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Practitioners' Essay

Setting Up a Medical Home for Chinese Immigrant Families with Children with Special Health Care Needs: A Step-Wise Approach

Sherry Shao Fen Huang and Loretta Young Au

Abstract

Children with special health care needs (CSHCN) require health services beyond what generally is required. CSHCN from immigrant families face additional challenges, including cultural, language, racial, and socioeconomic barriers. Federally qualified health centers provide an ideal setting to treat these children, providing comprehensive, family-centered care that fits their linguistic and cultural needs. This article describes the development of a National Committee for Quality Assurance level 3 medical home, addressing cultural perspectives and barriers to quality care for the Chinese immigrant community by highlighting Edward Wagner's Chronic Care Model, medical home criteria, electronic health records, parent engagement, staff development, and community collaboration.

Introduction

Children with special health care needs (CSHCN) are those children who require more than routine health and related services for ongoing physical, emotional, behavioral, and developmental conditions (McPherson et al., 1998). Although the prevalence rate is thirteen to fifteen percent of the general U.S. population (Palfrey et al., 2010), CSHCN account for 2.5 to 20 times more utilization of health care resources than children without chronic health conditions and for seventy percent of all health care resources for children (Ireys et al., 1997).

A medical home has been shown to improve health outcomes of CSHCN (Homer et al., 2008). A medical home is defined as a clinical practice committed to organizing and coordinating care based on child and family needs and priorities (Sia et al., 2004). Effective medical homes provide care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective (American Academy of Pediatrics, 2002).

Utilization of health care services is not equally distributed among various socioeconomic, racial, and ethnic groups. CSHCN in poor and minority families are less likely to have a usual source of health care (Berry et al., 2010). Harrington and Kang (2008) conducted a study that examined service utilization and expenditures provided by regional centers in California to individuals of all ages with developmental delay. The study showed that, after controlling for client needs, all racial and ethnic minority groups were less likely to receive services than were whites. In Massachusetts a study done on their Early Intervention programs showed that there were reduced referrals and participation by Asian mothers, foreign-born mothers, and mothers not proficient in English (Clements et al., 2008).

Numerous studies have looked at the characteristics of families with CSHCN to better understand their needs, level of satisfaction, and barriers to care (Blumberg et al., 2010; Inkelas et al., 2007; Ngui and Flores, 2006; Yu et al., 2004). These studies have found Limited English Proficiency (LEP), immigrant status, and level of maternal education to be associated with decreased health care utilization and poorer outcomes in CSHCN. In the samples of populations studied, Asian ethnic groups are underrepresented. There are only a handful of articles focusing on the specific needs of Asian families with CSHCN (Baker et al., 2010; Choi and Wynne, 2000; Huang et al., 2004).

Federally qualified health centers (FQHC) are an ideal practice setting for medical homes, especially for CSHCN, due to their mission to provide comprehensive and coordinated care (Adashi, Geiger, and Fine, 2010) and to serve low income, underserved minority and ethnic immigrant communities (Geiger, 2005). FQHC staff are usually from the same linguistic and cultural groups as their patients. The focus of FQHCs is patient- and family-centered care, including services such as health education and social work (Adashi et al., 2010).

Few studies have directly looked at the effectiveness of the medical home model in FQHCs. Moreover, the steps needed to establish a Patient-Centered Medical Home (PCMH) have not been well described, especially for a pediatric Chinese immigrant population with special health care needs. In this essay, we will share our experience in establishing and achieving a National Committee for Quality Assurance (NCQA) level 3 PCMH at the Charles B. Wang Community Health Center, a FQHC serving the Chinese immigrant population in New York City (NYC).

Early Years

Charles B. Wang Community Health Center (CBWCHC) was established in 1971 through the efforts of a group of volunteers who recognized the unmet health needs of the Chinese population in NYC (Hoobler and Hoobler, 2011). CBWCHC received FQHC status in 1978 after successfully demonstrating to the federal government that NYC Chinatown is a Medically Underserved Area. CBWCHC's mission is: "Be a leader in providing quality, culturally relevant, and affordable health care and education, and advocate on behalf of the health and social needs of underserved Asian Americans."

Starting in donated basement space of a local church, CBWCHC now resides in four locations within New York City. In 2013, there were over 250,000 visits. The clinical services include pediatrics, internal medicine, obstetrics/gynecology, mental health, dental, nutrition, and optometry. About ninety percent of CBWCHC patients are considered best served in a language other than English. At the Manhattan Chinatown site, the pediatric unit has eight full-time equivalent providers, serving over eight thousand patients in 2013.

CBWCHC has been in the forefront of quality improvement processes. The health center was one of the first group of FQHCs to join the chronic care collaborative initiated by the Health Resources and Services Administration (HRSA) in 2001, promoting use of the chronic disease care model as a way to improve patient outcomes (Wagner et al., 2001). The main components of Ed Wagner's Chronic Care Model include clinical information systems, decision support, delivery system design, and patient self-management. The goal of the care model is to develop informed, activated patients and a prepared, proactive clinical team, so that the patients

and the clinical team will work together to create productive interactions (Wagner et al., 2001).

Clinical Information Systems

The pediatric unit at CBWCHC participated in several learning collaboratives between 2001 and 2009 that utilized the Care Model and the rapid improvement Plan, Do, Study, Act (PDSA) cycle. Through our work, we developed patient registries for asthma, obesity, mental health conditions, and epilepsy. Clinical information reports based on our daily visits with our registry patients helped track and monitor for key health outcomes based on each chronic condition.

Decision Support

Our team learned the importance of using evidence-based guidelines to ensure high quality work. National recommendations, practitioner toolkits, and resource guides from the American Academy of Pediatrics, National Asthma Education and Prevention Program, and NY Epilepsy Foundation were used. Although the evidence-based guides provided national benchmarks we could compare with our results, we were also diligent in taking these clinical guidelines and adapting them to our population. We sought advice from the experts (including medical subspecialists and national researchers such as National Initiative for Children's Healthcare Quality) to interpret our findings in light of these adaptations.

Delivery System Design

Even with guidelines, delivery systems design *and redesign* were major parts of the work to ensure that the guidelines were incorporated into direct patient care. This component was the slowest in execution as it required team building, training of physician champions, learning from PDSA cycles, and development of clinical workflows. The team building that occurred while we defined our care delivery systems was vital to the later successful implementation of our medical home.

Patient Self-Management

A vital component of the Care Model is patient activation. In the case of the pediatric patient, the parents and the immediate family members are important parts of the engagement process.

We learned over several years that Chinese immigrant families rely on multiple caregivers. Self-management skills are dependent on the health literacy level of the caregivers. It is not uncommon that different family members will come with the patient for different visits, making it difficult to reinforce specific health messages. Caregivers often have differences in beliefs about causation and treatment of disease, resulting in disagreement over treatment goals or differences in their readiness to make changes to improve the health outcome of the patient.

Overall, the foundations of our medical home were established through our prior work using the Care Model. Our team leaders, physician champions, and senior administrators had developed trust in a team approach. The road to a medical home for CSHCN required a more rigorous application of the above components.

Establishing the Medical Home

In 2010, CBWCHC was recognized by the National Committee for Quality Assurance (NCQA) as a level 3 PCMH. The pediatric unit applied as a stand-alone site by identifying three chronic childhood conditions: asthma, obesity, and ADHD. For our 2013 reapplication, we identified CSHCN as a separate population of focus. Patients with epilepsy, autism, intellectual disability, chromosomal disorders, cerebral palsy, and other complex medical or psychiatric problems were placed into a High Risk (HRSK) registry. We identified the following key steps as paramount to achieving an effective PCMH.

Building Our Electronic Medical Records

Information technology plays an important role in chronic disease management and fulfillment of PCMH requirements (Kim and Zurhellen, 2011). CBWCHC was one of the early adopters of electronic medical records (EMR) in 2006. The EMR allowed us to track patients efficiently through patient registries. Disease specific management templates facilitated clinical decision making. Clinical information reports allowed us to identify areas for quality improvement and follow-up care.

Defining the Roles of Care Team Members and Clinical Workflow

An important aspect of a PCMH for CSHCN is having a team that is proactive and prepared for patient visits. In the process of their care at CBWCHC, families with CSHCN can regularly

interact with seven or more team members with varying roles. We found it important to define the tasks and responsibilities of each member of the care team, especially in relation to the care of CSHCN.

The care manager is an especially important member of our team. We found that having this central contact person greatly enhances access to care for our families with CSHCN and also reduces the burden of care coordination on the physician and the families. The care manager conducts previsit planning in order to anticipate needs for any upcoming visits (e.g., consultation reports, lab results, prescriptions for home services). The family is called prior to the visit to remind them of what to bring and, if needed, can meet first with the care manager. The care manager then also provides postvisit care coordination to assist in carrying out any plans that the families developed with the pediatrician. The care manager becomes familiar with all aspects of care through these multiple interactions. The care manager coordinates the communication among the entire care team through direct discussion as well as EMR documentation.

Staff Training

CSHCN can have significant medical and nonmedical needs. Medical needs include medication and equipment/device management. Nonmedical support includes community resources for respite, home health, finances, transportation, and special education (Sadof and Nazarian, 2007). Pediatricians and care team members who care for families with CSHCN may have inadequate knowledge of community resources, limiting effective partnerships with families (Sadof and Nazarian, 2007).

To build our staff knowledge and resources we cultivated relationships with community agencies, specialists, and hospitals, especially those with Chinese language capabilities (see Tables 1 and 2).

Table 1. List of Community Agencies and Specialists

1. NY Epilepsy Foundation
2. Neurology departments and specialists from Columbia University College of Physicians and Surgeons and Beth Israel Medical Center, New York
3. Behavior and developmental specialists from Bellevue Hospital and Long Island Jewish Hospital
4. General Human Outreach (GHO), a nonprofit agency that operates programs authorized by the New York State Office for People with Developmental Disabilities (OPWDD)

5. Resources for Children with Special Needs (RCSN), a nonprofit organization focused on providing assistance and training to parents of children with special needs
6. Movement Matters, a community provider of occupational therapy (OT), physical therapy (PT), speech services, and sensory gym
7. Birch Family Services, a community-based provider of education, habilitation, and residential services for children with autism and developmental disabilities
8. Hamilton Madison House, a nonprofit community settlement house
9. Occupational Therapy Department of Columbia University College of Physicians and Surgeons
10. Brooklyn Developmental Disabilities Council
11. Public Health Solutions, a nonprofit organization that develops, implements, and advocates dynamic solutions to prevent disease and improve community health
12. University Settlement, a nonprofit community social service institution
13. Dr. Chuan Chang, a private community developmental specialist
14. APEX, a nonprofit organization that seeks to empower youth through mentoring programs, educational services, and social services
15. Coalition for Asian American Children (CACF), a pan-Asian children's advocacy organization

Development of a Care Book

Comanagement and coordination of care can be complex for pediatricians and LEP parents. There is a strong relationship between parental LEP and poorer health care access and quality for CSHCN due to limits on a family's ability to understand and advocate for their child's needs (Eneriz-Wiemer et al., 2014). Specialists often do not provide adequate interpretation services and parents have difficulty expressing concerns or questions to specialists. Often records from specialists or schools are not readily available to the care team, and parents are unable to adequately express the treatment plans back to the pediatrician to maximize effects of coordinated care.

To overcome these communication barriers, we created a bilingual Care Book. The Care Book is a three-ring binder which includes contact information for the patient's care team, an appointment log, and a communication log to share questions or plans among the specialists, schools, and the pediatrician. An individualized Special Needs Action Plan (developed with the parent during medical visits), a medication list, summary medical history, test results, consultations, and formal educational evaluations are also included. The care manager trains our parents on how to use and maintain the Care Book with specialists, school staff, and therapists.

Parent Engagement

Immigrant families are at particularly high risk of alienation from systems of care and support services (Yu et al., 2005). Because parent engagement is a central tenet of a successful medical home, we involve our parents with CSHCN through workshops, one-on-one visits with the care manager, and our Parent Advisory Group (PAG). Our goals are to educate parents on managing their child’s condition, familiarize parents with community resources, improve parents’ ability to advocate for services and partner with the pediatrician, and assist parents by creating a support network.

Table 2. List of Parent Workshops and Staff Trainings

Parent Workshops

1. Epilepsy and Home Safety
2. Epilepsy Medication Management and Use of the Seizure Action Plan
3. Office for People with Developmental Disabilities (OPWDD) Qualification and Services
4. What to Expect in a Special Education Classroom for Children with Autism
5. Top 5 Rights in Special Education
6. Navigating Special Education Reform
7. Special Education Mediation
8. How to Access NYC Services, Programs and Community Services
9. What to Expect When You See a Pediatric Developmental Specialist
10. What Is Occupational Therapy?
11. Needs, Wishes, and Dreams: Programs and Services that Bring Relief to Parents of Children with Disabilities
12. Transition Planning

Staff Trainings

1. Medical Management of Children with Epilepsy
2. Management of Children with Autism Spectrum Disorder
3. Special Education Rights
4. How to Read an Individualized Education Plan (IEP)
5. Needs, Wishes, and Dreams: Programs and Services that Bring Relief to Parents of Children with Disabilities
6. Greenspan Floortime Approach for Children with Autism Spectrum Disorder
7. Resources and Services by General Human Outreach (GHO)
8. Occupational Therapy and Sensory Integration Problems
9. Transition Services for CSHCN
10. Early Intervention Program and Services

With the help of community agencies, we developed a series of parent workshops that are held at CBWCHC and conducted in Chinese (see Table 2). We inform patients on the registry about workshops using several modalities, such as sending a flyer to the home and posting information on the CBWCHC website and on-site bulletin board. Often, the care manager will make a personal invitation via phone call and e-mail. The care manager is essential to parent engagement efforts, due to the trusting relationship that has been built with the parents. Workshop topics are often chosen based on parent suggestions.

In order to benefit from parents' experiences and establish parents as true partners of the medical home, we created a PAG. The goals of the PAG were to learn about the concerns of parents with CSHCN, partner with parents to improve systems of care for CSHCN, assist in creation of resources and educational materials, and train parents to become better advocates. We started the monthly PAG in 2013 with six parents and have increased the group to thirteen parents for 2014. Valuable input from the PAG has resulted in changes in improving wait time for CSHCN patients as well as communication between the specialist and pediatrician. The PAG has helped to develop and review information pamphlets, the Special Needs Action Plan, and the Transition Plan currently in use. Parents who participated in 2013 were also trained to advocate on a personal, community, and political level.

Collecting and Sharing Resources

Collaboration with community agencies has provided a wealth of resources to share with parents and the care team. Parents also contribute information about agencies that they find especially useful. These resources are collected in a resource library and are available for review by parents or the care team. Because a large (and growing) percentage of parents with LEP use email, we found this method to be the most efficient and cost-effective method for sharing resources. In order to enable more parents to access web-based materials, CBWCHC has developed workshops to teach parents how to navigate the Internet and establish an e-mail account.

Lessons to Share

We did not envision the full range of positive outcomes from the medical home when we initially started in 2001, which was

when we joined the HRSA learning collaborative for chronic care improvement. As we continue our work, we see that it is not a static process. We still use the rapid improvement PDSA cycle to test out changes in our flow. Defining the role of team members has been very important in empowering the different interdisciplinary team members to take charge of their area of work/expertise. In particular, the physician champions have taken control of each of the different health condition registries and worked closely with their team members to initiate follow-up management and tracking of key outcomes. The Special Needs Team meets monthly to examine the HRSK registry patient concerns and to improve services.

A key factor to sustaining the changes that are incorporated into workflow is real-time data entry as services are being provided, avoiding the delay of inputting separate information at a later time. EMR templates serve as clinical decision supports (reminding the staff to ask for vital patient information) and also provide staff a way to record patient outcomes. EMR aids in the retrieval of population-level data to analyze trends. This is one of the reasons that a high-performing EMR is crucial to success.

We cannot stress enough the importance of working closely with community agencies and harnessing the resources that these agencies provide. Especially for CSHCN, a support network for the PCMH must be built to meet the needs of these families. We could not have provided the quality staff and parent trainings without the generosity of our community agencies.

What is vitally important is an overall shared vision for culturally competent and quality care in a PCMH. Senior leaders and executive administrators at CBWCHC have made this goal a priority. There is recognition of the work involved—including the needed human and financial resources. Incentives to the staff include productivity bonuses for providers to do the needed work. There is a celebration of the achievements of the staff and a showcase of successes is presented to the health center's Board of Directors.

Challenges Working with the Chinese Population

It is easy to highlight successes but also important to discuss challenges that we have faced. Working with our Chinese immigrant families with CSHCN is highly rewarding and equally difficult due to the limitations posed by their life circumstances.

Diversity and Language

Several studies have pointed to the relationship of immigrant status (foreign born) with poor access (delay in getting medical care), decreased utilization (no visits to the doctor in the past year), unmet mental health needs, and reports of fair or poor perceived health status of children (Inkelas et al., 2007; Javier, Wise, and Mendoza, 2007; Yu et al., 2004). Asian Pacific Islander (API) populations are diverse not only in language and culture but also in their immigration history. The importance of disaggregating Asian subgroups, especially for populations that have arrived more recently, may be important due to data showing substantial heterogeneity among the Asian ethnic groups in access and utilization of medical services (Yu, Huang, and Singh, 2004).

We have found this to be true with our Chinese immigrant families with CSHCN. Parents delay seeking services, especially those offered by government agencies, due to concerns about their own documentation status. More recent immigrants are not aware of available services or eligibility criteria. Lack of computer skills, coupled with LEP, are additional barriers to accessing services. While our services are bilingual in Chinese and English, our own providers often have difficulty communicating with Chinese immigrant families due to the multiple dialects of Chinese spoken. Recent immigrant family members (especially grandparents, who are the main caregivers) often speak only their native village dialect such as Fukinese, Shanghainese, and Toishanese. It is not uncommon that in a parent workshop we have multiple interpreters for each dialect.

Self-Advocacy

Self-advocacy skills are essential in the improvement of the quality of life for people with disabilities and their families (Huang et al., 2004). While Asian American parents score significantly lower in their levels of assertiveness and other self-advocacy skills than their non-Asian counterparts, this level of self-advocacy in Asian American parents is found to be higher when Asian American parents are supported by social workers and mental health professionals and when parents have lived a longer time in the U.S. (Huang et al. 2004). In our experience, we have also found this to be true. Chinese parents with CSHCN are hesitant to ask for services when deemed ineligible or when ongoing medical or edu-

cational services are discontinued. Many families need the health center's support to advocate for appropriate services.

Stigma

Cultural perception of the root causes of developmental disabilities need to be accounted for as well in understanding how best to engage parents and family members in seeking help or following through with evaluation and treatment (Choi and Wynne, 2000). In a qualitative study among Hmong and Mien families, it was demonstrated that parents blame themselves or see the developmental disability as a disgrace and an embarrassment for their family (Baker et al. 2010). Having a child with a severe developmental disability such as autism has been highly associated with severe internalization of stigma in Asian families (Mak and Kwok, 2010).

From our experience with Chinese families, there is often a level of blame on the mother. Often, a mother with a CSHCN would ask if it was something she did during the pregnancy that contributed to her child's condition. Parents do not ask for help to care for their CSHCN. In our families with CSHCN, we commonly see one parent as the relegated caregiver. The lack of a dual income makes it difficult for many of these families to pay for expenses and to save beyond immediate needs. The hardships of managing on limited finances, coupled with lack of extended family supports, cause a strong sense of isolation and stress on parents.

Conclusions

The CBWCHC medical home for CSHCN has served to address health inequity in Chinese immigrant families by understanding and addressing the specific needs of these families. We have been able to effectively gauge the specific concerns of these families because of the composition of our staff, many of whom live in the same neighborhoods as our patients and are from their same home countries. Our services are designed to provide a wide range of direct support that is customized to diverse and multiple needs. CBWCHC, similar to other FQHCs, has recognized the importance of enabling services such as health education, patient navigation, translation, and social work. We develop our frontline staff by giving them the training on health care systems and skills they need to deliver these services.

FQHCs are in a unique position to provide this enhanced ability to engage families at their level of readiness. As providers who speak their language and share similar cultural backgrounds, we are able to overcome their hesitancy to seek help beyond their immediate family and are able to gain their trust. It is only with this trust that we can partner with them and address not only their immediate needs but support parents to speak up for the community's needs as a whole.

In our description of the establishment of our medical home with a focus on CSHCN, we do not have a magic formula. We are deeply engaged in finding standardized ways to measure the efficacy of our initiatives. The story continues as we are constantly learning ways to empower our families to take the next step in participating in the decisions regarding their child's health. Our progress has been steady, and we found, as we engage our parents in our advisory group, that we learn even more about how to provide what is needed rather than what we thought would be useful.

We found on our road to becoming a medical home that we, as an FQHC, are at the forefront of quality improvement. When we seek expert advice, the advice often is not directly applicable to our population. Because of our focus on prevention and the ability to provide comprehensive support services, CBWCHC has been effective in early detection of families with higher health risks and addressing the related social as well as medical aspects. FQHCs serve as important safety nets for our communities and have the ability to be innovative, adaptable, effective, and efficient partners in improving the health of our most vulnerable communities.

We hope that sharing our experience will inspire other FQHCs serving other Asian and/or immigrant communities to take further action. The rewards that come with working closely with the families with CSHCN are tremendous, as their strengths are as great as their needs.

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