Chronic Complex Diseases of CHILDHOOD

A PRACTICAL GUIDE FOR CLINICIANS

CHRONIC COMPLEX DISEASES OF CHILDHOOD

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Preface

Recent advances in treatment of previously lethal pediatric illnesses has led to a growing population of children who require complex, chronic medical care. Most of this care is done at home or occasionally in chronic care facilities. Thus, the physicians including generalists, pediatricians and other health care personnel must provide acute and chronic care of these children in the office or emergency room setting.

This book was borne out of our own need for a concise, practical guide to assist in the care of children with complex diseases. This book focuses on the acute and long-term management of these children along with essential information regarding the pathogenesis, epidemiology, and prognosis of each disease. The diseases chosen for this book tend to be of a chronic, complex nature; require extensive specialized care; and lack readily accessible practice guidelines. Therefore, the authors have shared their knowledge and experience in order to assist primary care physicians better manage these illnesses. However, the more general chapters that focus on such issues as forming a medical home, management of medical devices, and disease drug interactions are relevant to the care of all children.

We thank all of our authors for their invaluable input and expertise and it is our hope that this guide book will assist physicians and other caretakers in improving the health and quality of life for these children and their families.

Shahram Yazdani
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1 Creating the Medical Home

Introduction

Children with special health care needs interact with and receive services from a myriad of complex systems, and their parents must learn to access, navigate and coordinate services related to health care, developmental disabilities, special education, mental health, insurers and more. In addition, families may face challenges related to language, culture, socioeconomic status, and the ongoing daily burden of caring for a child with a chronic health condition. A medical home is a practice model that can serve to assist families by providing high quality care for children that is comprehensive, family-centered and coordinated in nature.

The American Academy of Pediatrics (AAP) defines a medical home as "a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care." In March 2007, the American Academy of Family Physicians (AAFP), the AAP, the American College of Physicians (ACP) and the American Osteopathic Association (AOA) published the Joint Principles of the Patient-Centered Medical Home, which defined the patient-centered medical home (PC-MH) as "an approach to providing comprehensive primary care for children, youth and adults. The PC-MH is a practice paradigm that facilitates partnerships between individual patients and their personal physicians, and when appropriate, the patient's family."

Most medical home definitions make reference to primary care, and for most children, this care will be delivered by a primary care provider in the child's community. But, for some—as is the case of children with rare or complex conditions—the specialist-, university-, or children's hospital-based special care center may serve as the medical home. For children with chronic conditions, the medical home provides linkages to needed services and coordination of care, a central repository of information about the child, and a place for families to seek information and support. In addition, because the medical home provider knows the child well, parents and providers can work together as partners to assure that the needs of the child are met in a timely and efficient way. Literature suggests that the medical home can have a positive impact on both the individual child and family, and on the health care system, as emergency department use may be reduced. The medical home concept, by definition, improves coordination between primary and specialty care providers, and community based agencies and programs serving the child and family.

What Constitutes a Medical Home?

The joint position paper of the AAFP, AAP, ACP and AOA, describes the basic elements of the medical home to include the following:

- A personal physician for first contact, continuous, and comprehensive care.
- A physician-directed medical practice with a team of individuals to provide ongoing care.
- A whole person orientation in which the physician takes responsibility for providing or arranging for all of the patient's acute, chronic, preventive or end of life care.
- Care that is coordinated and integrated across all components of the health care system.
- Assistance in transition to adult centered health care systems and supports.
- Quality and safety of care including advocacy, evidence based practices, continuous quality improvement, patient participation in decision making, the use of information technology, and participation in voluntary recognition processes.
- Enhanced access to care, expanded hours, and new options for communication with patients.
- Payment that appropriately recognizes the added value of the medical home.

Simply put, a medical home provides a base from which families can operate in caring for the child's special health care needs. In addition to providing primary, preventive and episodic illness care, the medical home provider

- assists families in identifying needed services and supports,
- refers families to care providers as appropriate,
- coordinates the care between multiple providers,
- consolidates medical records in one location, and
- facilitates transitions between in- and outpatient-care; and from pediatric- to adult-oriented providers.

While the child's care may be delivered in multiple locations by various types of providers, the medical home and the family work together to oversee the big picture, and understand how all the services and supports work together to provide comprehensive care for the child. This prevents gaps or duplications in services, and results in care that is comprehensive and cost effective. In short, optimal health care.

Benefits of Medical Home

Although serving as a medical home is a significant responsibility, there are several benefits to be derived both for the practice and the family. Foremost, families have one central and unifying health care environment for their child and an ongoing source of information and support. For providers, a medical home model encourages increased practice efficiencies and innovation, allows for easier patient follow up, and provides for shared patient care responsibility with specialists and community based services.

Families play an important role in the medical home and its members are considered full partners in their child's care. While the primary care provider or specialist may be the expert in the *health* care needed by the child, the family is the *overall* expert in their child as a whole. They are the constant in the child's life and provide the primary day-to-day care and support. In the medical home, families can be empowered to take a more proactive role in their child's care. For instance, they can be encouraged to create care notebooks that can be used to organize their child's records and facilitate communication among providers. The medical home is also a place where they can be provided with information about their child's condition, services, and supports so that they can advocate more effectively on behalf of their child.

What Are the Goals of the Medical Home?

The aim of the medical home is to provide high quality health care that is family-centered and coordinated, and is a place where parents and providers work together to set goals, seek services, monitor care and advocate to achieve the best possible outcomes for the child. Goal setting is carried out collaboratively by the parent, child if appropriate, and physician, as well as other members of the care team. Goals should be realistic and achievable and may change as the child's condition or family circumstances alter.

Several factors come into play in achieving those goals. First, comprehensive primary, preventive and episodic illness care is provided by a team led by a personal physician. Other team members may include nursing staff, care coordinators and/or administrative support staff within the practice setting. Next, the medical home is responsible for meeting the standards of basic pediatric health care for the child, and providing ongoing health education and support to the family. In addition, the medical home provides referrals to appropriate specialists as needed, and services in the community, such as special education and therapies. Third, families are given information about how and where to receive services, and what to expect. Lastly, the medical home provider maintains contact with the family to assure that referrals are successful and that the child ultimately receives needed services.

In a medical home, care is patient- and family-centered. Patient- and family-centered care is "grounded in mutually beneficial partnerships among health care patients, families, and providers. Patient- and family-centered care applies to patients of all ages, and it may be practiced in any health care setting." The core concepts of patient- and family-centered care include

1) *Dignity and respect*: In which the provider listens to and honors patient and family perspectives and choices and incorporates patient and family knowledge, values, beliefs and cultural backgrounds into the planning and delivery of care.
2) *Information sharing:* Where providers communicate and share complete and unbiased information with patients and families who receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
3) *Participation*: Where patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
4) C*ollaboration*: In which patients and families are included in policy and program development, implementation, and evaluation, in health care facility design; and in professional education, as well as in the delivery of care (Institute for Family Centered Care, 2009). Providers and parents work as partners to identify child and family needs, and to locate and choose appropriate resources to meet those needs. This requires adequate time for communication with the family.

In order to optimize care and meet the family's goals, patient and family-centered care should be practiced by all members of the medical home.

A primary responsibility of the medical home is care coordination and chronic care management. This includes coordination among specialist physicians, community based resources, and service systems such as special education or the developmental disabilities system. Care coordination is more than making a referral. It includes ensuring that the family understands the reason for other needed services; assisting the family to access care; and periodically reassessing the effectiveness of the service and adjusting care accordingly. The medical home provides information to the referral on the one hand; while on the other obtains information from the service provider; incorporates it into the medical record; and shares and interprets the information for the family.

It is impossible for an individual physician to provide all elements of care in the medical home, and an understanding of resources in the community, as well as relationships with specialty care providers can assist in meeting the needs of children and their families. Certain core resources including the Medicaid or CHIP

program, mental health services, the State title V program for Children with Special Needs, the developmental disabilities system, the early intervention system, special education, family resource centers, Head Start, and the Special Supplemental Food Program for Women, Infants and Children (WIC) are used by many families of children with special needs. Learning about these basic resources and how referrals are made to each can help the provider both meet the child and family's needs and share responsibility for care with other programs, many of whom offer some form of care coordination or case management. Oftentimes, responsibility for learning about these entities can be delegated to support staff in the office who can then learn more about each and establish relationships upon which referrals can be built. Many of these programs also have outreach materials that can be kept in the provider's office and shared with families when referrals are made.

Transforming a practice into a medical home takes time, with gradual and ongoing changes in practices, processes and shifts in philosophy of care. The transformation takes persistence and patience to achieve desired goals. Serving as a medical home requires regular self assessment to ensure that family needs are met, and that the practice setting is operating in a cost effective and efficient manner. There are a number of tools that exist to assist providers in self assessment, and to make simple changes to enhance the quality of care in a medical home practice. Likewise, there are now voluntary recognition programs to acknowledge the efforts of a medical home. It is likely that some of the current voluntary efforts will become mandatory as a means of assuring quality in compensating medical homes for care. Two examples of tools for self assessment include: (1) The Center for Medical Home Improvement's Medical Home Index; and (2) the National Committee on Quality Assurance (NCQA) Physician Practice Connections- Patient Centered Medical Home program. The Medical Home Index measures the medical "homeness" of a practice across six domains including:

- organizational capacity;
- chronic condition management;
- care coordination;
- community outreach;
- data management; and
- quality improvement.

The NCQA program assesses whether physician practices are functioning as medical homes across nine standards, including:

- access and communication;
- patient tracking and registry;
- care management;
- patient self management support;
- electronic prescribing;
- test tracking, referral tracking;
- performance improvement; and
- advanced electronic communications.

Accumulating data increasingly supports the notion that the patient centered medical home for children with special health care needs can improve patient satisfaction while reducing inpatient hospital utilization and emergency room visits. For example, the Medical Home Program for Children with Special Health Care Needs is a medical home program in the resident continuity clinic at UCLA with a strong chronic care management component. When patient data was compared for one year prior to- and after-enrollment in the program, analysis of encounter data for patients enrolled in this program demonstrates a significant decrease in emergency room use. This finding is consistent with reports of other programs focused on populations of children with chronic disease. Thus, it is likely that parents of children with chronic conditions who are enrolled

in an active medical home are empowered to use telephone consultations or schedule outpatient appointments, and urgent care clinics to avoid emergency room visits. This hypothesis is supported by several parents reports in the UCLA Medical Home Program's parent advisory group who gave this explanation when they were shown data on emergency room use and asked to comment. In addition, when compared to normative data for medical homes, we have found that the UCLA program results in much higher parent satisfaction scores as measured by the Medical Home Family Index which is a module of the Medical Home Index. Of note, the use of Spanish speaking Family Liaisons has resulted in high parent satisfaction scores among Spanish speaking families that are not significantly different from those of English speaking families.

A medical home is only valuable to patients and families if it is accessible. Accessibility constitutes a variety of factors. One factor is physical and includes *structural accessibility* for families who need additional space, ramps and elevators to move wheelchairs, ventilators and other equipment when bringing their child for a visit, or a larger than usual exam room in order to accommodate their needs, or a height adjustable exam table to be able to transfer a child with mobility impairments. Another factor is more temporal: Accessibility to providers at times that are convenient to families—such as late in the day and Saturdays—and access to other means of advice when the office is closed. *Cultural and language accessibility* is important in providing a medical home so that families can speak in their native language to their providers and that their culture is respected as part of the medical home processes. Finally, *financial accessibility* is a consideration, with the goal of access to a medical home regardless of the payer source.

A significant challenge for medical home providers is appropriate compensation. The activities that define a medical home take time, resources and appropriately trained staff. Currently, third party payers do not typically reimburse for the care coordination component of the medical home, but recent health reform proposals have identified the medical home model as an important means of ensuring access, enhancing care, and improving cost effectiveness. With heightened attention to the model, the possibility exists for recognizing the necessity of appropriate reimbursement.

Establishing a Medical Home

A variety of roles need to be filled in order to carry out the activities associated with a medical home. Primary care, acute/episodic illness care, and chronic disease management are key elements. While typically the pediatrician or family practitioner carries out these activities, nurse practitioners or physician assistants may play a role as well. Care coordination is a critical piece of the services provided in the medical home. While the physician may serve as the care coordinator in a smaller practice, this role is often assumed by a nurse, social worker, medical assistants, lay case managers, or specially trained parents in larger practices. Adequate training must assure that the care coordinator is knowledgeable about community resources and public programs that families may need to utilize. In addition, the care coordinator must have interpersonal skills that facilitate partnerships with families as well as providers, agencies and programs to which families are referred. They should have experience with the care coordination process of assessing family strengths and needs, identifying appropriate resources, referrals, follow up and evaluation and revising the plan as needed. Finally, they should have the ability to communicate with families in the family's native language or through a medical translator.

Additional resources at the end of the chapter provide information and strategies for setting up a medical home, and practice management tools to enhance this effort. Some simple strategies; however, are virtually universal. It is helpful to identify the charts of those children with special health care needs. This allows the medical home practice to track the number of such children for purposes of resource allocation and arranging time-appropriate appointment setting allowing for additional time that these children often require.