

# Supporting Self-Management of Chronic Health Problems

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Adoption of a comprehensive model for self-management support (SMS) in pediatric care has the potential to improve health outcomes and to reduce utilization, costs, and caregiver burden. Self-management is “the daily activities that individuals undertake to keep illness under control, minimize its impact on physical health status and functioning, and cope with the psychosocial sequelae of the illness.”<sup>1</sup> It also includes the health behaviors that prevent disease and promote health. Children with chronic or complex physical, developmental, behavioral, or emotional conditions are a unique population for whom self-management activities are valuable, although sometimes burdensome, everyday responsibilities (Table 1).<sup>2</sup> Implicit in the assumption of these responsibilities is the understanding that families and children, to the extent they are willing and able, are active participants in care provision.

The increasing prevalence and duration of chronic illness have produced a growing burden of self-management for children and families and a greater need for an array of supports for them. These are termed “self-management supports” (Table 2) and encompass “the systematic provision of education, supportive interventions, encouragement and assistance to enhance families’ skills and confidence in health promotion and the management of their children’s health problems.”<sup>3</sup> Child health care professionals are well positioned to provide these supports.

Although SMS has been a component of adult chronic care for decades, research suggests that it remains underdeveloped and underutilized in pediatric care. There are few data on the extent of SMSs currently provided as part of chronic care or in the context of well-child care. *Bright Futures* mentions self-management in the chapter on adolescent visits.<sup>4</sup>

Many pediatric practices do provide some kinds of SMS through patient education and provision of written materials. According to the American Academy of Pediatrics Periodic Surveys, >90% of pediatricians offer language-specific materials and services such as urgent advice call-backs, 26% have secure e-mail communication with patients and families, 92% of pediatricians prefer educating patients one-on-one, and just 10% of pediatricians provide group discussions or well-child care in their practices. Expanding SMS is an opportunity for pediatrics to enhance child health outcomes and to reduce utilization, costs, and caregiver burden.

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## EVIDENCE FOR SMS FROM ADULT POPULATIONS

Most experience with and research on generic and disease-specific self-management has involved adults. Generic self-management programs are applicable to patients with a wide range of conditions and focus on skills including goal setting, action planning, symptom monitoring, and problem solving.<sup>5</sup> Disease-specific programs emphasize learning management skills for a particular condition. Both types of programs have been successful in improving outcomes for adults.

Several characteristics of self-management programs for adults are applicable to pediatric care.<sup>5</sup> First, programs should be comprehensive and address management in 3 areas of daily life: medical management, role management, and emotional management. Second, programs should activate and engage patients to support the acquisition of the knowledge, skills, and confidence requisite to their involvement in managing their health and care. Studies have shown that activated patients have better health outcomes and lower health care costs. Programs should also foster social support, because greater levels of reported social support are related to improved self-management behaviors. Finally, programs should focus on those problems to which patients ascribe priority.<sup>5</sup> These problems may not be the same as those identified by the provider but may be the areas in which patients and families are most motivated to improve.

## PROVIDING SMSS IN PEDIATRIC SETTINGS

Lessons from SMS for adults are relevant to the care of children, but the pediatric population has unique characteristics that must be addressed.<sup>6</sup> In pediatric care there are at least 3 participants: the health care provider, the parent, and the

**TABLE 1** Self-Management Skills and Activities

Skills <sup>5</sup>
Problem solving
Decision-making
Resource utilization
Forming partnerships with health care providers
Taking action
Activities
Symptom management
Monitoring for and recognizing symptoms
Responding to symptoms
Managing symptoms and recognizing acute episodes
Medication/treatments
Taking/administering
Refilling prescription
Monitoring for reactions
Using durable medical equipment
Appointments
Scheduling
Attending
Follow-up
General health behaviors
Maintaining diet and physical activity recommendations
Stress reduction and managing emotions
Mindfulness
Monitoring health status
Managing relationships
Health care providers
Family members
Siblings
Friends
School staff
Parent/child
Adapting to changes
Planning
New providers
Transition to adulthood
Continuity of care

child.<sup>7</sup> Pediatric patients are also distinguished by their development; thus, SMSs must be tailored to the changing status of the child and family, from infancy through childhood and adolescence.

As in adult medicine, pediatric self-management programs are already available for certain conditions such as diabetes, asthma, arthritis, epilepsy, cystic fibrosis, and irritable bowel syndrome (Table 3). Positive results have been reported from disease-specific SMS models, most notably for asthma. A recent systematic review of self-management interventions for 4 common chronic pediatric conditions

provided by lay health workers found modest reductions in urgent care use, symptoms, and missed work and school days and improvements in parental quality of life.<sup>8</sup>

SMSs for patients and families fall into several broad categories (Table 2). Informational supports are ways a practice can provide general information on health promotion or disease management. Peer supports are opportunities for patients and families to learn from one another and have been shown to improve parents' belief that they can cope with managing their child's illness. Coaching supports are designed to develop specific skills and may be provided by professionals or through peer networks. Supports for communication between providers, patients, and families come in many forms, all of which can lead to improved health status. Technological supports can facilitate information sharing, help integrate care processes into one's daily life, and increase access to self-management programs at a lower cost than in-person activities. Finally, training on skills to help manage day-to-day family functions, such as stress management, creating care checklists and schedules, and developing a system for managing administration of medications, has been shown to improve adherence and problem-solving skills. Practices need not offer all approaches to all patients and families, but having an array of SMSs available is important.

## ENHANCING THE CAPACITY OF PRACTICES TO PROVIDE SMSS

As described, most pediatric practices provide some SMSs. Anecdotally, self-management education in the pediatric setting is too often a one-time event, occurring at a time of considerable stress, with little reinforcement or individualization. In contrast, research suggests that SMSs should be multimodal, designed to

**TABLE 2** SMSs for Families

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Overarching care processes
Elicit family input on resources and materials
Invite family members to serve in advisory roles
Use written care plans, developed by families and practitioners
Address patient preferences, health literacy, and psychosocial factors
Assess caregivers for anxiety and depression and acknowledge their central role in the child's care
Ask patients and families about their main problems and suggest specific supports on the basis of those issues
Share involvement in communication and decision-making
Focus on increasing patient self-efficacy
Emphasize problem solving
Reassess family and patient needs periodically
Establish a learning health care system
Informational supports
Listings of available community resources
Training on how to evaluate health information
Understanding your condition
Condition-specific class for patients after diagnosis
Disease-specific refresher activities as child ages
Small patient education library in waiting room
Written visit summaries
Patient reminders about needed preventive or follow-up care
Decision aids
Written care plans
Peer supports
Peer liaisons to assist patient/family in achieving goals
Group appointments
Parent mentors
Newsletters for families
Family advisory teams
Support groups
Coaching supports
Sample dialogs for parents to use when speaking with medical professionals
Sessions to practice treatment skills and simulate self-management behaviors
Previsit chart review with coaches
Communication supports
Multiple modes of communication between patient and providers including the following:
Secure e-mail communication
Telephone
Text messaging
Social media
Video-conferencing
Automated disease management programs
Direct provider contact information for critical patients
One point of contact for patient/family
Technological supports
Community building and e-mentorship
Online gaming
Internet-mediated self-management programs, with social network components
Smart phone applications
Robotic devices
Family daily management supports
Stress management programs
Training on skills including managing administration of medications, making emergency checklists, following treatment plans, and tracking appointments
Self-monitoring journals

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provide ongoing, active assistance to families around a variety of skills, and use all available tools tailored to the families' needs and circumstances over the life course.

Although considered a best practice in the care of adults with chronic conditions, comprehensive SMSs are not typically available in pediatric practices and their provision likely

varies widely among practices and providers. It should be a goal of pediatrics to have SMSs become a routine part of care that is embedded in all encounters. To achieve this goal, health care systems, practices, and providers will have to overcome hurdles. Routinizing the provision of SMSs will require reallocating time and resources, and likely adopting some form of team care. Providers must learn and practice new skills and bring a life-course perspective to their patient care. Table 4 provides a list of systemic supports for practices that can increase their ability to provide SMSs and address these challenges.

As with other cognitive services, obtaining payment for SMSs is a challenge, especially in the absence

**TABLE 3** References for Select Disease-Specific Pediatric Self-Management Programs

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**TABLE 4** Systemic Supports for Practices

Role of providers
Provide information
Teach disease-specific skills
Facilitate development of care plan
Collaborate in goal setting
Motivate patients and families
Monitor and give feedback
Provide individual support and sustained follow-up via communication mechanisms
Assist with emotional impact of chronic condition
Staffing
Establish personnel with protected time and appropriate training
Management principles (eg, lean) that ensure that all work of RNs, pharmacists, LVNs, social workers, and trained patients adds value and limits waste, by improving work flow and using less to do more.
Use team approach to care
Nurses providing care between visits
Scheduling
Extended visits
Planned, nonacute visits
Group visits
Quality improvement
Assessment of current self-management practices and effectiveness
Medical home certification
Patient activation measures
Electronic health records that provide follow-up and screening reminders based on clinical guidelines to “detect, organize, and present information to patients and physicians”
Registries for patients with specific conditions

LVN, licensed vocational nurse; RN, registered nurse.

of research documenting a return on investing in enhanced care in pediatrics. Current avenues to pay for SMSs may include embedding

services within global visit reimbursement, billing using Current Procedural Terminology codes for complex chronic care coordination services, financial incentives for quality of care and improved disease management, and providing per member per month capitated payments.

### CONCLUSIONS

In the future, SMSs should be routinely incorporated into the child health care delivery system as an inherent part of health promotion and an essential component of chronic care. To routinize SMSs will require new levels of patient engagement and family-centered care, truly partnering with patients and families. Self-management support is a complex but powerful process that will require the creative use of collaborative health care teams, technology, asynchronous communication, and community resources not typically relied upon. These changes cannot occur unless policy makers and insurers provide incentives to patients, families, and providers to undertake greater SMS. These efforts are worth making, because effective SMS has great potential to help improve health outcomes and to reduce health care utilization, costs, and caregiver burden.

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