Internet Telehealth for Pediatric Asthma Case Management: Integrating Computerized and Case Manager Features for Tailoring a Web-Based Asthma Education Program

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Abstract

This article reports on the development of a personalized, Web-based asthma-education program for parents whose 4- to 12-year-old children have moderate to severe asthma. Personalization includes computer-based tailored messages and a human coach to build asthma self-management skills. Computerized features include the Asthma Manager, My Calendar/Reminder, My Goals, and a tailored home page. These are integrated with monthly asthma-education phone calls from an asthmanurse case manager. The authors discuss the development process and issues and describe the current randomized evaluation study to test whether the yearlong integrated intervention can improve

adherence to a daily asthma controller medication, asthma control, and parent quality of life to reduce asthma-related healthcare utilization. Implications for health education for chronic disease management are raised.

Keywords

asthma case management; medication adherence-pediatric asthma; pediatric asthma; program development-pediatric asthma; nurse case management; chronic disease selfmanagement; eHealth; interactive health communication

Asthma is the most common chronic childhood illness in the United States. Although more than 4 million children (5.8%) have asthma attacks each year, non-White and poor children have twice the rate of severe asthma as White or middle-class children (Dey, Schiller, & Tai, 2004). Pediatric asthma impairs quality of life for parents, children, and the family (Juniper et al., 1996); contributes to costly use of hospitalization and emergency care; and accounts for more than 10 million lost school days and 3 million lost workdays each year (Diette et al., 2000). Avoiding triggers, taking daily asthma-controller medication, and stepping up medications at early onset of symptoms can control asthma (National Asthma Education and Prevention Program [NAEPP], 1997). Avoiding airborne triggers might seem more challenging than following a medication regimen. But, in fact, low medicationadherence rates contribute to high pediatric asthma morbidity and mortality—especially for poor or minority children (Jonasson, Carlsen, & Mowinkel, 2000).

Education and nurse case management delivered via clinic, telephone, or home visits improve pediatric asthma management (Wolf, Guevara, Grum, Clark, & Cates, 2005), but several barriers (inconvenient time and location, lack of ongoing support or phone access) can impede participation in such interventions (Cabana & Le, 2005). Health education programs on the Internet (eHealth) have been used successfully for chronic disease management (Murray, Burns, See, Lai, & Nazareth, 2006). Home eHealth use is increasing across all social strata, and costs of delivery are decreasing (Fox, 2005). Thus, we hypothesized that integrating monthly, telephone, asthma-nurse case management into a tailored eHealth program could improve both case-management delivery and pediatric medication adherence and asthma control (Gustafson et al., 2004).

This article reports on the theoretical underpinnings, prior research, and development processes and issues associated with integrating telephone-nurse case management with the Comprehensive Health Environment Support System (CHESS): Living With Asthma eHealth program (now being tested in a randomized control study).

THEORETICAL UNDERPINNINGS OF THE PROGRAM DEVELOPMENT

Evidence-based research in asthma-medication adherence, educational interventions, and interactive health communication systems informed the program design and development.

Medication Adherence

Factors that affect general medication adherence include complex interplay between the illness experience, beliefs about oneself and the medication's necessity and effects, and personal and social resources—such as asthma knowledge and management skills, communication skills, social support, time, transportation, and money (Gustafson et al., 2001). Pediatric asthma-medication adherence may be even more challenging because parent, child, and family dynamic issues must be considered— especially balancing child autonomy and parental guidance. Two recent studies found that parents overestimate their child's actual adherence

and self-administration skills, which in turn accounts for poor asthma control (Grus et al., 2001; Schmaling, Hernandez, & Giardino, 2003; Winkelstein et al., 2000). Interventions to improve parental oversight must thus address asthma knowledge and skills for asthma management as well as parenting, communication, and self-care (Mansour, Lanphear, & DeWitt, 2000). In so doing, asthma management programs should address specific learning components outlined by self-regulation and self-efficacy theories (i.e., intrinsic goals, planning, self-monitoring) by providing information, guided feedback, and social support (Bodenheimer, Lorig, Holman, & Grumbach, 2002).

Educational Nurse Case-Management Interventions

Education using the NAEPP's (1997) Expert Panel II Recommendations has improved adherence to daily controller medications, asthma control, and quality of life (Wolf et al., 2005). Programs that build asthmamanagement skills have been more effective than those that merely provide basic information (Bodenheimer et al., 2002). But child care or transportation constraints inhibit participation in face-to-face programs— especially for the underserved (Lemaigre et al., 2005). Moreover, group sessions with preset instructional protocols do not provide timely individualized support that can help people master new skills nor the dialogic and reflective learning opportunities to adapt course material to idiosyncratic challenges (Hiemstra & Sisco, 1990). Face-to-face or telephone-nurse case management— with individual sessions to tailor asthma action plans, regular follow-up, and physician consultations—can overcome these limits (Greineder, Loane, & Parks, 1999). Nurse management has reduced asthma-related emergency care and hospitalization costs (Sullivan, 2005), but managing complex pediatric cases is labor and skill intensive (Lemaigre et al., 2005; Schulte, Musolf, Meurer, Cohn, & Kelly, 2004).

Interactive Health Communication (eHealth) Systems

eHealth systems with information, interactive planning tools, and communication with peers and experts have improved chronic disease management (Murray et al., 2006). Pediatric asthma eHealth programs using games, experiential learning, or skill-building exercises have focused primarily on the child. One had no effect (Huss et al., 2003), but others have improved asthma knowledge, self-efficacy, and behavior (Bartholomew et al., 2000; Krishna et al., 2003; Lieberman, 2001; Shegog et al., 2001). Tailored eHealth programs use patient data to provide relevant learning activities. Computer algorithms are more effective for reinforcing straightforward clinical guidelines than for coaching on complex psychosocial issues. Such tailoring requires large amounts of timely data, which may burden the user and raise privacy concerns. It also entails processing multiple variables, maintaining a large roster of canned responses, and increasing development and operating costs. Berk, Blank, Daniels, and Schatsky (2003) estimated that highly tailored systems cost 4 times more to operate than nontailored ones. Moreover, computer algorithms cannot match a skilled nurse's ability to read subtle cues (e.g., tone of voice, facial expression) nor sustain a responsive problem-solving dialogue. In fact, the jury is still out on whether users will accept highly personalized interfaces (Jupiter Research, 2003). Thus, we asked whether busy parents would use highly tailored systems enough to reap sufficient benefits.

Integrating eHealth With Case Management

To transcend these limits, some asthma eHealth programs integrate patient data with a nurse educator or case manager (CM). For adult patients, Finkelstein, O'Connor, and Friedman (2001) improved medication adherence using computerized peak-flow metering and self-reported symptoms to tailor eHealth education and prompt a nurse educator or physician to phone when needed. Adams et al. (2003) integrated electronic medical records with telephone patient self-reports to support nurse case management and clinical decision making.

"Health Buddy" improved the asthma outcomes of inner-city children (Guendelman, Meade, Benson, Chen, & Samuels, 2002). It included interactive telephone education; 11 asthma questions (each followed by a short tailored message); a clinic-based, asthma education session with a nurse who had reviewed the telephone data; and a physician examination. Chan, Callahan, Sheets, Moreno, and Malone (2003) found that e-mail pharmacy case management might have promising results for pediatric asthma behaviors. This program also included daily, interactive video monitoring (of the child's adherence and skill for medications, peak flow, and asthma diary), and either in-office or Web-based asthma education. At 3 months, medication adherence improved considerably but had diminished to 50% at 6 months (and only 7% for asthma diary adherence). The lack of usual care control group, small sample size, high attrition rate, and diminishing adherence rates suggest that integrating video monitoring with e-mail case management warrants more investigation. In sum, integrated systems can combine the strengths of 24/7, tailored eHealth with a face-to-face or telephone-nurse asthma case management. Most interventions focus primarily on the child, but given the importance of parental oversight and self-efficacy in pediatric asthma control (Grus et al., 2001; Schmaling et al., 2003; Winkelstein et al., 2000), we decided to focus primarily on building the parents' self-efficacy to help children manage their asthma and secondarily on building the child's asthma self-management skills (Mansour et al., 2000). As we describe below, we did this by developing separate online interfaces for the parent and the child—but provided the monthly, telephone case-management call primarily to the parent. Moreover, because adherence to peak flow and diaries is even lower than for medications, we used all our "adherence capital" on medications.

INTEGRATING TELEPHONE-NURSE CASE MANAGEMENT INTO ONLINE ASTHMA EDUCATION

The National Institute for Nursing Research funded "Internet Telehealth for Pediatric Asthma Case Management" to improve pediatric asthma control and medication adherence by integrating telephone case management with asthma eHealth. The project built on the Comprehensive Health Enhancement Support System (CHESS), which has developed and evaluated programs that provide technical, behavioral, and psychosocial support for managing several health conditions (Gustafson et al., 2002, 2005; Meis et al., 2002; Wise, Yun, & Shaw, 2000). CHESS content is guided by needs assessment (Boberg, Wang, Johnson, & Gustafson, 1998); reviewed by experts; organized into information, communication, and interactive skill-building services; and navigated by keyword, hierarchical menus, and tailored feedback based on user data. CHESS has improved quality of life, information competence, perceived social support, and health care utilization (Gustafson et al., 1999, 2002, 2005). The Living With Asthma program expands CHESS's scope by integrating telephone case management with in-depth, tailored eHealth selfmanagement education and establishing independent content for the parent (primary audience) and child (secondary audience).

Program development was guided by chronic disease self-management education (Lorig et al., 2001). Using self-efficacy theory (Bandura, 1997), self-management education creates patient-generated action plans to address medical self-management (e.g., symptom and trigger monitoring, taking medications), meaningful life goals (e.g., job or school, family and friends), and emotions and asthma-related limitations (Bodenheimer et al., 2002). We supplemented this research with in-depth interviews and focus groups with low-income parents and children. These firsthand accounts uncovered daily barriers to asthma management—such as uncooperative child and family—to tailor check-in feedback. They also uncovered several strategies. For instance, parents and children did not use peak-flow meters, but many had developed their own ways to read early onset of asthma (e.g., a droopy left eye, a subtle change in breathing) that signaled them to step up medication. Finally, we learned that children and

parents had considerable computer experience and/or interest. We also worked closely with the CMs, who reviewed and enriched CHESS content, guided the interface design, and refined the implementation protocol. Our primary focus was to improve parental guidance of child-self management. Thus, we established independent and overlapping content for both parent and child to facilitate parent, child, and family knowledge, skills, and communication.

Conceptualizing the Infrastructure: Data Sharing and Analysis

Integrating telephone case management with the tailored CHESS eHealth system required data sharing. As shown in Figure 1, CHESS collects and uses patient/ parent data (data inputs) to facilitate case-manager activities and tailor CHESS services (data outputs). Box 1 shows "Parent eHealth inputs" including (a) child's asthma profile (medications, triggers, home environment, and quality of life); (b) biweekly check-in of asthma status, medication adherence, exposure to triggers, and quality of life; and (c) CM mail, intra-CHESS secure e-mail in which parents communicate with the CM. Box 2 shows the "Case Manager Activities" that use parent input data including (a) monthly phone calls to the parent and (b) reading parents' CM mail messages. These CM activities result in "Case Manager and eHealth Outputs" to the parent (Box 3). These allow the CM to (a) recommend and post CHESS items on parents' home page, (b) summarize phone-call sessions for CM notes and e-mail to parent, and (c) respond to parents' CM mail messages; parent inputs are also used to tailor check-in feedback.

Core CHESS Services, Asthma Manager, and Interfaces for Three Different Audiences

The separate interfaces for school-aged children and CMs built on core CHESS services. Material was written for a sixth-grade reading level and reviewed by the CMs and by external asthma and allergy clinicians. The CM's interface was developed and tested in collaboration with the nurses who would later use it with their monthly case-management phone call. All three audiences have sidebar access to the core CHESS services, but the center of each interface is adjusted to the specific audience.

Core CHESS services, shown in Figure 2 (Box A), are available to all audiences. They are grouped into (a) information, (b) communication, and (c) interactive services.

Seven information services address the medical, behavioral, psychosocial, and socioeconomic aspects of pediatric asthma: (a) quick information provides about 300 items supplemented by audiovisuals and quizzes; (b) the library offers articles screened for currency, accuracy, and quality; (c) instructional videos show children using asthma medication and peak-flow devices; (d) personal stories features real-life accounts of parents' and children's asthma experience, challenges, and insights; (e) the resource guide includes tutorials on savvy use of health and social services, (f) local referrals provides information and links to local health, parenting, and social services; and (g) Web links displays high-quality asthma and parenting Web sites.

Three communication services include (a) discussion groups, passwordprotected asynchronous peer support groups facilitated by a CHESS researcher; (b) CM mail, intra-CHESS secure e-mail in which parents query the CM and receive an answer within 2 business days; (c) CM picks allows each CM to recommend and post CHESS items on the parent's home page.

Eight interactive services provide skill-building exercises with links to information and resources: (a) mood assessment, a screen for depression symptoms and information on contacting physicians; (b) stress assessment and feedback; (c) reframing automatic negative thoughts, or self-guided cognitive behavioral therapy; (d) journaling, open and guided exercises; (e) calendar/ reminder; (f) trigger action plans; (g) medication coach; and (h) goals.

The Asthma Manager (Figure 2, Box B) was newly developed for this project and includes check-in/ feedback, medication coach, and a tailored home page. It addresses the following

educational objectives: monitoring child's asthma, improving asthma management and quality of life, and encouraging participation in a monthly case-management phone call. Every 2 weeks, CHESS automatically prompts parents to "check-in" on the child's asthma status, medication adherence, trigger exposure, and parent, child, and family quality of life. The feedback message summarizes the child's asthma status with an option for more detail about the other factors. Brief feedback messages offer links to relevant Asthma Manager or core services.

Medication coach, shown in Figure 3, provides educational modules with information and practical exercises to overcome barriers to adherence. For instance, "Working Well with Doctors and Nurses" helps parents prepare a list of questions for their next appointment, and "Convenience in Getting Medications" links to the parent's pharmacy Web site for prescription refill and delivery.

The parent's home page, shown in Figure 4 with dummy data, displays personalized tools from the Asthma Manager. The left sidebar provides access to all CHESS core content by topics and service (including "For Kids," the child's interface). My Calendar and My Reminder (lower left and center) facilitates scheduling for asthma management and family activities. Parents select from a preset list of asthma management and family activities (prescription refills, doctor visits, school events, or birthdays) or add their own activity. When prompted, they designate who will do it and set a deadline. Clickable reminders are displayed for a full week before the event. Trigger action plans for cockroaches, dust mites, mold pet dander, and tobacco smoke use the calendar/reminder structure. Each plan links to information, has a preset list of activities (e.g., buying dust mite covers, removing mold), and offers prompts to assign tasks and deadlines. "My Goals for Living Better with Asthma" (upper-center column) uses intrinsic goal setting (Bodenheimer et al. 2002) to coach parents to select and achieve real-life goals that are *directly* (e.g., knowing early signs of an attack) or *indirectly* (e.g., keeping up in school, having a normal family life) related to asthma. Parents select a goal, get a motivational message with links to relevant CHESS content, and assess their progress biweekly via CHESS and with CM in the monthly call. "Case Manager's [Elisha's] Picks" is the centerpiece of the parent's home page. It links to CHESS content recommended by the parent's assigned CM after the monthly phone call.

Children's home page—In focus groups and interviews, 4- to 12-year-old children said they were proficient, comfortable, and intrigued with computers. Parents acknowledged that children might encourage and help them use CHESS. "For Kids" presents child-friendly information and activities about asthma, health, selfesteem, and getting along in school as well as recreation, friends, and adolescence. To accommodate the wide range of developmental stages and reading skills in our target 4- to 12-year-old audience, a digital character named "Audrey" narrates basic asthma information. Children can link to more detailed *"kid"* information or to the core CHESS services on the sidebar. To keep the content engaging, asthma facts are presented through interactive quizzes, instructional videos show step-by-step use of medication devices, and personal stories give examples of how other children have learned to live with asthma. To encourage self-expression and creativity, CHESS offers a kids-only discussion group and an art gallery for children to display their drawings, paintings, photography, poems, essays, and stories.

The Nurse Case Manager home page, shown with dummy data in Figure 5, organizes the caseload data alphabetically by the child's codename. The data are displayed in eight fields: (a) parent codename and date of study entry and last login; (b) child codename and date of birth; (c) parent/child profile (collected at the intake interview), including asthma history, medications, barriers to adherence, triggers, indoor environmental quality, and parent/child quality of life and goals for living with asthma; (d) monthly phone call manager with a template

to summarize the call and send it to parent's CHESS mailbox and a call scheduler to post on the parent's calendar/reminder; (e) Check-In CM can see current and previous parent data; (f) CM mail to write, send, and review parent messages; (g) Notes, an archive of all phone-call summary notes; and (h) Recommend (column 1) is a prescription pad to select and post salient CHESS items on the parent's home page and see which recommended items were accessed.

CHALLENGES IN DEVELOPING THE ASTHMA MANAGER AND CASE MANAGER TOOLBOX

Developing the tailored CHESS and CM features presented many exciting challenges given the diversity of the interdisciplinary team of researchers, designers, and clinicians. Three goals guided our collaboration— to improve medication adherence and asthma control, to optimize parents' CHESS use, and to best integrate the CMs.

Improving Medication Adherence and Asthma Control

Encouraging medication adherence and asthma control behaviors needed to address the parent's motivation and skills against the complicated set of barriers they faced. In choosing check-in questions and feedback style, we weighed researchers' preferences for hard peak-flow measures against front-line cliniciansand parents' overwhelming dismissal of it. Because improving peak-flow adherence was not our research objective, we decided to put all our adherence efforts into medication adherence, a direct objective and one with a greater likelihood of success. Research has since found that adding peak flow to symptom-based monitoring had no effect of pediatric self-management asthma (Wensley & Silverman, 2004)

Optimizing Parents' CHESS Use and Benefit

Optimizing parent's CHESS use entailed assuring that the check-in and feedback functions were relevant and easy to use. Our focus groups and interviews confirmed that parents had significant time constraints and low computer literacy. Thus, we decided to ask as few (just six) check-in questions with the simplest responses (yes/no or checklist) as possible. Likewise, in designing the feedback, we strove to assure that parents could access the feedback and medication coach when needed but to not nag them to the point of avoiding CHESS.

We considered the amount, depth, and pace of the feedback. We considered providing (a) feedback immediately after each check-in answer, as per "Health Buddy" (Guendelman et al., 2002); (b) a comprehensive response that addressed each answer after completing the entire check-in; or (c) a short feedback message on symptom status with options for more detailed feedback (or to go right onto their home page). We rejected the two uninvited feedback options because they not only took extra time, but it also ran counter to adult learning principles of autonomy and presenting material at the "teachable moment." Thus, we selected the third option, which allowed parents to select an asthma-control or quality-of life issue and to control the amount and pacing of the educational material. For instance, parents choosing to work on medication taking can select the most relevant module from the Medication Coach (see Figure 3).

In deciding how much to tailor the feedback, we considered the current limits of computerized tailoring, minimizing responder burden, and the likelihood that many barriers to adherence would remain stable from one check-in to the next and yield repetitive, "robot-like" feedback from session to session. Thus, we decided against highly tailored computerized feedback and opted for the CM to individualize CHESS after the monthly phone call.

Integrating the Case Managers Into CHESS: Optimizing Their Use of CHESS

Integrating the monthly CMs' phone call into CHESS entailed creating an interface that would easily facilitate the multiple tasks (scheduling, planning, reviewing parent/patient data, follow-up and CHESS recommendations, and field notes). To that end, we collaborated with the asthma nurses, who would later use it. The following four factors led to a successful collaboration:

1. Honoring their clinical expertise: They reviewed and created content and designed the implementation protocols.

2. Eliciting and satisfying their needs for user-friendly interface to facilitate efficient caseload management.

3. Respecting that practitioners, researchers, and designers approach issues differently.

4. Having CMs test their interface with dummy data and revising it to their requests.

With the "prescription pad," the CM can select and post salient CHESS content on the parent's home page and see which content the parent accessed. Because of these multiple functions, the tool was limited to only one of CHESS's three search strategies. In the process of designing and testing, we learned that the nurse CMs had different information-seeking styles than the Web site designers and content developers. Hierarchical topic menus, keyword indexes, and within-service searches were considered. The first prototype used keyword index (a method favored by information experts on our design team), but the CMs found that scrolling through the 200-plus alphabetical index was too cumbersome for selecting items from several categories. Guided by CMs' preferences, the final version used a flat-topic menu approach (e.g., Triggers, Medications), which were then subdivided by service (e.g., Quick Information, Library). CM training entailed using the toolbox to prepare for, conduct, and follow-up on phone calls during a period of time with role-plays of different parent/ child profiles. Thus, in addition to understanding pediatric asthma-management challenges, the CMs became intimately knowledgeable about CHESS content and structure before they began their field implementation.

DISCUSSION

This article described how an interdisciplinary team developed the CHESS: Living With Asthma eHealth system integrated with monthly telephone asthma case management. The system is now being tested in a randomized control trial to evaluate whether and how it affects medication adherence, asthma control, healthcare utilization, and parent's asthma quality of life. Four hundred parents of children with moderately to severely persistent asthma are being recruited through HMO and Medicaid claims databases and stratified by Medicaid status, asthma severity, and recruitment site. Enrollment occurs at a clinic; the CM recruits parents of study-eligible children, obtains consent/assent, and administers the intake interview, pretest survey, and child spirometry. On receipt of a 2-week asthma diary, parents are randomized to CHESS or the usual care control group. The CHESS group receives a training session on using CHESS and computer (a computer and Web access are provided, as needed).

Adherence measures include pharmacy refill data, survey questionnaire, and a 2-week asthma diary every 3 months. Measures for asthma control include Juniper, O'Byrne, Guyatt, Ferrie, and King's (1999) Asthma Control Questionnaire, claims data for reliever-medication refills, spirometry, and asthma-related health care utilization. All participants come to the clinic with their 12-month posttest and diary for the exit interview and child spirometry. Parents receive a small financial incentive on receipt of each survey, and children receive a gift certificate for receipt of each asthma diary. Automatically collected CHESS use data will address process questions: Will busy parents use CHESS and participate in the monthly CM calls? Will they

use CHESS? Who prefers CHESS, the CM, or the combined services, and why? What was the use and effects of the different CHESS features?

In sum, parents, clinicians, designers, and researchers worked together to develop a "high touch" and "high tech" Web site to help parents manage their children's asthma. The clinical trial will not only inform us about the effects of integrating telephone case management into comprehensive patient or family education but also will advance the science of integrating technology with clinic-based patient education for asthma and for other chronic disease self-management. We hope that CHESS helps families to live better with asthma.

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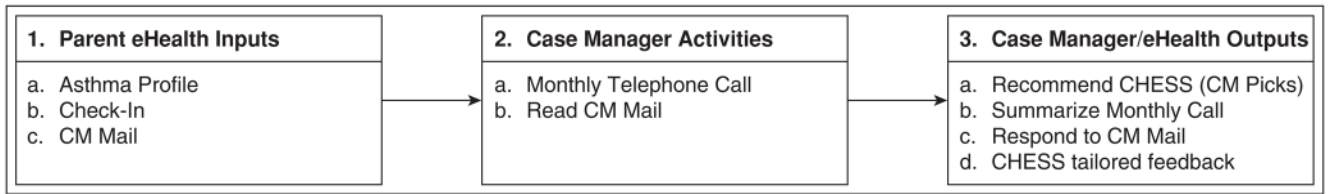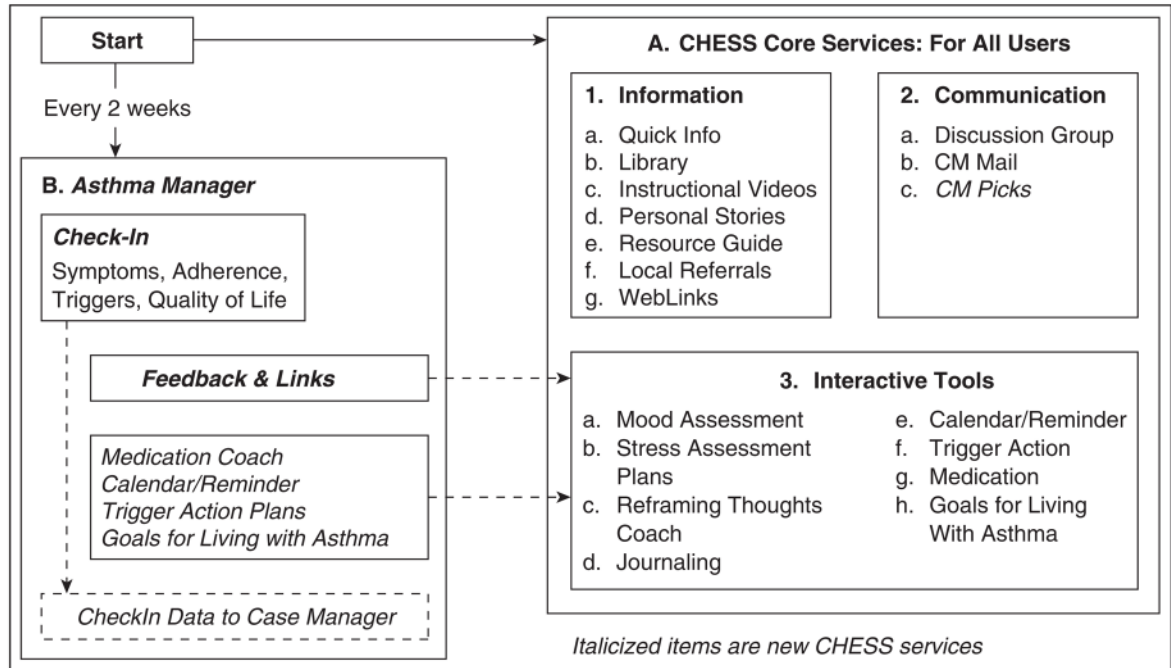
1. Parent eHealth Inputs	2. Case Manager Activities	3. Case Manager/eHealth Outputs
a. Asthma Profile b. Check-In c. CM Mail	a. Monthly Telephone Call b. Read CM Mail	a. Recommend CHESS (CM Picks) b. Summarize Monthly Call c. Respond to CM Mail d. CHESS tailored feedback

FIGURE 1.
Data Inputs and Outputs

FIGURE 2.
Model for the CHESS Parent Interface and Operation

Medication Coach

1. Working Well with Doctors and Nurses
2. When Asthma Medication Doesn't Seem Necessary
3. Dealing with the Cost of Asthma Medications
4. Making Medications Part of a Daily Routine
5. 10 Ways to Make Medication Taking Easier
6. Convenience in Getting Medications
7. When Asthma Medications Don't Seem to be Working
8. Remembering Medications
9. Dealing with Side Effects
10. Finding Support in Managing Your Child's Asthma
11. Understanding Asthma Medications
12. Getting Your Child to Take Asthma Medications

FIGURE 3.
Medication Coach Menu
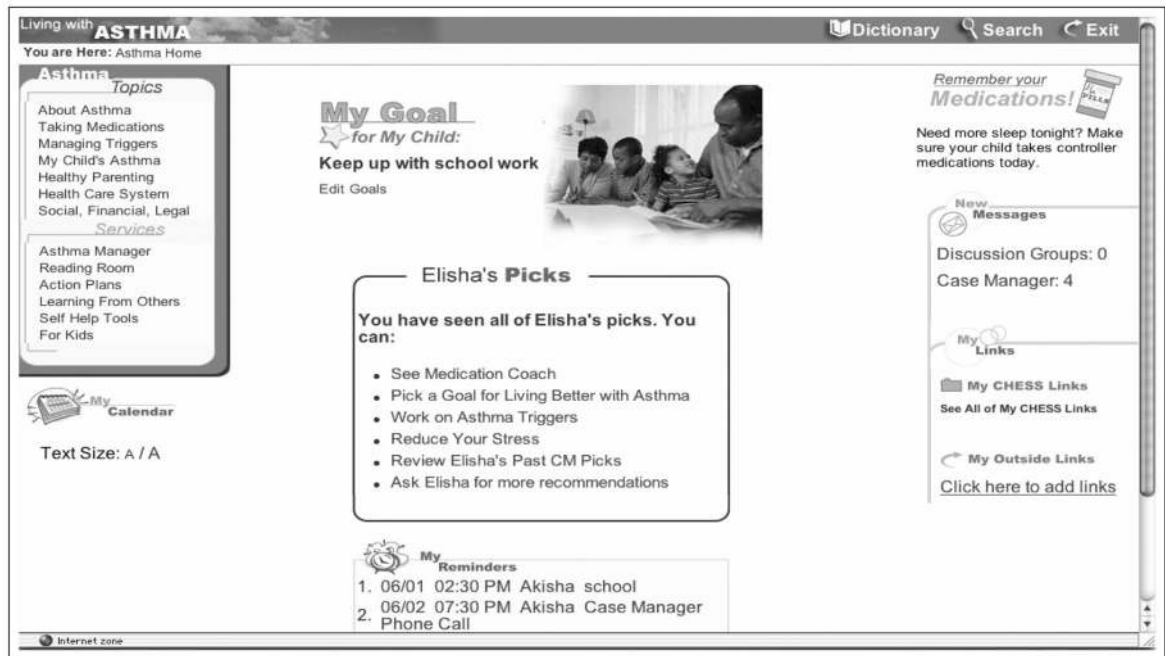
FIGURE 4.
Parent Home Page

FIGURE 5.
Case Manager Toolbox