

Adapting Models of Chronic Care to Provide Effective Diabetes Care for Refugees

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Caring for refugees with diabetes demands more than knowledge of clinical practice guidelines. When refugees arrive in the United States, their most common medical issues include infectious diseases, chronic pain, mental health concerns, and chronic illnesses such as diabetes.¹ The refugee experience of displacement because of persecution is central to their identity, and understanding their personal trauma is paramount to providing high-quality health care. Even with a careful view of the refugee experience in mind, several barriers to high-quality diabetes care include limited health literacy, alternative paradigms of health and illness, low self-efficacy, and complex community dynamics.

Two current models of chronic care that could be adapted to account for these barriers are the Chronic Care Model of Disease and the Primary Care Amplification Model. These models highlight the importance of patient-centered care in a complex health care system. Although it will prove challenging, the health care community must develop new paradigms to provide quality diabetes care to refugees by adapting current models of chronic disease management to account for the diversity of language, culture, and personal trauma typical of the refugees in the United States.

The United Nations defines a refugee as someone who, “owing to well-founded fear of being persecuted for reasons of race, religion,

nationality, membership of a particular social group, or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country.”² As such, a refugee’s personal history is marked by trauma (often torture), loss of family and friends, and cultural dislocation.¹

This transition to a new culture comes with many specific challenges. For example, refugees have learned by necessity to operate in crisis mode.³ As a result, they are less disposed than other immigrants to engage in long-term planning. This survival adaptation means that, for many refugees, the prevention of chronic disease is a foreign concept.

Limited English proficiency is another major barrier to high-quality health care for refugees. Despite their easy availability, family and friends are poor surrogates for

high-quality medical interpreters.⁴ When family or friends are used, major limitations include breaches of confidentiality, omission of pertinent information, and unfamiliarity with medical terms. Given the wide range of languages spoken by the refugees arriving in the United States each year, it is extremely challenging to provide consistent on-site, professional interpretation. With this in mind, we highly recommend the use of phone interpreters, even when there are family or friends who are proficient in English.

Diverse cultural views and a wide range of paradigms for health and illness also play a major role in how refugees understand diabetes. For example, fatalism is a belief that a person cannot change his or her destiny. In a medical context, fatalism manifests as the assumption that medical interventions are unlikely to effect positive change in health. For many refugees, this belief limits their ability to adhere to long-term treatment regimens.³

Refugees from many cultures believe that illness has non-material causes. For example, many Hmong attribute disease to a sense of being out of balance, and many Vietnamese identify the primary cause of diabetes as excessive worry or “sadness” and “perspiring less.”^{5,6} Many refugees also use traditional or herbal remedies in conjunction with Western medicine to try to control their diabetes. For example, in one study of Cambodian refu-

IN BRIEF

Adapting current models of diabetes care for refugees requires careful attention to diverse cultures, the refugee experience with trauma, and different paradigms of health and illness. Improving health literacy and self-efficacy, forming community partnerships, and providing community education will create the best chance for high-quality diabetes care in the refugee population in the United States.

gees,⁷ 73% of men and 83% of women had used a traditional treatment such as coining within the past year. Similarly, in one set of interviews with a Vietnamese population, Mull et al.⁶ highlight the importance of these viewpoints on diabetes with two illustrative quotations: “Eastern medicine is much safer than doctors’ medicine because it cools your body and brings it back into balance. Doctors’ medicine has a lot of strong hot chemicals—you can get really bad side effects if the dose is too high for you” and, “If you have to take insulin, for sure you’re going to die soon. Also, they say that some people go blind because of it.” With these perspectives in mind, it is clear that we must develop culturally relevant models of chronic disease to maximize our patients’ chances of receiving high-quality diabetes care.

Before we can begin to adapt our current models, we should first acknowledge that robust epidemiological data on diabetes health outcomes are lacking for the refugee population. One major complicating factor is a lack of uniformity: the U.S. Office of Immigration Statistics reports that roughly 74,000 refugees from at least 65 countries arrived in the United States in 2009 (Table 1).

The rate of resettlement has also varied considerably in recent years. The terrorist attacks of September 11, 2001, brought about a sharp decline from the hundreds of thousands of refugees who arrived annually in the past decades. Despite this decline, however, the past 6 years have seen steady growth in refugee arrivals.⁸ Because of such wide variation in the refugee experience, we are forced to extrapolate what we know about all immigrants to shed some light on the growing problem of diabetes in refugees.

One thing we do know is that diabetes is a burgeoning problem in the foreign-born population in

Table 1. Arrival Statistics by Fiscal Year and Region for Refugees to the United States⁸

Refugee Arrivals by Fiscal Year		Refugee Arrivals by Region for 2009	
2000	72,143	Africa	9,678
2001	68,925	Asia	58,309
2002	26,765	Europe	1,693
2003	28,305	North America	4,800
2004	52,840	South America	57
2005	53,738	Unknown	65
2006	41,094		
2007	48,218		
2008	60,107		
2009	74,602		

the United States. When immigrants and refugees first arrive, they have a relatively low prevalence of chronic disease. This is known as the “healthy immigrant effect” and is especially evident in Hispanic and Asian populations.⁹ Unfortunately, as refugees remain in the United States for longer periods of time, their incidence of diabetes increases.⁹ For example, recent evaluation of National Health and Nutrition Examination Survey (NHANES) data for immigrants demonstrated that the prevalence of diabetes increases in the first 10 years in the United States independent of age and BMI. In fact, the prevalence of diabetes among immigrants who are 25–44 years of age when they arrive increased from 1.4% at 5 years of residence to 11.1% at 15 years of residence.¹⁰ This increase in chronic illness is likely caused by alterations in nutrition, exercise, and social support.¹¹

Further evidence for the growing problem of diabetes in the

immigrant population comes from survey data from immigrants who have been in the United States for longer periods of time. For example, an analysis of NHANES data from New York City revealed an 8.6% prevalence of diabetes and a 34.5% prevalence of impaired fasting glucose in Chinese-American immigrants.¹² A more disturbing trend was evident among a well-established Hmong population in Wisconsin, in which 41% of the patients surveyed were at high risk of developing diabetes.¹³ It is thus becoming clear that diabetes will become a central factor in the health care needs of refugees the longer they stay in the United States. With this in mind, it is now important to consider the complex interactions between health literacy, culture, and self-efficacy that hinder our ability to provide excellent care to this ever-changing population.

The MacColl Institute for Healthcare Innovation and the Robert Wood Johnson Foundation have developed the Chronic Care Model of Disease for delivering care to patients with chronic illness (Figure 1). Two of the key elements of this model are 1) to encourage self-management of disease by empowering patients to see their central role in their health and 2) to mobilize community resources to meet the needs of patients.¹⁴ These elements have practical goals that enable health care teams to adapt this model to specific populations and health conditions. Limited health literacy, low self-efficacy, and complex community dynamics are three areas in which refugees face specific barriers to these goals.

Limited health literacy is a prime reason why encouraging self-management for refugees is challenging. Broadly defined, health literacy is a patient’s ability to understand and follow a health care provider’s

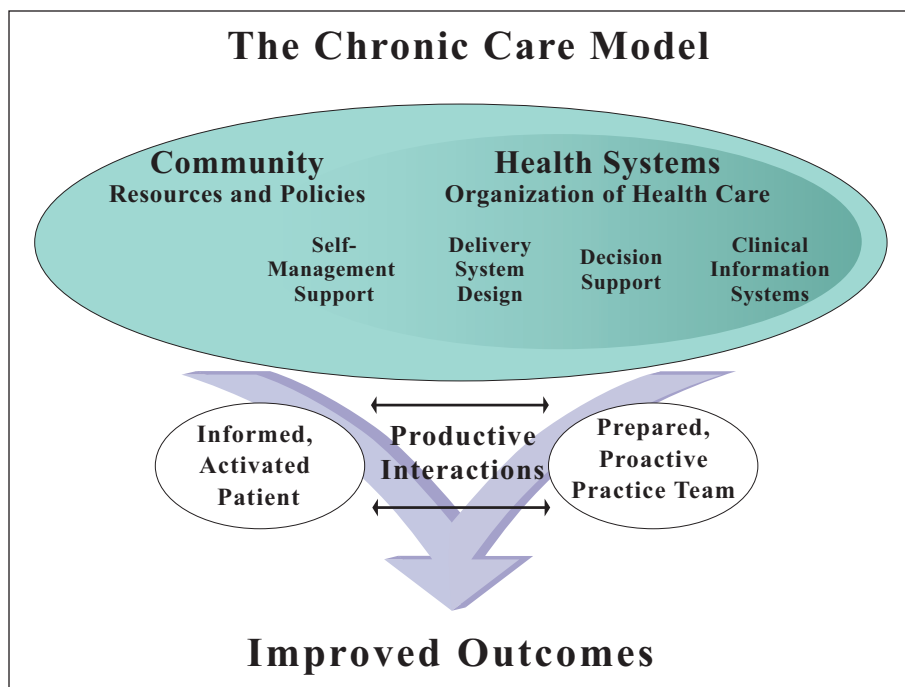


Figure 1. The Chronic Care Model of Disease. The Chronic Care Model acknowledges the interaction between community resources and self-management of disease. Adapting this model in the refugee population requires an understanding of the complex interaction between limited health literacy, low self-efficacy, and complex community dynamics. Reprinted with permission from Wagner EH: Chronic disease management: what will it take to improve care for chronic illness? *Eff Clin Pract* 1:2–4, 1998.

recommendations. Although it is known that lower socioeconomic status is associated with poor glycemic control and higher levels of impaired fasting glucose,¹⁵ low health literacy is not unique to the poor. In 2002, Schillinger et al.¹⁶ evaluated health literacy in two primary care clinics in San Francisco, Calif. They found that low health literacy was independently associated with worse glycemic control even after adjusting for age, sex, income, language, social support, and a host of other factors.

In the refugee population, health literacy is further affected by limited English proficiency and dramatic changes in culture.¹⁷ Although refugees consistently rate diabetes as a primary health concern,¹⁸ they often cannot understand what it means to manage a chronic disease.¹¹ For example, in our experience, many

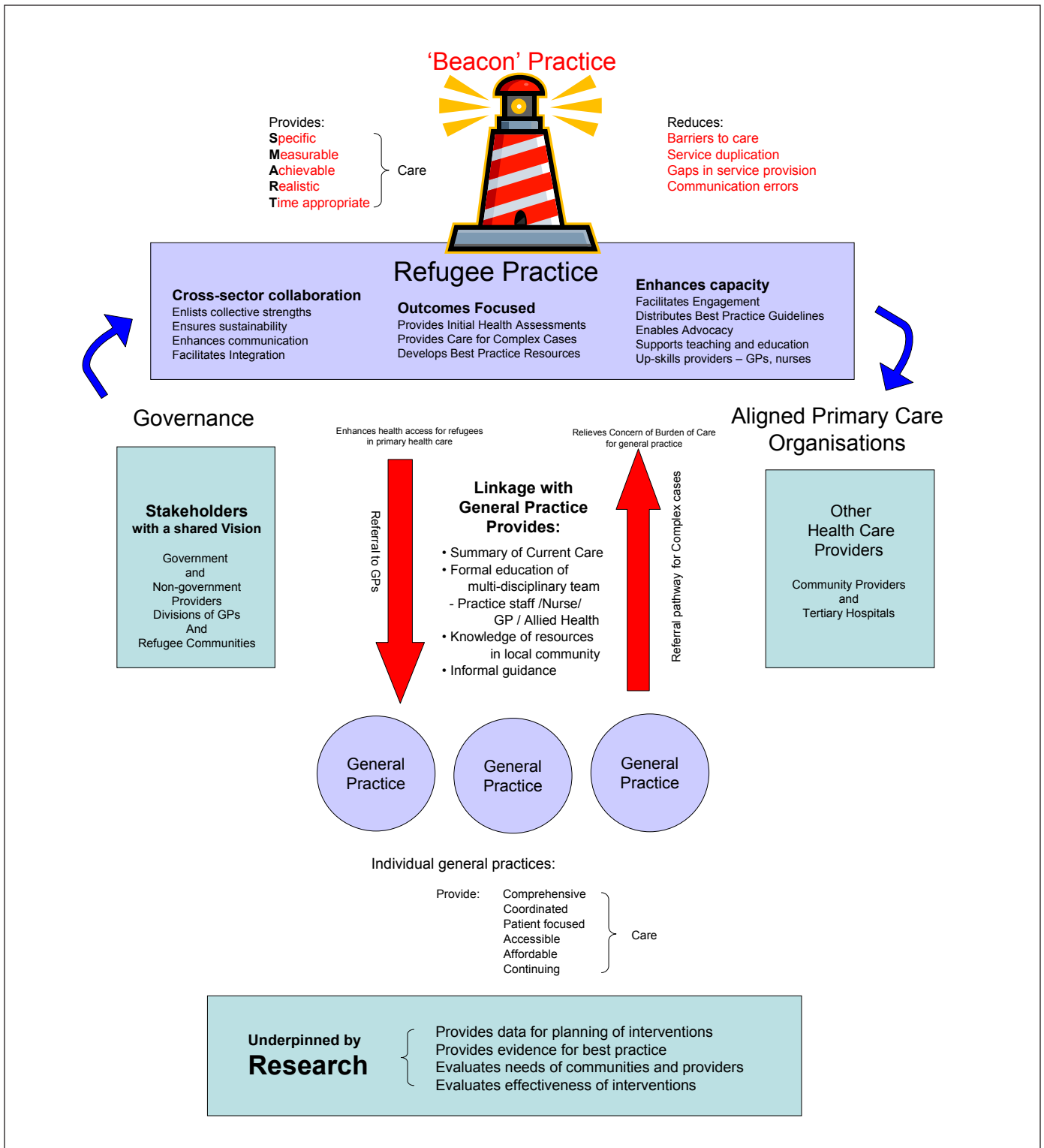
refugees do not understand that diabetes requires lifelong therapy. They often will not return to a clinic when a prescription runs out of refills, thinking that they have completed treatment for diabetes. Similarly, they frequently do not understand the differing roles of subspecialists and primary care doctors. So, when they miss appointments, they will often return to their referring doctor, who is the primary source of their care.¹ Finally, non-Western refugees often have a different concept of time. This not only makes it challenging to obtain the history of present illness, but also causes refugees to misunderstand appointment times, making it difficult for them to interact with a complex health system.¹

Low self-efficacy is another typical characteristic of refugees

that impedes self-management of diabetes. Self-efficacy is a person's perception that he or she has the intrinsic capability to attain a goal. Even if fatalism were not a pervasive cultural worldview in many non-Western populations, the overwhelming loss of control that characterizes the refugee experience would clearly contribute to a diminished sense of self-efficacy.

Taking this into consideration when teaching refugee patients how to manage their diabetes will be a crucial step in achieving quality care. For example, in one recent study of low-income Latino patients,¹⁹ hands-on skills teaching facilitated the development of self-efficacy, which was a necessary component to effective glycemic control. In another study²⁰ of minority patients that included Asian/Pacific Islanders, Latinos, African Americans, and whites, improvements in self-efficacy were associated with improvements in diabetes outcomes; increasing self-efficacy was related to improved diet, exercise, self-monitoring of glucose, and foot care. These findings were statistically significant after controlling for race/ethnicity and health literacy levels. This suggests that educational initiatives that target self-efficacy may yield improved diabetes outcomes despite the low health literacy and differing cultural viewpoints of refugees.²¹

The second pillar of the Chronic Care Model that deserves specific adaptation to the refugee population is community involvement. Beyond identifying barriers to health care, providers must be willing to engage refugee communities as partners through health fairs, focus groups, and small-group educational settings. To be most effective, community outreach should identify key elders who have significant influence in the cultural community



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Figure 2. The Primary Care Amplification Model. The Primary Care Amplification Model identifies a central beacon practice to help coordinate refugee health care. This model allows for local primary care and specialized refugee care, maximizing opportunities to provide high-quality health care to refugees. Reprinted from ref. 26 with permission from La Trobe University and CSIRO Publishing. GP, general practitioner.

and involve them in planning these interventions.⁷ Outreach should also involve local businesses, religious institutions, and existing social groups.

One way to tap into the cultural and social strengths of the community is to train and encourage lay health advisors who can implement training and education for members of the community.⁷ To help bridge the gap between health care providers and non-English-speaking communities, lay health advisors present health information and management strategies in a culturally acceptable way.²² Moreover, home health interventions have proven to be incredibly effective. In one Somali population, home health visits showed an improvement in A1C levels from 8.8 to 6.5%, in mean LDL cholesterol levels from 151 to 108 mg/dl, and in mean systolic blood pressure levels from 152 to 135 mmHg.²³

One natural extension of community outreach is community education, which often can be provided by lay health advisors. Nevertheless, culturally tailored health education has not yet been demonstrated to provide lasting improvements in glycemic control. A 2008 Cochrane Review of culturally appropriate health education in minority groups²⁴ showed that A1C levels were improved at 3 months after educational interventions, but that effect did not persist at 12 months. Refugees' limited English proficiency, poor knowledge about available health services, difficulty accessing health information, and reluctance to change lifestyle habits are cited as key reasons why educational efforts have failed.²¹

Going forward, however, we recognize several aspects of educational interventions that seem to make them more successful. These include cultural tailoring of the intervention,

use of lay health advisors from the community of interest, one-on-one interventions, focus on behavior-related tasks, and high-intensity interventions that are delivered over a long duration.²¹ Moreover, specific education should include teaching about appropriate diet, how to take action based on glucose meter results, the services that a diabetes clinic offers, and information about diabetes complications.²⁵ A multidisciplinary team should deliver these interventions, focusing on teaching self-management skills and improving patients' sense of self-empowerment.²¹

In the typical primary care or subspecialty clinic setting, providing this level of comprehensive, culturally competent care to a small number of refugees can be extremely challenging. In fact, adapting a chronic care model for refugee diabetes care seems operationally impossible for many small clinics.

To address this, Kay et al.²⁶ recently described a Primary Care Amplification Model used in Australia that identifies a central clinic specializing in providing care to refugee populations (Figure 2). This model identifies a "beacon" refugee practice that has close ties to the community, local private practitioners, and other key stakeholders. Such clinics provide initial health assessments for refugees with onsite interpreter services and translated patient educational materials. Refugees are subsequently linked with other local providers for routine care. These clinics then support the teaching of skills relevant to provider needs, link refugees to tertiary subspecialty care as needed, and develop key research questions to aid refugee health outcomes. One limitation of this model is that validation is still ongoing to determine whether it improves refugee health outcomes. Given the complexities of adapting

diabetes management to refugee populations, however, we strongly recommend that providers identify a local clinic specializing in refugee care.

Finally, in our experience in an urban clinic that provides care to refugees in a major metropolitan city, we find that long-term doctor-patient relationships provide the bedrock for chronic disease management. Initial refugee health visits are often met with ambivalence on the part of refugees. They usually have minimal trust of the medical system and limited experience with Western concepts of disease. Therefore, it is exceedingly important to develop trusting relationships with refugees to negotiate a mutually acceptable understanding about the nature of their disease. We have also found that partnering with refugees' local religious communities allows for a more meaningful trust to develop, especially in the context of chronic disease management.

In summary, adapting our current models of chronic care to include an understanding of refugees' complex social and cultural influences will allow for the best chance for improvements in long-term diabetes outcomes. The refugee experience of trauma, different paradigms of illness, and limited English proficiency contribute to limited health literacy and low self-efficacy. These barriers to self-management of diabetes need to be overcome by community education and partnerships that empower refugees to understand their illness and develop a paradigm of long-term disease management. With a growing and diverse refugee population that is characterized by a wide array of languages and cultural beliefs, no single intervention will prove effective for all groups. Instead, we suspect that using central "beacon" refugee practices that can effectively

adapt the Chronic Care Model will have the best chance at providing quality improvement in diabetes care for refugees in the United States.

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