



Patient & Family Self-Management

In This Issue:

- 1 Introduction
- Improving Outcomes for People with Chronic Conditions
- 2 Sign up: Electronic Subscription
- 3 Editorial: Quality of Care for Children and the Role of Patient Self-Management
- 7 Outreach Worker Fosters Asthma Self-Management Among Families
- Camp Super Breathers: Asthma Management for Children
- 8 Self-Management Concepts Applied to ADHD in Children
- 9 Services for Refugee Families with Children with Disabilities
- 10 Patient Self-Management in Community Health Centers
- 12 Calendar
- References and Resources on Web

Introduction

The term “patient self-management” may not be in the vocabulary of most in MCH. Is it only a new name for case management, health education, or outreach? Patient self-management encompasses these activities and goes beyond them to include the system within a medical practice as well as routine assessments of effectiveness.

The ground-breaking work on patient self-management as part of health care quality improvement is supported nationally by the Bureau of Primary Care within the U.S. Health Resources and Services Administration. This model was developed for the care of people with chronic illnesses. Though applications to children are still few and far between, some of that work is being done in the Northwest.

New models of care delivery are always scruti-nized closely by those who must live with the implementation: providers and patients. At first glance, patient self-management may seem to be a reincarnation of past system changes that shifted patient care responsibilities inappropriately to vulnerable patients or their parents as part of cost-cutting efforts. Major issues in

Continued on page 2



Improving Outcomes for People with Chronic Conditions, Including Children

By Judith Schaefer, MacColl Institute for Healthcare Innovation, Group Health Cooperative of Puget Sound, schaefer.jk@ghc.org, (206)287-2077

Chronic illnesses represent the most prevalent and expensive health care problem in the US today. Although older persons represent the highest prevalence group, the incidence of some chronic conditions in children and teens is increasing dramatically as well. Childhood diabetes, depression, obesity, ADHD, and asthma are all on the rise. Yet most management of chronic illness takes place outside the medical setting, performed day to day by the people with the illnesses and their families. Growing realization of this fact is having a profound effect on the organization of health care for people with chronic conditions.

Self-Management and the Chronic Care Model

Although medical providers and systems have important roles to play in medical management of chronic illness, the behaviors crucial to carry out treatment regimens and to maintain functional lives and meaningful relationships occur away from medical providers and outside systems of care. These activities have come to be called self-management.

Continued on page 5

Sign up now!
ELECTRONIC
SUBSCRIPTION
to NW Bulletin
 See page 2 for details

Northwest BULLETIN: Family and Child Health is published periodically for the Northwest Region by a consortium of organizations including the Maternal and Child Health Program, University of Washington (UW) School of Public Health and Community Medicine, and the Healthy Mothers, Healthy Babies Coalition of Washington State, with support from the Public Health Seattle-King County, the Western Washington Chapter of the March of Dimes Birth Defects Foundation, and the Bureau of Parent-Child Health Services, State of Washington Department of Health, and the state health departments of Alaska, Idaho, Oregon, and Washington. It is produced under MCH Grant #6T76MC00011, with additional grants and in-kind contributions.

Editorial Board

Michelle A. Bell, Associate Professor, Maternal and Child Health Program, School of Public Health and Community Medicine, University of Washington

Anna Hundt, Public Health Seattle-King County

Rachel Hein, Western Washington Chapter, March of Dimes Birth Defects Foundation

Carolyn Gleason, Regional Nutrition Consultant Public Health Service, Region X. U.S. Department of Health and Human Services

Cynthia Shurtleff, Healthy Mothers, Healthy Babies Coalition of WA State

Talibah Chiku, NW Regional Primary Care Association

Lisa Simono, Family and Community Nutritionist, Maternal Child and Family Health, DHHS, State of Alaska

Helen Stroebel, MCH Consultant, Idaho

Molly Emmons, Center for Child & Family Health, Oregon Health Division

Janna Halvorson, CHILD Profile Manager, Maternal and Child Health, Washington State Department of Health

Ruth Francis Williams, Maternal and Child Health, Washington State Department of Health

Board Editor of this Issue: Talibah Chiku

Guest Editor: Judith Schaefer, Group Health Cooperative of Puget Sound

Managing Editor: Deborah Davis Stewart

Comments about the *Northwest Bulletin* and reports of maternal-child health-related news from throughout the Northwest, activities of state legislatures, upcoming meetings and events are welcome; however all materials submitted are printed at the discretion of the Editorial Board.

Comments and other correspondence should be addressed to: Deborah Davis Stewart, Managing Editor, **Northwest BULLETIN**, Maternal Child Health Program, Box 357230, U.W., Seattle, WA 98195-7230, stewad@u.washington.edu.

The web site is: <http://depts.washington.edu/nwbfch/>

Introduction, continued from page 1

that effort were lack of systemic follow-up, oversight, and evaluation, along with lack of sensitivity to barriers and cultural issues.

This issue includes an explanation of the model for care of adult chronic conditions developed by the MacColl Institute of Group Health Coop-erative of Puget Sound, with applications pertaining to people within the context of primary health centers. Ways in which the model is being adapted for care of children with asthma and ADHD are also featured, as well as a new project for recent immigrants with children with special health care needs. The usual presentation of state reports is omitted, since application of the model to children's needs is not yet widespread.

The goal of *Northwest Bulletin* is to provide information to MCH and public health professionals about trends and issues. The treatment and management of chronic conditions involve an increasing amount of time and money. Patient self-management is one new tool to improve practice. The challenge for *Northwest Bulletin* readers is to understand this new trend and its possible applications in their practices or organizations. While this topic may not be strictly a public health issue, it does potentially affect the quality of the lives of many children and families. In particular, it could affect the care for children with Medicaid coverage and groups that are a focus of the public health sector, such as immigrant families. This is an area where public health and clinical medicine overlap to help address the needs of children and families with chronic care needs.

Subscribe to Free NW Bulletin On-Line

NW Bulletin will soon be available primarily on the web. Issues will be posted in PDF format on the Northwest Bulletin: Family and Child Health (NWBFCHE) site. Readers can sign up there for notification of new issues. Many back issues also will be posted there.

To Subscribe

Go to the website: <http://depts.washington.edu/nwbfch/> and click on "To Subscribe" at the bottom of the home page. This will give you instructions for entering your e-mail address into the system.

How NW Bulletin will appear

We will post issues as PDFs (Portable Document Format). Acrobat Reader, which handles that format, is easy to obtain, and free. To download, click on the yellow "Get Acrobat Reader" button on our site. Whenever you select a PDF file, the Reader will open it automatically.

Newsletters will be formatted as they are at present. That will allow you to print attractive copies from the PDFs and make reprints, should you wish to share the issues with colleagues or take them to a conference.

Please help spread the word

The Editorial Board would like your help in promoting on-line subscriptions. On the site you will find a flyer that you can download and distribute at meetings and conferences. Please also share the news with other on-line news groups or e-mail lists in your state or discipline.

Editorial

Quality of Care for Children and the Role of Patient and Family Self-Management

Charles Homer, MD

National Initiative for Children's Healthcare Quality,
a program of the Institute for Healthcare Improvement

The Institute of Medicine (IOM) recently affirmed that the purpose of the health care system is "to continually reduce the burden of illness, injury, and disability, and to improve the health and functioning of the people of the United States." To fulfill this purpose, the IOM urged the health care system to adopt as its vision the achievement of six aims: safe, effective, efficient, patient-centered, timely, and equitable care. The IOM reported that these aims were key to meeting the needs of persons with chronic conditions, a group that is both most vulnerable and currently ill-served by the health care system.

Although the IOM report itself scarcely mentioned specific health care concerns faced by children, issues of quality of care are essential to children's well being. Many observers rarely consider child health issues when considering problems in quality, or strategies for its improvement. Yet all children require health services for preventive care and anticipatory guidance, almost all need treatment of acute conditions, and a significant number (possibly as high as 25 percent) for the treatment of one or more chronic conditions.

The health status of children has improved in dramatic ways over the past several decades. Infant mortality has plummeted. Common, severe infectious diseases—such as measles, hemophilus influenza type B infection, polio—have all been profoundly reduced. Most children with severe congenital disorders, such as cystic fibrosis, now survive to adulthood. Many of these advances have occurred because of real break-throughs in medical science.

Yet advances in technology and science have masked deficiencies in the ways care is delivered for children. Evidence indicates that many children receive services they don't need—for example, antibiotics for viral infections, or tympanostomy (ear) tube placement with insufficient justification. Conversely, often children don't receive treatments we know are effective—for example, fewer than half of children with chronic asthma receive maintenance anti-inflammatory therapy. Medication errors in the care of children are at least as high as errors in caring for adults. (1) Moreover, parents report problems in communication, problems that become even more pronounced when the child has a chronic condition. (2, 3) Taken as a whole, this evidence highlights the need for improvement in children's health care, and the potential for a new and better way of

providing care to make a difference in children's lives. The chronic care model developed at the MacColl Institute in Seattle effectively improves the system of care for children. We in the National Initiative for Children's Healthcare Quality, a program of the Institute for Healthcare Improvement dedicated exclusively to improving quality of care for children, have adapted this model with some minor—but significant—modifications. We have applied it in initiatives to improve care for children with asthma and children with attention deficit hyper-activity disorder. We also find it a useful framework for our efforts to improve preventive services, and are beginning work to apply it to the generic health care needs of children with special health care needs (not limited by a specific condition).

As described elsewhere in this issue of *Northwest Bulletin*, the model specifies that a health care system oriented toward caring for persons with chronic conditions requires leadership and alignment at the organizational level; an information system that enables proactive management of the entire population under care; the incorporation of evidence-based recommendations into the clinical care environment; the design of the delivery system to emphasize team-based care and proactive management over time; and close integration between the health care system and the community—all in the service of supporting the patient's ability to manage his or her own care.

In child health, we are hampered for many conditions by the limitations of the evidence base with which to guide care. Some conditions are so rare, or so ill studied, that good evidence about treatments that work just are not available. However, for many other conditions—such as asthma or ADHD—the evidence does exist, and simply must be implemented.

Children are more disadvantaged economically as a group than adults and are in a period of rapid development. These characteristics make the larger community a more important element of the care model, as reflected in the asthma support program provided at the Odessa Brown Children's Clinic in Seattle, Washington. We have found that establishing links with schools and day care is an almost universal requirement of providing coordinated and integrated health care services to children with special health needs.

The most obvious difference, though, between chronic care for many adults and care for chronically ill children is that young children are cared for by their parent(s) and older children divide responsibility for self-care with their parents

Continued on page 4

Editorial, continued from page 3

while assuming an ever increasing role. Thus, the unitary concept of self-management support becomes the somewhat more complex concepts of child self-management support and parent/family-management support.

Addressing and supporting the parents' role in managing their child's illness is in some ways easier for the care team than adult self-management support. The parent does not personally experience the condition being treated, so they do not feel ill themselves or experience the side effects of medications. At the same time, parents may either over-estimate or under-estimate symptoms or impairment. They also may be paralyzed by guilt or denial, or too preoccupied with the many tasks and responsibilities of raising a family to focus on the child's management needs. These conditions speak for using the same approach to parent and family management as to self-management—identifying current perceptions and priorities, clarifying readiness and capabilities, and formulating joint goals and plans for achieving them.

In our work with over 100 clinical care teams, we have found that, at the outset of our activities, clinicians most often identify the parent as the source of the problem in management. “Why don't they come back for follow-up visits?” “Why won't the parent keep the child on their preventive medicine?” “Why can't they follow through on what I've told them to do?” are typical complaints we hear when we ask clinicians to identify barriers to improved outcomes for the children in their practices. Getting practice teams to undertake traditional educational activities has been relatively easy (if poorly reimbursed). Working with them to identify the parent's actual treatment goals, develop shared treatment approaches, assess confidence in fulfilling these approaches, and then revise plans takes longer but is ultimately far more rewarding. We have begun involving parents and children directly in our training programs, for example, in panels during which they have the chance to describe their perceptions of their condition and their care. Such panels have profoundly affected the focus of the clinical teams that are trying to improve their work.

Some pediatric practices have gone even further than individual goal setting. In addition to taking to heart their role in supporting parent and self-management, these practices have involved parents of children with chronic conditions in the overall management of the practice—helping design practice policies and procedures, serving as liaisons between parents and the care team overall. Several programs with such parent liaisons exist across the country.

The challenges become greater as the child with a chronic condition matures into middle school age and adolescence. Such children increasingly need to be directly involved in their care, and—particularly in adolescence—have effective

veto power over any management approaches that do not address their goals and their needs. A powerful video documentary filmed by adolescents with asthma who were working with Michael Rich, MD, at Children's Hospital, Boston, graphically demonstrates the profound gap between what clinicians see and hear about a teen's life with a chronic condition, and the reality of these children's lives.⁽⁴⁾ Self-management support with teens is all about breaking down the barriers to communication, and honestly negotiating about goals and approaches to meeting them. At the same time, parents need to remain ultimately responsible and also need to be engaged in goal setting and planning. Some of the goal setting and negotiation for care of children with special health care needs is in many ways little different than that with which any parent needs to engage in an adolescent—clarifying what the limits are and where the responsibilities rest. The difference is that the clinical team is also involved, and the immediate and long term health stakes are large. In many practice settings, having a team approach—with nurses or social workers—helps facilitate this involvement.

Outcomes for children have improved enormously over the past two decades through the application of basic science to the health problems of children. A comparable focus on improving the delivery of care, particularly emphasizing the central roles of children, parents, and families in managing a child's condition and well being, is likely to achieve similarly profound results. Such a focus can bring clinicians, parents, and children to the same side of the table—both looking at how to solve a common problem rather than blaming the other for failing. Practice teams can make real improvements by taking several simple steps:

1. Make a commitment to improving the care you deliver by being more focused on addressing patient- and family-centered needs.
2. Learn about methods to promote positive behavior change—read work by Kate Lorig, Russ Glasgow, and Noreen Clark.
3. Involve parents and youth in the process—find out what they think. Ask them open-ended questions; run a focus group; ask them to film their struggles with living with their chronic condition and to review it with you.
4. Involve your colleagues—improvement is a team sport.
5. Start to make changes right now—small ones, bit by bit. Don't be afraid to fail, and learn from your “failures.” Your patients and their families will benefit, as will the care you provide to them.

Charles Homer, MD, National Initiative for Children's Healthcare Quality, www.nichq.org

- 1) Kaushal R, Bates DW, Landrigan C, McKenna KJ, Clapp MD, Federico F, Goldmann DA. Medication errors and adverse drug events in pediatric inpatients. *JAMA*. 2001 Apr 25; 285 (16): 2114- 20.

Continued on page 5

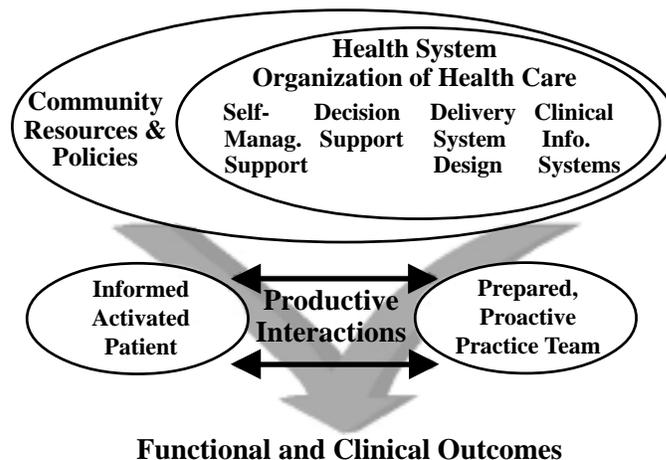
Improving Outcomes, continued from page 1

Awareness of the central role played by patients and their families in managing chronic conditions is reflected in a model of care developed in the Northwest by Dr. Ed Wagner and colleagues at the MacColl Institute for Healthcare Innovation at Group Health Cooperative of Puget Sound. The institute is the home of Improving Chronic Illness Care, a National Program Office of the Robert Wood Johnson Foundation with a mission to assist health care systems nationwide in delivering effective care to people with chronic conditions in order to improve their health. The Chronic Care Model (CCM) provides system-wide indications for changing the current acute care-oriented delivery systems to systems that are proactively prepared to be responsive to the needs of people with chronic conditions.

The heart of the Chronic Care Model is enhancement of the effectiveness of interactions between patients and their health care providers. It offers a framework within which a proactive, prepared practice team comes together with an informed and empowered patient and family to produce improved outcomes in health status, patient and provider satisfaction with care, and appropriate utilization of healthcare.

The CCM considers care as being delivered not only within the health care system, but increasingly in the community in which it resides as well. Systems of care can provide leadership to ensure program support of chronic conditions and can align incentives so providers can practice effectively. Just as importantly, community organizations can have policies and offer resources that enhance quality of life for people with chronic conditions.

Self-Management Support: At the clinical practice level, self-management support is one of four elements essential to effective chronic illness care (see Model Graphic). It means that practitioners work closely with patients to develop a care



plan that reflects patient values and abilities as well as clinical treatment indications. To be effective, care plans must help patients and families set goals, find solutions to barriers, assess skills and attitudes, and learn self-care behaviors.

Delivery System Design: To improve care delivery, systems must undergo change. Innovations in practice organization and new kinds of visit structures have been found to maximize efficiency as well as benefits to patients. A multidisciplinary team clarifies tasks among its members to utilize them to their scope of practice, with access to clinical case management services for complex cases. Care visits planned at regular intervals for screenings and assessment are opportunities to check in with patients and prevent problems. Innovations such as group visits, during which multiple providers see groups of patients with the same diagnosis, offer opportunities for patient self-management education sessions, and supportive interactions among patients themselves.

Decision Support for Evidence-Based Care: Information about illness and treatment is critical to both providers and patients. Educating patients and families about evidence-based guidelines pertinent to their care helps them know what to expect of their healthcare and understand what to ask of themselves in their role as self-managers. Primary care teams apply innovative methods to access specialists. This ensures that they use interventions of proven effectiveness.

Clinical Information Systems: Modern clinical information system registries can facilitate access to clinically useful and timely information on all patients. A registry helps providers identify patients who have not received necessary screenings or preventive care visits and generate reminders and feedback for providers and patients. Patient summaries printed from

Continued on page 6

Editorial, continued

- 2) Homer CJ, Fowler FJ, Gallagher PM, Shaul J, Uyeda M, Zaslavsky A, Wilson V, Cleary P. The Consumer Assessment of Health Plan Study (CAHPS) survey of children's health care. *Jt Comm J Qual Improv.* 1999 Jul;25(7):369-77.
- 3) Homer CJ, Marino B, Cleary PD, Alpert HR, Smith B, Ganser CM, Brustowicz RM, Goldmann DA. Quality of care at a children's hospital: the parent's perspective. *Arch Pediatr Adolesc Med.* 1999 Nov;153(11):1123-9.
- 4) Rich M, Lamola S, Amory C, and Schneider L. Asthma in Life Context: Video Intervention/Prevention Assessment (VIA). *Pediatrics* 2000 105: 469-477. www.pediatrics.org

Improving Outcomes, continued from page 5

the registry can provide a take-home document for patients recording collaboratively set self-management goals, as well as lab results and screening information. Such an information system would also evaluate outcomes and help providers tailor care as patients' individual abilities and needs change.

Efficacy of Self-Management

Dr. Noreen Clark, Dean of the School of Public Health, University of Michigan, whose "Opening Airways" program for children with asthma has been implemented nationwide in health systems and in public schools (Clark, 1991), has defined three tasks of self-managing chronic conditions:

- Taking care of health problems – taking medicine, exercising, going to the doctor, changing diet
- Carrying out normal activities – chores, school, social life
- Managing emotional and role changes that occur with chronic illness – frustration at curtailed stamina, uncertainty about the future, changed expectations and goals

Dr. Kate Lorig, director of the Stanford Patient Education and Research Center, has developed the Chronic Disease Self-Management Program, a tested workshop for the chronically ill. She has demonstrated the interdependence of the self-management tasks and the important role they play in maintaining health despite an incurable condition. (Lorig, 1999) For example, exercising and staying as active as possible is an excellent antidote to depression, helps maintain meaningful social roles, and may mitigate the effects of the disease process in some conditions. In the traditional model, support of these activities is often ignored by providers and health care systems. Setting behavioral goals collaboratively with patients and providing routine telephone follow-up support and access to specialist support are all important components of model-based care.

Self-Management Support by Health Care Providers

Medical systems and providers have long provided some degree of patient education to people with chronic health conditions. Although information is an important component of good patient care, there is mounting evidence that didactic patient education is simply not enough to help patients engage successfully in complex treatment regimens (Lorig, 1989). Supporting patients and families in self-management requires a change in the roles of providers. When the patient takes major responsibility for health behaviors, the role of the effective provider becomes one of collaborative coach and teacher in partnership with the patient. The bottom line is that the health care practice must help patients and families develop the conviction that healthy behaviors can positively affect both the impact the disease has on their life, and the confidence that they can accomplish the behaviors.

1. Clark NM, Becker MH, Janz, NK, Lorig K, and Rakowski L. Self-Management of Chronic Disease by Older Adults. *Journal of Aging and Health*. 1991 Feb; 3(1):3-27.
2. Lorig K, Seleznick M, Lubeck D, Ung E, Chastain RL, and Holman HR. The beneficial outcomes of the arthritis self-management course are not adequately explained by behavior change. *Arthritis Rheum*. 1989 Jan; 32(1):91-5.
3. Lorig KR, Sobel DS, Stewart AL, Brown BW Jr, Bandura A, Ritter P, Gonzalez VM, Laurent DD, and Holman HR. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Med Care*. 1999 Jan; 37(1):5

Self-Management Support

What can health care professionals do to support patients and families in living a healthier life with chronic conditions?

1) Engage the patient and family.

Develop and sustain a trusting relationship by eliciting a patient's story with open-ended questions and reflective listening.

2) Ask, don't tell.

Finding out a patient's goals first allows you to connect the behavior change to the patient's feelings and values, providing important motivational energy to begin or sustain difficult changes.

3) Tailor information to patient needs.

Whenever possible, provide information in response to patient questions, using the patient's own lab values or data.

4) Create a plan with the patient/family.

Specify, anticipate barriers, brainstorm supports from the patient environment. Recognize cultural or socio-economic constraints. Plan for success. Write up the plan and give the patient a copy.

5) Recognize that change is incremental.

Start where people are now, and remember that people gain most from experiencing success by attempting small, steps that they can realistically accomplish.

6) Roll with resistance.

If you experience resistance, you're probably going too fast. Step back and reestablish the patient's goals. Remember, a change is only effective if a person actually does it!

7) Sustain follow-up.

Patient needs and capacities change over time. Ongoing support maximizes opportunities for learning and helps maintain behaviors over the rough spots.

Outreach Worker Fosters Asthma Self-Management Among Patient Families

By Judith Schaefer

Odessa Brown Children's Clinic (OBCC) in Seattle's Central District bustles with sociability. Parents, children, and staff call out greetings to each other. Children play in the waiting areas. The atmosphere hints that a health care system behind these walls might extend the definition of medical care beyond prescriptions and paperwork. Located in the heart of Seattle in an underserved, high-risk community, the Odessa Brown Asthma Outreach Program reaches into the fabric of community life to help children with asthma and their families get the care they need. Through the asthma clinic, OBCC delivers excellent evidence-based clinical care and also help families of children with asthma to gain the skills and support they need to manage symptoms at home and improve quality of life.

The Asthma Outreach Program is a partnership between OBCC and the Seattle King County Department of Public Health. Dr. James Stout, Program Director, originated the program to coordinate care in a variety of settings within the community and to support families in managing asthma care at home. LaTonya Rogers, the asthma outreach coordinator, is a full-time health department employee based at the clinic. Hired for her ability to relate to the target community, she has been trained in asthma management and has become a trailblazer in implementing interventions in the home and community.

Although families are clearly concerned for their children's health, the complex treatment regimens that are necessary to manage asthma in the home can sometimes be overwhelmed by the concerns of everyday life. The outreach program uses a case-management approach, providing a liaison to the health care system who can assess, educate, and help the family create a home asthma management plan. Ms. Rogers explains, "Sometimes I just need to find the person in the household who will make sure the child gets his medicine. For other times, like when there are smokers in the home, we have to find good compromises for the health of the child." Rogers also establishes relationships with school and day care staff, who often lack information about asthma management plans, symptoms, and appropriate treatment for acute crises.

"The team's the thing," says Stout. "Everybody brings important information to the table. LaTonya helps us identify barriers and find supports that make the care plan work." Collaboration between doctor, outreach worker, and medical assistant create a team approach that makes for effective intervention. The initial asthma clinic office visit addresses clinical and educational issues. In a subsequent home visit, the outreach worker assesses family structure, leadership and caretaker roles, and competing issues that might undermine

the asthma care. She makes sure that the child and caretaker are able to take a proactive role in the asthma management protocol. She develops care strategies with the family for managing competing issues and empowering the family leader. She helps implement necessary modifications in the physical environment. Subsequent visits ensure that patients and families receive the educational reinforcement and follow-up care that is needed, according to the severity of the illness and psychosocial profile for the family. Quarterly phone calls guide follow-up efforts, and families are seen in the clinic and by the outreach worker as needed.

Rogers' final word: "I try to look at what changes can be done today, and still remember that change takes time."

Camp Super Breathers: Asthma Management for Idaho Children

Michele J. Andrew, MS, RCPT MICHANDR@sarmc.org
Pulmonary Rehabilitation Coordinator
Saint Alphonsus Regional Medical Center, Boise, Idaho

Taking a hike, singing around the campfire, making crafts, new friends ... all of these make up many people's fond childhood memories of summer camp. Children with asthma have limited access to camps. Many camps do not want the responsibility of a child with a chronic illness who must take daily medications. Some offer no medical supervision at all. Parents, physicians, and children are apprehensive about an experience that might exacerbate an asthma attack. Camp Super Breathers addresses these fears.

The mission of Camp Super Breathers is to promote optimal health and wellness for children with asthma in a camp setting. It offers a child-centered educational and social experience while providing opportunities to learn asthma management skills for life. The camp recognizes the importance of fun and recreation in building self-esteem, self-reliance, and social skill.

Asthma is on the rise worldwide. National statistics indicate that 7.3 percent of school children have asthma and it is the leading cause of school absenteeism. Medical costs may run as high as \$14 billion. In Idaho, the 1999 Behavior Risk Factor Surveillance System survey and the School Nurse Study showed that 10 percent of Idaho school children have asthma. Teaching patients and their families specific management skills is a cost-effective tool, improving asthma

Continued on page 8

Asthma Camp, from page 7

management, reducing the use of emergency services, and improving quality of life. The Asthma Coalition of Idaho seeks to implement education and prevention programs statewide.

Reducing the exposure to environmental allergens and pollutants reduces frequency and severity of attacks for children with asthma, reduces their need for medication, and improves their lung function. In reality, this is very hard to do. While it is possible to improve the home environment, there are other situations that cannot be controlled. Schools, shopping areas, sporting events, and recreational activities can expose children to environmental triggers. Cigarette smoke, air pollution, fumes, dust, and pollens as well as exercise are all triggers that must be dealt with routinely. Children need to learn to cope with these situations in order to stay out of trouble.

These facts led a group of respiratory therapists and a school nurse to open Camp Super Breathers for children aged 9 to 13 with asthma. It is sponsored by Saint Alphonsus Regional Medical Center and the American Lung Association of Idaho/Nevada. It began four years ago on a shoestring budget with donations from area businesses and the Saint Alphonsus Auxiliary. Most participants come from low-income families and are sponsored by area businesses, hospitals, and individuals.

Campers spend five days in the Central Idaho mountains. Many of these children have never been away from their parents due to their asthma. In camp, they learn independence as well as asthma management skills. Camping fun is interspersed with education sessions where campers learn signs and symptoms, triggers, and medications. They also learn breathing skills and relaxation. Education is given through videos, games, and hands-on learning. Asthma and allergy physicians, RTs, and RNs provide medical supervision. All children are given their medications on a routine basis as determined by their physician. Battery-powered nebulizers are taken on hikes. By the end of camp, the children have individualized Asthma Management Plans. They know their Peak Flows, medications, triggers, and symptoms.

One success story is a 10-year-old girl with unmanaged asthma who used her relief inhaler whenever she began to get short of breath. At camp, the staff taught her how to distinguish normal shortness of breath due to exertion from a true asthma attack. She learned how to rest, assess her breathing, and determine if a puff of her inhaler was needed. She also learned how to use her inhaler correctly. On a long bike ride she became dyspneic (short of breath). She stopped and evaluated herself, then correctly took a puff of her albuterol. This showed how much she had gained. Successes like this inspire the volunteers who created Camp Super Breathers to keep the camp going.

Self-Management Concepts Applied to ADHD in Children

Harlan R. Gephart, M.D.

*Medical Director, Center for Attention Deficit Disorders
Group Health Cooperative of Puget Sound*

Attention-Deficit Hyperactivity Disorder (ADHD) is the most commonly diagnosed mental-health condition in childhood. It accounts for 30 to 50 percent of mental-health referrals and 8 to 9 million physician office visits yearly. With the overall prevalence of 3 to 5 percent, there are approximately 4 million children diagnosed with ADHD in the United States. Boys are diagnosed four times more commonly than girls. Boys are also more likely to be hyperactive/impulsive than girls, who are more frequently inattentive. At least 50 percent of children with ADHD have symptoms that persist into adulthood, making this condition a life-long problem.

ADHD, as a chronic disorder, benefits from the organized, evidence-based care described in the Chronic Care Model. Although there are proven, evidence-based treatments for ADHD, long-term success cannot be accomplished unless behavioral self-control and educational goals are achieved. Medication is highly successful at treating symptoms, but the symptoms return if the medication is discontinued, making self-management a high-priority for sustaining behavior change. Other treatments, such as training parents in behavioral modification techniques can also be effective. Sadly, medication is the only treatment offered to many children.

Self-management for younger children with ADHD means parental or family management. As children reach older childhood and adolescence, self-management becomes more important. After the initial diagnosis, parents need to educate themselves about ADHD symptoms and treatment. The health care professional should direct parents to seminars, books, and organizations like Children and Adults with ADHD (CHADD) for information and to become aware of treatments that are controversial, unproven, or proven ineffective.

There are two proven, evidence-based treatments for ADHD: medication and behavioral management. A recent, large governmental study (a multi-treatment assessment of about 600 children) found that, although both medication and intense behavioral management were effective, in many cases the best results came when both techniques were employed together. Therefore, recent American Academy of Pediatrics (AAP) Guidelines for ADHD suggest using both treatments. The Center for Attention Deficit at Group Health Cooperative of Puget Sound has developed family-oriented services that support both approaches.

Continued on page 9

Self-Management with ADHD, continued from page 8

Successful medication management requires a great deal of family involvement. Medications may cause side effects like loss of appetite. Parents must be diligent in making sure the child maintains caloric intake and growth as well as keeping follow-up physician visits where weight and height are monitored. In addition, parents' communication with the child's teachers to assess the effect of the medication is important, not only regarding symptoms, but also the behavior problems caused by ADHD. Such behaviors include not completing homework or fighting on the playground.

Behavioral therapy, the other evidence-based ADHD treatment, has three proven components: parent training, daily report card, and summer camp experiences. Exclusively working with the child, for example with one-on-one cognitive therapy, psychotherapy, or play therapy, has been shown to be largely ineffective. Parent training involves teaching families such proven behavioral modification techniques as praise, timeout, and rewarding consequences. Daily report card use monitors both school and home behavior. The summer camp experiences encourage self-management in a specially designed setting that allows children and families to interact with and support each other. All of these examples demonstrate the importance and necessity of family involvement in management of this disorder.

The Group Health Center for Attention Deficit Disorders in Seattle offers families educational materials and access to classes, including scholarships if necessary. Center staff support parents' contacts with their children's schools to help make sure children are placed properly and are getting remedial help. Staff are available to discuss problems with teachers. At times, the center has arranged respite care for parents and tutoring for children and other supportive services.

Advocacy for their child with ADHD in both the health care and educational settings is a crucial role for parents. They need to find a health-care provider who is both knowledgeable about ADHD and empathetic; one who is willing to assist them in setting goals and in developing a management plan for their child's ADHD. Parents need to build a team that includes the child's physician, psychologist and/or counselor, and educators to assist the family on a regular basis. Especially important, they must advocate at the child's school to make sure their child gets the educational help he or she needs for success. They must keep thorough medical and educational records to guarantee consistent care over time, especially when their child changes schools or health-care providers.

Most importantly, parents need to develop a strong relationship with their child. They must provide encouragement and opportunities to build on the child's strengths, provide settings that will allow their child to learn social skills and enhance their self-esteem.

Attention Deficit and Hyperactivity Disorder is typical of those conditions for which family and self-management can make a tremendous difference. The Group Health ADHD Center has found that, with enough involvement and support, children and their families can successfully manage ADHD.

AAP Clinical Practice Guideline, Treatment of the School-Aged Child With Attention-Deficit/Hyperactivity Disorder, PEDIATRICS, 108:4, October 2001: <http://www.aap.org/policy/s0120.html>

Culturally Competent Services for Refugee Families with Children with Disabilities

Developing culturally competent services that promote family involvement in children's care is one facet of Better Regional Access for Immigrants with Developmental Disabilities (BRAIDD). This project, based at Harborview Medical Center (HMC) in Seattle, Wash., seeks to improve service delivery to children with developmental disabilities in immigrant and refugee families by forming support groups for families with limited English capability.

Families of children with developmental disabilities face considerable emotional and practical challenges. Language and cultural differences in immigrant and refugee families compound these challenges and increase their feelings of isolation. BRAIDD, funded by the American Academy of Pediatrics, was developed and coordinated by Dan Doherty, M.D. when he was a pediatric resident at HMC. This project identified 50 children with developmental disabilities in limited English speaking families served by the Children and Teen Clinic at HMC. These families have experienced many risk factors for health problems, including poverty, poor nutrition, inadequate access to medical care and exposure to diseases such as tuberculosis, HIV, and meningitis. The greatest need reported by parents of these children was for more information and culturally appropriate advocacy and referral services.

Continued on page 10

Services for Refugee Families, continued from page 9

To address this need for information in the Somali population, Dr. Doherty organized a support group for Somali families. Support group speakers have educated parents about their right to give input regarding their child's school program and the need to be involved with their child's Individual Education Plan (IEP). In addition, families have learned much from each other. Dr. Doherty and HMC staff have established medical homes for several children who were without a consistent health care provider.

Using the key components of the BRAIDD project as a model, HMC, The Arc of King County, and The Refugee Women's Alliance (ReWA) have received a new Health Tomorrows Partnership for Children Program (HTPCP) grant. It will develop support groups for Somali, Spanish speaking, and Vietnamese families (BRAIDD-2). This is a 5-year grant beginning in the spring of 2002.

The project will train a Bilingual/Bicultural Family Advocate for each language group to organize support groups that will allow families to feel safe and feel that they are understood. Past experience indicates that a support group consisting of families from multiple language groups is not the most effective model. Easy and comfortable communication is essential and having to use multiple interpreters bogs down communication. Family Advocates will provide community advocacy, interpretation and referral services around issues that arise as a result of support group meetings, including applying for services and interacting with the schools. Family Advocate responsibilities will include helping parent leaders arrange meeting locations, meeting topics, outside speakers, and food for meetings. They will also facilitate the distribution of a newsletter summarizing each meeting and gather data to evaluate the effectiveness of the program. Support services such as on-site childcare, respite care reimbursement and transportation assistance will be provided to ensure accessibility for project participants.

The Arc, ReWA, and HMC have worked together in the past to serve children with disabilities but this relationship had not been formalized. The cooperation between these three organizations brings together a unique and powerful combination of strengths and resources to the aid of a severely underserved population, advocacy for children with disabilities and their families, advocacy for immigrants and refugees, and advocacy for underserved populations with medical problems.

Laurie Holscher
Arc of King County (206-364-4645, x 127)

Patient Self-Management from the Community Clinic Point of View

Talibah Chiku, Clinical Program Manager, NW Regional Primary Care Association, with assistance from local clinic correspondents

A number of community, migrant, and homeless health centers in the Northwest are implementing the Chronic Care Model, of which patient self-management is an essential part (see page 5). This is part of an effort to reduce health care disparities that grew out of the 1998 implementation of quality improvement activities through the Bureau of Primary Health Care (BPHC) and the Institute for Health Care Improvement (IHI). BPHC partnerships with IHI and the McColl Institute for Health Care Innovation in Seattle have led to collaborative efforts around the country using the McColl Institute's Chronic Care Model.

Since 1998, 350 interdisciplinary health center teams across the country have participated in these collaboratives. These efforts have changed practice and improved health outcomes for patients living with diabetes, cardiovascular disease, asthma, and depression. Outcomes illustrating the effectiveness of this approach* include:

- Diabetes: Average HbA1c (glucose test) levels have decreased from 9.2 to 8.5 in more than 12,000 patients in Diabetes I Collaborative and from 8.9 to 8.3 in more than 22,000 patients in the Diabetes 2.
- High Blood Pressure has shown a 20 percent improvement in five months among 4700 patients taking part in the Cardiovascular Collaborative 1.

Following are descriptions of how four Northwest primary health clinics implemented strategies for patient self-management as part of the Health Disparities Collaborative. While these examples deal with diabetes projects, the strategies have application to many chronic conditions of children as well as adults.

Implementing Client Self-Management in Multnomah County (Oregon) Health Department

Mark Spofford, then manager of Behavioral Health Care at the Multnomah County Health Department, Oregon, reported several helpful implementation strategies.

The first was to train staff in motivational interviewing,** a therapeutic technique that allows intervention with people in different ways depending on what stage they are in accepting a problem and deciding to make behavioral changes to address it. The second was to develop "self-care action plans" for setting

* Policy Information Notice 12, BPHC (Bureau of Primary Care) January 2002

** Miller & Rollnick, 1991 (see bibliography on web site—see p. 12)

PSM in Community Clinics, continued from page 10

disease management goals with patients and agreeing on the changes that will be attempted.

The following clinic strategies have been particularly beneficial to making client self-management work:

- complete action plan forms in duplicate (one copy for the client, one for the chart) and have them readily available in the exam room to facilitate consistent followup;
- encourage providers to delegate work to clinical support staff, such as nurses or social workers, where appropriate;
- emphasize keeping it simple—success breeds success, so one goal is adequate if the patient actually meets it;
- use a tracking registry for identifying clients who are in need of a self-care plan; and
- identify a care manager to track completion and to help clients overcome barriers.

Goal Setting in Rural Alaska

The Sunshine Community Health Centers, Talkeetna, Alaska, serve mostly low-income clients for whom individual goal setting is not usually part of life. The clinic became part of the National Diabetes Collaborative in January 2000. Jessica Stevens, MD, medical director, reported that helping patients develop their own self-management goals was new to clinic personnel. Staff had to go through a change process to try out and incorporate this technique.

Clinic personnel first developed a work sheet to help patients set goals, based on the traditional goals for diabetics: exercising more, eating healthier, quitting smoking, etc. “Then we tried to broaden our thinking,” explains Stevens, “exploring the obstacles that patients (and professionals) have toward change, and trying to rethink the process. What emerged were a series of much bigger questions. What is important in your life? Where do you see yourself in one, three, and ten years? How do you think diabetes is stopping you from getting there?”

Since there was diverse opinion among the clinic team members about the usefulness of these larger “life” concepts, they opted to do a rapid change cycle, (Plan, Do, Study, Act*) during one of the clinics to see what responses they would get. “We were surprised!” says Stevens. “By addressing the bigger questions, we discovered obstacles such as abusive husbands, poorly running vehicles, and no money for gas, all real roadblocks to changing behaviors.”

By combining these questions with the more straightforward list, the staff was able to generate a realistic plan to use with diabetes patients. Though divorcing an abusive husband might not immediately seem to be part of a diabetes self-management plan, once it became clear that the husband was controlling food, money, and access to medicine, it became clear that the obstacle was not “patient non-compliance.”

“We learned that in order to help patients be involved and invested in their care, we needed to open our horizons about what issues really have an impact on people’s capacity to do that,” Stevens concluded. “It was a great learning experience, and one that we are trying to incorporate into our primary health work at many different levels.”

King County Community Clinics Support Self-Management

When Community Health Centers of King County (CHCKC) joined the Washington State Diabetes Collaborative in October of 1999, no one on the original Pilot Site Team understood the concept of patient self-management. “If asked at that point to explain self-management support,” David Selvage, PA-C, says, “I probably would have mumbled something about making certain that patients with diabetes fully appreciated the importance of regular home glucose monitoring, or something about achieving optimum glucose control, or maybe the value of maintaining normal BMI. I understood the medical model, but I was relatively clueless about the meaning of chronic illness from the patient’s perspective and how this patient-based reality translates into daily disease self-management.”

The team realized members must provide clinical expertise, disease management tools, education, and psychosocial support. Knowing that this is not a natural role for medical providers, they are now planning trainings for providers in how to conduct self-management support in the context of a 6- to 12-minute patient interaction. However, most of the self-management support conducted at CHCKC has been done by nurse educators.

Data from the CHCKC diabetes registry documents self-management goals during any diabetes patient visit. This documentation indicates that, of the four CHCKC clinics participating in the collaborative, the clinic where patients get the most one-on-one time with the nurse educator is the clinic with the greatest amount of self-management support. The current challenge at CHCKC is finding enough available nurse education time to accommodate all of the diabetes patients.

Self-Management Classes In Moses Lake, Washington

In Moses Lake, Wash., the Community Health Center has developed self-management classes around diabetes. Terri Carpentier, RN, diabetes case manager, said that training received at Stanford University’s Chronic Disease Self-Management Course, enabled the clinical team to implement new tools and new ways of establishing and using action plans in patient self-management care.

Calendar

The 2nd Annual Western States Maternal and Child Health (MCH) Epidemiology Conference

May 30-31, 2002, Portland, Oregon

For State, local, and tribal public health care workers from western states who have—or will have—leadership, epidemiologic, programmatic, or data analytic responsibilities in public health programs involving maternal and child populations.

Goals are to enhance the skills and knowledge of MCH and epidemiologic public health workers and to provide a forum for sharing experiences, learning from one another, and forming professional relationships that will enhance their effectiveness.

<http://depts.washington.edu/sphcm/mchepi>

Email: sanjose@u.washington.edu
Phone: 206-685-2931 (Trudy White)
Fax: 206-616-9415

Joint Conference on Health

“Public Health Priorities, Balancing your Core Mission with Emergency Preparedness.”

October 7–9, Wenatchee, WA

Washington State Public Health Assn., Washington State Department of Health, and Chelan Douglas Health Dist.

<http://www.wspha.org/JCH1.html>

Fall 2002 Primary Care Conference

October 26–30, Westminster, CO

Northwest Regional Primary Care Assn. and Community Health Assn. of Mountain/Plains States

<http://www.nwrpca.org/>

Health Literacy Institute

November 3–6, Albuquerque, NM

“Write It Easy To Read: Creating Plain Language Health Materials With Impact”

<http://www.une.edu/com/othrdept/hlit/programs.htm>

American Public Health Assn.

November 9–13, Philadelphia, PA

<http://www.apha.org/meetings/>

Self-Management Support: References and Resources

An extensive bibliography on this topic is included on the *NW Bulletin* web site with this issue.

Go to:

<http://depts.washington.edu/nwbfch/>