientific knowledge that set an agenda for future research. Studies of the impact of sociocultural and health care system influences on patterns of self-management, treatment adherence, and relevant health outcomes are underrepresented and very much needed. Documenting the levels of adherence for specific self-management behaviors that influence symptom control and other important health outcomes is another important need for future research.[152] Research on the comparative effectiveness of alternative provider-based self-management interventions (eg, use of different technologies to provide feedback to providers and families about patterns of self-management) on health outcomes and costs of care will have important clinical implications. The self-management model presented here provides a useful framework for the design and evaluation of innovative interventions to change critical self-management processes and improve health outcomes. For example, 1 hypothesis suggested by this model is that self-management interventions delivered across multiple contexts in a coordinated manner will have greater impact on long-term health outcomes and health care costs than isolated, uncoordinated interventions.[153] Another critical unanswered question is What is the optimal timing and duration of self-management promotion to achieve maximum clinical benefit? There is emerging evidence that self-management interventions can be very effective, but they need to be sustained for maximum long-term benefit.[140] Self-management promotion may be most effective if strategically delivered at times of maximal impact. For example, patients' and families' readiness for self-management intervention is heightened during periods of vulnerability (eg, during transitions from hospital-based intensive treatment to home-based care).[154] Developmental transitions (eg, onset of adolescence, transition to adulthood)[24] are critical windows of opportunity to institute family and health care system-based interventions to sustain adaptive self-management.[155] Our model of self-management provides a comprehensive, testable framework to guide future research, clinical, and policy efforts aimed at promoting self-management and improving health outcomes.

REFERENCES

1. Van Cleave J, Gortmaker SL, Perrin JM. Dynamics of obesity and chronic health conditions among children and youth. *JAMA*. 2010;303(7):623–630
2. Newacheck PW, Halfon N. Prevalence and impact of disabling chronic conditions in childhood. *Am J Public Health*. 1998;88(4):610–617
3. Newacheck PW, McManus MA, Fox HB. Prevalence and impact of chronic illness among adolescents. *Am J Dis Child*. 1991;145(12):1367–1373
4. Newacheck PW, Taylor WR. Childhood chronic illness: prevalence, severity, and impact. *Am J Public Health*. 1992;82(3):364–371
5. van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. Prevalence and characteristics of children with special health care needs. *Arch Pediatr Adolesc Med*. 2004;158(9):884–890
6. Cystic Fibrosis Foundation. *Patient Registry 2003: Annual Data Report*. Bethesda, MD: Cystic Fibrosis Foundation; 2004
7. Fiese BH, Everhart RS. Medical adherence and childhood chronic illness: family daily management skills and emotional climate as emerging contributors. *Curr Opin Pediatr*. 2006;18(5):551–557
8. Drotar D. *Promoting Adherence to Medical Treatment in Chronic Childhood Illness*. Mahwah, NJ: Lawrence Erlbaum Associates, Publishers; 2000
9. Rapoff M. *Adherence to Pediatric Medical Regimens*. 2nd ed. Issues in Clinical Child Psychology. New York, NY: Springer Science+Business Media; 2010
10. Modi AC, Monahan S, Daniels D, Glauser TA. Development and validation of the Pediatric Epilepsy Medication Self-Management Questionnaire. *Epilepsy Behav*. 2010;18(1–2):94–99
11. Quittner AL, Modi AC, Lemanek KL, levers-Landis CE, Rapoff MA. Evidence-based assessment of adherence to medical treatments in pediatric psychology. *J Pediatr Psychol*. 2008;33(9):916–936, discussion 937–938
12. Ingerski LM, Modi AC, Hood KK, et al. Health-related quality of life across pediatric chronic conditions. *J Pediatr*. 2010;156(4):639–644
13. Guilfoyle SM, Crimmins NA, Hood KK. Blood glucose monitoring and glycemic control in adolescents with type 1 diabetes: meter downloads versus self-report. *Pediatr Diabetes*. 2011;12(6):560–566
14. Meng YY, Pourat N, Cosway R, Kominski GF. Estimated cost impacts of law to expand coverage for self-management education to children with asthma in California. *J Asthma*. 2010;47(5):581–586
15. NIH Adherence Network. 2010. Available at: http://obssr.od.nih.gov/scientific_areas/health_behaviour/adherence/adherencerresearchnetwork.aspx. Accessed May 11, 2011
16. Gonder-Frederick LA, Cox DJ, Ritterband LM. Diabetes and behavioral medicine: the second decade. *J Consult Clin Psychol*. 2002;70(3):611–625
17. Grey M, Knafl KA, McCorkle R. A framework for the study of self- and family management of chronic conditions. *Nurs Outlook*. 2006;54(5):278–286
18. Ryan P, Sawin KJ. The Individual and Family Self-Management Theory: background and perspectives on context, process, and outcomes. *Nurs Outlook*. 2009;57(4):217–225, e6
19. Fiese BH, Sameroff AJ. Family context in pediatric psychology: a transactional

perspective. *J Pediatr Psychol*. 1989;14(2): 293–314

20. Creer TL. Self-management and the control of chronic pediatric illness. In: Drotar D, ed. *Promoting Adherence to Medical Treatment in Chronic Childhood Illness*. Mahwah, NJ: Lawrence Erlbaum Associates; 2000:95–129
21. Vassilev I, Rogers A, Sanders C, et al. Social networks, social capital and chronic illness self-management: a realist review. *Chronic Illn*. 2011;7(1):60–86
22. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med*. 2003;26(1): 1–7
23. Bayliss EA, Bosworth HB, Noel PH, Wolff JL, Damush TM, Mciver L. Supporting self-management for patients with complex medical needs: recommendations of a working group. *Chronic Illn*. 2007;3(2): 167–175
24. Institute of Medicine. *1st Annual Crossing the Quality Chasm Summit: A Focus on Communities*. Washington, DCNational Academy of Sciences, Board of Health Care Services; 2004:57
25. Achille MA, Ouellette A, Fournier S, Vachon M, Hébert MJ. Impact of stress, distress and feelings of indebtedness on adherence to immunosuppressants following kidney transplantation. *Clin Transplant*. 2006;20(3):301–306
26. World Health Organization. *Adherence to Long-Term Therapies: Evidence for Action*. Geneva, Switzerland: World Health Organization; 2003
27. Christensen AJ. *Patient Adherence to Medical Treatment Regimens*. New Haven, CT: Yale University Press; 2004
28. Haynes RB. Introduction. In: Haynes RB, Taylor DW, Sackett DL, eds. *Compliance in Health Care*. Baltimore, MD: Johns Hopkins University Press; 1979:1–7
29. Chesney M. Adherence to HAART regimens. *AIDS Patient Care STDS*. 2003;17(4):169–177
30. Paterson DL, Swindells S, Mohr J, et al. Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Ann Intern Med*. 2000;133(1):21–30
31. Bronfenbrenner U. Toward an experimental ecology of human development. *Am Psychol*. 1977;32:515–531
32. Becker MH. The health belief model and personal health behavior. *Health Educ Monogr*. 1974;2(4):324–473
33. Anderson B, Ho J, Brackett J, Finkelstein D, Laffel L. Parental involvement in diabetes management tasks: relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *J Pediatr*. 1997;130(2):257–265
34. Feinstein S, Keich R, Becker-Cohen R, Rinat C, Schwartz SB, Frishberg Y. Is noncompliance among adolescent renal transplant recipients inevitable? *Pediatrics*. 2005;115(4):969–973
35. Jónasson G, Carlsen KH, Mowinckel P. Asthma drug adherence in a long term clinical trial. *Arch Dis Child*. 2000;83(4): 330–333
36. Masterson TL, Wildman BG, Newberry BH, Omlor GJ. Impact of age and gender on adherence to infection control guidelines and medical regimens in cystic fibrosis *Pediatr Pulmonol*. 2011;46(3):295–301
37. Tebbi CK, Cummings KM, Zevon MA, Smith L, Richards M, Mallon J. Compliance of pediatric and adolescent cancer patients. *Cancer*. 1986;58(5):1179–1184
38. Lorenz RA, Christensen NK, Pichert JW. Diet-related knowledge, skill, and adherence among children with insulin-dependent diabetes mellitus. *Pediatrics*. 1985;75(5): 872–876
39. Patino AM, Sanchez J, Eidson M, Delamater AM. Health beliefs and regimen adherence in minority adolescents with type 1 diabetes. *J Pediatr Psychol*. 2005; 30(6):503–512
40. Steele RG, Grauer D. Adherence to antiretroviral therapy for pediatric HIV infection: review of the literature and recommendations for research. *Clin Child Fam Psychol Rev*. 2003;6(1):17–30
41. Wysocki T, Taylor A, Hough BS, Linscheid TR, Yeates KO, Naglieri JA. Deviation from developmentally appropriate self-care autonomy. Association with diabetes outcomes. *Diabetes Care*. 1996;19(2):119–125
42. Holmes CS, Chen R, Streisand R, et al. Predictors of youth diabetes care behaviors and metabolic control: a structural equation modeling approach. *J Pediatr Psychol*. 2006;31(8):770–784
43. Malee K, Williams PL, Montepiedra G, et al; PACTG 219C Team. The role of cognitive functioning in medication adherence of children and adolescents with HIV infection. *J Pediatr Psychol*. 2009;34(2):164–175
44. McNally K, Rohan J, Pendley JS, Delamater A, Drotar D. Executive functioning, treatment adherence, and glycemic control in children with type 1 diabetes. *Diabetes Care*. 2010;33(6):1159–1162
45. Mitchell WG, Scheier LM, Baker SA. Adherence to treatment in children with epilepsy: who follows "doctor's orders"? *Epilepsia*. 2000;41(12):1616–1625
46. Ho J, Bender BG, Gavin LA, O'Connor SL, Wamboldt MZ, Wamboldt FS. Relations among asthma knowledge, treatment adherence, and outcome. *J Allergy Clin Immunol*. 2003;111(3):498–502
47. McQuaid EL, Kopel SJ, Klein RB, Fritz GK. Medication adherence in pediatric asthma: reasoning, responsibility, and behavior. *J Pediatr Psychol*. 2003;28(5):323–333
48. Van Winghem J, Telfer B, Reid T, et al. Implementation of a comprehensive program including psycho-social and treatment literacy activities to improve adherence to HIV care and treatment for a pediatric population in Kenya. *BMC Pediatr*. 2008; 8:52
49. DiMatteo MR, Lepper HS, Croghan TW. Depression is a risk factor for noncompliance with medical treatment: meta-analysis of the effects of anxiety and depression on patient adherence. *Arch Intern Med*. 2000; 160(14):2101–2107
50. Hommel KA, Denson LA, Crandall WV, Mackner LM. Behavioral functioning and treatment adherence in pediatric inflammatory bowel disease: review and recommendations for practice. *Gastroenterol Hepatol (N Y)*. 2008;4(11):785
51. Hood KK, Huestis S, Maher A, Butler D, Volkening L, Laffel LM. Depressive symptoms in children and adolescents with type 1 diabetes: association with diabetes-specific characteristics. *Diabetes Care*. 2006; 29(6):1389–1391
52. Naar-King S, Idalski A, Ellis D, et al. Gender differences in adherence and metabolic control in urban youth with poorly controlled type 1 diabetes: the mediating role of mental health symptoms. *J Pediatr Psychol*. 2006;31(8):793–802
53. Shaw RJ, Palmer L, Blasey C, Sarwal M. A typology of non-adherence in pediatric renal transplant recipients. *Pediatr Transplant*. 2003;7(6):489–493
54. Helgeson VS, Escobar O, Siminerio L, Becker D. Relation of stressful life events to metabolic control among adolescents with diabetes: 5-year longitudinal study. *Health Psychol*. 2010;29(2):153–159
55. Berg CA, Wiebe DJ, Beveridge RM, et al. Mother child appraised involvement in coping with diabetes stressors and emotional adjustment. *J Pediatr Psychol*. 2007; 32(8):995–1005
56. Gudas LJ, Koocher GP, Wypij D. Perceptions of medical compliance in children and adolescents with cystic fibrosis. *J Dev Behav Pediatr*. 1991;12(4):236–242
57. Grey M, Boland EA, Davidson M, Yu C, Sullivan-Bolyai S, Tamborlane WV. Short-term effects of coping skills training as adjunct to intensive therapy in adolescents. *Diabetes Care*. 1998;21(6):902–908

58. Buck D, Jacoby A, Baker GA, Chadwick DW. Factors influencing compliance with antiepileptic drug regimes. *Seizure*. 1997;6(2):87–93
59. Burkhart PV, Rayens MK, Bowman RK. An evaluation of children's metered-dose inhaler technique for asthma medications. *Nurs Clin North Am*. 2005;40(1):167–182
60. Kaufman FR, Halvorson M, Carpenter S. Association between diabetes control and visits to a multidisciplinary pediatric diabetes clinic. *Pediatrics*. 1999;103(5 pt 1):948–951
61. Overstreet S, Goins J, Chen RS, et al. Family environment and the interrelation of family structure, child behavior, and metabolic control for children with diabetes. *J Pediatr Psychol*. 1995;20(4):435–447
62. Vreeman RC, Wiehe SE, Pearce EC, Nyandiko WM. A systematic review of pediatric adherence to antiretroviral therapy in low- and middle-income countries. *Pediatr Infect Dis J*. 2008;27(8):686–691
63. Harris MA, Greco P, Wysocki T, Elder-Danda C, White NH. Adolescents with diabetes from single-parent, blended and intact families: health-related and family functioning. Fam Syst Health. 1999;17(2):181–196
64. Modi AC, Rausch JR, Glauser TA. Patterns of nonadherence to antiepileptic drug therapy in children with newly diagnosed epilepsy. *JAMA*. 2011;305(16):1669–1676
65. Brownbridge G, Fielding DM. Psychosocial adjustment and adherence to dialysis treatment regimes. *Pediatr Nephrol*. 1994;8(6):744–749
66. Lurie S, Shemesh E, Sheiner PA, et al. Nonadherence in pediatric liver transplant recipients—an assessment of risk factors and natural history. *Pediatr Transplant*. 2000;4(3):200–206
67. Rapoff MA, Belmont JM, Lindsley CB, Olson NY. Electronically monitored adherence to medications by newly diagnosed patients with juvenile rheumatoid arthritis. *Arthritis Rheum*. 2005;53(6):905–910
68. Auslander WF, Thompson S, Dreitzer D, White NH, Santiago JV. Disparity in glycemic control and adherence between African-American and Caucasian youths with diabetes. Family and community contexts. *Diabetes Care*. 1997;20(10):1569–1575
69. Snodgrass SR, Vedanarayanan VV, Parker CC, Parks BR. Pediatric patients with undetectable anticonvulsant blood levels: comparison with compliant patients. *J Child Neurol*. 2001;16(3):164–168
70. Ashton CM, Haidet P, Paterniti DA, et al. Racial and ethnic disparities in the use of health services: bias, preferences, or poor communication? *J Gen Intern Med*. 2003;18(2):146–152
71. Alvarez O, Rodriguez-Cortes H, Robinson N, et al. Adherence to deferasirox in children and adolescents with sickle cell disease during 1-year of therapy. *J Pediatr Hematol Oncol*. 2009;31(10):739–744
72. Anderson BJ, Auslander WF, Jung KC, Miller JP, Santiago JV. Assessing family sharing of diabetes responsibilities. *J Pediatr Psychol*. 1990;15(4):477–492
73. Ellis DA, Podolski CL, Frey M, Naar-King S, Wang B, Moltz K. The role of parental monitoring in adolescent health outcomes: impact on regimen adherence in youth with type 1 diabetes. *J Pediatr Psychol*. 2007;32(8):907–917
74. Reed-Knight B, Lewis JD, Blount RL. Association of disease, adolescent, and family factors with medication adherence in pediatric inflammatory bowel disease. *J Pediatr Psychol*. 2011;36(3):308–317
75. Wysocki T, Nansel TR, Holmbeck GN, et al; Steering Committee of the Family Management of Childhood Diabetes Study. Collaborative involvement of primary and secondary caregivers: associations with youths' diabetes outcomes. *J Pediatr Psychol*. 2009;34(8):869–881
76. Gavin L, Wysocki T. Associations of paternal involvement in disease management with maternal and family outcomes in families with children with chronic illness. *J Pediatr Psychol*. 2006;31(5):481–489
77. Wysocki T, Gavin L. Paternal involvement in the management of pediatric chronic diseases: associations with adherence, quality of life, and health status. *J Pediatr Psychol*. 2006;31(5):501–511
78. Dashiff C, Morrison S, Rowe J. Fathers of children and adolescents with diabetes: what do we know? *J Pediatr Nurs*. 2008;23(2):101–119
79. Cameron LD, Young MJ, Wiebe DJ. Maternal trait anxiety and diabetes control in adolescents with type 1 diabetes. *J Pediatr Psychol*. 2007;32(7):733–744
80. Eckshtain D, Ellis DA, Kolmodin K, Naar-King S. The effects of parental depression and parenting practices on depressive symptoms and metabolic control in urban youth with insulin dependent diabetes. *J Pediatr Psychol*. 2010;35(4):426–435
81. Hazzard A, Hutchinson SJ, Krawiecki N. Factors related to adherence to medication regimens in pediatric seizure patients. *J Pediatr Psychol*. 1990;15(4):543–555
82. Cunningham NR, Vesco AT, Dolan LM, Hood KK. From caregiver psychological distress to adolescent glycemic control: the mediating role of perceived burden around diabetes management. *J Pediatr Psychol*. 2011;36(2):196–205
83. Gerson AC, Furth SL, Neu AM, Fivush BA. Assessing associations between medication adherence and potentially modifiable psychosocial variables in pediatric kidney transplant recipients and their families. *Pediatr Transplant*. 2004;8(6):543–550
84. Mellins CA, Brackis-Cott E, Dolezal C, Abrams EJ. The role of psychosocial and family factors in adherence to antiretroviral treatment in human immunodeficiency virus-infected children. *Pediatr Infect Dis J*. 2004;23(11):1035–1041
85. Vann WFJ, Jr,Lee JY, Baker D, Divaris K. Oral health literacy among female caregivers: impact on oral health outcomes in early childhood. *J Dent Res*. 2010;89(12):1395–1400
86. Monaghan M, Hilliard ME, Cogen FR, Streisand R. Supporting parents of very young children with type 1 diabetes: results from a pilot study. *Patient Educ Couns*. 2011;82(2):271–274
87. Hilliard ME, Guilfoyle SM, Dolan LM, Hood KK. Diabetes-specific family conflict predicts adolescents' glycemic control one year later: the meditating role of blood glucose monitoring adherence. *Arch Pediatr Adolesc Med*. 2011;165(7):624–629
88. Stepansky MA, Roache CR, Holmbeck GN, Schultz K. Medical adherence in young adolescents with spina bifida: longitudinal associations with family functioning. *J Pediatr Psychol*. 2010;35(2):167–176
89. DeLambo KE, Ievers-Landis CE, Drotar D, Quittner AL. Association of observed family relationship quality and problem-solving skills with treatment adherence in older children and adolescents with cystic fibrosis. *J Pediatr Psychol*. 2004;29(5):343–353
90. Dew MA, Dabbs AD, Myaskovsky L, et al. Meta-analysis of medical regimen adherence outcomes in pediatric solid organ transplantation. *Transplantation*. 2009;88(5):736–746
91. Guilfoyle SM, Goebel JW, Pai AL. Efficacy and flexibility impact perceived adherence barriers in pediatric kidney post-transplantation. *Fam Syst Health*. 2011;29(1):44–54
92. Hsin O, La Greca AM, Valenzuela J, Moine CT, Delamater A. Adherence and glycemic control among Hispanic youth with type 1 diabetes: role of family involvement and acculturation. *J Pediatr Psychol*. 2010;35(2):156–166
93. La Greca AM, Auslander WF, Greco P, Spetter D, Fisher EB, Jr,Santiago JV. I get

by with a little help from my family and friends: adolescents' support for diabetes care. *J Pediatr Psychol*. 1995;20(4):449–476

94. Pai AL, Gray E, Kurivial K, Ross J, Schoborg D, Goebel J. The Allocation of Treatment Responsibility scale: a novel tool for assessing patient and caregiver management of pediatric medical treatment regimens. *Pediatr Transplant*. 2010;14(8):993–999
95. Anderson BJ, Brackett J, Ho J, Laffel LMB. An office-based intervention to maintain parent-adolescent teamwork in diabetes management. Impact on parent involvement, family conflict, and subsequent glycemic control. *Diabetes Care*. 1999;22(5):713–721
96. Wysocki T, Harris MA, Buckloh LM, et al. Randomized, controlled trial of Behavioral Family Systems Therapy for Diabetes: maintenance and generalization of effects on parent-adolescent communication. *Behav Ther*. 2008;39(1):33–46
97. Amillategui B, Calle JR, Alvarez MA, Cardiel MA, Barrio R. Identifying the special needs of children with type 1 diabetes in the school setting. An overview of parents' perceptions. *Diabet Med*. 2007;24(10):1073–1079
98. Hayes-Bohn R, Neumark-Sztainer D, Mellin A, Patterson J. Adolescent and parent assessments of diabetes mellitus management at school. *J Sch Health*. 2004;74(5):166–169
99. Jacquez F, Stout S, Alvarez-Salvat R, et al. Parent perspectives of diabetes management in schools. *Diabetes Educ*. 2008;34(6):996–1003
100. Wagner J, James A. A pilot study of school counselor's preparedness to serve students with diabetes: relationship to self-reported diabetes training. *J Sch Health*. 2006;76(7):387–392
101. Zupanc ML, Haut S. Epilepsy in women: special considerations for adolescents. *Int Rev Neurobiol*. 2008;83:91–111
102. Hains AA, Berlin KS, Davies WH, et al. Attributions of teacher reactions to diabetes self-care behaviors. *J Pediatr Psychol*. 2009;34(1):97–107
103. Coffman JM, Cabana MD, Yelin EH. Do school-based asthma education programs improve self-management and health outcomes? *Pediatrics*. 2009;124(2):729–742
104. Maslow GR, Lobato D. Diabetes summer camps: history, safety, and outcomes. *Pediatr Diabetes*. 2009;10(4):278–288
105. McCaleb A, Cull VV. Sociocultural influences and self-care practices of middle adolescents. *J Pediatr Nurs*. 2000;15(1):30–35
106. Funck-Brentano I, Dalban C, Veber F, et al. Evaluation of a peer support group therapy for HIV-infected adolescents. *AIDS*. 2005;19(14):1501–1508
107. Janicke DM, Gray WN, Kahhan NA, et al. Brief report: the association between peer victimization, prosocial support, and treatment adherence in children and adolescents with inflammatory bowel disease. *J Pediatr Psychol*. 2009;34(7):769–773
108. Pendley JS, Kasmen LJ, Miller DL, Donze J, Swenson C, Reeves G. Peer and family support in children and adolescents with type 1 diabetes. *J Pediatr Psychol*. 2002;27(5):429–438
109. Dolgin MJ, Katz ER, Doctors SR, Siegel SE. Caregivers' perceptions of medical compliance in adolescents with cancer. *J Adolesc Health Care*. 1986;7(1):22–27
110. Hains AA, Berlin KS, Davies WH, Smothers MK, Sato AF, Alemzadeh R. Attributions of adolescents with type 1 diabetes related to performing diabetes care around friends and peers: the moderating role of friend support. *J Pediatr Psychol*. 2007;32(5):561–570
111. Jacobson AM, Hauser ST, Wertlieb D, Wolfsdorf JI, Orleans J, Vieyra M. Psychological adjustment of children with recently diagnosed diabetes mellitus. *Diabetes Care*. 1986;9(4):323–329
112. Drew LM, Berg C, Wiebe DJ. The mediating role of extreme peer orientation in the relationships between adolescent-parent relationship and diabetes management. *J Fam Psychol*. 2010;24(3):299–306
113. Cantrell K, Fischer A, Bouzaher A, Bers M. The role of E-mentorship in a virtual world for youth transplant recipients. *J Pediatr Oncol Nurs*. 2010;27(6):344–355
114. Clay DL, Mordhorst MJ, Lehn L. Empirically supported treatments in pediatric psychology: where is the diversity? *J Pediatr Psychol*. 2002;27(4):325–337
115. Prieto LR, Miller DS, Gayowski T, Marino IR. Multicultural issues in organ transplantation: the influence of patients' cultural perspectives on compliance with treatment. *Clin Transplant*. 1997;11(6):529–535
116. Ross LF, Walsh C. Minority children in pediatric research. *Am J Law Med*. 2003;29(2–3):319–336
117. Flores G. The impact of medical interpreter services on the quality of health care: a systematic review. *Med Care Res Rev*. 2005;62(3):255–299
118. Jacobs EA, Lauderdale DS, Meltzer D, Shorey JM, Levinson W, Thisted RA. Impact of interpreter services on delivery of health care to limited-English-proficient patients. *J Gen Intern Med*. 2001;16(7):468–474
119. Peña Dolhun E, Muñoz C, Grumbach K. Cross-cultural education in U.S. medical schools: development of an assessment tool. *Acad Med*. 2003;78(6):615–622
120. Thom DH, Tirado MD, Woon TL, McBride MR. Development and evaluation of a cultural competency training curriculum. *BMC Med Educ*. 2006;6:38
121. Office of Minority Health. Assessment of state minority health infrastructure and capacity to address issues of health disparity: final report. 2000. Available at: http://minorityhealth.hhs.gov/Assets/pdf/Checked/1/0MHHealthDisparityFRSept00.pdf. Accessed September 1, 2010
122. Barkin S, Balkrishnan R, Manuel J, Hall MA. Effect of language immersion on communication with Latino patients. *N C Med J*. 2003;64(6):258–262
123. Virtanen M, Pentti J, Vahtera J, et al. Overcrowding in hospital wards as a predictor of antidepressant treatment among hospital staff. *Am J Psychiatry*. 2008;165(11):1482–1486
124. Van Bogaert P, Meulemans H, Clarke S, Vermeyen K, Van de Heyning P. Hospital nurse practice environment, burnout, job outcomes and quality of care: test of a structural equation model. *J Adv Nurs*. 2009;65(10):2175–2185
125. Rowlands J, Noble S. How does the environment impact on the quality of life of advanced cancer patients? A qualitative study with implications for ward design. *Palliat Med*. 2008;22(6):768–774
126. Rossberg JI, Melle I, Opjordsmoen S, Friis S. The relationship between staff members' working conditions and patients' perceptions of the treatment environment. *Int J Soc Psychiatry*. 2008;54(5):437–446
127. Fiks AG, Localio AR, Alessandrini EA, Asch DA, Guevara JP. Shared decision-making in pediatrics: a national perspective. *Pediatrics*. 2010;126(2):306–314
128. Sisterhen LL, Blaszak RT, Woods MB, Smith CE. Defining family-centered rounds. *Teach Learn Med*. 2007;19(3):319–322
129. Rosen P, Stenger E, Bochkoris M, Hannon MJ, Kwoh CK. Family-centered multidisciplinary rounds enhance the team approach in pediatrics. *Pediatrics*. 2009;123(4). Available at: www.pediatrics.org/cgi/content/full/123/4/e603
130. Muething SE, Kotagal UR, Schoettker PJ, Gonzalez del Rey J, DeWitt TG. Family-centered bedside rounds: a new approach to patient care and teaching. *Pediatrics*. 2007;119(4):829–832
131. Knoderer HM. Inclusion of parents in pediatric subspecialty team rounds: attitudes of the family and medical team. *Acad Med*. 2009;84(11):1576–1581
132. Rappaport DI, Cellucci MF, Leffler MG. Implementing family-centered rounds: pediatric residents' perceptions. *Clin Pediatr (Phila)*. 2010;49(3):228–234

133. Mittal VS, Sigrest T, Ottolini MC, et al. Family-centered rounds on pediatric wards: a PRIS network survey of US and Canadian hospitalists. *Pediatrics*. 2010;126(1):37–43
134. Coad J, Flay J, Aspinall M, Bilverstone B, Coxhead E, Hones B. Evaluating the impact of involving young people in developing children's services in an acute hospital trust. *J Clin Nurs*. 2008;17(23):3115–3122
135. Lorig KR, Sobel DS, Stewart AL, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Med Care*. 1999; 37(1):5–14
136. Hains AA, Davies WH, Parton E, Silverman AH. Brief report: a cognitive behavioral intervention for distressed adolescents with type I diabetes. *J Pediatr Psychol*. 2001;26(1):61–66
137. Sahler OJ, Varni JW, Fairclough DL, et al. Problem-solving skills training for mothers of children with newly diagnosed cancer: A randomized trial. *J Dev Behav Pediatr*. 2002;23(2):77–86
138. Anderson BJ, Wolf FM, Burkhart MT, Cornell RG, Bacon GE. Effects of peer-group intervention on metabolic control of adolescents with IDDM. Randomized outpatient study. *Diabetes Care*. 1989;12 (3):179–183
139. Rapoff MA, Belmont J, Lindsley C, Olson N, Morris J, Padur J. Prevention of non-adherence to nonsteroidal anti-inflammatory medications for newly diagnosed patients with juvenile rheumatoid arthritis. *Health Psychol*. 2002;21(6):620–623
140. Drotar D. *Psychological Interventions in Childhood Chronic Illness*. Washington, DC: American Psychological Association; 2006
141. Wysocki T, Harris MA, Buckloh LM, et al. Effects of behavioral family systems therapy for diabetes on adolescents' family relationships, treatment adherence, and metabolic control. *J Pediatr Psychol*. 2006; 31(9):928–938
142. Chin MH, Alexander-Young M, Burnet DL. Health care quality-improvement approaches to reducing child health disparities. *Pediatrics*. 2009;124(suppl 3): S224–S236
143. Kelly CS, Morrow AL, Shults J, Nakas N, Strope GL, Adelman RD. Outcomes evaluation of a comprehensive intervention program for asthmatic children enrolled in medicaid. *Pediatrics*. 2000;105(5):1029–1035
144. Drotar D, Crawford P, Bonner M. Collaborative decision-making and promoting treatment adherence in pediatric chronic illness. *Patient Intelligence*. 2010;2:1–7
145. Glasgow RE, Goldstein MG, Ockene JK, Pronk NP. Translating what we have learned into practice. Principles and hypotheses for interventions addressing multiple behaviors in primary care. *Am J Prev Med*. 2004;27(suppl 2):88–101
146. Cincinnati Children's Hospital Medical Center. *CCHMC Self Management Guideline Implementation*. Cincinnati, OH: CCHMC; 2009
147. Wagner EH, Glasgow RE, Davis C, et al. Quality improvement in chronic illness care: a collaborative approach. *Jt Comm J Qual Improv*. 2001;27(2):63–80
148. Cutler DM, Everett W. Thinking outside the pillbox—medication adherence as a priority for health care reform. *N Engl J Med*. 2010;362(17):1553–1555
149. Porter ME. A strategy for health care reform—toward a value-based system. *N Engl J Med*. 2009;361(2):109–112
150. American Diabetes Association. Standards of medical care in diabetes—2011. *Diabetes Care*. 2011;34(suppl 1):S16–S27
151. Osterberg L, Blaschke T. Adherence to medication. *N Engl J Med*. 2005;353(5): 487–497
152. Pai AL, Drotar D. Treatment adherence impact: the systematic assessment and quantification of the impact of treatment adherence on pediatric medical and psychological outcomes. *J Pediatr Psychol*. 2010;35(4):383–393
153. American Academy of Pediatrics Medical Home Initiatives for Children With Special Needs Project Advisory Committee. Policy statement: organizational principles to guide and define the child health care system and/or improve the health of all children. *Pediatrics*. 2004;113(suppl 5): 1545–1547
154. Liptak GS, Burns CM, Davidson PW, McAnarney ER. Effects of providing comprehensive ambulatory services to children with chronic conditions. *Arch Pediatr Adolesc Med*. 1998;152(10):1003–1008
155. Pai AL, Schwartz LA. Introduction to the special section: health care transitions of adolescents and young adults with pediatric chronic conditions. *J Pediatr Psychol*. 2011;36(2):129–133