

Supporting Self-Management in Children and Adolescents With Complex Chronic Conditions

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abstract

Self-management improves health outcomes in chronic illness not only by improving adherence to the treatment plan but also by building the individual's capacity to navigate challenges and solve problems. Support for self-management is a critical need among children and adolescents with (medically and/or socially) complex chronic conditions. Self-management support refers to services that health systems and community agencies provide to persons with chronic illness and their families to facilitate self-management; it is a collaboration between the patient, family, and care providers. Evidence has guided the development of self-management support approaches and tools for adults and has led to an increased adoption of best practices in adult chronic illness care. However, adult models fail to account for some key differences between children and adults, namely, the integral role of parents and/or caregivers and youth development over time. There is a need for self-management support models that take into account the developmental trajectory across the pediatric age range. Effective approaches must also recognize that in pediatrics, self-management is really shared management between the youth and the parent(s) and/or caregiver(s). Health systems should design care to address self-management for pediatric patients. Although clinicians recognize the importance of self-management in youth with complex chronic conditions, they need standardized approaches and tools to do the following: assess the self-management skills of youth and families, assess modifiable environmental influences on chronic conditions, collaboratively set self-management goals, promote competence and eventual autonomy in youth, share the responsibility for self-management support among nonphysician members of the health care team, and leverage community resources for self-management support.

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Dr Lozano conceptualized and designed the manuscript and drafted the initial manuscript; Dr Houtrow conceptualized and designed the manuscript and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted.

DOI: <https://doi.org/10.1542/peds.2017-1284H>

Accepted for publication Nov 1, 2017

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Shaun (not his real name) is a 16-year-old boy with sickle cell anemia and asthma who is a high school sophomore. Shaun has been hospitalized at least twice per year for the past 7 years and has had an episode of acute chest syndrome, for which he required care in the PICU for 3 days last year. His spleen was removed when he was 13 years old, but he doesn't understand why. He gets pulmonary function tests every 6 months. One doctor told him it was because of his asthma, but his sickle cell nurse said it was because he had sickle cell anemia. He gets transcranial Doppler ultrasonography every year.

Last year, an MRI after a concerning Doppler study showed silent cerebral infarcts. This made his mother cry, but he doesn't think it is a big deal because he feels fine except when he has pain crises. Shaun's mother has scheduled neuropsychological testing after talking with the neurologist. She's nervous because she thinks Shaun is having more trouble in school than he did before. He also seems frustrated by schoolwork and gives up easily. Shaun has missed many days of school because of appointments, fevers, and pain crises. The thing that bothers Shaun the most is that he can't keep up on the basketball court with his friends. He gets short of breath quickly, and his inhaler doesn't always help. He wants to play water polo like his friends, but he has trouble treading water.

Shaun sees multiple medical specialists, including his pediatrician, his pediatric pulmonologist, the sickle cell team (a hematologist, nurse coordinator, and social worker), and a neurologist. Going to all these appointments is challenging because the children's hospital is an hour and a half away by bus (including 2 transfers), and the pulmonologist doesn't have appointments available on the same day as the sickle cell clinic.

At today's visit, Shaun reports he has done well following his action

plan for preventing vaso-occlusive crises (staying hydrated and dressing warmly). Shaun and his mother talk about medications with the provider. Shaun has 3 pills to take before going to school, 1 to take with food at dinner, and 4 to take each evening. Shaun has the physical and cognitive skills necessary to self-administer the medications. Shaun's family lives paycheck to paycheck. Sometimes toward the end of the month, when they don't have enough food at home, Shaun skips his pills that require food to make sure his younger sister gets enough to eat. The care plan is revised so that Shaun takes the medication at school, where he receives free lunch, and after this, Shaun self-administers his medication without difficulty for several months.

One year later, Shaun has started to have trouble remembering his medicines, no matter how many times his mother reminds him. His MRI reveals no change, but neuropsychological testing reveals significant problems with attention. His mother speaks with the school psychologist about strategies to help him. Shaun and the psychologist create alerts on his phone to remind him to take his medications.

The following month at the sickle cell clinic, the medical team congratulates him on his successful problem-solving. Shaun asks the nurse in private if he could pass sickle cell anemia to his children. They discuss the fact that Shaun is sexually active with his girlfriend; the nurse provides contraception counseling. After this visit, Shaun starts to think about applying to a health professions program at the community college for next fall and considers the idea of working for a sickle cell program someday.

SELF-MANAGEMENT IN CHILDREN WITH COMPLEX CHRONIC CONDITIONS

Children with medical complexity are at a high risk for adverse medical,

developmental, psychosocial, and family outcomes¹ and have functional limitations that may be associated with transient deficits or long-term disability.² Chronic illness and disability place demands on children and families that may strain their personal resilience, economic resources, and social capital. Medical and social complexity are intertwined; social determinants of health may add considerable complexity even when the biomedical profile does not meet the definition of medically complex. Consider the following 2 children: 1 is a medically complex child, a toddler who was born prematurely and has cerebral palsy and respiratory, gastrointestinal, and cognitive issues; the other is a second-grade child who carries a single medical diagnosis of type 1 diabetes whose mother is a single parent with limited English proficiency and works 2 low-wage jobs. Although the intensity of their tertiary medical care needs may differ substantially, these children face an overlapping set of health-related challenges. For this reason, we include both medical and social complexity in our definition of children with complex chronic conditions. The case of Shaun, an adolescent with sickle cell anemia, demonstrates this interplay between medical and social factors.

Self-management is the set of behaviors that people engage in as part of living with a chronic health condition (Fig 1). Self-management includes a set of common tasks aimed at optimizing health and well-being for the individual with a chronic condition, such as medication adherence, symptom or biometric monitoring, nutrition, physical activity and/or fitness, skill-building, goal-setting, problem-solving, the use of an action plan, sleep, and stress reduction.³ Self-management tasks fall along a spectrum. They include responsibilities that are directly related to health care (such

as checking blood glucose) as well as social and lifestyle behaviors that impact and are impacted by wellness in a more holistic sense (such as attending school, trying out for a football team, playing video games, or participating in an art class). Shaun's story provides many examples of self-management behaviors. Taking medications, drinking plenty of fluids when trying to avert a pain crisis, attending to his schoolwork, sitting out on a basketball game because of shortness of breath, making a clinic appointment, and considering how he should weigh his sickle cell anemia in planning for his future are all examples of Shaun's self-management. Self-management improves health outcomes not only by improving adherence to the treatment plan but also by building the patient's capacity to navigate challenges and solve problems. In children and youth with complex chronic conditions, self-management is made more difficult by biomedical issues, social determinants of health, and the added logistical, financial, and psychosocial demands of chronic illness.

THE NEED TO FOCUS ON SUPPORTING SELF-MANAGEMENT IN PEDIATRICS

Self-management support refers to the set of services that health systems and community agencies provide to persons with chronic illness and their families to facilitate self-management.⁴ Self-management support is a collaboration between the patient, family, and health care providers.⁵ In adults, self-management support is associated with improved health outcomes and patient experience.⁶⁻¹⁰ Self-management support is an established part of high-quality care for adults with chronic conditions.¹¹⁻¹³ There are evidence-based best practices and care models to inform self-management support for a 55 year old with type 2 diabetes, obesity, and depression,

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| <ul style="list-style-type: none"> • Monitor clinical status and/or symptoms • Avoid triggers • Manage symptoms • Administer medication and/or treatment • Adjust medication and/or treatment regimen • Manage home health technology and devices • Attend to diet (restrictions and requirements) | <ul style="list-style-type: none"> • Prevent crises and/or flares • Problem-solve • Implement an action plan when needed • Accommodate activity limitations • Cope with the functional impact of the condition • Cope with the emotional stress that is due to the illness • Prevent and/or manage complications |
|---|---|

FIGURE 1
Self-management tasks.

for example, or for a 70 year old with heart failure, arthritis, and mobility limitations. Although there is evidence that supporting self-management in pediatrics improves chronic illness outcomes,¹⁴ self-management support models aren't as well developed for children and adolescents with complex chronic conditions, and as a result, self-management support is not formally integrated into pediatric care.¹⁵ National expert and professional organizations that provide guidelines and tools for self-management support have thus far produced such resources that are primarily (or exclusively) adult focused.¹⁶⁻²⁰ In fact the National Academy of Medicine's Living Well report¹⁹ on this topic makes little mention of children and youth with chronic conditions.

The contrast between the well-developed arena of adult self-management support and the more nascent field of self-management support in pediatrics can be explained largely by some of the key differences that child health services researchers have noted between the 2 age groups.^{21,22} Three differences are particularly relevant and help explain this observed gap:

1. **Dependency.** Whereas adults with multiple chronic conditions may rely on others in various ways (and those with serious, advanced illnesses or disability do depend on caregivers), most chronically ill adults have considerable autonomy in their daily lives. In contrast, children depend on

parents and caregivers for some or all of their care, so pediatric care nearly always involves >1 agent of self-management.

2. **Development.** The pediatric age range encompasses a spectrum across all facets of development: cognitive, motor, language, social, and emotional. At any point in time, youth capacity for self-management is evolving. Clinicians who serve children and adolescents tend to be adept at providing care that accounts for this developmental trajectory. However, there is little evidence about how to tailor support of self-management for youth at different stages of maturity.
3. **Differential epidemiology.** A small number of diagnoses (eg, atherosclerosis, diabetes, hypertension, and arthritis) account for the majority of adult chronic illnesses, allowing primary care providers to develop great proficiency in their management, in most cases. This has also led to the development, evaluation, and implementation of generic interventions of chronic disease self-management for adults.^{6,12} In contrast, a vast array of diverse diagnoses, each with relatively low prevalence, is responsible for chronic illness in those aged <21 years. Primary care pediatricians typically manage the more common conditions, such as asthma, but must rely to varying degrees on subspecialists for some portion of care for children with complex chronic conditions. One

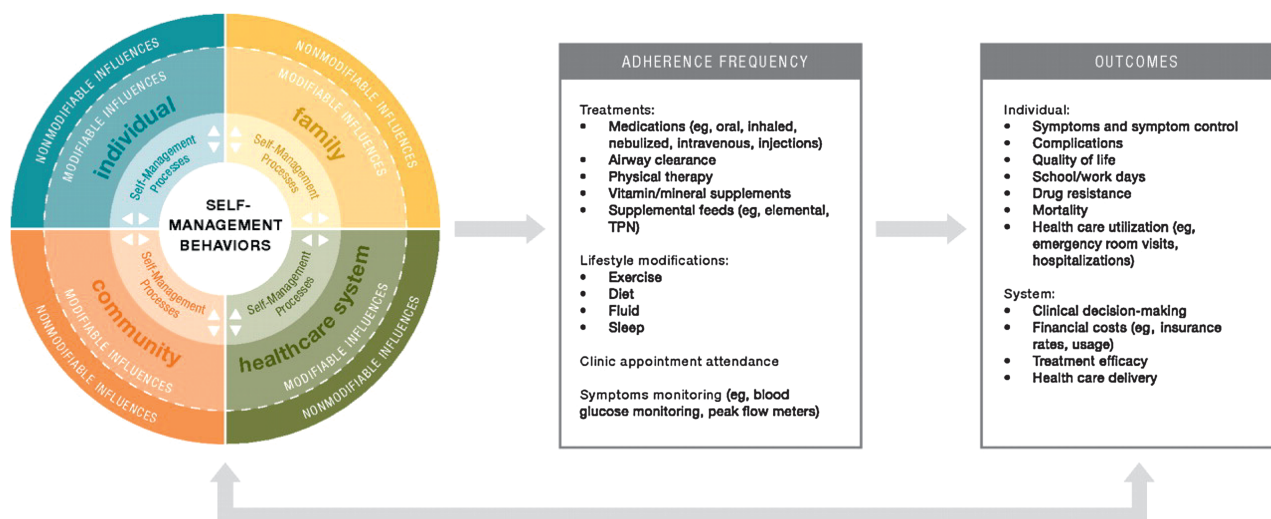


FIGURE 2 Pediatric self-management model. Self-management behaviors (left) operate within individual, family, community, and health care system domains. Modifiable and nonmodifiable, domain-specific influences impact self-management processes through underlying cognitive, emotional, and social processes. Self-management affects adherence and ultimately outcomes. (Reprinted with permission from Modi AC, Pai AL, Hommel KA, et al. Pediatric self-management: a framework for research, practice, and policy. *Pediatrics*. 2012;129[2]. Available at: www.pediatrics.org/cgi/content/full/129/2/e473.)

consequence of this epidemiology is that health systems tend to create silos for different pediatric chronic conditions as compared with the generic perspective for adult chronic illness. Yet despite differences in the treatment of different diagnoses, pediatric chronic conditions share many common self-management elements (Fig 1). Researchers, clinicians, and health systems have been slow to take a generic approach to supporting pediatric self-management.

FRAMEWORKS FOR PEDIATRIC SELF-MANAGEMENT

We sought to identify frameworks that might be used to address these challenges in self-management in pediatrics. We turned to 2 complementary models that could potentially serve as organizing frameworks for self-management in children with complex chronic conditions: the Pediatric Self-Management framework²³ (Fig 2) and the *International Classification of Functioning, Disability and Health*^{24,25} (ICF) (Fig 3). Both models take a

generic (as opposed to diagnosis-specific) view of pediatric chronic illness and disability, and both contribute to our understanding of self-management in pediatrics.

Modi et al²³ proposed the Pediatric Self-Management framework as a way to examine multilevel, contextual influences that promote or detract from self-management behaviors across chronic conditions through cognitive, emotional, and social processes. As an adaptation of the Social Ecological Model,²⁶ the Pediatric Self-Management framework enumerates a comprehensive list of individual-, family-, community-, and health system-level influences on pediatric self-management that ultimately affect youth adherence to treatment (Fig 3). The Social Ecological Model provides a vocabulary for discussing the environmental influences on health and health care ranging from the microsystem (eg, the family, household, school, and neighborhood) to broader societal and cultural realities (eg, economic policies and institutional racism). Factors at all these levels

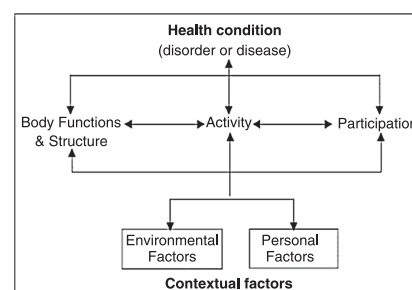


FIGURE 3 Interactions among the components of the ICF. (Reprinted with permission from World Health Organization. *International Classification of Functioning, Disability and Health: Child and Youth Version: ICF-CY*. Geneva, Switzerland: World Health Organization; 2007.)

play a role in self-management²⁷; Modi et al²³ focus on the influences of these factors on pediatric self-management. In this framework, youth are placed at the center of this interconnected social system, and the authors suggest that pediatric self-management can only be understood when taking into account the complex influences at different levels.

The World Health Organization's ICF^{24,25} provides a common framework for considering functioning and disability in the context of an individual's health

conditions and contextual factors (Fig 3). The ICF is used to integrate biomedical, psychosocial, and social-ecological perspectives and is centered on 3 core components for functioning²⁸: body function (ie, physiology), activities (ie, skills and abilities), and participation (ie, the use of skills in a social context). Two contextual components, the environment (external) and personal (internal), influence functioning in dynamic and complex ways and can impact an individual's capacity to perform skills, such as those described in Shaun's case. The ICF has been applied in various pediatric settings: children with chronic illness and/or disability,²⁹ adolescents who are transitioning from pediatric to adult health care systems,^{30,31} and children with medical complexity.²⁸ Although, to our knowledge, it has not been used to explore self-management processes, we suggest that self-management tasks and behaviors can be mapped onto the ICF constructs of activities and participation, making the ICF a useful framework for examining the factors that influence chronic illness self-management in children and youth.

Taking a generic view, both of these frameworks provide an alternative to the silos of pediatric chronic illness and encourage a focus on common elements across conditions. A consideration of Shaun's case in light of these 2 frameworks provides some additional insights into pediatric self-management:

ENVIRONMENTAL FACTORS AT ALL LEVELS CAN INFLUENCE PEDIATRIC SELF-MANAGEMENT

A salient feature of both of these complementary frameworks is the influence of environmental context not just on pediatric health and health care but on pediatric self-management in particular. The Pediatric Self-Management framework points to environmental factors at the levels of the family, community, and health

care system and classifies them as modifiable or nonmodifiable, suggesting that modifiable influences are the critical intervention targets. Making accommodations for barriers that cannot be altered and addressing those factors that can be improved increases the likelihood of successful self-management. The ICF similarly calls out the environmental context as an influence on the central functional domains. Among the environmental factors that influence self-management in Shaun's case are the interplay between household financial resources and the school lunch program. Asking about home, school, and community environments to identify factors that influence a child's health is a common part of pediatric practice. Standard approaches could help bring the same scrutiny to self-management as a discrete set of family and individual behaviors that are shared across different diagnoses.

THE GAP BETWEEN YOUTH CAPACITY FOR AND PERFORMANCE IN SELF-MANAGEMENT CAN FOCUS ATTENTION ON SELF-MANAGEMENT AND HELP IDENTIFY BARRIERS

Although it is clear that self-management of chronic health conditions does not occur in a vacuum, we as clinicians sometimes instruct children and families about self-management in isolation from contextual factors. Although a child or adolescent may have the capacity for self-management tasks (such as cognitive or motor skills), many factors may prevent him or her from performing it in daily life. Food insufficiency in Shaun's household and his sense of responsibility for a younger sibling forced him to consider whether to take a pill that must be taken with food. Rather than focusing on educating Shaun about the importance of taking his medicine, his care team supported him by identifying this barrier and changing his regimen so he could take his medicine with lunch, which is provided at school.

The ICF distinguishes between 2 features of the activities and participation components: capacity and performance. Capacity is the individual's intrinsic ability to complete a task or action in a standardized environment, whereas performance is how well the individual is able to actually perform the task in his or her own environment.³² When a young person's capacity for a task exceeds his or her performance, the ICF points to potential barriers in the environment and personal contexts.³³ For Shaun, environmental factors resulted in a capacity-performance gap. In other cases, personal factors (such as health beliefs, intrinsic motivation, or self-efficacy) can prevent a capable youth from performing effective self-management. The constructs of capacity and performance may be helpful to clinicians who are trying to assess and support youth self-management.

IN PEDIATRICS, SELF-MANAGEMENT IS REALLY SHARED MANAGEMENT

The construct of self-management arose first in the care of adults, in which case the patient is primarily in charge of self-care tasks.³⁴ However, in pediatrics, even the term self-management is inherently challenging. In reality, the parent(s) and/or caregiver(s) and the child or adolescent must share the role of manager. The term shared management reflects this notion.³⁵ Shaun's sickle crisis prevention plan (which includes staying hydrated, dressing warmly in the winter, and problem-solving early symptoms of a pain crisis) provided a tool for shared management and an opportunity for him to assume a greater role over the course of elementary and middle school. During that time, the primary responsibility for ensuring that the care plan was followed shifted from Shaun's mother to Shaun. Similarly, as an adolescent, he started having 1-on-1 visits with his sickle cell clinic

nurse that allowed him to receive confidential sexual and behavioral health services. Pediatric clinicians intuitively focus self-management support efforts predominantly on the parents and caregivers of younger children and on the patient in the case of older adolescents. However, there is little empirical evidence to explicitly guide the transfer of locus of control from the parent and/or caregiver to the youth, and neither framework specifically addresses this issue.

SUPPORT FOR SELF-MANAGEMENT SHOULD FOLLOW THE YOUTH DEVELOPMENTAL TRAJECTORY

Developing skills is at the heart of self-management. Competency evolves along a continuum, and mastery comes in steps. Whereas a beginner will struggle with new contingencies, the expert can successfully adapt.³⁶ Over the course of his childhood, Shaun gained the ability to monitor his asthma symptoms, self-administer his β -agonist inhaler, and problem-solve when he experienced worsening shortness of breath. Shaun had a series of opportunities to practice these skills, which allowed him to gain both competence and confidence. Typically developing youth may grow into self-management as they gradually acquire more skills. Youth with developmental disabilities may follow a modified trajectory, as was the case when inattention (probably because of cerebral infarcts) became a significant problem for Shaun. By being mindful of the dynamic nature of youth development, clinicians and caregivers can tailor self-management support to the developmental trajectory. There is a lack of evidence-based tools to guide such tailoring. Strategies to promote self-management need to consider the competency stage of the individual (from novice to expert), the complexity of the activity, and the factors in the environment that may influence the task.³⁷

IMPLICATIONS

The Pediatric Self-Management and ICF frameworks emphasize some critical issues in pediatric self-management but do not address other key features, such as shared management in the context of the parent-child dyad or supporting youth along a developmental continuum. The considerable differences between adult and pediatric self-management make it difficult to simply adapt adult best practices to children and adolescents; more research is needed.

Notwithstanding, best practices in adult self-management³⁸ can provide some guidance for pediatric care. Below, we recommend some actions that health systems, clinicians, and families can take to promote self-management. These actions are consistent with the defining characteristics of the medical home^{39,40}: accessibility, family centeredness, continuity, comprehensiveness, coordination, compassion, and cultural effectiveness. Our recommendations are built on previous calls to shore up the medical home model³⁹ and design innovative health care–financing strategies⁴¹ (such as value-based purchasing) to ensure that health systems meet the needs of children with chronic illnesses or disabilities. Alongside these recommendations, we also articulate gaps that researchers and policymakers should address.

CARE PLANS

Care plans^{12,42} should be a foundation of care for youth with complex chronic conditions. They should set forth specific self-management goals, provide opportunities to practice specific skills in supportive environments,⁴³ and address the respective roles of the youth and the parent or caregiver in shared management. Care plans should be readily available to the health care team and family and be updated regularly. Parents and caregivers

should request care plans; clinicians should engage families in developing their care plans collaboratively.

Although care plans (or action plans) are an established best practice for some conditions, such as asthma,⁴⁴ they have not been widely adopted in clinical practice. Quality-improvement efforts are needed to promote the implementation of care plans into routine care for youth with complex chronic conditions. Health systems should invest in integrating care plans into electronic health records to facilitate the sharing of the care plan among the stakeholders, including the family and care teams. Research is needed to develop and evaluate care plan templates that account for the evolution of self-management skills over time and are based on the youth developmental trajectory as well as the transfer of responsibility, and that can be used in children with a wide array of conditions.

SELF-MANAGEMENT ASSESSMENT AND BEHAVIOR-CHANGE COUNSELING

Clinicians (including primary care physicians, nurse practitioners, and pediatric subspecialists) should routinely assess self-management skills, self-efficacy, and relevant environmental factors as the first step in supporting self-management. They should use behavior-change techniques to assist families in goal-setting and problem-solving. *Current Procedural Terminology* codes that can be used for services that support self-management in children and adolescents are shown in Table 1. Parents and caregivers should articulate their concerns about self-management and ask health care providers for care plans and to collaborate⁵ with them in shared management.

Child health researchers should focus their efforts on developing methods for assessing self-management behaviors³² as well as assessment tools that are adapted for shared management. There is also a need for coaching models that

TABLE 1 CPT Codes That Can Be Used for Services That Support Self-Management in Children and Adolescents

Type of Service	Rationale	CPT Code and Service
Counseling ^a	Self-management support requires counseling, often repeated encounters over time.	99401-4; preventive medicine counseling at an encounter separate from a preventive medicine visit ⁴⁵ The code is time based. Providers should document the extent of the counseling. ⁴⁵ This should be used for counseling that addresses self-management globally (eg, self-efficacy), not for counseling that is considered part of the treatment of a specific illness (eg, teaching asthma inhaler technique). ⁴⁵
Screening	Assessing youth ability to participate in self-care may be an important first step in supporting self-management. Developmental testing can inform the provider, family, and youth about potential areas in which to focus self-management efforts.	99420; administration and interpretation of a health risk assessment ⁴⁵ 96110; developmental screening ⁴⁶ 96111; developmental testing by using standardized instruments with interpretation and report ⁴⁶ This is often used in young children but may also be appropriate for older patients if the ability to participate in self-management is in question.
	Behavioral disorders may inhibit a young person's ability to set goals and engage in self-care.	96127; brief emotional and/or behavioral assessment ⁴⁶
Care management	Oversight of care management of youth with complex medical problems is often needed but may be undercoded.	99490; chronic care management directed by a physician or other qualified health professional (up to 20 min per mo) ⁴⁷ 99487; complex chronic care management (60 min per mo) ⁴⁷ 99489; complex chronic care management (each additional 30 min) ⁴⁷

CPT, *Current Procedural Terminology*.

^a These codes may not be reimbursed by some insurance plans, including Medicaid. In these situations, coding that is based on the time when >50% of the visit is dedicated to counseling may be considered.

adequately address the sharing and eventual transfer of self-management between parent and youth and the evolution of youth self-management along the developmental trajectory. Medical education should prepare clinicians to use behavior-change approaches that are collaborative rather than didactic (eg, motivational interviewing-based counseling and health coaching).

DESIGNING FOR SELF-MANAGEMENT SUPPORT AS A TEAM RESPONSIBILITY

Health systems can best support self-management through the intentional design of team roles and structured health care encounters.¹² Planned visits are structured encounters that

are used to address chronic illness needs proactively^{44,48} and allow for a focus on self-management support. Providers should familiarize themselves with documentation and coding standards (Table 1) that are relevant to planned visits. Planned-visit models that were developed for adults should be adapted for pediatrics in ways that support emerging autonomy in a shared-management context.

The adult literature has come to define self-management as a team function rather than being the sole responsibility of the physician. Nurses, medical assistants, pharmacists, and lay health workers can all play a role in supporting self-management in chronically ill

adults.^{49–53} There is a need to better understand the potential of such diverse team members to support self-management in youth with complex chronic conditions. Those in nursing and allied health education must prepare pediatric clinicians to play these roles. Supporting self-management may overwhelm providers who are already pressed for time. High-functioning teams with thoughtfully defined roles have the potential to mitigate this burden by optimizing each team member's scope of practice.

COMMUNITY LINKAGES

When possible, clinicians should leverage community resources for self-management education and support.¹² Admittedly, these are more available for the more common adult chronic conditions than for pediatric chronic conditions. By recognizing the central role of self-management across conditions, advocates for children should explore ways to focus the existing network of community agencies and tertiary-based resources on self-management support and lobby for services and policies to support self-management support for youth and families.

Clinicians, health systems, advocates, and researchers should build on the adult self-management best practices and incorporate pediatric evidence to develop, implement, and promote effective, patient- and/or family-centered, and feasible approaches to self-management support for children and adolescents with complex chronic conditions.

ABBREVIATION

ICF: *International Classification of Functioning, Disability and Health*

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: Supported by the Lucile Packard Foundation for Children's Health.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

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