Experience, Communication and Trust:

The Role of Cultural Health Navigators in Mediating Refugee Families' Access to Health Literacy and Pediatrics Care

by

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ABSTRACT

This dissertation explores findings from a year-long investigation of the context-driven practices, strategies and beliefs of five multilingual Cultural Health Navigators (CHNs) working in a local pediatrics clinic serving large numbers of refugee families from a variety of cultural backgrounds who are experiencing a range of healthcare challenges. Grounded in a methodology of engagement (Grabill, 2010), this inquiry systematically documents and analyzes the range of ways in which the CHNs assist refugee families and their healthcare providers, their rationale for the decisions made and actions taken, and their concerns about the challenges they encounter. I show that while much of what the CHNs do to assist refugee families and their healthcare providers is routine and can be expected, CHNs also tend to manage complex work involved in mediating refugee families' interactions with healthcare providers and the healthcare system in ways that cannot always be anticipated in advance. Through a close analysis of their practices and reflections, I show how their various interactions, actions and decisions are responsive to specifics of the situation at hand, informed by their lived experiences as CHNs and immigrants/refugees, and influenced by a dynamic, emergent and embodied notion of context. The findings of this study demonstrate how the CHNs' collective and distributed knowledge production work shapes experiences with acquiring health literacy, and the material consequences of such efforts and practices.

Drawing on ethnographic research methods and critical-incident methodologies that involved the CHNs in the inquiry process, this study provides a nuanced analysis of the different kinds of work they do, the constraints they encounter, and how they creatively respond to such constraints in real time. The findings demonstrate that a collaborative engagement with critical incidents as a method of intercultural inquiry facilitates a more robust and dynamic understanding of the distributed nature of decision-making practices and ways of knowing. Embodying sensitivity to situated ways of knowing and dynamic practices in institutional settings, this study demonstrates the value of combining social science methodologies with rhetorical inquiry methods to conduct interdisciplinary and cross-institutional research to address pressing social problems in ways that benefit historically marginalized groups.

For my mother, Sarina, who left this world too soon.

I wish you could have seen this.

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CHAPTER ONE

MAKING A CASE FOR INQUIRY

Statement of the Problem

Over the past two decades, the global population of forcibly displaced people has gone from 33.9 million in 1997 to 65.6 million in 2016, the highest number since World War II (UNHCR, 2016). In 2016, while former President Obama was still in office, he raised the cap on admissions goals from 70,000 in previous years to 85,000, reflecting the recent upsurge. In 2017, not long after President Trump took office, he temporarily suspended the refugee resettlement program and decreased admissions by nearly half—the lowest it has been in years despite the steady increase of refugees and other forcibly displaced individuals and families worldwide. It is estimated that nearly twenty people are forcibly displaced every minute, and 22.5 million of those who have been displaced in the past few years are under the age of eighteen (UNHCR Website, 2018). These numbers are unprecedented. Overall, approximately 67% of individuals fleeing their countries are women and children who have spent extensive time in refugee camps, sometimes for decades, and are often the victims of torture (Zong & Batalova, 2017). Many are in need of urgent and ongoing medical attention. Once resettled in the U.S., this is not always what they receive. For many refugees, important connections to the healthcare system may not be made during the initial resettlement process—making it all the more difficult to make those connections later on and/or without the support of resettlement agencies. And although access to and utilization of healthcare services is clearly needed and important during resettlement, most health care providers are underprepared and/or ill-equipped to meet the needs of this large and growing population.

Upon arrival, refugees first must go through the first phase of the resettlement process. Resettlement agencies provide initial reception and “cultural” orientation, place families or individuals in homes and connect them with a variety of social services. For those responsible for resettling refugees, the focus is often on finding employment and housing, both of which impact one's capacity to connect with resources and reach a place of self-sufficiency (Beiser & Hou, 2001). However, without feeling healthy, it is difficult to obtain and maintain employment, go to school, learn a new language, establish support systems and connect with resources, such as the healthcare system (Refugee Health, ORR website, 2017). Research on refugee resettlement indicates that resettlement does not happen quickly; indeed, for refugees, figuring out how to navigate in a new context is a lifelong process involving different institutional needs at different phases (Beiger, 2009; Beiser & Hou, 2001; DeVoretz, Pivnenko, Beiser, 2004; Hou & Beiser, 2006). This is to say that the process of resettlement does not begin and end with the support of local resettlement agencies, and factors such as unemployment, schooling, and healthcare have differential impacts depending on the refugees’ phase in the resettlement process. Considering the initial emphasis on self-sufficiency and the complex factors involved in resettlement, it is not surprising that not all needs are met at the times in which they are needed.

When it comes to seeking care, navigating the healthcare system is not easy. It is complex, multilayered, dispersed, disconnected and highly textually mediated; knowing where to go, how to get there, where to obtain information, and how to navigate the multitude of auxiliary and supplementary services (e.g. pharmacy, physical therapy, occupational therapy) are only a few of the many facets of the U.S. healthcare system. For resettling refugees already encountering so many new ways of being and acting in their local environments, the system may seem overwhelming at first, which is why connections need to be facilitated upon arrival. The first experience, which is typically a health screening, can set a precedent for what is to follow, as it is the first point of contact with the U.S. healthcare system. It can also be an important step towards establishing trust (Annamalai, 2014) and identifying urgent medical needs so that the necessary referrals can be made. Unfortunately, this first experience does not always lead to appropriate referrals or future connections to health providers, and many refugees are left stranded with no clear path to care. In the absence of navigational support and a clear and trusted path to care, many refugees may not seek care at all.

When connections to the healthcare system are not made early on, and there is no trusted support to help facilitate these connections later, they may never be made. Even when connections are made, refugees continue to face a number of structural "barriers" accessing and navigating the healthcare system (e.g. Davidson et al., 2004; Edberg et al., 2011; McKeary & Bruce, 2010). Among the most cited are language, [health] literacy, culture and trust, each of which can restrict one's capacity and/or desire to seek and receive care. In response to these identified barriers, many medical and health communication researchers and health professionals are calling for more "culturally and linguistically appropriate care" (e.g. Annamalai, 2014; Betancourt et al., 2005), reflecting a growing awareness of the importance of cultural sensitivity in healthcare and a shift towards more patient-centered care (Betancourt & Green, 2007). The term "culturally and linguistically appropriate care" is rarely operationalized, but several techniques have been suggested including hiring and retaining staff to reflect the diversity of patients served, using interpreters, providing cultural competency training for providers, and using materials that reflect the languages of those commonly encountered in the service area (Department of Health and Human Services, 2001).

One way to provide more culturally and linguistically appropriate care, and to also support refugee patient's connection to and navigation of the healthcare system, is the use of Cultural Health Navigators (CHNs). CHNs—also known as community health workers, community health advisors, lay health workers, patient navigators, and community health representatives are typically members of the communities they serve, acting as liaisons, links and intermediaries between health services and their communities (American Public Health Association, 2009). As multilingual "insiders" with an emic understanding of their communities, CHNs facilitate important connections and relationships to/with the healthcare system and can be powerful sponsors for refugee families access to and pursuit of literacy in the health context. CHN's offer a distinct category of non-clinical knowledge and skill-sets based on life experience or "experience-based-expertise" (Gilkey et al., 2011). Their employment is not contingent upon more traditional criteria or educational credentials associated with healthcare professionals; although a social work background is helpful, emphasis is placed on having experience and situated/local knowledge of their communities. As "insiders" to the communities they serve, they are able to identify and generate meaningful messages that integrate medical and local knowledge and draw on practices within their communities. Some CHNs, for instance, bring knowledge of the culturally specific storytelling practices that are common within many American Indian/Alaskan Native communities, and they draw on this knowledge to help implement diabetes programs (Acton et al., 1999; Mayer et al., 1998). The merging of local and medical knowledge is just one of many important and yet not well understood responsibilities that constitute the work of CHNs.

The goal of most recent scholarship on CHNs has been to evaluate their efforts in relation to health outcomes and cost effectiveness (e.g. Brownstein et al., 2011; Norris et al., 2006; Witmer et al., 1995). While current research has acknowledged CHNs and their potential value within the healthcare system, it reflects a narrow understanding of the work they do by emphasizing only the quantifiable aspects of their efforts, such as increases in preventative services. What is missing from scholarship on CHNs, is *how* the CHNs do the work they do, what they think and say about that work, and what else they believe might be useful or needed. Current research tells us little about the kind of support CHNs offer, the needs they meet and how those needs are met (for patients and providers), the knowledge and experiences they bring to their work and how their embodied knowledge informs their practices. Without a better understanding of *how* CHNs do the work they do to support their communities, it is difficult to determine what needs they are meeting (or could use more support meeting), how they are able to meet those needs, and how their past experiences and situated, local knowledge inform their efforts since they are hired based on their life experiences. This study responds to calls for more research on the strongly recommended but not well understood work of community health workers and the roles they play in supporting underserved communities' connection to the healthcare system and access to quality care. There are three sets of questions that guide this study.

Research Questions

1. What practices and resources (e.g. language, artifacts, people) do the CHNs use to assist and support refugee families navigating the healthcare system? What practices and resources do the CHNs say are valuable/beneficial for refugee families; what is valuable about them?
    - 1.1 What practices and resources are commonplace (used by multiple CHNs across varied situations and contexts) and what practices and resources are distinctive (used by few CHNs or not very often)?
    - 1.2 What challenges do the CHNs encounter while working with refugee families and how do they respond and problem-solve and what are their reflections on those challenges and responses?
2. What do the CHNs say about their prior lived experiences trying to navigate the healthcare system (e.g. as recently arrive refugees). Do they say that their prior experiences seem to influence the work they currently do to serve refugee families attending the pediatrics clinic?
3. Do the CHNs talk about their current practices in ways that indicate shared assumptions, expectations, understandings or beliefs? In what ways?
    - 3.1 What do their shared and distinct understandings reveal about the kinds of knowledge needed to address the complex-health related challenges facing marginalized groups?

With these questions as guides, this study explores and investigates the context- and experience-driven practices, strategies and beliefs of five Cultural Health Navigators (CHN) working in a refugee pediatrics clinic in a metropolitan city in the southwest. Grounded in a methodology of engagement (Grabill, 2010), this study systematically documents and analyzes the range of ways that CHNs assist refugee families and their healthcare providers, their rationale for the decisions made and actions taken, and their concerns about the challenges they encounter while doing their work. I also endeavored to understand the CHNs' views on what changes might facilitate more effective and higher quality-care delivery for the families they work with. This study responds to calls for different approaches to examining the work that CHNs do, the needs they are meeting and how they are meeting them, and the experiential and embodied knowledge that guides their practice.

To pursue this research agenda, I draw on ethnographic research methods (e.g. observations, interviews, artifact collection) to help document and assemble the ideas, arguments, practices, activities and tasks that connect and constitute the work the CHNs do to support refugee families at this clinic. This process of documentation and assemblage supports a particular kind of engagement in this study: intercultural inquiry. In this study, I also employ research and writing to learn from the CHNs about their experiential and situated knowledge in order to generate certain kinds of narratives or stories—specifically the critical incident (Flanagan, 1954). This study demonstrates that a broader engagement with these critical incidents through the process of intercultural inquiry with the CHNs facilitates a more nuanced understanding of the work the CHNs do, the distributed nature of their practices and understandings, why certain choices and actions make sense within specific cultural and interactional contexts, and how their lived experiences as refugees and/or immigrants inform their efforts. By involving the CHNs in the analysis of data, I provide a robust and nuanced analysis of the different kinds of work they do, the constraints they encounter, and how they creatively respond to the day-to-day constraints they encounter.

Refugee Families Navigating the Healthcare System: Challenges and Responses

As the Office of Refugee Resettlement (ORR) recognizes, "physical and emotional wellness, as well as access to healthcare, are foundations for successful resettlement. Without feeling healthy, it is difficult to work, to go to school, or take care of a family. Without health insurance, an injury or illness can threaten economic self-sufficiency" (ORR website, 2017). In order to pursue employment opportunities and participate in and make use of the many services offered during the initial stages of resettlement and later, physical and emotional wellness are crucial. Yet, the emphasis on "self-sufficiency" and the short window of support obfuscate their relevance and impact on this process. For many refugees, this tends to generate patterns of living focused more on survival and social goals as opposed to maximizing health (Edberg, Cleary & Vyas, 2011). When medical needs (e.g. nutritional deficiencies, infectious diseases, PTSD) are deemphasized during the initial resettlement process, many important connections may not be made. It is important that refugees have access to trusted support systems (and CHNs create such systems) in order to make sustained connections to resources that ultimately help them establish a lasting relationship with the U.S. healthcare system.

If and when refugees do make it to the clinical context, it is likely that the practices, processes, interactions and people involved in healthcare delivery will be unfamiliar. Without guidance and support, it may be difficult to make sense of the experience. Obtaining, for instance, coherent medical histories can be challenging (Lawrence et al., 2005; Mirza et al., 2013). In these encounters, restricted communication and a lack of trust can impact the histories obtained and the kind of care received. In the absence of accessible information or interpreters to facilitate communication, refugee patients may have difficulty asking questions and discussing concerns, and may not realize where and when they can, or that they have a right to do so. There may also be discordance between ways of explaining symptoms and complaints that result in misunderstandings and uncertainty among providers, which may lead to a potential misdiagnosis (He et al., 2010; Ivbijaro et al., 2005; Lawrence & Kearns, 2005; Mirza et al., 2013; Morris et al., 2009; Pavlish, Noor & Brandt, 2010; Sheik-Mohammed et al., 2006). When there is inadequate language support and interpreter services in the clinical context, it is difficult if not impossible for refugee families and their health care providers to communicate effectively about a range of issues (e.g., symptoms, treatment plans, follow-up care) and a number of problems emerge—including a lack of trust, limited independence, and reduced agency in the decision-making process (Ashton et al., 2003; Donnelly et al., 2011; Feldman, 2006; Jatua, 2011; Mirza et al, 2013). Negative experiences in the clinical encounter may discourage future participation in much needed services.

For refugee families that have resettled in the U.S., having trusted support to facilitate connections to the healthcare system and health-related resources is crucial, but does not always happen. Establishing trust can be further challenged by perceptions of discrimination and treatment bias thought to be, or reflective of, a lack of “culturally and linguistically appropriate care” (Annamalai, 2014; Bhatia & Wallace, 2007; Edberg et al., 2011; Edge & Newbold, 2012; Herrel et al., 2004). Without trust, it is unlikely that effective communication will take place between patients and providers; this is especially true of refugee patients who are already wary of institutions and authority (e.g. Colucci et al., 2012; Sheikh-Mohammed et al, 2006).

Health Literacy

Over the past few decades awareness of the relationship between literacy and health (Nutbeam, 2008) has grown. In 2009, the WHO Commission on Social Determinants issued a report identifying literacy as having a “central role” in determining inequities in both rich and poor countries (WHO Commission on Social Determinants, 2009). The commission concluded that achieving high levels of literacy is a vital development goal that would produce substantial public health benefits. In 2007 the National Health Literacy Act was passed—the goal of which was to enhance efforts to eliminate low health literacy by improving measurements, research, development, and information dissemination. More recently, the Affordable Care Act has attempted to integrate health literacy into the “law of the land,” arguing that individuals with “low levels of health literacy are least equipped to benefit from the ACA, with potentially costly consequences for both those who pay for and deliver their care, as well as for themselves.” Provisions include communicating health and health care information clearly and in more “culturally and linguistically appropriate ways,” and by extension, “readable” for those with low literacy levels.

Having acknowledged the relationship between literacy and health, numerous researchers have attempted to define and operationalize *health literacy* within larger conversations about health equity, disparities, promotion and access (e.g. DeWalt et al., 2004; de Leeuw, 2012). As more researchers attempt to operationalize this term, the more disagreement and confusion there seems to be surrounding the concept, particularly between and within two fields in which health literacy is most frequently discussed: biomedicine and health promotion. Each of these fields also represents what Chinn (2011) refers to as two waves of health literacy research that have taken shape over time, but which have dominated the field of health literacy research. Much of the biomedical research is situated within the first wave while much of the research emanating from the field of health promotion is situated in the second. More recent research and scholarship on health literacy suggests there may be a third wave on the horizon as the field expands and becomes more interdisciplinary (e.g. Hunter & Franken, 2012; Papen, 2009); the findings of this study will likely be a part of this emergent conversation.

Research on health literacy within the biomedical field, where health literacy research first emanated, tends to frame health literacy as a risk factor with a focus on literacy assessment in relation to health outcomes (e.g. Baker, 2006; Dewalt, Berkman, Sheridan & Lohr & Pignone, 2004; Ratzan & Parker, 2000; Paasche-Orlow, Wilson, McCormack, 2010; Parker, 2000). Within this framework, health literacy involves reading, writing and numeracy skills and is viewed as something that needs to be *managed*. The focus is on the individual and their capacities. Often called the “individual capacities model”, there is a strong emphasis on the role of reading fluency and prior knowledge (i.e. vocabulary, conceptual knowledge of health and healthcare) in understanding health. Indeed, within this framework, reading is understood as *the* primary way to gain conceptual knowledge on health and healthcare. In short, the assumption is that, “Health literacy occurs when the skills and ability of those requiring health information and services are aligned with the demand and complexity of information and services” (Parker & Ratzan, 2010, p. 2). This scholarship generally frames health literacy as a problem *of* patients, not for necessarily *for* their providers or the system.

In recent years, some biomedical research has moved beyond this central focus on the individual and their deficiencies to consider the role of context and environment. The Institute of Medicine (2000), for instance, views health literacy as a “dynamic state” of the individual during a health care encounter. The IOM has emphasized the healthcare *system and context* as well as the *individual* in their definition, now adopted by the US Department of Human Health and Services, National Institute of Health, and more recently by the Affordable Care Act. Here, literacy is defined as, “The degree to which individuals have the capacity to obtain, process, and understand basis health information and services needed to make appropriate health decisions” (Ratzan & Parker, 2000). Although individual capacities are still central to this understanding, the model does attempt to account for the contexts in which individuals understand, pursue or access health information and healthcare. The definition stresses the importance of a clinical environment that is more “sensitive” to the needs of individuals with low literacy. The underlying theory being that health literacy can be assessed prior to communicative exchanges (as measured by tests like the Rapid Estimate of Adult Literacy in Medicine), and the numerical score (or reading level) provides health professionals with the information they need to successfully communicate and/or adjust the way in which they communicate with patients to support more ‘sensitive” practice. How assessment tools should influence communication strategies and how language is accounted for in these tests and exchanges is unclear.

Research on health literacy from a public health and health promotion perspective also focuses on individual competencies in relation to the relevant medical context (e.g. Abel, 2007; Campbell, 2000; Chinn, 2011; de Leeuw, 2012; McCray, 2005; Nutbeam, 2000; 2008; Peerson & Saunders, 2009). However, much of this scholarship also takes into account contexts outside of the clinical setting where health information is obtained, decisions are made, and actions taken. Rather than viewing health literacy as a potential "risk factor" to one's health, health literacy is considered to be an asset and an *outcome of health education*. With a view of health literacy as multiple and varied, this scholarship generally considers the ability to read and write (i.e. functional literacy) to be a foundation on which a range of complementary skills can be built. This stands in contrast to biomedical definitions which seem to privilege reading in particular as a way of conceptualizing, assessing, and improving health literacy.

Researchers within health promotion acknowledge the role of individual capacities but attempt to move beyond an exclusive focus on the individual to consider context and situation (e.g., the *consumer* identity in the broader context of health promotion and public health). In addition, health literacy from a health promotion perspective is not restricted to clinical settings and identities. Here, attention is paid to the role of education, knowledge, and the development of social and personal skills as the means by which one may improve and build their health literacy. In this way, health literacy, engagement, participation, choices, health outcomes and opportunities are intertwined and mutually influential. With a focus on patients' empowerment and participation, this research investigates patients as *consumers of health messages and health education*. Educational initiatives influenced by this literature advocate tailoring education and information by drawing on relevant personal experiences of the consumer rather conducting an arbitrary assessment of one's literacy level during the clinical encounter.

Much of the existing scholarship on health literacy reflects relatively static notions of health literacy that tend to focus on individual cognitive skills and abilities such as reading and writing, while failing to account for the mitigating factors and necessary processes that influence development. By emphasizing the individual, important social aspects of health decisions and actions are obscured, despite evidence showing that consumers of healthcare services rarely make decisions on their own without any influence or input from others (Rapley, 2008; Edwards et al., 2015*).* In general, the onus of responsibility for "improving" health literacy and overcoming other language-related "barriers" tends to be placed on patients, leading to ineffective top-down interventions targeting patients that fail to consider the full ecology in which health literacy is situated (Blommaert, Collins, Slembrouch, 2005). Much of the existing scholarship on health literacy and health outcomes also tends to rely on quantitative measures using decontextualized standardized instruments or tests (e.g. Rapid Estimate of Adult Literacy in Medicine), which do no help us understand how people interact with health information in real life situations (Chinn, 2011). Some health literacy researchers suggest that qualitative approaches involving interviews, observations and ethnography can help us move beyond understanding health literacy as an individual achievement, but rather as distributed competencies dispersed through individual networks (Chinn, 2011).

With this project, I challenge narrow definitions of health literacy and interrogate simplified portrayals of healthcare access and delivery by showing the social contexts of health literacy and health care delivery processes. By examining the situated, dynamic, and distributed social practices that emerge between providers and families *in the doing* of health communication and health care delivery, I document and demonstrate the value of CHNs practices, beliefs, and interpretations as they work across contexts, spaces, agencies and social networks to address the health-related questions and concerns of refugee families with a wide range of health care needs. Using qualitative methods, I analyze how (and when) CHNs facilitate health literacy development while care is being sought in order to show how nuanced understandings of health and wellness (i.e., health literacy) emerge within specific contexts of health care delivery and practice.

As I will discuss in the next chapter, there are several new and emergent models and perspectives on health literacy that attempt to complicate our understanding and respond to the above concerns; however, they have not yet been used as windows to examine health literacy in action. Drawing on ethnographic methods to devise an intercultural rhetorical inquiry, I study the work of CHNs and their reflections on that work to understand how the CHNs' knowledge production shapes health literacy with material consequences for refugee families trying to navigate the healthcare system.

Cultural Health Navigators

According to a year-long study in 1998 by a group of researchers and CHNs attempting to document the kind of work CHNs do, there are roughly (though more recent statistics are needed) 120,000 CHNs working in neighborhoods, homes, schools, worksites, faith-based organizations, health departments, clinics, and hospitals throughout the U.S. (Rosenthal et al., 1998). Many work for short-funded projects addressing specific, targeted issues like diabetes or health literacy campaigns (Rosenthal et al., 2010). CHNs go by many titles including lay health advisors, neighborhood workers, indigenous health workers, community health representatives, health aids, consejeras, promotoras, patient navigators and most commonly, community health worker (Nelson et al., 2002). They have also been self-described within American and Alaskan Native communities as "the in-between-people" (Satterfield et al., 2002). CHNs have been described as "community members who work almost exclusively in community settings and who serve as connectors between health consumers and providers to promote health among groups that have traditionally lacked access to adequate care" (Witmer et al., 1995, 1055). CHNs are known to offer a distinct category of non-clinical knowledge and skill-sets based on life experience or "experience-based-expertise" (Gilkey et al., 2011). In social science terms, they can be understood as 'local' (Gertz, 1983) or 'situated' (Haraway, 1988) forms of knowledge acquired from experience rather than education, offering different viewpoints on the problem of illness and challenges of health promotion (Gilkey et al., 2011). Their "insider" or emic understandings of their community's cultural strengths and values provides them with the background needed to choose effective health communication approaches (Satterfield et al., 2002, p. 162).

CHNs have been shown to "empower" individuals to participate in services and advocate for themselves (e.g. Henderson et al., 2014; Perca-Lima et al., 2013). Research shows that their attention and care constitute an important step towards improving health outcomes and increasing engagement among those with limited resources and/or restricted access to services (e.g. Colucci et al., 2012; Mayfield-Johnson, 2001). The mediational and supportive work of CHNs facilitates important connections that encourage participation and engagement in primary, preventative and follow-up services. It is through participation that patients are drawn into literacy practices (Papen, 2009) that facilitate access, navigation, and help actualize and cultivate trusting relationships that encourage more ongoing and consistent participation. Specifically, it is through guided participation that patients become familiar with the practices, processes and people, and agencies involved on the path the care, even if they do not yet speak the dominant language of healthcare delivery (i.e. English). For CHNs, the more their patients work with them, the more likely they are to develop trusting relationships, shared ways of talking about health and illness in the context of healthcare delivery, and effective rhetorical and communicative strategies to mediate interactions between providers and patients.

The CHNs model of healthcare delivery began with the “natural” assistance system that emerged from a lack of “formal” doctors or “formal” medicine, particularly in rural areas throughout the world. The “barefoot doctors” of China are one such example. The Chinese government, during the Mao Tse-Tung era, began to train villagers to treat common illnesses, promote sanitation and immunizations. Similarly, the *promotoras* of Latin and Central America have been providing basic health education and outreach to poor and underserved communities, helping them organize and advocate for themselves for decades (Berthold et al., 2009). The first and oldest CHN program in the U.S. was the Community Health Representative (CHR) program created in 1968 by Indian Health Services in collaboration with American Indian Tribes. The CHR programs were designed to “bridge gaps between people and resources and to integrate medical knowledge about disease prevention and care with local knowledge" (Landen, 1992; Mayer, Brown, Kelly, 1998, p. 168). Members in tribal communities were hired to "foster cross-cultural understanding through their shared tribal language and experiences (Satterfield et al., 2002, p. 168). In the 1980's, the AIDS epidemic motivated activists to invest more in community health outreach and programs. It was at this time that many CHNs from a variety of diverse communities were hired, and their success at this time largely influenced the development of the CHN field (Berthold et., 2009). By 1998, the original CHR program reported almost 2.3 million client contacts (Satterfield et al., 2002).

Currently, there is no single curriculum or standard credentials mandated to become a CHN, and most tend not to be highly educated, with 31% holding college degrees and 35% having completed high school. For more educated health professionals, CHNs role and level of authority may come into question (Berthold et al., 2009). Some states, like Texas and Ohio, have initiated credential mandates, and there are some existing educational programs such as the one developed by the City College of San Francisco in the early 1990s. Funding has also been an issue for the work of CHNs, as it tends to be inconsistent and dependent upon temporary grants aimed at addressing specific community issues. Some states are attempting to remedy this situation. In 2007, the legislature in Minnesota approved direct hourly reimbursement of CHNs under Medicaid, and in 2008 the Centers for Medicare and Medicaid approved a Medicaid state plan amendment authorizing the hourly payments of CHNs who work under supervision of Medicaid approved physicians (Rosenthal et al., 2010). In Massachusetts, CHNs were given seats on the state's expanded Public Health Council, signaling a greater recognition of their work. Most recently, the U.S. Bureau of Labor Statistics, in their 2009 Occupational Outlook Handbook, included CHNs (referred there as community health workers) under the category of social and human service assistants—their first appearance and recognition as an occupation in a government-issued document.

The roles and activities of CHNs are different but "complementary" to other members of health care teams (Anthony et al., 2009). Roles tend to vary, but there have been some general consistencies documented. In a yearlong study of CHNs nationwide, seven key roles were identified by both researchers and CHNs participating in the study (Rosenthal et al., 1998):

- Cultural mediation between communities and human services
- Informal counseling and social support
- Providing and producing culturally and linguistically appropriate health education
- Advocating for individual and community needs
- Assuring people get the services they need
- Building individual and community capacity
- Providing direct services

More specific roles and activities that have been documented are supporting patients in managing their risk factors and disease and linking them to resources (Brownstein et al., 2011), developing problem-solving and healthy coping skills (Davis et al., 2007), educating patients about preventive care, exploring patient barriers to screenings and tailoring interventions to meet individual needs (Perca-Lima, 2013), providing educational outreach to local residents (Mayfield-Johnson, 2011), and functioning as "health care extenders" by delivering direct services to patients while bringing cultural sensitivity and community understanding of patients spoken and unspoken needs (Thompson et al., 2007).

CHNs' contributions have, for the most part, been documented in terms of health outcomes. Their effectiveness in promoting the use of primary and follow-up care for preventing and managing diseases has been recognized for a variety of health conditions including asthma, hypertension, diabetes, cancer, immunizations, maternal and child health, nutrition, tuberculosis, and human immunodeficiency virus/AIDS (American Association of Diabetes Educators, 2009; Bloom et al., 1987; Brandeis University, 2003; Brownson & Heisler, 2009; Brownstein et al., 2005; Brownstein et al., 2007; Chin et al., 2007; Davis et al., 2007, Findley et al., 2009; Fedder et al., 2003; Norris et al., 2006; Satterfield et al., 2002; Thompson et al., 2007; Witmer et al., 1995). The work of CHNs has also been shown to prevent unnecessary and costly emergency department and specialty services, thus cutting down costs (Witmer t al., 1995). This is especially problematic for many refugees who tend to seek care at these facilities because they do not know where else to go. In more qualitative studies, CHNs have been shown to encourage and motivate patients (Davis et al., 2007), improve healthcare organizations ability to identify needs of the community (Baker et al., 1997) and improve general wellness through informing community members about resources and facilitating access to services (Rodney et al.,1998). And yet, what remains unknown or often misunderstood is how they do what they do, the needs they meet and how those needs are met (for patients and providers), the knowledge and experiences they bring to their work and how these resources inform their practices.

Significance of the Study

Understanding the complementary role CHNs play in the delivery of healthcare is important to healthcare teams and their effective integration in the healthcare system. There is much we do not know about the nature of their work and their overall contributions (Brownstein et al., 2011). We know that one of their key identified roles is tailoring services and resources to meet the needs of their communities. Yet, few studies have investigated the specific processes involved in tailoring services to the cultural, linguistic and structural needs and resources of the communities served (Nguyen & Kahawa-Singer, 2008). In other words, the nature of interactions with clients, how CHNs identify community problems and needs, develop innovative solutions and translate them into practices, procedures and/or resources is not well understood (Witmer, 2000). A list of roles and responsibilities is insufficient for understanding and unpacking the processes and hidden logics behind how CHNs identify exigencies in their communities or among their patients (and providers), respond to and make meaning of the identified concerns, and translate them into practice or material resources. We still know little about the less visible and less obvious aspects of the work CHNs such as the thought processes behind decisions made and rhetorical strategies employed and the ways in which meaning is negotiated in the face of conflicting logics.

In order to really understand CHNs contributions and the value of their experiences and emic understanding of their communities, we need to move past the obvious and quantifiable. If we want to know *how* CHNs work with (and sometimes foster independence among) the refugee families that they work with and encourage their participation in the healthcare system, we need to take a closer look at what it is they are doing, what they say about what they do, how they accomplish and construct their goals, the role of their lived experiences in their practices and decision-making, the challenges they face, and how they respond to such challenges. This project responds to the call for new and different research methods to examine the emergent understandings and dynamic work of the CHNs (Nelson et al., 2002; Nguyen & Kagawa-Singer, 2008; Rosenthal et al., 1998). This study demonstrates the value of combining social sciences methodologies with rhetorical inquiry methods to conduct interdisciplinary and cross-institutional research that helps us move beyond the lists of roles and responsibilities reported in existing scholarship.

By collaboratively exploring the obstacles that health professionals routinely face when trying to implement the many recommendations that have been made to provide care in more culturally and linguistically appropriate ways, my research may also address a substantial gap in the growing body of literature on the challenges refugees continue to face when accessing healthcare services and navigating the healthcare system. Embodying sensitivity to situated ways of knowing, dynamic practices in institutional contexts, and the complicated process of relationship building, the findings of this study promise to enhance local communities' capacities to identify and develop practices and policies needed to address some of the challenges experienced by refugee families and other marginalized and/or underserved groups when accessing and utilizing healthcare services.

Overview of Chapters

In the following chapter I discuss the central theories and concepts that inform my research project from three fields of study: literacy and language learning, health literacy and health communication. In Chapter 2, I discuss two models of health literacy that I drew upon in this study that challenge more traditional theories discussed in Chapter 1 while also offering a framework for theorizing social support in relation to health literacy from the field of health communication.

In Chapter 3, I begin by describing the methodology in which I ground the study and the procedures for collecting and analyzing data including the critical-incident-interview technique. Next, I discuss the challenges and limitations I encountered as a researcher in this study and my strategies for mitigating those limitations. I conclude the chapter by discussing the research context, participant recruitment procedures and by providing brief biographies of the five participants.

I report my key findings in Chapters 4, 5 and 6. In Chapter 4, I show how the CHNs routinely make important connections between refugee families and the healthcare system, how they guide families through multiple literacy practices and facilitate a variety of interactions and procedures with people, agencies and texts at multiple and critical stages on the path to care. The chapter demonstrates how their work is situated, dynamic and full of new experiences, outcomes, encounters and people. By examining the CHNs routine practices and the CHNs stated reasons for engaging in such practices, I demonstrate the critical role they play in the refugee families access to quality care and providers capacities to deliver that care.

Chapter 5 builds and expands upon Chapter 4 by exploring three types of advocacy work the CHNs are involved in and under what circumstances, while also surfacing more of what the CHNS know and how they know it. To do so, I identify and examine incidents or events elicited during interviews with the CHNs that demonstrate what this work looks like in action. By doing so, I illuminate some of the dimensions of the context or “force field” in which the CHNs operate and some of the tensions, contradictory agendas, and voices they have to navigate and negotiate on a regular basis. The findings in this chapter show how the CHNs serve as valued and trusted linguistic and cultural resources that help families take part in practices that are needed to gain access to healthcare and by engaging in those practices, at times, for them.

In Chapter 6, I invite readers to look through the eyes of the CHNs as they make sense of and respond to three data-driven scenes (elicited using methodologies outlined and discussed in Chapter 3). Each of the scenes, which the CHNs perform, captures one of the three types of advocacy work examined in Chapter 5 and include critical elements of the incidents analyzed. I examine the reflections, insights, and questions that emerged during the group conversation as the scenes unfolded and how our interactions and dialogue expanded and challenged our individual and collective understandings of the situated, context-dependent nature of their advocacy work. The chapter helps to make the CHNs sense-making and thinking patterns more visible, demonstrating the ways in which their ongoing experiences as CHNs and past experiences as refugees or immigrants shape and inform their current efforts and understandings on a regular basis as well as the potential value of having more intercultural dialogues among the CHNs.

In Chapter 7, I discuss and reflect on the practical/pedagogical, theoretical and methodological implications of the study. I consider the studies possible contributions to the fields of literacy and health literacy studies and the value of combining social science methodologies with rhetorical inquiry methods to conduct interdisciplinary and cross-institutional research to address social problems in ways that benefit historically marginalized and underrepresented groups. I conclude with future directions for research.

CHAPTER TWO

CONCEPTUAL AND THEORETICAL FRAMEWORKS

In this chapter I identify and discuss the central theories and concepts that informed my research project from three fields of study: literacy and language learning, health literacy and health communication. More specifically, I focus on sociocultural theories of literacy and learning which laid the foundations from which I analyzed and interpreted the data collected in this study. I also discuss two models of health literacy that I drew and expanded upon in this study: *health literacy as situated and distributed social practice* and *health literacy as cultural capital accumulated in and through practice.* Finally, I present a framework for theorizing social support in relation to health literacy from the field of health communication.

Sociocultural Theories of Learning and Literacy

The central questions that guide this study are informed by sociocultural theories of learning and language learning. Drawing on Vygotsky (1978), I understand that human learning and development are situated in social activities that are mediated by tools, most significantly language, and also located, or situated, in particular contexts. Vygotsky viewed learning as social in nature and as a process through which individuals “grow into the intellectual life around them” (1978, p.38). Thus, within the sociocultural framework, development is seen to take place through participation in particular contexts, organized by social activities, and therefore cannot be separated from or examined outside of its context (Lave & Wagner, 1991). As a researcher, then, I understand that action and learning emerge from situated engagement with others and from affordances and constraints of particular contexts.

Within this framework, I also draw on the notion of the zone of proximal development (ZPD) (Wells, 1999), which views social interaction as a mechanism for individual development whereby a more experienced or “capable” participant guides or scaffolds learning for less experienced or “novice” participant. In this study, I understand the work that CHNs do to facilitate learning and health literacy development to illustrate one way that the ZPD might be operationalized in the context of health care delivery. As the research and my findings show, because people do not learn to navigate the healthcare system alone, decontextualized assessments that attempt to measure one's health literacy are not fair indicators of all an individual is capable of doing. This is an important foundational theory for my understanding of health literacy as realized and enacted in and through social practice.

Sociocultural theories of literacy also inform my understanding of literacy as situated and dynamic in context (Gee, 2012; Heath, 1983; Street, 1995) as well as multiple insofar that there are multiple modes of meaning-making and textual forms and diverse linguistic landscapes in which texts mobilize and circulate (Kress, 2003; New London Group, 1996). I also understand that literacy has the capacity to travel, endure, and integrate into new and multiple social and geographical spaces (Brandt & Clinton, 2002; Lam & Warriner, 2012). This is to say that I adopt perspectives that fall under the umbrella of sociocultural theories—namely that literacy is situated social practice, literacy is multiple, and has the capacity to travel, integrate and circulate. I also agree with Farnell (2012) that literacy practices are primarily about meaning-making and involve embodied socialization into shared systems of meaning. With this in mind, like

Gee (2012), I argue that literacy is influenced and shaped by Discourses—or ways of using language and symbolic expressions, feelings, believing and valuing to identify oneself as a member of a socially meaningful group or social network.

Theories of literacy as situated social practice emphasize the contextual and embedded nature of literacy, where social relationships and interactions are key in the development and shaping of literacy practices and learning. Healthcare, for instance, is shaped by relations of authority, and literacy is a part of the process of establishing and actualizing those relationships of power (Papen, 2009). This connects back to earlier discussions about the relationship between literacy and trust, and how both work together in the shaping of relationships and literacy development through participation. This perspective highlights the social and contextual nature of literacy and literacy development not reflected in more traditional theories of health literacy. In this study, I draw specifically on the notion of literacy practices, which can be understood as repeated, goal-directed and socially organized social practices situated in broad contexts, cultural goals and history, with some practices being more dominant than others and often involving unequal asymmetrical distributions of power (Barton & Hamilton, 2000). By identifying and documenting the repeated practices observed I, along with the CHNs, began to make sense of how participation in particular practices help actualize relationships in the healthcare context, how they are distributed and what shared and multiple meanings have emerged in the process of this ongoing work.

A theory of multiliteracies helps me to account for the multiple and varied modes of communication and ways in which meaning is negotiated and shared. As multilinguals serving emergent multilinguals/bilinguals, CHNs facilitate (and acquire) multiple literacies simultaneously—that is, in order to construct relevant messages, they must negotiate, integrate and make sense of multiple literacies (i.e. ways of doing, thinking, valuing) related to health and illness in multiple languages. This process has involved the integration of new literacy artifacts into the CHNs and the clinic's everyday practices and procedures and/or the repurposing of current ones. Literacy artifacts can be viewed as social agents in terms of making links between contexts; through movement and interaction, literacy artifacts can get incorporated into potentially new activities, networks and systems of power (Brant & Clinton, 2002). This is to say that literacy has the capacity to move, endure, travel and integrate into new social and geographic spaces. In this study, this perspective helps to account for the fact that literacy in the context of the healthcare system is not static, stagnate or isolated; it has the capacity to evolve and change. In this study, I show how the CHNs have integrated new literacy artifacts into new activities, practices and systems of power to generate more relevant and meaningful messages and resources for the families they serve. For instance, they co-developed a questionnaire for refugee families exclusively which has now been incorporated into the routine intake process at the clinic. In other words, the CHNs are in a unique place to know what literacy artifacts or practice might be needed in order to more effectively deliver healthcare for refugee families, making them important sponsors of literacy.

Sponsors of literacy, as Brandt (1998, 2001) describes them, are "agents, local or distant, concrete or abstract, who enable, support, teach, model, as well as recruit, regulate, suppress, or withhold literacy—gain advantage by it in some way" (p.166).

They can also be viewed as delivery systems for the economies of literacy and represent the causes in which people's literacy often gets recruited (Brandt, 1998, p. 167). In the health context, emphasis on the correlation between health literacy and health outcomes has frequently represented a prominent cause, but this was not necessarily the case for the CHNs. For the CHNs, the "cause" can be viewed as a desire to help families reach a place of greater "independence" where families rely less on the CHNs for help, meaning they are in a better position to dialectically interact and participate in the system as agents in it. After years of experience working within the healthcare system and navigating the tensions between refugee families and medical culture, the CHNs have become powerful sponsors of refugee families access to and pursuit of literacy in the healthcare context. In this study, therefore, it was important that I pay attention to what kinds of roles the CHNs play at the "scenes of literacy learning" that they participate in as a way to understand the different aspects of this process of sponsorship—such as explicit teaching—noting how they assist, permit, support, model, and in some ways coerce refugee families into literacy and literacy practices.

Models of Health Literacy

As I mentioned in Chapter 1, more traditional perspectives on health literacy tend to focus on particular cognitive skills and abilities such as reading and writing. Research drawing on these perspectives have, for the most part, remained within traditional boundaries either of biomedicine or health promotion and education (Chinn, 2011). Subsequently, we have an abundance of scholarship examining health literacy as a patient "risk factor" centered around compliance in relation to health outcomes, and interventions aimed at improving clarity of information (de Leeuw, 2012). It would be impossible to refute claims that reading, and writing are not necessary and important skills to possess within the highly textually mediated world of healthcare; and at its foundational core, literacy *does* involve reading and writing. The problem is that literacy is more complicated, and such approaches to health literacy fail to account for its complexities. They also continue to frame health literacy as a problem *of* patients and not *for* patients—that is the onus continues to be placed on patients to improve their health literacy skills to meet the demands of the healthcare system. In alignment with sociocultural theories of learning and views of literacy as a social practice, I do not view health literacy as an individual “problem” but rather as a collective opportunity for growth and development. In the remainder of this section, I discuss several emergent perspectives on health literacy that inform how I theorize and operationalize the practice of health literacy in contexts of health care delivery. Some of these perspectives are more developed than others, but each merge disciplinary theories in a way that challenges the dominant paradigm of skills deficits (Hunter & Franken, 2012), reconnecting with the more emancipatory goals of health promotion (Chinn, 2011).

One model that has largely advanced the field of health literacy research is Nutbeams’ (2000) three level model of health literacy, which he describes as “functional,” “interactive” and “critical.” Each level, Nutbeam argues, progressively allows for greater autonomy, a goal or function of health literacy, and a hope among many providers for their patients, including the CHNs. Drawing and building off of Nutbeams' model, Chinn (2011) describes and analyzes *critical health literacy* in terms of three domains: critical appraisal of information, understanding the social determinants of health, and engagement in collective action. The three domains of critical health literacy identified by Chinn (2011) draw attention to the problems with the widespread assumption that the “underlying messages of biomedical research are basically neutral and benevolent, though they may offer a bewildering array of choices that are not easily judged by the naive and sophisticated” (p. 62). Chinn goes on to suggest that in an age of information overload, people may need more advanced and critical media analysis skills to arrive at these underlying messages and/or to assess their relevance and meaningfulness to their lived experiences and health goals. Together, Nutbeam’s (2000) model and Chinn’s (2011) expanded discussion of *critical health literacy*, inform my view of how health literacy might be defined, operationalized and theorized in this project. Through ethnographic methods and a methodology of engagement, I look beyond individual behaviors and skills to understand what health literacy looks like in action, how it is distributed, and when it is shared. Nutbeam’s (2000) model has also laid a foundation for other theories and perspectives to emerge within the field of health literacy.

As Rubinelli et al. (2009) suggest, “Critical health literacy reflects the individual's’ capacity to contextualize health knowledge for his or her own good health, to decide on a certain action after a full appraisal of what that specific action means for them in their own world” (p. 309). Contextualizing information is the first step towards being able to apply knowledge through action. Once it has been contextualized, an individual can determine whether or not it has meaning or relevance to one's circumstances and to what extent. By drawing on Bakhtin (1981), I understand that this process involves information and knowledge that are internally persuasive to the individual. Some messages may be persuasive, some may not concern or appear to concern the individual and, so, are rejected. Some more “authoritative” messages and ideologies (moral, political, religious) may either be totally rejected or affirmed, resting on a hierarchical differentiation between the power of the generator of messages/information and the receiver (Dufva & Aro, 2015, p. 40). The critical appraisal of information may be difficult for refugee families since messages are often laden with cultural specificities and ideologies that may not be readily contextualized, thus restricting one's agency to dialogically interact and negotiate meaning. As mentioned in earlier sections, CHNs play a valuable role in helping to generate meaningful messages and explanations that help with contextualization. For instance, as my analysis of data will demonstrate, the CHNs often help clarify and contextualize the medical encounter so that families know why certain questions are being asked, what the goals of the interaction are and what will happen during the exam, making the process less threatening. As CHNs, they recognize some of the implicit assumptions and take-for-granted practices of this encounter—those which refugee families have no frame of reference for or experience with and respond accordingly.

As I previously indicated, the health context is highly textually mediated and there is a great deal of information to sift through. For this reason, building off of Nutbeam’ (2000) model of health literacy, Chinn (2011) argues that part of being health literate (specifically critically health literate) involves being able to critically examine or analyze information and messages, and use that analysis as a way to contextualize the social determinants of health. This framework looks beyond individual healthy behaviors to investigate how structural factors such as income, education, and social exclusion impact health—factors that the CHNs are much more aware of and knowledgeable about when considering both their personal and professional experiences. When thinking about health literacy sponsorship, it is important that whoever is doing the sponsoring understands the structural and social "barriers" on the path to care and in the pursuit of literacy. At this time, I want to focus specifically on the critical appraisal of information because I believe this process facilitates the other two (i.e. understanding the social determinants of health and engagement in collective action) and is most relevant to this study and the work of CHNs in supporting refugee families and their literacy development in the health context. In order to tailor resources and services, messages and information need to be contextualized within a patient's lives and experiences so that they are relevant, make sense, can be assessed and used to support or inform action, meaning and decision-making. This is often where CHNs merge medical and local knowledge--a process that is not well understood but is explored in this study.

Health literacy as situated and distributed social practice.

As I discussed in the Chapter 1, the second wave of health literacy draws on the notion of multiple literacies. The developments within this wave (including the influential model above) have largely stemmed from developments in New Literacy Studies (e.g. Barton & Hamilton, 2000) and more sociocultural perspectives on literacy already discussed. Some health literacy researchers, drawing on similar perspectives, now view health literacy not just as an abstract “attribute” or “generic” ability, but rather, situated social practices that people are drawn into as a result of changes in health status and experiences in their lives (Edwards et al., 2015; Papen, 2009). In other words, individuals are drawn into new literacy practices *as needed*, and the ways in which patients access and comprehend health information, make sense of their experiences and resources are multiple and situated. From this vantage point, health literacy is understood as situated social practices embedded in social relationships and institutional processes and practices. This is an important distinction because it implicates the social and situated aspect(s) of health literacy—a significant departure from more traditional or normative notions of health literacy which do not account for context or situation, but rather place emphasis on the individual as either having “it” (i.e. health literacy) or not.

An understanding of health literacy as situated social practices that individuals are drawn into *as needed* highlights the highly contextual nature of these experiences. This understanding also suggests that just because one may not have developed certain skills in the health context or on the path to care, it does not mean they are not capable of developing them when they *are* needed. A problem for many refugee families is that they may never (or rarely) get the opportunity to purposefully participate in *as needed* practices to navigate the healthcare system and get the care they need. How, then, can they begin to develop their health literacy? How might a lack of relevant (and/or linguistically accessible) resources make this difficult and in what ways? As this study shows, trusted social support and relevant (e.g. linguistically, culturally) resources are crucial to the pursuit of health literacy, as they open communicative channels for information sharing and learning and support participation in *as needed* practices, which might then be drawn upon in other situations within the healthcare context.

Papen (2009), for instance, describes health literacy as shared resources. When faced with difficulties or limitations, people frequently draw on family members, friends, neighbors or "literacy mediators" (such as the CHNs) for advice and assistance. In this way, Papen (2009) suggests that health literacy is also "distributed." He adds that:

> An individual's' health literacy could thus be seen as the sum of what she knows and is able to do herself and what she is able to achieve with the support from friends, family and other significant people in her environment. At a more general level, this view of health literacy as being collectively achieved also challenges individualized notions of responsibility and risk, which underlie current health policies (p.27).

Health literacy, according to this view, is not a one-size-fits-all "thing" or ability that an individual possesses, but rather a collective distribution of knowledge, values, beliefs and practices situated within particular contexts, circumstances and experiences. Edwards et al. (2015) share this perspective, but with a focus on decision-making, arguing that the pathway from knowledge to action, referred to as the "health literacy pathway," is often distributed over people and emerges transformed through multiple interactions with multiple others, significant or otherwise, over a period of time. Health literacy as a pathway to action is understood as dispersed and distributed among individual's social networks (e.g. family, friends, colleagues). From this perspective, movement and participation in the health context are *as needed* literacy practices; that is not the result of individual effort, but rather, collective effort(s).

Thus, by drawing on all of these frameworks (e.g., Barton & Hamilton, 2000; Chinn, 2011; Edwards et al., 2015; Gee, 2012; Papen, 2009; Vygotsky, 1978), it seems ineffective to measure one's "health literacy" individually using decontextualized instruments would not reflect all a person is capable of doing or understanding within the healthcare context and their real lived experiences with it. In contrast to this limited (and limiting) and decontextualized understanding of literacy, Papen offers a perspective that places a great deal of emphasis and importance on one's social networks. For many refugees (especially recent arrivals), however, their social network(s) may be limited, or (as will be discussed in following section) lacking in cultural resources or capital that might facilitate movement and participation in the healthcare system, thus restricting their "field of possibilities" (Bourdieu, 2011) to act.

Theorizing health literacy as cultural capital in and through practice.

The concept of practice connotes *doing*—doing in both the historical and social context that gives structure and meaning to what it is that is being done (Wenger, 1998, p. 47). In this study, I consider the practices involved in the work CHNs do to support refugee families access to care and navigation of the healthcare system to see how that work is actually accomplished, drawing attention to how knowledge is situated in a particular locale or site. Since practice is such an important aspect of this study, it is important for me to be clear about how I conceptualize and situate practice, and what I practice helps me understand when examined through particular lenses. My theory of practice integrates two distinct but similar concepts, specifically the notion of "figured worlds” (Holland et al, 1998) and “fields” (Bourdieu, 1990; 2011), both of which help me to think about practice in different but complementary ways. Couched in this discussion of practice (which is framed within Bourdieu's sociological theory more broadly) is the notion of “capital” (Bourdieu, 2011), which I then draw on to theorize an additional/alternative approach to health literacy.

By figured worlds, I mean a “socially and culturally constructed realm of interpretation” in which particular actors are recognized (e.g. doctor, nurse, patient), significance is assigned to certain acts (e.g. making an appointment at a clinic), and particular outcomes are valued over others” (Holland et al., 1998, p. 53); the healthcare system can be viewed as one such “realm” of interpretation. The ability to “sense” or “read” one’s world becomes embodied over time through continual participation (p. 53-54), as the internalized reading eventually begins to regulate one's’ behavior within the world. With a focus on the day-to-day interactions and practices, figured worlds provide the contexts of meaning and action in which social positions and social relationships are named and conducted; they also provide the “loci” in which people fashion themselves. What was of interest in this study, was how CHNs “read” of the healthcare system and the communities they serve has influenced their own “fashioning” of self as CHNs (among their multiple and potentially conflicting identities), their practices and how they support refugee families’ entries in/navigation of the system through their own continued participation in it. What figured worlds do not help explain is the relationship between practices within larger, institutional structures of power that go beyond the immediate "order of interaction" (Holland, et al., 1998, p. 57), which is why I draw on Bourdieu's sociological theory.

As Bourdieu has argued, “the social world is accumulated history,” and the everyday, routine and unexpected occurrences in our lives and how we react and respond to them are located within a broader context, or what Bourdieu calls “fields of power” (Bourdieu, 2011, p.15). This is to say that there is a structure to society, and though we are all agents in that society, our capacity to move and act dialectically with our world is embedded in a history that came before us and will likely outlive us. The point I wish to emphasize here is that every moment is not independent of the last one, and anyone cannot become anything at any moment; the social world cannot be reduced to a discontinuous series of “instantaneous mechanical equilibria” between agents who are treated as interchangeable (Bourdieu, 2011, p. 15). Our “field of possibilities” as individuals are varied and stratified and represent the set of constraints (and affordances) inscribed in the reality of our world. These sets of constraints and affordances determine the chances of success (or not) of practice. Engendered through the interaction between habitus (i.e. norms, values, dispositions) and capital (i.e. material and symbolic resources that directs actions or “fields of possibilities”) within particular fields (i.e. the context or setting in which habitus and capital interact (Bourdieu, 1986), our practices make these relational dynamics more visible and subject to examination.

The notion of fields and Bourdieu’s schematic logic of practice helps to account for the aspect of structured hierarchy and status that go beyond the immediacy of interaction; much like a deep-sea current that you cannot see, it is a powerful force that is not readily visible. Thus, locating practices within particular “fields of power” help to explain the larger structural forces at work that shape our “fields of possibility” within the broader context of history, not just the local, everyday contexts of our lives. Central to this framework or logic for practice is the notion of capital—that is resources generated by “accumulated labor” (Bourdieu, 1990; 2011). In this study, for instance, the capital gains that the CHNs make through their accumulated labor as CHNs can be viewed as potential gains for the refugee families they serve.

Social Support, Social Networks and Health

Since social support and networks are essential to how I am conceptualizing health literacy, it is important that I am clear about what I mean by social support and the kinds of social support the CHNs provide families to help them participate in the healthcare system and make capital gains. Here, I draw on a framework put forth by Goldsmith and Albrecht (2011) to theorize social support in relation to health literacy. Research on supportive conversations and networks in particular shows how health is embedded in the content and structure of relational life outside of the clinic and alongside media messages (Goldsmith & Albrecht, 2011). In the absence of relevant and meaningful media messages, so much of what refugee families learn about the healthcare system is communicated during conversations and exchanges with the CHNs or in the process of participating in various literacy events and practices on the path to care. The CHNs, as I have argued elsewhere, appear to be an integral part of many refugee families’ social networks and lives. To help explain and characterize the kind of support CHNs provide refugee families and how this support contributes to health literacy development, I use the following four-part framework. This framework focuses specifically on *enacted social support*, which describes support received, support transactions and/or behaviors—all of which help explain how conversations and networks may enhance health and health literacy development.

The first kind of enacted support is *informational support,* which often involves giving advice or sharing information. The CHNs play a vital role in opening up communication channels so that this kind of sharing and dialogue can take place, and families have the opportunity to learn and negotiate meaning. The second is *emotional support* which involves expressing caring and acceptance by listening and sharing. Emotional support is an important aspect of establishing trust, but it is also important to one's overall well-being. The CHNs know that many of the families they work with do not have this kind of support but may be in need in light of their often-traumatic experiences as refugees. The third kind of enacted support is *tangible support*, meaning resources or assistance that is provided when completing certain tasks or activities. Most of what the CHNs do can be viewed as *tangible support* as they are constantly facilitating actions, interactions and practices that help families access care and participate in the healthcare system. Finally, there is *appraisal support* which involves helping interpret an event or assess coping options when one has limited resources for understanding, interpreting and/or navigating a certain situations, activities or tasks. *Appraisal support* aligns well with Chinn's (2011) notion of *critical health literacy*, as the CHNs often help enhance or increase the resources for understanding and communicating in the context of healthcare delivery and access. Taken together, this framework highlights how important ones' social networks are in relation to health, while offering a way to theorize the kind of social support CHNs provide in relation to health literacy development—an idea I expand upon through this study.

Collectively, the frameworks introduced in this chapter inform how I have analyzed data and presented findings in Chapters 4 through 6, where I show the many ways that health literacy development is influenced by one's "read" and/or "sense" of the world in which they are participating as well as their existing social networks and the resources they have for interpreting and making sense of the healthcare system and their experiences within it (e.g. language). As I have demonstrated in this chapter, the theories presented here inform and build upon one another. Sociocultural theories of language and learning lay a foundation for interpreting data in this study but are expanded upon by the two models of health literacy—both of which highlight the situated and distributed nature of health literacy within the context(s) of healthcare delivery and access. Finally, the framework for theorizing social support in relation to health literacy helps to further unpack and describe the social and distributed dimensions of health literacy and healthcare delivery.

CHAPTER THREE

RESEARCH METHODOLOGY, PROCEDURES AND CONTEXT

In this chapter, I discuss the research methodology, procedures and context(s) of this research project. I begin with a discussion of the methodology in which I ground this study, followed by a description of the method(s) for collecting data and analysis. Here, I provide a more detailed account of the critical incident and the critical incident interview technique. After discussing the data collection and analysis procedures and processes of this study, I reflect on my own limitations throughout the research process. I conclude the section with an overview of the research context, participant recruitment and brief biographies of the participants involved in the study.

Methodology of Engagement

One of the challenges for researchers and other health professionals attempting to understand what “it” is that CHNs *do* and how it is they do “it,” is that so much of CHNs’ sense-making and decision-making has remained unsaid, unarticulated, unexplained, unseen and acted out in languages that are unfamiliar or inaccessible to those doing the looking and listening. I would argue that a central aspect of the work that CHNs do can be understood as intercultural rhetoric. By culture, I refer not to a fixed entity or particular context, but rather, a set of practices that emerge *in the doing*, in and through activity and interactions—that is our “visible selves” as embodied through action and regulated and organized by our “read” of our environment (Scollon, Scollon & Jones, 2011). This is to say that culture can be viewed as a heuristic for development that mediates the self and world.

Intercultural rhetoric, as Flower (2003) has argued, operates in a “force field” of potentially “contradictory agendas and conflicting voices” (p. 64). This “force field” is an important feature of the context in which the CHNs operate, though they may not be entirely cognizant of the many voices and agendas they navigate and make sense of on a daily basis, since so rarely do they have time to take a step back, talk, share and make sense of it all. The CHNs’ repeated practices, ongoing tasks, activities and interactions, however, not only enable them to do what they do, but also embody ideas and arguments that have been invented and distributed in response to exigencies both emergent and preexisting; this is true of both the families they serve as well as the health professionals they work alongside.

Inquiries, as Flower (2003) has suggested, “are driven by questions, concerns and desires” (p. 54). With that said, while I was *an* [intercultural] inquirer in this study, I was not *the* [only] inquirer, as I viewed the CHNs as inquirers also driven by questions, concerns and desires; some of which were shared among each other and myself, and some of which were not. In designing this study, I recognized that there was much about their inquiry process that has remained tacit, uncommunicated and articulated, but reflects the diverse and situated knowledge they bring to countless intercultural interactions on a regular basis. What was needed was to do what the CHNs have little time to do: to assemble the practices, activities, tasks, ideas and arguments that constitute the work the CHNs do as well as their rationales for their decision making so that they could be examined and discussed. An intercultural inquiry is understood here as a literate practice that tries to elicit difference for the purpose of building more complex and actionable representations of shared problems (Flower, Long & Higgins, 2000). Rather than polarizing or silencing people, the attention to difference seeks out multiple ways of representing what it is that people know and how they know it. Intercultural inquiry pursues and itself constructs a “hybrid discourse,” asking how people’s shared and situated knowledge can translate ideas and arguments into wise actions, practices and outcomes (Flowers, 2003, p. 64). As this study shows, the ideas and arguments embodied in the CHNs’ practices signal existing, new and conflicting exigencies that they have identified and responded to; and it was this inquiry process that this study sought to render more visible.

Considering the somewhat hidden or obscured “status” of situated knowledge, the “running hypothesis” is that this unspoken or hidden knowledge could be transformed into interpretive resources *if* people could describe the rich and contextualized “stories behind the story” at work in their own meaning making and decision making (Flower, 2003, p. 42). As a researcher engaging in intercultural rhetoric, it was important for me to listen, to question and to actively seek out the complexities of how the CHNs made sense of their worlds and their place in it; it is through one’s experiences that meaning plays out in the world and decisions are made, many which have consequences for others’ well-being. In the interest of conducting an intercultural rhetorical inquiry, I employed a particular kind of interview-based research method to elicit a particular kind of story—the critical incident. Critical incident interviews (which I discuss in the data collection section) use research and writing in order to elicit “funds of knowledge” about, for instance, health and healthcare (Gonzalez, Neff, Amanti & Moll, 2006); an effective critical incident invites others to share insights into hidden or less visible logics, potentially leading to a better understanding of what made the incident puzzling or problematic in the first place. Eliciting these problem narratives helped me "pursue" the complexities of how CHNs make sense of their worlds, the competing logics and discourses and conflicting values and beliefs that make up their "force field." In this study, I used writing in the service of research to listen and learn from CHNs about their situated knowledges (often encoded in stories of their experiences) in order to generate critical incidents, we explored together. By supporting a broader engagement with these incidents through the process of inquiry *with* the CHNs, this study enacted its methodology of engagement (Grabill, 2010).

Underlying a methodology of engagement is the notion that the public, knowledge-building work of rhetoric may be (in part) to support the work of others; to help other people write, speak, and make new media and other material objects effectively (Grabill, 2010, p. 193). This understanding of rhetoric is conceptually grounded in Latour's methodological argument that the social is not a realm, but a particular movement of re-association and reassembling. In other words, the social is not a taken-for-granted "thing" or fixed entity but is assembled and continuously reassembled. A methodology of engagement encourages the researcher to pay attention to and follow the performances of group formation or the ongoing construction of boundaries (of a we); to allow actors to make sense of their social worlds; to note the range of agencies, not necessarily to who or what is the agent, to trace the string or of action(s) where each participant is treated as a mediator or actor—that is actions that can be assembled and used to describe rhetorical work; and finally to interrogate the agencies at play so that matters of fact and concern can be distinguished (Grabill, 2010, p. 205). A methodology of engagement framework emphasizes who we are *together* when we are doing rhetoric—what brings us together, how we communicate and talk about what we are doing, what communication channels are used to share what is learned and to hear from others, what they are learning in the process of "getting something done." In the case of the CHNs, when we talk about *what* is being assembled, we are talking about the ideas, arguments, practices and activities that create nameable connections that can be understood as rhetorical and rhetorical creations.

A researchers first step in a methodology of engagement is to assemble what is being done and how—in this case, to bring together the ideas, arguments, activities and practices that have created connections and constitute the rhetorical work of CHNs engagement. The process of assemblage is figuring out what *is* being connected and how, as well as studying the kinds of associations that are actively created and re-created. I sought to identify what comprises CHNs' processes of assemblage and inquiry—that is, what is being connected and how, and what kinds of associations are actively being created and re-created. To do so, I drew on ethnographic research methods (observations, artifact collection, interviews, which I elaborate below). A methodology of engagement is particularly useful for helping to unpack what is being done; how those involved understand or make sense of their experiences and roles; how knowledge is generated, communicated, shared and distributed (i.e. "knowledge work)—all of which renders more visible and "actionable" the "scene of rhetoric" (Grabill, 2010, p. 205). With such goals in mind, I observed, listened and learned from CHNs about their situated (and distributed) knowledge so that I could generate particular kinds of stories or scenes (as I refer to them here) that become part of the intercultural inquiry. By integrating these stories or scenes into the collective inquiry process, I was able to support a broader engagement with them—a goal driven by my own commitments to be “useful” and to support the knowledge-work of others, specifically, the CHNs.

Data Collection Methods

As part of this methodology of engagement, I also utilized qualitative research approaches, including ethnographic techniques that have been adopted and adapted. As Wolcott (1994) recommends, I endeavored to engage in “borrowing ethnographic techniques” (p. 44) rather than doing or writing a conventional ethnography. Some of the ethnographic techniques that I borrowed included observations, interviewing and artifact collection. While conducting my observations, I kept detailed field notes that incorporated commentary and reflections on methods and procedures. I also drew on the critical-incident- interview technique, where I employ writing in the service of research to generate or elicit certain kinds of stories or “problem incidents,” to be examined and explored through intercultural rhetorical inquiry with the CHNs. In what follows, I offer a detailed description of my data-collection process, followed by a section on how the data was analyzed for the purposes of this study.

Critical incidents and the critical-incident-interview-technique.

Critical incidents have been used in many different ways and have been viewed from different paradigmatic perspectives (Spencer-Oatey, 2013). Initially critical incidents were used in psychological research to “obtain first-hand reports, or reports from objective records, of satisfactory and unsatisfactory execution for the task assigned. The cooperating individual described a situation in which success of failure was determined by specific reported causes” (Flanagan, 1953, p. 329). Since then, critical incidents have been used in pedagogical research on transfer (e.g. Yancey, Robertson & Taczak, 2014), research on interpersonal relations in the workplace (e.g. Orbe and Camara, 2010) and in the study of intercultural interactions and relations (e.g. Spencer-Oatey, 2002). The term “critical” has been associated with “extreme behavior” (Flanagan, 1954) “emotions and evaluations” (Cope and Watts, 2000) and as “self-defined” and/or “created” (Tripp, 1993). In this study, however, critical incidents and the critical-incident-interview technique were used as a way to develop methods of intercultural inquiry.

Since critical incidents and the critical-interview-technique are central to this study and the methods of data collection and analysis, I first make clear how I understand both—that is, what a critical-interview-technique is and helps to accomplish and what a critical incident is, does and means in this study. I begin with what a critical incident is and what it is capable of doing or rendering. For this discussion, I draw on and merge others’ understandings that help illustrate and explain my own interpretations and use of this method of research and writing. According to Tripp (1993), critical incidents are not “things” that exist independently of an observer—that is, they are not waiting to be discovered and found. Instead, critical incidents are created and produced by the way we look at and interpret a situation. In other words, our interpretations of an event or incident deems it *critical*. We may remember certain incidents as being significant or memorable but may not be totally cognizant of why and how without further analysis and reflection, which is rarely something the CHNs have time for.

By adopting a critical-incident-interview technique throughout data collection, I listened for moments where someone's story "got traction" or "raised tension" with my own or others involved (Clifton, Long & Roen, 2016). This technique is particularly useful for surfacing local "funds of knowledge" that directly inform decisions made or actions taken but that otherwise remains hidden from view and therefore examination, which was one of the goals of this study. It was the coding of these moments that shaped my emergent criteria for what made incidents "critical" in this study. In other words, I drew on the critical-incident-technique as both an interview technique and mechanism for coding. When looking for compelling incidents or moments in incidents elicited during interviews, I drew more explicitly from theories of critical incidents (e.g. Clifton et al., 2016; Clifton, 2015; Tripp, 1993). By "compelling," I refer to anything that:

- dramatizes a particular moment or situation relevant to the daily challenges of being a CHN
- offers a freeze-frame of a particular moment
- is important and something that should be talked about and understood better in relation to the goals of the study and the nature of the work of the CHNs
- features a situation that does not appear to have an easy resolution or answer
- does not villainize or glorify anyone of the CHNs or other indirect participants

While I initially used these criteria when listening for and coding incidents, I eventually expanded upon this criteria as it emerged through the retelling of the incidents during interviews coupled with my own analysis of the incidents and any of the CHNs reflections. My criteria included the following: 1) there was a “so what” factor relative to my study 2) It was something that needs to be unpacked further, has been communicated in different ways as a problem, concern, success and 3) It reflects some tension or rub between medical culture/the health system in the U.S. and the lived experiences and realities of refugee families and/or the CHNs. These criteria were collaboratively generated throughout the entire data collection, coding and analysis process, which is one of the affordances of the critical incident interview technique—it promotes collaborative, intercultural inquiry and decision-making. In Chapter 5, for instance, the incidents I share began as memorable moments elicited during interviews but were rendered critical (or elements of them were) through my analysis and interpretive work. After writing Chapter 5, I was prepared to create composite critical incidents for the group to consider—inviting the CHNs once again into the research and writing space of this study.

Observations.

In order to observe and document the practices, tasks, activities and interactions involved in the work the CHNs do to support refugee families and other health professionals at the clinic, workplace observations were conducted at the pediatrics clinic between the months of May and August of 2017. The observations also enabled me to document the seemingly mundane or routine tasks and/or activities that were not mentioned in interviews, and yet, were important moments where transformative rhetorical and “knowledge” work took place (Grabill, 2010), such as the informal interactions between CHNs in their office. Since the CHNs were scheduled to work in the pediatrics clinic on Tuesdays and Fridays, I observed them on these days from start to finish—that is between the hours of 8am to 5pm. In what follows, I walk readers, especially those interested in or considering conducting qualitative research at a medical facility, through the process of conducting observations. Specifically, I focus on the logistics of observing the CHNs (and refugee families and other health professionals by default) and navigating some of the tensions encountered in the process. What I discuss is not exhaustive, but it is intended to address some of the more significant and at times challenging dimensions of my observations, while offering a glimpse of what I did and how and the lessons learned along the way.

Logistics.

Considering that each of the CHNs works, for the most part, on their own and with their own group of patients, I knew from the beginning it would be challenging to figure out how I might schedule my time in order to observe each of them individually and also allow time to be flexible and responsive to the specific events taking place on any particular day. How much time could or should I spend with each? Could I find a balance? Under what circumstances would observations not be possible? During my first week of observations, we discussed the logistics involved in observing them do their work. Initially, the CHNs were hesitant to have me shadow them while they worked, especially for long stretches of time since they are often mobile. It was during this conversation that I realized that my observations might not be neat, consistent or balanced. During that conversation, we agreed that rather than schedule specific times to observe each of the CHNs, I would instead be prepared to change plans according to the ebb and flow of the clinic, their work the CHNs were doing, and the needs of the families they were working with. We agreed that, if a CHN was comfortable with me observing them or wanted me to observe them, then I would follow. I made sure to clarify that I would be happy to follow their lead and would rely on them to tell me when it was appropriate or acceptable for me to observe. As I got to know the CHNs better, and as they became more familiar with me, my questions, and my observations, they invited me to observe them more often. Over time, I also became better at interpreting whether my presence was appropriate or welcome. Eventually, as our relationships deepened and our abilities to read each other improved, the CHNs assumed my interest and extended “official” invitations less often. When I was asked “Why didn’t you follow me today?” I realized how much rapport I had established with the CHNs.

I observed the CHNs in multiple locations within and around the clinic. The observational sites included the clinic in general (e.g. exam rooms, nurse stations). I also sometimes followed the CHNs to other clinics including but limited to the lab or the Neonatal Intensive Care Unit (NICU). Most of my time was spent in the exam rooms in the pediatrics clinic, since this is where the CHNs spent the majority of their time. In order to gain access to the medical consultations between the provider and refugee families, I had to get consent from the parents of patients. Following the institution's IRB requirements, I provided a parent consent form for this study to the CHNs for them to review. They were to use the forms as a guide to request verbal consent for my being and conducting observations in the exam room. This process was typically carried out in languages I did not speak, which made it difficult for me to determine what was actually being said, but I tried to make sure the CHNs were clear that this was necessary. The CHNs became quite adept at communicating who I was and why I was there when entering the rooms and obtaining verbal consent from the parents. There were a few times here and there where a parent did not want me in the room or asked me to leave, but generally, most parents agreed to me being there.

Another logistical aspect of my observations was how I approached observing—that is what I was doing when I was observing and how I positioned myself in relation to those I was observing. The exam rooms were perhaps the most challenging as they were small with limited seating and standing room; often multiple children's' appointments were scheduled at once, which meant there were two-three exams taking place in the same room. How, I wondered in the beginning, would I take notes in this space? Where would I stand? To what extent should I *be* in the room versus being an observer in the room? There are no single responses to any of these questions, but I will talk a briefly about my approach. Generally, in the exam rooms, I would try to find a place that was out of the interactional or exam space; I would stand in the corner of the room, or away from where activity was taking place; I would pay attention to the movement of the providers and the family and make adjustments as needed. Initially, I had my notepad out and tried to capture as much as possible while the exam was taking place, particularly if everyone was preoccupied. The more time I spent in exam rooms, however, the more sensitive I became to moments or situations where my note-taking was a distraction or potentially inappropriate. I had to learn to put my pen and paper down sometimes, because sometimes I needed to just be present in the room and not documenting everything*;* this was especially true with the children. The exams can be scary for children, and sometimes they needed smiles of reassurance and conversation and not a stranger taking notes. I also had to learn when to pay attention to the many side conversations that took place with the CHNs, between the CNs, or between the CHNs and other providers, as these too were important interactional moments. For instance, I listened and observed a long conversation between the CHNs and attending physician of the clinic, Dr. Day as they tried to plan a presentation for medical students on working with refugee families and children. I heard and took note of how they negotiated what they felt this group of health professionals should know within the time constraints of the presentation.

Navigating tensions and discomfort.

The more I observed, the more I noticed how with their interpreter badges, the CHNs were often able to move through most of the facility's spaces with no questions asked. This was not true for me, however. There were some places where my presence brought questions. Often the CHNs' explanations of who I was and what I was doing (even though who I was had not been established in the way it was within the pediatrics clinic), was acceptable and I was allowed to stay; but sometimes, I was asked to leave. I recall the first time this happened. A Somali mother had a newborn baby with jaundice. While my presence in the exam room seemed acceptable, the mother did glance at me now and then; I could not tell if she had more questions, or if she felt uneasy with me being there. When the exam was done, Samira (one of the CHNs) led her to the lab and invited me along. I followed, as I usually did, but something did not feel right. When one of the lab technicians called us in, again Samira invited me along, and again I felt uncertain. I did not feel comfortable standing there while the mother held her child, and as the technician continued to struggle to draw blood from a newborn. I finally asked

Samira if it was alright that I was there. She said yes, but shortly after the mother spoke to her while looking at me. Samira turned to me and asked if I could leave because the mother was feeling uncomfortable with me there. I immediately respected her wishes and left.

How did this incident shape future observations? I learned that being invited by the CHNs did not always mean I was going to be invited by others or that it was appropriate to follow. Sometimes the family did not express any discomfort with me being there, but sometimes I felt there were too many people in the room; in these moments I was especially attentive to what it seemed the children might need or want. For instance, on one occasion, the CHN named Kriti invited me to follow a family into a room where a hearing test (for the son) would take place. Because it was a large family that barely fit in the exam room, and because it was a procedure that might be scary for the child, I decided not to follow. Could I have? Yes, I could have. I was invited by the CHN and the family had given verbal consent; but neither of these factors mattered to me at that moment. At that moment, I was most interested in the comfort of the child. I tried to remember that the CHNs were doing their jobs and going where they usually go, and none of this was out of the ordinary for them; but it was for me and the families. Over time, I learned how to pay attention to and read the families responses, actions and behaviors, especially the children so that I could assess the situation on my own and try to understand what seemed most appropriate given the situation at hand. This is all to say that sometimes you cannot rely on your participants as a gauge for access and that it is important to be cognizant of ones’ outsider status.

Artifact Collection.

Throughout the different stages of the study, print materials, media and other documents or resources used or generated by the CHNs were collected and analyzed. From my observations I was able to identify what texts and media circulate and mediate interactions, activities and tasks that CHNs do to support refugee families and other health professionals they work with. The collection of these texts, media and other material resources was discussed with participants both formally and informally to understand their views on the role of these literacy materials in supporting refugee families' navigation of the healthcare system, while eliciting some of the ideas and arguments behind their creation or use. I often identified these items while conducting my observations. Sometimes, the CHNs shared them with me without prompting, as a way to share what I could not see or would not be able to observe. For instance, one of the items they shared and discussed with me during observations was a "graduation list" they had created together. The list was comprised of tasks and interactions families should be able to do themselves in order to no longer need the support of the refugee pediatrics clinic. This is not a list that is in "use" per say—at least officially as the CHNs described "having it in mind" when they are working. Because this was not a document in use, I would not have come across it in my observations of regular and routine practices. This list, like several other documents they have created, remain invisible to the world (as do the ideas behind them) as they sit in folders both physical and digital; they are not in use but in progress; and it was just as important that I pay attention to and seek out these artifacts as well, most of which can be found in the Appendix.

Individual Interviews.

During and after observations and artifact collection and analysis, I conducted and recorded interviews with all participants. To conduct the interviews in a way that would help me respond to my research questions, carry out the assembly work described above, and engage in an intercultural rhetorical inquiry with the CHNs, I modified Seidman's (2006) three-part interviewing technique as well as the critical-incident interview technique (Flanagan, 1954), merging them together. The first set of individual interviews took place in June, the second in July and the third in September. Each of the interviews took anywhere between thirty minutes to an hour depending on the CHNs' availability. It was not always easy to schedule interviews given the CHNs' limited time. In a few cases, the CHN was called to assist in an exam room in the middle of an interview. Fortunately, in most of these situations we were able to pick up where we left on later in the day.

The first interview, following Seidman's model, helped to establish a context for the participants' experiences focusing on their past lives and experiences migrating to the U.S. and navigating the healthcare system. During these interviews with the CHNs, I learned about where they were from, when they arrived in the U.S., when they learned to speak English, what healthcare was like for them back in their countries or in the refugee camps in which they lived, what they knew about the U.S. healthcare system before they came and how they navigated the system once they were here. I also learned about the past job and volunteer experiences that led up to their work as CHNs, why they became CHNs, and what their initial experiences were like as CHNs, including what kind of training they received. These interviews helped me get a sense of where they had come from, their journeys here and experiences of migration (whether forced or not), and the various work and volunteer experiences in the community that connected them with refugee families. All of these experiences, as discussed in future chapters, played a role in relationships they have established in the community, their reasons for pursuing this career path, and the ways in which they carry out their responsibilities.

The second interview, following Seidman's' model was focused on detailed experiences of and reflections on their present work as CHNs. The questions asked during this interview were open-ended and called on the CHNs to describe the routine and regular practices, activities and interactions that constituted the work they do on a daily basis. This interview was also used to better understand what they considered to be their main responsibilities and roles as CHNs within this clinic. Other questions asked the CHNs to consider the challenges they experience, and what of their practices they believed were most helpful for the families they work with. Again, the goal of this interview was to get a better sense of their work as CHNs, what they say about what they do and how they do it (e.g. the rationales and logics). This interview in particular, and in combination with my observations, field notes and artifact collection, shaped the findings reported in Chapter 4, where I focus on their routine and regular practices, responsibilities, goals and sense-making processes as CHNs. The second interview also elicited incidents (i.e. memorable or significant moments or events) that were identified and coded and which informed and helped to characterize the questions for interview three.

With the third interview, I had two goals. The first goal was to learn more about the incidents already mentioned during previous interviews that aligned with the critical incident criteria. The second goal was to elicit additional incidents for further analysis. Because I was writing questions that reflected what the CHNs had brought up during prior interviews (or in some cases conversations), I had to customize the interview questions as they did not all bring up the same incidents. The interviews questions, therefore, were characterized by the incidents elicited during previous interviews and my own coding for and of those incidents. When I say that the interview questions were characterized by incidents brought up during previous interviews that were then coded (based on my emergent criteria), I mean that I identified an incident that seemed to get a lot of traction through the CHNs retelling and generated a more open-ended question to try to bring the CHN back to the story or thinking space where the incident or memorable moment was shared. A number of the questions began with, "During the last interview you talked about…." followed by an open-ended question or request for elaboration or clarification. In most cases, the questions elicited additional incidents or prompted the CHNs to supplement incidents previous discussed, offering a more nuanced account that helped to contextualize the incident.

Group conversation.

The first group conversation, which took place in September of 2017 and lasted for nearly ninety minutes, was the first time the CHNs were brought together to meet with me in this study. The conversation itself was focused on the events depicted in scenes I wrote based on my understandings and analysis of incidents from previous stages of data collection (observations, interviews, document collection). Recall that critical incidents are not found, they are co-constructed; and it was through my coding for incidents from interviews and my analysis of them in Chapter 5 that rendered them or elements of them critical. I created three distinct scenes that reflected three key findings from Chapter 5 and my analysis of incidents that helped illustrate and unpack those findings. In other words, the elements of the scenes, which were written much like play (i.e. there were characters and it was dialogue-based), emerged through my analysis of incidents in Chapter 5 where they were rendered critical. Each scene, as I explained to the CHNs, had a specific focus or something I was hoping to understand better. For instance, in the first scene I was most interested in their decision-making processes under a certain set of circumstances observed from the retelling of incidents during interviews. The overall goal, was to invite the CHNs into a literate practice that would facilitate or serve as an anchor for intercultural rhetorical inquiry. The scenes also served as a way to share preliminary findings which I was able to share with the CHNs, but in a less traditional way.

When we met, I provided the CHNs a document that both introduced and explained what we were doing. I indicated that through this conversation, I was inviting them to participate in a practice that is used in other settings to support dialogue that crosses cultures to explore complex problems in different ways. This practice, as I explained, involves discussing "problem incidents" reflected in the scenes I wrote, based on the data I both collected and analyzed. I drew their attention to certain aspects of their work (e.g. decision-making) to make sure that we remained focus, so that we could address the complexities of the scenes and their work, and so that the conversation would elicit their situated and experiential knowledge in ways the individual interviews were not fully capable of doing on their own. I also described three possible ways to respond: the first was by talking about what might "behind the scenes" of what they were performing—that is details or information that was not included that might help explain what was; the second was the rival perspective where the CHNs were encouraged to explore rival perspectives or “what if” responses that would help expand understandings; and the third was the wise action response, where they could talk about what action they might take to address the situation effectively. The CHNs never did use the cards but seemed to instinctively respond in one of these three ways on their own.

After introducing what I was inviting them to do, what I was hoping to learn more about, and potential (not required) ways they might respond to the incident, we shifted to the scenes themselves. Each of the three scenes had a narrator and multiple characters that were familiar to the CHNs (e.g. front desk staff, nurse, mother). It is important to note that while writing these scenes, I decided that instead of performing the scenes in full and then looking back that I would instead select specific moments in the scene to stop, pause, process and discuss. My rationale for structuring the performance of this dialogue or conversation(s) in the way I did was that I hoped to capture the CHNs *in-action thinking* rather than reflections after the fact. Reflections meant the scene was over and, in a sense, the CHNs knew how the scene unfolded and what the outcome(s) were. Having gotten to know the CHNs, the more I felt this approach would not capture the nuances and complexities of their thinking patterns and processes as they interacted with different kinds of information and wrestled with the many uncertainties they face on a regular basis. Why would I create scenes where there was more certainty than in their real working lives? To capture the CHNs in-action thinking, I placed visible markers next to particular junctures in the scene—usually where a decision needed to be made, where an important interaction took place, or where I provided contextual information to help understand or interpret what was taking place in the scene. In other words, I asked the CHNs to press pause with me and slow down what was happening so that we could dialogue *together*.

Data Analysis

In this section I talk about the analytical work that generated the findings presented in this study. I begin with Chapter 4 and how I produced an inventory of what the CHNs do, what they say about what they do, the decisions that they make and how they understand their roles and responsibilities as CHNs. After observing the CHNs at the clinic for approximately three months and having conducted interviews one and two with each of the participants, I started to engage in more deliberate data analysis to respond to my first research question(s) (e.g. What practices and resources do CHNs use to assist and support refugee families navigating the healthcare system?). My analysis of the data began with the second interview where they were prompted to talk about the work they do and routines they keep. The interview provided an anchor for me to look for similar content in my observations. Once I had identified the routine practices and activities they do to support refugee families (and providers), I created an inventory. This inventory included the practices and routines identified (and by whom) as well as reflections on those practices and any examples of them. Once I had created the inventory, I engaged in *thematic coding* with a focus on the contexts in which the activities and tasks were taking place (e.g. getting to the clinic, during the visit). All of this work—the data collection, the inventory and analysis of the data—helped me begin the assembly process described in earlier sections.

The findings in Chapter 5 emerged from the above data collected (i.e. interviews one and two) as well as new data collected through the third interviews, ongoing observations and artifact collection. Recall that the third set of interviews were characterized by memorable and/or significant moments the CHNs had brought up during previous interviews. After conducting the third interview, I once again coded for incidents in the interviews (with a focus on the third interview) and then coded the incidents themselves. I was looking, again, for the contexts in which these incidents occurred and if there were any themes or patterns. The three themes that emerged from my coding became the contexts for analyzing and interpreting the incidents in Chapter 5.

The findings of Chapter 6 emerged from the analysis of the group conversation. Among the goals of this chapter was to render more visible the situated and experiential knowledge the conversation elicited through the inquiry and innovation process (i.e. not necessarily “solutions”). The contexts for the three scenes were themes examined in Chapter 5, but the critical elements that helped shape the scenes emerged through the analysis of the incidents. After I transcribed the group conversation, I once again looked for moments in the conversations where a particular detail, idea or interaction got traction or raised tension. My analysis of the conversation focused on the CHNs’ sense-making and decision-making processes at these critical moments during the scenes—that is, where there was tension, unresolved issues and shared and distinct (between and among the CHNs) interpretations of what was happening. Again, one of the goals of this conversation (and my analysis), was to make their thinking more visible through this collective invention process, not necessarily to come up with “answers” or “solutions.”

Limitations

This study focused on the CHNs, the work they do and the kind of support they provide refugee families. One limitation of this study was my restricted access for observations. In addition to their work at the pediatrics clinic, they also work at the women's clinic in the health center, local faith-based organizations and apartment complexes where refugee families live. Important activities and practices take place in these contexts and across them. I was not able to follow CHNs outside of the clinical context to conduct a multi-sited study, which means that I was not able to identify, examine and capture *all* they do. Pursuing access to these spaces outside of the clinic, such as families' homes would have required different kinds of access and research procedures which would have created additional obstacles for myself as a researcher; it had already been challenging enough to gain access to the pediatrics clinic let alone refugee families' homes. Refugees, in particular, are considered a "vulnerable" population, and even listening in on conversations between the CHNs and their patients required consent, despite the families not being my focus. Through my study's design, I came up with strategies to mitigate this particular limitation. One way I did so was by eliciting stories and testimonies of the CHNs work outside of the clinic during interviews and other informal conversations (e.g. educational outreach). With their consent, I also asked that they share with me any materials or resources used, created or discovered outside of the clinic to integrate into my inquiry. One such example is an advertisement for a dental facility that the CHNs located and decided to partner with to help families' get the dental care they need *and* have that care be covered by insurance. This is to say that throughout the study, when possible, I sought out practices, tasks and activities that took place outside of the clinic since I could not be there.

The five participants were all multilingual with English not being any of their primary or dominant languages. At the time the study took place, I did not speak any of their primary languages, or the languages most used with the families' they worked with. While I can only speculate, I suspect the study would have yielded qualitatively different and richer findings had I been able to understand or talk with the CHNs in their dominant language(s). I should point out, however, that all the CHNs were fluent in English and did not need an interpreter to communicate complicated ideas with me. Should they have requested an interpreter, as my consent form indicated, I was prepared to provide one. Language-related issues also affected my observations of interactions between the CHNs and refugee families. Throughout my study, I was often a listener to what I could not understand. While I could observe interactions between CHNs and families, I could not understand or participate. In some ways, this protected the privacy of patients in ways that might not have been possible otherwise; however, not having access to those conversations and exchanges was a significant limitation. A month or so into my observations, I suggested recording a few conversations in exam rooms so that they could be translated and examined. I approached the CHNs with the idea individually and asked if that might be possible at some point. Most of the CHNs seemed reluctant to have their conversations recorded at that time. I decided not to pursue this idea further. With that said, patients were not the subject of this study, and not having access to those conversations did not prevent me from carrying out what I proposed to do.

In addition to the aforementioned limitations as a researcher, I am also what I call a “double-outsider.” First, I am not a healthcare professional or expert. I do not have insider knowledge of medical culture and its diverse discourses, institutional policies, procedures and practices. I do have many experiences with the healthcare system as a *patient,* which at times made me feel like a partial insider, but not fully. Having an insider perspective on healthcare and the healthcare system would have helped me to contextualize the work the CHNs do within the larger “field of practice” (Bourdieu, 1977). As I conducted my research, I became increasingly aware of my outsider status, but also what I was learning in the process. It was very important when conducting my observations and interviews to ask questions when I needed to; I often referred to the CHNs as my teachers, which they were. When the CHNs mentioned a person, place, agency or organization that I was not familiar with, I asked for more information. When they mentioned a practice or policy I was not familiar with, I asked what that practice or policy was. As a partial outsider to the healthcare system, I learned that asking questions was very important to fill in gaps in my own knowledge. For instance, I am not from the state in which this study was conducted and was unfamiliar with how the Medicaid and Medicare program worked, or how people applied. I asked questions and researched the program online to support my understandings of the work the CHNs do. In other words, I engaged in my own research process to fill in gaps in my knowledge as a way to mitigate this limitation. With this said, there were some benefits to my outsider status. When you are not fully entrenched in a particular context, you often can see things that those that operate regularly in the context may not see or think to question or reflect upon because so much has become commonplace and routinized.

It should also be noted that I am not a refugee or immigrant, which makes me an outsider to the refugee families seeking care at the clinic and the refugee experience and to the CHNs themselves. I do not know first-hand what it is like to be a refugee. I do not know first-hand what it is like to migrate to a new country. I do not know first-hand the pressure of having to learn a new language to survive, not just because of interest or family ties. I do not know what it is like to be forcibly displaced and to live in a refugee camp for years, and in some cases decades. It would be impossible for me to fully appreciate the experiences of the young children who sat in the exam rooms with me as well as their parents. As much of dissertation shows, it is not easy to raise children in new cultural context; I do not know their struggles. I can only read and hear about the experiences, challenges and successes of refugees—their resilience, loss, pain and hope(s) for the future. During this study, I could only observe and listen and try to educate myself and address my own ignorance where and when it presented itself. While conducting the study, I also did not have any working relationships with the refugee communities served. With this said, among the many ethical and epistemological concerns linked to working with refugees are the ways in which researchers fail to recognize their agency, experience and wisdom. As a way to respond to these concerns, I designed a study that enabled me to engage in intercultural rhetorical inquiry as a kind of “transformative participation” (Pittaway & Bartolomei, 2013) between myself as the researcher and the CHNs as participants. With this approach, I shared the power to identify and develop local knowledge *with* the CHNs. In other words, the CHNs—as refugees and immigrants themselves were involved in the research process. Throughout the data collection, analysis and writing (i.e. of findings, interview questions) of this research project, the CHNs' wisdom, knowledge and experiences were sought out and called upon—demonstrating their valued place in this inquiry.

Research Context

Since 1980, the southwest state in which the study was conducted accepted over 82,000 people, making it one of the largest resettlement communities in the country. Most refugees that have resettled in the area have been from Afghanistan, Bhutan, Burma, Bosnia, the Democratic Republic of Congo, Somalia and Vietnam. Over the past few years, the majority of people resettling in this state have come from the Republic of Congo, Iraq, Afghanistan, Somalia and Burma. For those that are accepted in to the state, being accepted is only the beginning of a long and complex process of resettlement. Within the first 30 days of arrival, case managers from local resettlement agencies place new arrivals in homes, link them with the short-term refugee medical assistance program (RMA), provide transportation to a health screening at the Department of Public Health and assist as they apply for social security cards and refugee public assistance benefits. A lot happens within a very short period of time, making it potentially challenging to make sense of and use of the various services and resources available when they *are* available.

As discussed briefly in Chapter 1, for recently arrived refugee families, to find out about and make use of local health care services requires many types of assistance. In some cases, connecting with the healthcare system may start and stop with the screening at the Department of Public Health—either because no follow-up care is needed or because appropriate referrals and connections are not made even when there is a need for them. After the first 30 days, in collaboration with the Office of Refugee Resettlement (ORR), local resettlement agencies and ethnic community-based organizations offer a variety of services for different periods of time depending on the refugees' status. Federally funded needs-based cash assistance and health benefits are available for a maximum of eight months, which means if a family is unable or does not have help locating and applying for insurance, they may go without it or may not know how to get it. Other kinds of support include employment services, case management, and English language instruction for up to five years (though first arrivals get prioritized). Most of these services fall under the categories of immigration or employment—the goals of which are to get resettled refugees to a place of "self-sufficiency" as quickly as possible.

As I have mentioned elsewhere, health and one's overall well-being play an important role in the ability to reach a place of self-sufficiency. Health and wellness are typically listed under "self-sufficiency" by most of the local resettlement agencies. Specific services include men and women's health classes and cooking and nutrition classes aimed at helping refugee families better understand the U.S. marketplace for food. Where agencies struggle is making connections to health-related services and information beyond the walls of the agency. Resettlement agencies tend not to have well-established networks in the healthcare system, making it difficult to help refugees make important connections, such as establishing a primary care physician (PCP). Even with the services they do offer, there is no guarantee that refugees are utilizing them, nor does it guarantee any kind of gains from these experiences, particularly in light of more pressing concerns such as employment, childcare, transportation and housing. As a result of the many complicated factors involved in resettlement, many refugees are left stranded with no clear path to care.

The healthcare center and the pediatric clinic

The health center where the pediatrics clinic is housed is located in a metropolitan city in the southwest and offers outpatient primary and specialist care services. The center treats both the pediatric and adult population and provides primary care services including family and internal medicine, pediatric care and obstetrics/gynecology. The center also provides dental care for children and adults. Other services include, antepartum testing, cardiopulmonary clinic, dialysis ear-nose-throat clinic, radiology, pharmacy, surgical vascular clinic and a women’s care clinic. This is a comprehensive facility that offers many of the services that refugee families need, making them more accessible (i.e. they are located in the same building). The services that are used most frequently by refugee families tend to be the dental clinic, pharmacy, laboratory and women's’ care clinic. Many of the patients that seek care within this center are covered by the state’s Medicaid/Medicare agency, which means that most of the services accept this form of insurance in addition to others.

Located within the health center is the general pediatrics clinic, and within that clinic, the refugee pediatrics clinic. This clinic offers specialized care to refugee and immigrant children with the assistance of a team of health professionals, including doctors, nurses, medical assistants, social workers, care coordinators and the CHNs. The refugee clinic has one primary attending pediatrician, Dr. Day, who had been working at the clinic for around a year when I began my observations. The CHNs work closely with this provider as well as the primary medical assistant assigned to the clinic. The clinic includes exam rooms, a triage station, a large room where residents and medical providers meet and work, a small social worker office where the CHNs often spend their time waiting between exams, a small kitchen area, and an immunization room (among other features and rooms). In the clinic you can hear the sounds of children and babies crying, laughing, yelling, talking; you can see parents walking with strollers or holding their newborns' close; it is often busy and full of movement and sound as languages and people circulate throughout the day. The clinic is also multilingual insofar that the majority of health professionals speak both English and Spanish. Other languages represented include Amharic, Arabic, Burmese, Chin, Hindi, French, Karen, Kinyarwanda, Kirundi, Nepali, Maay, Somali, Swahili and Uzbek, respectively. The clinic is situated adjacent to a learning center for families which offers health-related materials in English and Spanish (mostly), videos, computer access and classes for parents and children.

In recent years, the pediatrics clinic received grant awards totaling 2.4 million dollars in funding from the state's early childhood development and health board, which has helped provide/fund the pediatric care coordination/medical health programs that are staffed by social workers, nurse care coordinators and CHNs. These programs are available to families at several of the affiliated health centers. The care coordination team visits with newborn and new patient families providing education about medical home, clinic, services, breastfeeding, and community resources. The team provides reminders for delayed vaccines and maintaining insurance enrollment and stress the importance of follow up with their physical after an emergency department visit.

In 2012, the first CHN was hired to address the specific needs of the refugee and immigrant families seeking health care at the pediatric clinic. The program also provided three (now four) CHN/Interpreters (CHN-I) to serve as interpreters for the pediatric clinic. At the time, the clinic had a population of approximately 191 refugee and immigrant patients, but as of March 2018, the number of refugee and immigrant children being seen reached nearly 1,500 and will likely continue to increase. Thus far, the CHNs have found ways to reach out to communities, routinely going directly to communities to provide education on the importance of well child visits, immunizations, health literacy and the U.S. healthcare system.

The CHNs' primary office, or "box" as they tend to call it, is connected to the walls of the clinic, but the entrance is not. There are no windows, only desks and desktop computers, landline phones, boxes full of donated items, folders full of information and other miscellaneous items. The care coordinators for the general clinic work within this small space as well. The CHNs tend to share the office space, including the desks and computers depending on who is or is not in the room. Only the care coordinator/CHN, Angela, remains a fixture at her desk, as much of her work involves detailed documentation of the teams' efforts; her desk is full of different items including post-its, folders and toys or books that she often gives to the children. Sometimes, all of the CHNs are in the office, especially in the early morning when patients are just arriving. But for the most part, they move in and out of this space over the course of their shift. They use the space to make phone calls, talk with one another, and fill out their interpreter logs which they are required to write daily. Usually when in the room I hear the sound of multiple languages speaking at once; they are either talking to patients or each other. This is a space where I have witnessed joy, sadness, frustration, boredom, worry, exhaustion, excitement and anger. It is perhaps the only space where all the CHNs might be found together at once. Sometimes others come in to speak with them, but typically there are few visitors. Early on when I was conducting my observations the CHNs designated a vacant desk in the room for me to sit, work, watch and listen, which I did often.

Participants and Participant Recruitment

In order to be eligible to participate in the study one needed to be a CHN working at the refugee pediatrics clinic, even if only part time or on call like Angela, the care coordinator. In early May of 2017 a recruitment meeting was held with the four current CHNs at the clinic and the care coordinator/CHN—that is there were five in total. During this first meeting I distributed consent forms for their review and provided a verbal overview of what the study was all about, what I was hoping to accomplish, how they would be involved and what they could expect (should they choose to participate). It was during this time they could ask any immediate questions that they had before taking the consent for home to review. A few of the CHNs signed the form after the meeting and returned it to me, while a few others waited until I returned a week later to meet with them all again. It was during the second meeting that I provided an overview of the study again and responded to any lingering questions. By the end of the meeting, I had collected all consent forms. At this point I had collected consent forms for five participants—all of whom I provide brief biographies of in the following section.

Kriti

Kriti is originally from Burma. She speaks both Burmese and Chin in addition to English, which she was formally taught throughout her schooling in Burma. Growing up, her father worked for the government as a judge, which required a lot of moving and adjustments for the family. Her father's position and their frequent movement meant a few things relevant to her work as a CHN. First, it meant she was exposed to other dialects (though she does not consider herself entirely fluent in any of them); and second, as she described in an interview, it meant that she did not experience the kind of discrimination (e.g. religious, ethnic) that many within her country did. While she was aware of what was taking place in her country and certainly felt the residue of such profound turmoil, much of what was happening did not have a direct impact on her everyday life. Kriti also obtained a bachelor's degree and two associate degrees while still living in Burma, one of which is in mathematics. Prior to coming to the U.S., she worked for the World Vision Organization (WVO), where she gained experience as a mediator between funders and fundees in support of increasing educational opportunities for children in her country, since there is no a public-school system there.

In January of 2007, she moved to the southwest U.S. to pursue a research assistant position within a health-related foundation targeting adolescents with behavioral issues. She met the founder while in Burma and decided to apply. Upon her acceptance, she applied for a three-year U.S. work Visa. While she was in the U.S., she met her husband, who works at one of the refugee resettlement agencies in the area. She eventually left the foundation when she had her first child. Not long after, and with her husband's contacts, she volunteered at an apartment complex where many Burmese refugees happened to live. It was at the complex that she first started making contact with refugee families and learning about their experiences and needs—all of which fostered a strong desire to help. After nearly three years of volunteering, she had another child and stopped working again. It was during this time she was recruited to work as an interpreter at a local clinic serving mostly refugees. She worked at this clinic until she met one of the founders of a women's clinic for refugees at the center. The co-founder, aware of Kriti's extensive experience working with refugees *and* her interpretive work, asked her to join their clinic as a CHN. In 2010, she became one of the first CHNs at the clinic. Like the other CHNs, she eventually started working at the pediatrics clinic as more refugee families had children. When I met her, she had over seven years of experience working as a CHN.

Samira

Samira is originally from Somalia. She speaks English, Maay, Somali and some Swahili. She is the only CHN (other than the care coordinator/CHN) who is a refugee herself. From 1992 until 2004 a refugee camp in Kenya was a place she called home. She spent much of her childhood and adolescence there. While in the refugee camp, she attended school, where she continued to study and learn English. Her schooling was disrupted, however, because her family needed her support financially. The International Rescue Committee (IRC) was looking for someone who spoke English to teach hygiene classes. Despite her age (she was in sixth grade), which she confessed lying about, she was hired. She described the classes as similar to those that the CHN now offer through the clinic, and how valuable they were to families in the camp. Her experiences in the refugee camp were often a reminder to the rest of the group, including myself, that not all refugee camps are the same; some put forth more structure in life (e.g. school, work) and may have more resources than others. Samira does not say much about her experiences before living in the camp, but she has a large family which, for the most part, managed to stay together even after the resettlement process.

In 2004, she relocated to Chicago with her family. When discussing her initial experiences in the U.S. and with the healthcare system, she mentioned that her family had a sort of “sponsor”—a woman who helped them out considerably. The woman worked for a non-profit agency in Chicago, which had connections to her resettlement agency. According to Samira, this woman took a liking to her family (they still talk) and proved to be a valuable resource for connecting and navigating the many new contexts in which her family found themselves. Her family did not spend too long in Chicago, however, as her mother did not like the cold. In 2005 they moved to the southwest—a move Samira was not particularly happy about; everything seemed more difficult, especially without a car. And as the oldest in the house, many responsibilities often fell upon Samira, including the healthcare of her mother and grandmother, which is where her interest in health and medicine began. After high school, she went to college and studied to be a medical assistant. It was during this time that she volunteered for the Somali-Bantu community and first learned of the women’s clinic for refugees; but it was not until she did her internship for her medical assistant program that she reached out to the clinic. Her position began as an intern, and then shifted quickly to a volunteer role while she simultaneously worked as a teacher's' assistant for an early head start program. The more she volunteered, the more families needed her; and so, like Kriti, after months of volunteer work she was eventually hired as a CHN at the women's clinic and then the pediatrics clinic as well.

Casey

Casey is originally from Burundi and speaks Kirundi, Kinyarwanda, Swahili, French and English, which makes her one of the more in demand CHNs. She started learning English in high school. She pursued a bachelor's degree at a bilingual Christian university that had both Burundi and U.S. instructors. She studied economic sciences, specifically information systems technology. Casey grew up in the city in Burundi which, as she indicated, meant she did not experience some of the difficulties many refugees from the countryside experienced, as they often had to travel long distances to connect with critical resources. She describes herself and her family as being very religious; they often participated in various charities including raising money to help families' pay for healthcare services. In Burundi, if you cannot afford the healthcare you receive, you may be detained and held in a "jail" indefinitely. Casey and her family did what they could to help families in this situation. In 2011, she moved to the U.S. She did not come as a refugee, but as a "visitor." She decided to stay because home "was no good" and she was approved to immigrate.

Like Samira and Kriti, when Casey arrived in the U.S., she began volunteering at the women's clinic for refugees in the center, which she found out about via the co-founder (also Burundi). It was during her experiences at the women's clinic that she said started to realize how hard it would be to live in the U.S. and not know the language; but more specifically, she saw how challenging this could be as a patient. She also worked for a group home which is where she says she learned the most about the healthcare system here (before becoming a CHN). Many of her "clients" needed help setting up transportation, making medical appointments and following treatment plans—practices she was learning how to do in the process of helping others. In 2012, she also started volunteering through her local church, where she helped refugee families with transportation as well. It was not until 2016, however, that she started officially working at the health center. Unlike the other CHNs, she did not begin working at the women's clinic. During a Burundi community event she was made aware of an opening at the pediatrics clinic for someone with her experience and language skills. She applied and was hired. When I met her, she had been working at the clinic for about a year and served all families from the African Great Lakes Region (e.g. Burundi, the Democratic Republic of Congo, Rwanda, Tanzania, Kenya).

Reem

Reem is originally from Iraq but spent approximately twenty-eight years living in the United Arab Emirate. Her living in the UAE played an important role in her ability to understand and speak numerous Arabic dialects including those from South Sudan, Iraq, Morocco, Algeria and Syria (to name a few). Not all Arabic speakers come with these linguistic resources. Before relocating to the UAE, she earned a bachelor's degree in the English language and married her husband. One of the reasons for the move was because of the economic and political turmoil in Iraq. Another reason was because her husband was contracted by a company in the UAE as an engineer. After relocating, she applied for a job within the Ministry of Education and was hired to teach the English language. In the beginning she worked at a preparatory school, but within five years started working at a high school where she taught grade twelve. In addition to teaching English, she taught content courses in English like biology, which she indicated being helpful with her CHN interpretive work.

In 2010, Reem and her family immigrated to the southwest U.S. When asked about the move she explained that it was not a major adjustment as she had visited the U.S. many times and had family here. Like the other CHNs, she began volunteering within the Iraqi community; she already had many connections due to her family ties in the U.S. She helped with interpretation and transportation to medical visits. She grew to like this work and decided that she did not want to return to teaching. Through her ongoing volunteer work she heard about the women's clinic and applied to volunteer online. She volunteered for around six months. While volunteering she took a medical interpretation class and got certified to interpret for patients and all departments. After she received her certificate, she learned that there was an opening in the women's clinic for an interpreter of Arabic speakers and she decided to apply. She was hired not long after since she had already been volunteering and could work with a wide array of Arabic speakers. But it was also her background as a teacher that proved useful as well. When asked how she remembered so much about the families she works with without much documentation she would often say, "Remember, I was teacher."

Angela

Angela, a refugee herself, is the refugee and immigrant care coordinator, but she was once (and sometimes still acts as) a CHN. In 2012, she was hired by the director of the pediatrics clinic, because, as she explained, the clinic wanted someone to work with the increasing refugee population. According to Angela, her role mirrors what other care coordinators do such as helping families connect with needed resources or get information about resources—that is, they *coordinate* with families, providers and other stakeholders in the community to get their patients the services they need. However, because she works with refugees, she said she often finds herself providing “basic health education” as there are many resources or habits that may be considered “known” or “taken for granted” by the general population, but which refugees are unfamiliar. She also works closely with the local resettlement agencies, schools and a number of apartment complexes (housing larger numbers of refugees) to collaborate on educational outreach initiatives. Angela and the CHNs work together to help families apply for Head Start programs, schedule referral appointments to specialist providers and follow up on those appointments. Sometimes she steps in as a CHN when able or appropriate. She and Casey speak the same languages, so when Casey is overbooked or overwhelmed, Angela may step in to help. Finally, because the whole care coordination team (which is comprised of the CHNs) is grant funded, she spends much of her time documenting their work for their funders.

Summary

In this chapter I began with a discussion of the methodology of which this study is grounded (i.e. a methodology of engagement). I presented the data collection methods and procedures which drew on both ethnographic research methods (e.g. interviews, observations, artifact collection) and more rhetorical research methods like the critical incident interview technique—all of which took place over a seven-month period. Observations began in May of 2017, the group conversation was conducted in November of 2017, and a final debriefing meeting with the CHNs where I shared some of my findings took place in March of 2018. I also discussed the ways in which data was analyzed and how much of this analytical work was collaborative and emergent (e.g. what is "critical" in an incident). Throughout this chapter, I demonstrate the ways in which data, analysis and findings were often co-constructed with the CHNs, and how chapters build upon and informed one another. This chapter also provided information about the research context which included more detailed information about the clinic (e.g. services included, layout, people). Finally, I provide brief biographies of each of the CHNs that offer snapshots of their lives before coming to the U.S. and after, as well as descriptions of how they became CHNs. In the next chapter, I respond to my first research question, but also begin the assembly work discussed in the section on a methodology of engagement. It is in this first findings chapter that I begin to assemble the various practices, activities, tasks and interactions that constitute the CHNs work (and how they make sense of what they are doing). Recall that this assembly work is an important and necessary step towards being able to unpack what "it" is that the CHNs are doing together as a collective, but also as individuals.

CHAPTER FOUR

YOU HAVE TO HAVE SOME KIND OF HEART: MAKING SENSE OF CULTURAL HEALTH NAVIGATION

I am with Reem in the office shared by all the cultural health navigators while she is making phone calls. Reem hangs up her phone and places it down on the desk. Before she can make another call, the phone rings. She picks up and says, "Yes, I'm coming." She tells me, "I have a patient." She gets up and I follow her to the clinics' conference room where she grabs a sandwich that remained on a tray served during a going away party that took place earlier that day. As we walk to the exam room she says, "This mother, she has been here for hours, she must be hungry." We then enter an exam room where a young mother and her newborn baby are waiting quietly. The baby, she tells me, was recently released from the natal intensive care unit (NICU) but still needs an oxygen tank. The mother looks tired and worried as she clutches her baby close. Reem walks in smiling and says hello. The mother smiles back when she sees her. Reem sits down next to the mother and they start speaking in Arabic. She hands the mother the sandwich. Reem's phone starts to ring as they are talking but she does not pick up.

Dr. Day and one of the head nurses enter the room. They are trying to resolve an urgent prescription issues for the newborn. They tell her that she filled the prescription too early and they are having difficulty getting the prescription filled again. While the doctor is talking to the mother, Reem is listening and watching as he points to buttons on the tank. She speaks to the mother in Arabic whenever he pauses. Her phone rings again but she ignores it. Within a minute or two the phone rings again. This time she picks it up and looks down at the number and shakes her head. She places the phone down on her lap and shifts back to the conversation. The phone rings again. She finally picks up and covers her mouth with her hand as she whispers into the phone in Arabic. The doctor waits until she is off the phone to continue the conversation. When she is done she places her phone down and says, "I'm sorry," and they continue. After a few more minutes of speaking with the mother, Dr. Day and nurse leave.

Reem speaks to the mother briefly after they exit and then stands up to leave. As she walks out of the room she makes a call in Arabic. She steps into the former social worker office nearby to complete the call. Angela is in the room sitting with papers waiting to assist the Dr. Day with an exam. When Reem completes the call, she gets another call only seconds later. She picks up, speaks quickly in Arabic, hangs up and makes another call--this time in English. While on the phone she quickly turns to me and whispers, "I have to go get a patient outside" and starts walking away. Moments later the attending medical assistant is standing in the doorway asking if Reem is available for an intake or if anyone knows where she is. Angela says she just left, but she can try her work number. A minute or so later a resident physician steps in to the office and asks if Reem is available for interpretation. Angela tells him Reem will be back soon. After both *have left Angela turns to me and says, "That's how it goes, you can be everywhere and nowhere.*"

Making Sense of Cultural Health Navigation

In this chapter, I discuss how the CHNs make sense of their experiences and roles within the refugee pediatrics clinic, and as members of the care coordination team. Specifically, I focus on how they understand their responsibilities and the exigencies they are responding to, what their goals are as CHNs, what they value, what it takes to be a CHN, how they understand the clinic and its goals and missions, and their attitudes towards their work. The goal of this chapter is to make more visible how the CHN's "fashion themselves" within this particular "figured world" and make sense of their realities and experiences as CHNs within it (Holland et al., 1998). As described in more depth in Chapter 2, by "figured world" I mean a "socially and culturally constructed realm of interpretation" in which particular actors are recognized (e.g. doctor, patient, nurse, social worker), significance is assigned to certain acts (e.g. obtaining a patient's' medical history) and particular outcomes are valued over others" (Holland et al., 1998, p. 53). In this framework, one's ability to "sense" or "read" one's world becomes embodied over time through continual participation (p.53-54), as the internalized reading will eventually begin to regulate one's behavior within the world. I also examine the everyday routine practices, activities and tasks that constitute the work CHNs do in the clinic, as well as what they think about what they do, including the rationales or logics behind their actions and decisions.

Responsibilities.

To begin, I describe and analyze what I learned about their primary responsibilities as CHNs based on observations, informal conversations, and interviews I conducted with the CHNs about their roles, duties, and routine practices. I consider what the CHNs think they do to meet the most pressing needs of their families such as arranging transportation to and from the clinic (or to other clinics when referrals are made), providing language support during exams and other encounters at the clinic and helping sign consent forms for treatment. To accomplish some of this work (like making transportation arrangements) the CHNs work closely with the state's Medicare/Medicaid agency, which contracts a number of health plans that insure the majority of families served at the clinic. Among the many services that these plans cover is transportation to medical visits. During my time at the clinic I learned that many of families they work with do not have cars and/or phones, have difficulty navigating the public transportation system, are unsure how to call their insurance agency, and/or do not feel confident in their ability to communicate in English. CHNs try to make sure their families and patients make it to their scheduled appointments safely by arranging transportation for them. Reem described the value and importance of such practices—but also the weight of responsibility she feels for making sure this kind of work gets done:

> We feel we are responsible for these people. Yesterday I called a family, the husband told me the wife left at 10:30 and the time was at 12, and she’s not at the clinic. I called the [taxi] company, I called the insurance agency, I called everywhere. Till she came, I felt more comfortable…. Because as you know, it is

> our responsibility. These people, they don’t speak English, sometimes they don’t have cell phones. So, if you don’t make sure they are, they got the ride and they are going home, I can’t leave…I am responsible. Especially if she is a young mom and a young girl. She doesn’t speak English, she has no cell phone. How can I contact her? How can I reach her? So, I make sure.

Like Reem, other CHNs who participated in this study talked about feeling responsible for their families. I often observed them looking out windows to see if a family had been picked up by their taxi. One day Kriti was needed in too many places (much like in the opening vignette) and was worried about making sure one of her families made their way home. She ended up asking me if I could make the phone call for her. I told her I would. She quickly jotted down the number and the information I needed and went directly to the exam room. I waited on the phone for about fifteen minutes before I spoke with anyone but was able to make the transportation arrangements with the insurance agency. Later when Kriti was done with the exam and saw that the family had been picked up by a taxi, she thanked me for helping. They recognize that making and keeping appointments is important for families that need to be seen at the clinic, but making sure they keep the appointment, show up on time and arrive safely is a significant challenge for most families without the support and assistance of the CHNs. Often the CHNs connect families with taxi services through their insurance that take them where they need to go; other times the CHNs actually go outside with them and watch them get into the taxi. As I saw daily, however, even with the assistance of the CHNs, sometimes families do not make it to their appointments on time.

Another important role they play is providing interpretation. Many of the families that come to the clinic speak little or no English, or they do not feel comfortable communicating during certain kinds of visits (e.g. newborn, well-check, sick) because they have never experienced the encounter before. For instance, I observed an incident where a mother's' primary language had been changed to English in the system even though she had limited proficiency in English, and when the provider met with her for a newborn visit she requested a CHN. When the provider came to Angela for help, I overheard Angela explain that the mother had older children and when she came for those appointments the questions were easier, but with the newborn visit there was "new vocabulary" and she needed help with "key terms." As described in Chapter 3, the CHNs provide interpretation for up to ten languages, which represent the primary languages spoken by the refugee families that seek care at the clinic. They often draw on their bilingualism and/or multilingualism to improve communication between physicians and families in the exam room. They each have described this responsibility in slightly different ways, but their accounts share an emphasis on the important role they have in making sure that both the family and the provider are heard and the "right" or "accurate" information is communicated between them so that the patient gets the care they need. For instance, when asked what she considered to be one of her main responsibilities Kriti explained, "The main responsibility is to work between the patient and the provider. To give the right information to the patient and also follow up with the patient." Reem responded similarly to the same question indicating that, "The most important part of our job is the interpretation. Yeah, we have to be very accurate."

However, the CHNs also indicated that interpretation was insufficient on its own for addressing the needs of the families they work with. Most of the families that seek care at the clinic are new or relatively new to the U.S. and the U.S. healthcare system, and there is so much they are unfamiliar with—like what takes place during a medical consultation, what questions they will be asked and for what purposes and what will happen to their child during the exam. Without explanation or context, the abundance of questions asked may be intimidating, confusing or uncomfortable--responses and reactions the CHNs know well from their own first encounters with the U.S. healthcare system. As Casey recounted from her first medical visit, "They ask me many questions and I was like, why all these questions?!?! I didn't know why they were asking!" For these reasons, among others, the CHNs believe they spend a significant portion of their time on what they have called "education."

Education comes in many different forms such as formal classes or informal lessons during the medical encounter. It often takes place when the CHNs sense that a family needs it, when parents ask specific questions or seem confused about what is taking place and why. In other words, education is often provided in context and when needed. When asked about the education she provides her families Casey explained:

> My responsibility is that all my patients follow the appointment. If they are sick to know how to call me or the clinic. If there is ANY question related to health or other things we can help with in this clinic. I must remind them we do this and this and this…. we are here to help...even if you think you don't need help you can tell me, maybe we can find resources. Because if you have a problem, it's related to health. And, yeah, my responsibility is to help my patient to navigate

> the health system and to know how things go in this country, and how they can seek help, how they can become independent.

To Casey, it seems as if education involves making sure families have the information they need about health and navigating the healthcare system—including what services the facility and the CHNs offer, how and where to ask for help, what and how to communicate with providers, and how to seek follow-up care. Education also seems to take the form of cultural navigation or “knowing how things go in this country.” This, as I have indicated elsewhere, is difficult for anyone, as the system is extremely complex, multi-layered and dynamic with new experiences and ways of doing things constantly emerging. As I discuss in more detail in upcoming sections, the CHNs talked about what they do to help “clarify” or contextualize the medical experience for their patients, to help them make sense of what is going on and why, and to help families advocate on their own behalf. They are also there to deliver information in a way that is accessible to increase the families’ capacity to make their own decisions to take action and know what they action will mean for them.

Valued outcomes and goals.

According to the CHNs I have talked to, their overarching goal is for refugee families to “graduate” from the refugee clinic and reach a place of greater independence. As an example, they want refugee parents to understand how to obtain assistance with transportation or navigational support around the facility and continues to develop from there. In some cases, their efforts are so successful that CHNs do not even realize their families are at the hospital. As Samira explained during my observations, “I had a lot of patients that needed interpretation. They learn English and don’t need help. Many, they transitioned. Sometimes, I don’t even know they’re here” (Field Notes, May 19th, 2017). During an interview when I asked Angela what being “independent” meant in this context, she told me:

> Being independent means not needing the refugee care team anymore…. No, I will not even go that...because even us in the system we still need somebody to answer some questions. So, definitely yes...we keep the doors open if the person has a question. But the basic part is he or she is able to do it by themselves...like making and keeping appointments for their child, transportation, either having their own car or being able to call the health plan to provide transportation, having mastered enough English to be able to communicate with the doctor in the consultation room, not only answering but also being able to ask their own questions or give their own comments or really being comfortable in the consultation room for their child...that’s what we see that would be being successful and independent.

For Angela, being independent does not mean that a family or patient no longer needs any kind of support as it is rare for most people (refugee or not) to navigate the healthcare system and make health-related decisions on their own. Instead, she focuses on being able to do specific tasks that the CHNs often help them with and being able to communicate more independently with medical providers--not only by responding to questions but being able to ask their own as well. Casey described a similar account of what it means to be “independent” which resonated with the rest of the CHNs as well:

> I want them to know how to call, how to do transportation. If they don’t see the taxi, what to do. That’s what I want them to do. I want them to know how to come

> here to the second floor, because some of them I must go down and pick them up. I must go with down to the lab, emergency. I want them to be independent. I want them to know what do, not to wait. Because if the baby is sick Friday, you will wait for me till Monday? Because it happen all the time. That’s why I want them to at least to know what to do at this time, because I don’t think they must wait for me.

Casey, too, would like her families to be able to do many of the things she assists them with on a regular basis such as scheduling transportation and keeping their appointments, but also not waiting to bring their child in if they are sick because it is the weekend. She does not think they should be waiting for her and should be able to respond to their children’s needs on their own, especially in more urgent situations. During an interview, Angela offered what she viewed as a “success story” in this regard:

> For example, when they go to the third pregnancy with everything coming together in place...now maybe they have a job, so they were able to buy a car and the dad or the mom drives, and they also take the classes in the community, the English classes, or in the resettlement agency. And at the third pregnancy they don’t need us anymore, and they will feel good about that...that’s a success. It’s a success story that now they can be independent.

In light of this goal, the CHNs have worked together to create a “graduation list” (See Appendix G) which they shared with me during my observations. Although this list is always a work in progress, it captures many of the tasks and practices that they think their patients (but mostly parents) should be able to do on their own in order to “graduate” from the clinic. This is not an “official” graduation list of requirements, nor is there any official documentation process to chronicle progress, but they said that they do keep this list in mind when working with families. The list includes tasks like understanding the content of consent forms and interpreting medication dosages and captures multiple stages that families go through while trying to access healthcare services (e.g. the intake process, the encounter with providers in the exam room). These are goals the CHNs have in mind for their families when they work with them at the clinic, many of which require outside work as well, like going to ESL classes. In the remaining sections of this chapter, I explore the CHNs' views on the work they do and the role they play in fostering independence and health literacy among the parents who attend the refugee pediatric clinic.

Attitudes towards their jobs.

When asked how they feel about their job, the CHNs indicated that it can be stressful and that they often get frustrated. For instance, when I asked Reem if she considered her job challenging she immediately started talking about transportation and said, "Yeah, we have many challenges in our job. The worst thing is transportation. Yeah, sometimes we call two times, three times and sometimes our patients miss their appointments because of transportation." I observed a number of situations where despite their efforts to help a family they were not entirely successful. This was often true when it came to transportation (i.e. getting families to and from the clinic) and helping families follow treatment plans.

Still, the CHNs in this study all seemed to generally enjoy the work they do. During one of our interviews, Reem made a point at the end of the conversation to add, "I like this job, although it is tiring. But I like it because I'm doing something human, I'm helping others. I feel when I help these people, I feel so happy, so comfortable.” The desire to help others and their “communities” and/or “people” seemed to be a significant and shared driving force behind all of their efforts, as was the fulfillment they seemed to get from their experiences working at this clinic. Kriti described what drives her interests and commitments in ways that resemble what I learned from other CHNs:

> I feel like I really want to help the people, especially from my community because I know about their problems...they really need help, they really need somebody who can show them how to live here.

While the term “community” is invoked throughout the interviews, its meaning does not seem to be consistent, fixed or stable. The CHNs sense of community seems to be in the process of being reconfigured as people, providers, families and patients come and go, move and relocate. As another example, when Reem reflected on her first experiences in the U.S. and how she started doing volunteer work she explained:

> When we first arrive, because they know that I speak English fluently, I started helping people. The Iraqi people, when they go to the clinic without being paid for anything, just for free. I used to go with them to the clinics, to the hospitals and interpret for them.

Here, Reem uses “people” and “Iraqi people” to describe who she was working with. But in other conversations she also used “community” and “patients” which often encompassed more than Iraqi families, but any families that she worked with that spoke Arabic (e.g. those from South Sudan, Syria, Afghanistan). And so, while the term “community” permeated interviews, the CHNs also used different ways to describe who they were helping or wanted to help. Sometimes the CHNs talked about helping their "patients," sometimes they talked about helping their "community" and other times they talk about helping their "people," and still other times they referred to helping specific populations based on nationality (e.g. Somali, Iraqi, Burmese).

Valued characteristics and qualifications.

When asked what it takes to do their jobs and help their communities, each CHN indicated how important it is as CHNs to have an understanding of the refugee communities they serve. Kriti in particular talked about this across interviews. The first excerpt is from the second interview where I asked if she considered her job challenging:

> The things is understand refugee background. The refugee they never seen a doctor in the refugee camp, right? So, after they arrive here especially new people like...they have appointment at 9...they might get here around 10...they didn't know that they had to be on time, they don't speak English, they don't understand the culture here. So, this is a lot of challenge for them. So, it will bring in the clinic too.

The second excerpt is from the third interview where I asked her what advice she would give to a new CHN:

> Do you really understand refugee people? Do you really understand refugee community? If you don't understand it's gonna be tough for you. So, you need...if your background from there it will be really easy for you...you can understand them easily. If you don't know their background, it's gonna be tough between you and patient...like, what is she talking? So, first you need to understand.

When Kriti thinks about what is challenging about the work she does and the advice she would give, both responses show that she has extensive knowledge of the refugee experience—not only who they are, their stories, and where they have come from but also what they have lived through and are having to navigate as they resettle in the U.S. Here, she emphasizes how this kind of understanding provides a context for interpreting *their* actions and understandings, how it also fosters a greater awareness of and sensitivity to the many challenges they may face (e.g. making and keeping their appointments) when navigating the healthcare system, and how it helps them communicate more effectively. What Kriti described resonates with much of what I heard from all the CHNs--in interviews and informal conversations. Samira, a refugee herself, described how actually *sharing* a background can be a valuable and powerful asset as a CHN at this clinic:

> When you have been through what the other person had gone through, both have understanding without talking. You understand each other better. For example, there's a patient upstairs right now at the hospital...they ask me, 'Which camp did you live?' I said [name of] camp. They said, 'What block?' They got excited. 'What block?' Um, D5. They're like, 'We lived in A7!' Oh, that's like a couple blocks from each other. And they wanna talk about, 'When do you come here?!'Wait, let's finish the doctor's questions, we'll talk about it later. Now they wanna open up. They wanna share whatever. They wanna tell the doctor, okay, now I know this person, she lived in the camp where I was. Now I can tell you about me.

Samira describes an implicit understanding that comes with sharing a similar background and story with an individual, and how this understanding helps with trust-building; the patient can see themselves in Samira and feels more comfortable opening up during the medical consultation. Again, it is the understanding of where the patient is coming from, what they are currently experiencing, the challenges they may be encountering and the resilience they may possess to get through it all. All of this knowledge is so important to being able to do their job in a way that meets family’s needs *and* keeps them returning to the clinic. In the excerpt above, Samira seems to imply that she knew exactly where the patient was coming from and how this helps build understanding and trust. The woman saw someone familiar, someone who spoke her language and knew where she had come from and it made her feel more comfortable opening up.

In addition to having an understanding of refugee backgrounds and experiences and/or the communities served, the CHNs also identified several characteristics (most shared, some distinct) that they felt help them do their job. When asked during the third interview what advice they would give new CHNs, each of the CHNs responses included patience. I share parts of Casey’s and Samira’s responses to this question as they capture what the other CHNs shared as well:

> To be patient because if you are not patient you cannot do this job. And try to listen to them because sometimes it’s difficult to communicate with the patient. You need to gain, how you call it? The trust…if they don’t trust in you they cannot communicate with you, they cannot because if they trust you they will tell you everything and they will listen to you. But if you just, oh I’m high. No that cannot work with our patients. You need to respect them. Trust them first and they will trust you. And be patient because every day is a new experience. I cannot say now I know everything. No, every day is a new experience. Everyday it is a new experience. For my patients, for the transportation, for everything.

As Casey highlighted, and as I have seen, every day at the clinic is a new experience with new encounters, issues to address, families to work with and things to learn and do. All the CHNs communicated needing patience to be able to walk into such experiences of uncertainty day after day. According to Casey, patience also plays an important role in their capacity to establish trusting relationships with families. Samira added to this during her interview:

> Cause it takes patience to deal with the refugee patients. If you're not patient and you're always want things to be perfect…No you won't be able to handle it. No, it will be tough on you. There's no such thing as perfect.

Samira's key advice, it seemed, was that to do this job one cannot expect perfection; things do not always work out according to plan, and a CHN needs to have patience to keep going. According to the CHNs, it takes patience to reconcile all the uncertainties and unknowns while still moving forward and getting things done.

Not once did any of the CHNs mention "pay" or "money" as their reason for doing what they do. Instead, they talked about caring for their communities and doing for them what they may not be able to do for themselves. And it is the "heart" that they have that can make the job easier. As Samira described in an interview, "You know, when you're doing something from your heart and you know you're helping somebody, it's not hard. So, it was just okay now I have to do this, help this person get things done. It wasn't hard." Most of the CHNs also described having "heart" as an important characteristic or quality that helps them do their job. In my first interview with Kriti where I asked her about her initial experiences as a CHN, she explained that:

> If you really have some kind of heart. You have to have this some kind of heart so it’s easy for you. If not if you don’t have this, like, I don’t know how to say...this kind of heart ...it’s really hard for you. So, if you are happy you really want to help it’s easy and it can make you enjoy your workplace and then happy it can make you feel good. If not, it’s a lot of stress. Even like I really enjoy help (people) here but sometimes it makes me stressful.

The desire to help their “communities” and “people” seems to emanate most significantly from a place of empathy and compassion.

Several of the CHNs in this study talked explicitly about the value and importance of respect for families and the challenges they face, especially in cases where the CHN was younger than the parents they are working with, as there is often a generational hierarchy within many of the refugee communities the clinic serves. Casey talked about this during our first interview when we were discussing her first experiences as a CHN:

> You must be humble. And if you are talking with a patient, don’t show them that you know everything, don’t tell them they are nothing, don’t show them that you are superior, show them that you are equal. Show them that you don’t understand everything and explain them how. Because sometimes they don’t know what older than me. I’m young. I must respect them. They don’t see oh you know to do, and sometimes you can say, ‘Oh, how can you do this and this?’ Go slowly, make them understand how it works here, and yeah, just put yourself in their situation and try to be nice. If you just go...they will just go and say we are not coming back there because of this and this...they don’t respect. Show them respect,

> because back home it's...because most of the parents they are this and this. No, respect first. That's why with my patients they listen to me.

Here Casey highlighted how her age is an important factor when it comes to how she interacts with the families she works with, and this is true of some of the other younger CHNs like Samira and Kriti. Angela, however, is much older than most of the families she works with but has her own ways of showing respect. During a conversation where we were talking about names, Angela explained how only the patient's names are listed in the system and not the parents. Despite the parents not being her patient(s), she said she always tries to learn the names of the mothers and fathers when they come in. If for whatever reason she does not know the parent's name, out of respect, she will say, "Mama" plus the child's name. She said that this "creates a greater connection" and parents generally appreciate her using their names. She added that because of her age, those that do not know *her* name, as a sign of mutual respect, call her "grandma" or "tata" (in Burundi). Much like patience and heart, respect is important when it comes to establishing trusting relationships with their families, which as the scholarship suggests is so important when it comes to delivering and receiving quality care.

The Routine, the Regular: What Cultural Health Navigators Do

In the following section, I present and examine the specific practices, activities, tasks and interactions that facilitate their goals of the CHNs and their efforts to support refugee families (and providers) at different stages or junctures on the path to care. Specifically, I focus on how the CHNs help families get to the clinic, what they do during and after visits and their reflections on what they do and how they do it. Some of what is presented in this section can also be found in their interpreter logs where they document their routine practices daily, but without the kind of reflective, descriptive and analytical work that can be found here.

Getting to the clinic.

According to research on refugee families' access to health care and according to my observations of the CHNs in action, one of the challenges that many refugee families face is making it to their appointments and making it to their appointments on time. During informal conversations I had with the CHNs, I learned about a few of the reasons they thought made this process so challenging for families. One reason is that many of the families do not have the resources to get to the clinic (e.g. no car). Another is that many of the parents do not speak English, or limited English and must rely on the CHNs to arrange transportation for them—a process often fraught with difficulties and miscommunication. They also all talked about how time was a factor. Angela in particular often emphasized that many of the families they work with tend not to have a "time frame." After living for years, and in some cases decades, in refugee camps where there was little if any structure or activities *mediated by time,* she talked about how many of the families do not think of time in the same way as medical culture. In many (but not all) refugee camps, days roll into days, and each day is like the next, and when it comes to healthcare in the camps, as Samira recalled, it was "first come first serve."

At the clinic, however, activity *is* mediated by time. Appointments are scheduled in advance to signal when activity is supposed to begin and approximately how long it will take. For many of the families that seek care at the clinic, this reflects a new way of thinking that they must get used to if they want their children to be seen by healthcare providers. The lack of a shared sense of appropriate "time frame" may explain why, even when help is provided for arranging transportation, many refugee families do not make it to their appointment on time, or at all. To respond to this particular exigency and help guide families into participating in activity mediated by time, the CHNs have developed a system they all use. According to Angela, the system has been so useful and successful (not always, but often enough) that the general pediatrics clinic now uses it as well:

> The other thing the refugee clinic inspired is notably reminding the patient...to call like 3 days in advance for transportation. Our CHNs calls for the transportation for our patients, but now the care coordinator assistant for the general population, she now calls 3 days in advance to remind them of the appointment and to make sure the parent has the transportation. And she told me one time that several times the parents didn’t, if the car broke, they didn’t know they had the right to transportation through [Medicare/Medicaid] so they learn from there.

The system, as Angela described, involves a phone call to parents three days before the visit to remind them that they have an appointment and what that appointment is for or what kind of appointment it is (e.g. well-check visit, follow-up). During this phone call, they check to see if the family needs transportation support to the visit. If they do, the CHNs make arrangements with the patient's insurance company. Sometimes they make these calls in their office, sometimes in the clinic, sometimes while walking between clinics. Once they have established that transportation support is needed, they call the families’ insurance company or make a notation, so they can make the phone call later. As Casey explains, “Like for example if they have [name of insurance plan] you call [the insurance agency] to request transportation and the insurance agency will ask you which

[taxi] company." The insurance company then makes direct arrangements with the taxi companies, but it is the CHNs that set this process in motion and see it to completion (i.e. the family makes it to the clinic).

Making sure families get to the clinic the *day-of* the appointment is perhaps one of the most stressful and frustrating aspects of their jobs, and often begins long before they arrive at the clinic. In addition to the three-day reminder, they also remind patients the day of the appointment as well to make sure they are ready for the taxi, which often they are not. As Kriti explained in an interview, "So, we have to remind the patient before the day and we start receiving a call from the taxi at 7 because we give the number. Like that's how we start every morning. [It] was stressful before we even get in the office."

The CHNs also often spend a lot of time on the phone with patients, drivers and insurance agencies throughout the day trying to coordinate efforts to get their patients to the clinic on time (and back home). The following is a snapshot of what this work looks like in action when the CHNs are at the clinic:

> Casey walks into the now vacant social worker office where I'm seated alone and sits with her back facing me at a small round table with two chairs facing the window. She picks up the landline phone and makes a call. She is already on her work cell phone. She now has one phone on each ear. She speaks, and I hear faintly the sound on the landline. It is not English. Casey sounds a little frustrated, the sound of her voice gets louder. "Can you meet at the leasing office because she can't see you? She listens and responds, "It's just near the gate. What is the color of the car?" She speaks to a parent on the other phone. She then asks the driver, "you don't see them?" She speaks to the woman again. She turns back to

> me with both phones and shakes her head. She turns back around and says, "she's outside" and gives the address. She says again, "she's outside at the leasing office." She speaks to the parent; her voice is getting louder. She says, "you don't see her?" She speaks to the woman and then says to the driver, "they are just sitting outside the leasing office." She finally hangs up. (Fieldnotes, July 14th, 2017).

The above expert captures the stressful nature of the situation that the families are in as well as the value of the CHNs availability to respond to phone calls that come in during moments of urgency and/or crisis. While the CHNs initiate a reminder call to families, the CHNs often end up having to mediate between families and taxi drivers who are experiencing difficulty connecting with each other. Their phones seem to be ringing constantly—in exam rooms, in the office, when they are walking between clinics, when they are trying to eat their lunch, as they are leaving, and when they are home getting ready to come to work or have already clocked out for the day. Angela described her work phone as her "third arm" because they have them with them at all times. Sometimes, the ringing phones can be a disruptive distraction, especially if they are in the exam room, which is the one place they are not supposed to pick up; however, at times, due to the persistence of the calls, they may quickly pick up to let the parent (or whoever) know they are with another family and will call them back as soon as they can. Although the CHNs spend a great deal of time and energy managing the refugee families' challenges with securing transportation (e.g. to and from their appointments), it is difficult work that does not always turn out as they hoped it would. As Casey described during an interview, "Transportation, it's a hard. I don't know how to explain it but sometimes it's our patients, other times it's the company because to do transportation we call [Medicare/Medicaid agency]."

During an informal conversation that I had with Angela, she offered a few possible explanations for why this process is often so challenging. One possible reason was that often the names of patients are "too complicated" for taxi drivers to say when they try to pick them up. If the family does not speak English and does not have a phone, it is less likely that they will enter a cab under these circumstances. Another possible reason Angela provided was that despite the CHNs requests to have the taxi drivers knock on family's doors (especially if they do not have phones), they do not follow through with this request. And nearly all the CHNs talked about how for many families, even with the reminder calls, they still do not remember their appointments or remember to pay attention to the time that the taxi is supposed to arrive, which may explain why sometimes families are not home when the taxi arrives. This process, as I have witnessed, can be extremely frustrating, and yet, the CHNs remain persistent. If a taxi driver and family do not connect the first time, they will call for another taxi. After Casey got off the phone in the above scene, she told me that the taxi driver she was speaking to was the sixth driver she had tried to connect the family with, and finally they were on their way. This coordinated effort, often carried out in multiple languages simultaneously is not easy, but when successful, families make it to their appointments, avoiding yet another obstacle to care.

During the visit.

When a family does make it to the clinic, either alone or with the support of the CHNs, the facility itself can be daunting, especially for those who have never been to a facility like this and don’t know what to expect, or what they might be walking into. After arriving for the first time, some parent's will call the CHN to come to one of the center entrances and get them and bring them to the clinic on the second floor. Sometimes the parents try to get to the clinic on their own and get lost and the CHNs have to go find them and bring them to where they need to register in the clinic. I recall one such incident from my observations with Samira where she had to go get a lost mother:

> It’s 8:30 am and Samira asks if I want to follow her to go get a patient of hers who she thinks may be in the women’s clinic instead of the pediatrics clinic. She says she knows she’s here in the center but she’s not sure where. I follow her to the women’s clinic. She sees the mom seated in the waiting area and the mom sees her and smiles, Samira takes the car seat for the mother and leads her to the pediatrics clinic. They walk up to the check in. They verify the family’s address and are asked by the front desk to provide the patient's insurance. After hearing this request Samira speaks to the mother in Somali. The mother takes out a blue envelope and hands Samira a card. Samira stands at the check in with the mother looking over papers, talking and pointing to places where the mother needs to sign. Samira is doing most of the writing, however. She hands the papers to the receptionist and says something to the mother and we walk back in the clinic (Field Notes, June 6th, 2017).

The excerpt above shows what many of the interactions at the front desk look like when a family needs assistance. The parent stands beside the CHN as the CHN speaks with both the front desk staff as well as the parent. Like Samira, the CHNs often talk through the forms the parents need to sign and point to where their signatures are required. Not all parents are able to sign their names, however. I recall seeing one woman sign using the symbol of a cross. As an onlooker of these interactions, I was not always clear what was happening and what kinds of forms they were filling out with families. When I asked Kriti in an interview to help me understand what happens at the front desk and what she does, she said:

> If the patient did not update their profile they have to update...so they have to ask the patient, is it still the same address? They need to update. So, by that time we have to go to front. They have to wait that kind of patient because they need to register, they need to sign the form again every year. So, that’s why [I’m] at the front desk. They have to fill out three forms or something. The form is like is this visit related from an accident or something. So, they have to fill out and sign. And the other one is who should we give the confirmation, like emergency contact or something they have to fill out that one. And the other one is the patient, they are receiving care from this clinic. So that acknowledgement. So that three forms. So, they have to sign fill out and give back to the front desk.

As Kriti explained, when the CHNs are requested by families to go to the front desk it is often because the parents need help updating their profiles (i.e. address, phone number). My understanding is that the profiles are important life-lines between refugee families and the clinic as many do not have phones and frequently move. The CHNs also may need to quickly walk families through three important forms (all of which are written only in English and Spanish) that need to be signed by parents in order for their children to be seen at the clinic. These forms include a consent to treatment, HIPAA privacy authorization and acknowledgement of the “no show” policy which holds families’ accountable for missed appointments. Without signing these forms, the clinic does not have authorization to examine or treat patients. The CHNs are not always able to work closely with the parents to go over *all* the information on these forms, but they do make sure to quickly help the parent understand what the purpose of the form is and what signing it means (e.g. their children can now be seen by the clinic). In these instances, which I view as “scenes of literacy” (Brandt, 2001), the CHNs help actualize important relationships within the context of healthcare delivery (e.g. patient-provider) while also making sure that the families information is protected.

Intake.

Once families have registered, then they wait. When a room is available the attending medical assistant calls the CHN to let them know their patient is ready, much like how the vignette begins at the start of the chapter. Many of the CHNs entrances are met with instant smiles of recognition and greetings from the parent(s) as if they were old friends; they talk, laugh, the CHN may shake the hand of the young child or give them a high five, maybe pick them up if they are small. I recall one experience with Samira where her entrance and presence seemed to break up some of the tension between a medical assistant and a mother. The mother had forgotten to bring diapers to the visit for her newborn boy, and while he was on the measuring table, he urinated. When Samira walked in, the medical assistant seemed frustrated and told her that the mother needs to bring diapers when she comes. Samira responded by saying, “When you do this to a boy this is what happens” accompanied by some laughter. She then went to grab diapers and came back to help the mother clean. The scene suddenly felt less tense and more comical as the two women wiped the floor and the table clean—laughing and joking with one another. This does not characterize all entrances and interactions with the parents; sometimes the CHNs walk into silence and stares—by parents and children alike. Other times they may walk into frustration or distress. As I have seen, it depends on the family, the relationships the CHNs have established (or not) with the family, and the circumstances surrounding the visit. Over the course of my observations, I witnessed many interactions (like the one above) between CHNs and families that seemed to humanize the experience and cultivate a feeling of comfort in a place that is not always so comfortable and humanizing.

After the medical assistant leaves, the CHN initiates multiple literacy events mediated by several forms and languages. I focus on two forms in particular that the CHNs all described as very useful. First, the Parent's Evaluation of Developmental Status (PEDS) Tool. This form is used nationally and internationally by clinicians and non-medical professionals, and is printed in English, Spanish and Vietnamese, but can be translated into a variety of languages including many of those spoken by the families and CHNs. At this particular clinic, only the English and Spanish versions are available. Instead, they use the English version, and the CHNs work with the parents to fill it out. Every question begins with, "Do you have a concern…" about something related to the child's development (e.g. about how your child talks and makes speech sounds). The CHNs ask the question and circle the response, which include, "no," "yes," and "a little." In general, the form elicits "parents' opinions" about their children. This practice of calling upon the parents as experts stands in contrast to much of what is discussed in existing scholarship on refugee's access to healthcare, where refugee patients are portrayed as not often being involved in making decisions about their own care. During the intake process, the CHNS use their linguistic repertoires to help involve parents and increase participation in their children's health care in spite of their sometimes severely restricted communicative capacities in English.

The second form that the CHNs help the parents complete is introduced during the first few minutes of the visit and involved input from the attending physician, Dr. Day. It is called “Well Child Questions” (see Appendix H) and is specifically and only used with refugee families. As with the first form, completing the Well Child Questionnaire positions parents as experts in their children's lives but focuses on other questions related to the family and the home. For instance, there are questions like whether or not the child has seen a dentist, if anybody in the family is working and who cares for the child during the day if they are not in school.

According to the CHNs and Dr. Day, the questions reflect common concerns among families (e.g. employment) and the provider (e.g. dental health) and give the provider and the CHN (if they are not already familiar) a sense of what is going on in the home and in the lives of the children outside the specific reasons for the present appointment. I observed that sometimes these questions seemed to elicit unexpected responses, like a mom opening up about the fact they their family might be evicted, and no one is currently working. During an interview/conversation with Kriti, she said Dr. Day had suggested including a question about whether or not the family had food stamps, but the CHNs advised against it. When I asked Kriti why, she explained that the CHNs felt it was more “family” rather than “medically” related and would open up doors they didn’t want to open; doors they sometimes open (e.g. enrolling in insurance plans), but do not want to advertise officially. The questions that *were* included invited refugee parents to participate in a dialogue with their providers, which for many parents, as I discuss in upcoming chapters, is an unfamiliar practice, especially when interacting with a medical doctor.

Medical consultation.

According to the CHNs daily logs, most of their time is spent in exam rooms interacting with patients and providers. Many of these visits involve multiple siblings, and though each patient is scheduled for 15-20-minute consultations, they often take longer. As Casey explained in an interview, "Refugee clinic is not easy to manage. Other clinic they say 15 minutes, but our clinic, it's not just 15 minutes. That's why we cannot be on time, we are always behind." If a parent requests the CHN, or if they do not speak English or limited amount of English, the CHN needs to be present for the consultation when they can be. Each consultation usually begins with a resident physician since it is a teaching hospital. The resident asks the parents most of the routine questions for the visit. They also do their own examination of the children. After the resident leaves, the family waits for the attending physician to see them as well. This is all very time consuming and new for families. What remains consistent, however, is the CHN and the attending physician (Dr. Day) of the clinic stay constant over time, and *all* CHNs reported that the families value working with one provider.

Each CHN communicated the value of their presence during the consultations in different ways and for different purposes. Samira, a refugee herself, talked about the importance within the context of her own experiences:

> I myself lived in a refugee camp from about 1992 to 2004...so I know how life back home was in the refugee camp, how hospital setting was...how like the appointment thing was never there...the first come first serve, and that you will wake up early in the morning for that...and although some of the doctors were speaking the languages there were other doctors that would speak Swahili and it's hard to understand if there was no interpreter so now I know that it's important that I'm here.

In this excerpt, Samira talked about living in a camp for over a decade and how there were no such things as "appointments" in the camp and how difficult it was to interact with providers when they did not speak her languages. Others communicated the value of their work by juxtaposing it to phone interpretation, which is used throughout the rest of the hospital. Casey explained, "Because doing on the phone, you don't know who you...I don't want to know all their life, but I want to meet them, to see how they react, because sometimes they don't answer, they do body language, and how can you help them by the phone? I want to see, to talk." As I heard from the other CHNs as well, it is important for the CHNs to see the families they work with because sometimes things are communicated nonverbally. It is also important because they are not *just* interpreters—a distinction they often feel they have to make to others they work with.

As I have discussed here and elsewhere, the medical consultations are full of questions—some repeated, some familiar, some that are new. For a refugee new to the U.S. and new to the U.S. healthcare system, the questions being asked and the purposes for those questions may not be clear, and if they are not clear this can lead to confusion, silence, and/or questions if they feel comfortable asking them. Samira described the work she does in the exam room in a way that seemed to mirror much of what the other CHNs have said to me as well. She explained that, “The doctor comes in, I do interpretation, if they need clarification, clarify things, if they need some advocacy, then advocate for them.” One reason clarification is needed, as she explained, is that many medical terms do not translate to the patient's language. If it is a new concept, idea or condition they have never translated before, they need to figure out how to delivery information in a way that will make sense to their audience. In other words, the CHNs have to co-construct ways of talking about health and illness with their families on a regular basis. Kriti offers one account of this:

> I have one patient it was from the hospital. So, the doctor said kidney stone, right? You have a kidney stone, we have to operate, to take it out, the kidney stone. So, the kidney stone, the way you translate is like we call in Burmese it’s only one word...like *kyaut cut* right? So okay, but some patient, they speak Burmese too, but we have different ethnic groups, right? So, some different ethnic groups do not understand what *kyaut cut* is, so ok what is *kyaut cut*? What does it mean? So, and then she left from the hospital and she said she couldn’t sleep the whole night. The next morning, early morning, she calls me, ‘Kriti, why I never eat stone’ and the body... if the body or digestion system it can make a stone in your body?’ I said what kind of stone? ‘I don’t know. Yesterday I went because I had a hard time to pee and something and they check ultrasound and after everything they say I have a lot of stones in my stomach’ Oh my god that’s not right! That’s not what they mention. Ok so do you understand what is *kyaut cut*? ‘No’ Oh okay, then now I got it. This is not the stone. You know the water sometimes, when you

> boil water, right? Okay, sometimes you see the white under the boil. If you boil so many times and then it's stinky, white stinky, that's there on the pot. She said 'Yes.' Okay, exactly like this. You eat and then drink and the water is not clear, it can cause your kidney, kidney is a part of your body. So, I have to explain everything.

The example illustrates the kind of interpreting and rhetorical work that the CHNs may have to do in order to make sure that their patients understand what conditions they have or other concepts and terms the provider may use that may not have a direct translation. Not only did Kriti have to establish what the woman thought was happening and what she was told (i.e. the situation), but also whether or not she understood the word she was using to help her understand (i.e. audience analysis), which she did not. In light of this response, she tried to figure out a way to describe what was happening to her kidney in a way the woman might understand (i.e. delivering a new tailored message). She had to assess her audience, the situation and think quickly think of a way to deliver an accessible and meaningful message. Her approach stands in contrast to what the woman experienced with the phone interpreter, where the message was translated directly, and no clarification was provided.

I also observed and heard about situations where the CHNs were called upon to explain why a provider was asking certain questions as some of the questions may come across as intrusive or off-putting to refugee families. Casey provided an example of this aspect of her interpretive work and why it is so important:

> It's helpful to be there for them because sometimes the doctor ask the question. I must explain. So, for example, if you ask, 'How is the poop?' They will not, they

> do not want to talk about poop. And they will look at you, and I just explain [to] them, it's normal that the doctor will know if there is issue or not. If you don't say it, say what color.

As Casey's example illustrates, without understanding the purpose of the question, parents (or patients) may not see how the question is relevant to the visit or they may feel uncomfortable and not want to speak at all. I have often seen confused faces after the CHNs translate certain questions. For instance, several of the CHNs brought up in conversation how the word "concern" in a question like, "Do you have any concerns today?" was confusing for some parents. When I asked why they talked about how it seemed to make parents feel like they *should* be worried about something. As families experience more visits, they start to see how the diagnostic process unfolds. Explaining questions can help contextualize the experience so that parents understand why certain information is being requested and how it is relevant to their child's visit; this also includes what occurs during the physical examination as well—another part of the diagnostic process. As I have seen, checking with parents to make sure they are okay with the examination is a regular practice in the clinic. Sometimes, however, clarification or explanation is *for the provider* as they may not see the relevance in a response or may be confused by something a parent has said. Samira talked about clarifying things for providers in an interview:

> Like for example when the patient is talking sometimes people from our background, people from our culture, they leave the topic of what the doctor ask for example. If they ask how is your child? And they will say, 'he's good' but they will talk something that happened two years ago. And then the doctors like

> confused I thought you were here for a checkup and then you have to clarify...okay she’s just letting you know what happened in the past but right now the baby's okay and she’s here for the checkup.

Here, Samira was there to reassure the doctor that the mother understood the question and was responding, but in a way that did not align with the providers expectations and therefore did not seem relevant to his question. Sometimes, as Samira would tell me, the parents she worked with would go “off topic” during the medical consultations, and she had to work with them (and the provider) to help bring them back to the focus of the conversation. This work is important as it helps to establish trust between the two (parent and provider), despite not sharing the same language. By keeping both participants in the conversation informed about why the other is saying or asking something that may not be entirely clear, the CHN is helping the two understand where each other are coming from while trying to support more effective communication. As important as it is for patients to have trust in their providers, it is also important for providers to be able to trust their patients and what they say as well. As I observed and have experienced first-hand myself, trust is bi-directional the healthcare context, and the CHNs are often there to help scaffold more trusting relationships through these interactions.

During the exams, the CHNs also do what they refer to as “advocacy”—an idea I expand upon later as I view most if not all of the work they do as advocacy. There are a few different ways in which the CHNs have talked about their advocacy work during the medical consultations. One such way is by encouraging parents to advocate for their children, and to make sure they communicate what it is their child is or has been experiencing. Samira weighed in on the need for this kind of work during an interview:

> Cause their children can't know. And some parents will be like, 'Tell the doctor where it is hurting?' Uh, she told she was in pain. Okay she will say here, but here or down? The mom has to be advocating for her own child, telling exactly what is happening because the child can't know. If she's constipated, she thinks she has one piece of poop, she pooped, it's done, but no, she's constipated, this is happening. Ask the child to show you their poop if you're worried, things like that.

As I have seen, sometimes parents leave it to their children, some of which are very young, to tell the doctor what is going on, or describe what they are feeling. This seems to happen more when the child speaks English and can speak directly to the doctor. The doctor may ask a question about the child and the parent may remain quiet. This is where the CHNs may step in and advocate on behalf of the child by encouraging the parent to speak up for them or as Samira put it, "Tell them everything so that you don't leave here without getting treatment or what you came for. Then the person feels comfortable talking about what their child feels." It is almost as if the parent may need to hear from the CHN that it is okay to speak up for their children—that they are involved in the conversation.

Another form of advocacy they have identified is stepping in when they feel that a family or patient is not being treated appropriately or fairly by a provider. By this, they often refer to how a parent or family is being perceived and/or spoken to during the exam. Samira, for instance, told me a story about a provider who made one of her families feel bad for not having learned English yet:

> There was a situation where one of the provider's…the patient came in and then she called for me for translation, interpretation. And then the provider be like, ‘Oh um, why don’t you speak English? You’re in America. You’re supposed to learn English since you go to Walmart and do your own thing’ or ‘Next time come in with your own interpreter, we don’t have time.’ Things like that I have to go in and tell them like...the rules.

When I asked Samira what she meant by “the rules” she said that at first, she was not sure if the provider was being sarcastic or not, but after making similar comments as those above, she decided that it was time to speak to a supervisor. She did not believe her patient was being treated fairly or with respect and she felt that the line of questioning was inappropriate. She called on a supervisor in this case to speak with the provider. Samira added that, “It’s just you have to be there and show them, okay, this is not how you talk to this person and just make things clear between the provider and the patient so that the patient doesn’t get offended and the provider don’t get offended.”

Other situations are less serious and involve teaching more effective ways to communicate with parents. For instance, when Dr. Day first began working in the clinic, he would often ask multiple questions at a time as he had been trained to do. Some of the CHNs brought this to his attention, and he started to observe more closely how they interacted and spoke with families. When I asked him about this during an informal interview, he reflected on how his own change in practice over time emerged out of his interactions with the CHNs working in the clinic:

> I used to, I’d ask the families like multiple questions at once. Like, ‘Hey um have you had any fever, cough, vomiting, diarrhea?’ So, Casey would interpret as I

> did...and the family would respond, ‘Yes’ and then I realized, Michael that’s a terribly ineffective way of doing things you have to break it down and be more simple. And seeing how the families work with our CHNs I realized that I’ve had to most certainly adjust the way in which I communicate with our patients via the CHNs...that’s definitely something that I’ve had to get used to and the cadence, the rhythm, the speed, the diction that I use is most certainly something I think I’ve adjusted throughout the course of this last year, and hopefully to the betterment of communication.

Asking one question at a time may seem simple, but it saves time and helps avoid miscommunication. As I often observed, Dr. Day would make it a point to sit close to the CHN while maintaining eye contact with the parent and ask one question at a time, leaving space for the CHN to interpret and for the parent to respond, usually with a “yes” or “no.” In other words, while providers tend to ask more open-ended questions during medical interviews, by working with the CHNs and the families, Dr. Day realized that “yes” or “no” were needed as they tend to be easier to answer. When one question is asked at a time rather than as a series, parents can get used to the cadence and the rhythm of these conversations and start to learn where and when they have the opportunity to respond and seek clarification. In an interview with Angela she talked about how asking, “Do you have any *other* questions” typically opens up doors for families to speak and bring up issues that may not be related to the visit, but which are related to their child's’ health. Over time and with experience, it serves as a signal to them that it is time to bring up those questions. Angela told me that the practice of asking if parents have *other* questions has been so effective at eliciting parents’ concerns, opinions and questions that may not be relevant to the visit but are health-related that it is now asked by providers within the entire pediatrics clinic. This is important as it signals a larger effort within the clinic to respond to all patient's needs.

Discharge and Tailoring Information.

In addition to clarification and advocacy, the CHNs also all talked about how they provide on-site, informal education to parents, particularly during the discharge exchange where the medical assistant returns with paperwork, forms, and/or referrals from the visit. Many families are then sent to other locations in the health center after the visit but may not know how to get there, or what to do or expect when they arrive. In cases such as these, Casey explained, "If they are new at this clinic, I show them, I do a tour, a show them what is the pediatrics clinic. If they need women's clinic, they can go. If they send them to the pharmacy, lab, or emergency room and the hospital, I show them." While tours do not happen for every visit, I often saw the CHNs guiding families to the pharmacy or the laboratory. They also make sure to go over medication instructions with the families verbally as so much is written and in English. What this means is that the CHNs use other ways to explain treatment plans. They go over the instructions orally and explore the use of other modalities of expression. For instance, in situations where multiple medications have been prescribed, Casey described how she may color code in order to help families understand how much medication to take and when:

> I must mark the syringe to show them this medication. If it's for example two medications I will mark with two different color. Because if the first bottle I will put for example red, the other one yellow and the syringe will go with the color of the medication. Because if I don't do that they will mix medication.

Color coding medications and/or syringes is one way the CHNs try to help parents keep track of which medication is which if they are unable to read the labels. They also demonstrate a practice they want families to adopt and ask them to try it for themselves in front of them—like using a nasal spray for allergies. Sometimes, as I have seen, parents may be afraid or unsure how to administer medication or use other recommended devices. Being able to see the provider and/or the CHN demonstrate first tends to make them feel more confident to try themselves. I recall one exam where a mom expressed being scared to try a bulb syringe designed to help clear newborns noses, mouth and ears. The doctor then retrieved a sample syringe to give her and showed her how to use it. He watched as she nervously tried it herself. I remember her smile after she successfully used the device to clear out her baby's nose. These kinds of demonstrations and oral/visual instructions are important for many of these families who cannot speak or read in English.

The discharge experience also comes with paperwork and other instructions, all of which are written and printed in English. Parents of newborns in particular are inundated with instructional packets of information which is overwhelming for all new parents but especially overwhelming and confusing for those with limited proficiency or literacy in English. There are numerous well-check visits leading up all the way to school. Casey described how she goes over these instructions with her parents:

> For example, they have a newborn, I told them, you must follow the appointment, show them the calendar. This is the steps you can follow till the baby goes to school. If you don't follow the appointment maybe there will be someone that will tells you your baby missed this and this and this.

Like Casey, the CHNs provide parents with calendars and use them to go over when the parent will need to bring in their child in for well-check visits depending on their age (e.g. one-month, two-month, one-year). However, as I have articulated elsewhere, many refugee families' orientation to time is different than that of medical culture, and because it is unclear how effective these calendars are, the CHNs are trying to figure out alternative ways of reminding and educating families about the many visits they would like them to keep. I overheard Angela one day talk about creating a pocket calendar for families with the dates and places of the appointments. She felt this would be more mobile and easier to keep track of; but no adjustments had been made to their current practices at the time of my observations.

In addition to newborn instructions, they also often go over immunizations. Samira described her approach in an interview:

> Although you can't read the whole part...but you just scan through and tell them oh ok this is the shots your child is gonna get and this is the side effect, and this is what's gonna happen if you see this reaction call the hospital...whatever it says on the paper but...no you educate them.

This is a scene I observed many times during the discharge process. I recall watching the CHNs flip through packets of information where every immunization was listed and described in detail (and in English). Because there is so much content to cover and a limited amount of time to cover it they have developed strategies to summarize this information quickly for families—to identify what is essential for them to know (e.g. side effects to look for) and what is less essential to communicate (e.g. all the medical details about what the immunization) in multiple languages. In other words, the CHNs have developed ways to assess information for relevance and necessity while delivering that information quickly, succinctly and in a way that is helpful for families in the language(s) that they speak (i.e. they know what to expect).

The CHNs often use the discharge exchanges to respond to other questions that parents might have. Sometimes, these questions *involve things that were said during the visit that they didn't want to ask the provider about*. For instance, providers talk about how it is important for newborns to sleep on their backs and to sleep alone in a crib. Many refugee families, however, place their babies on their stomach when they sleep because this is what they have been doing and what they believe is best for their child. Most families also have their babies sleep with them rather than in a crib. When the provider goes over all of this, parents may not always understand why this practice (sleeping on the back and alone) is best, and they do not always feel comfortable asking about it in front of the doctor. During an interview, Angela talked more about what happens in this situation:

> Often, they come after if the doctor was may be busy or went fast they say why we will do that when in our culture we do the other way? And I explain, and they are happy to learn. And we've been really seeing many, many patients, many parents becoming more involved in the life of their child.

Angela described these conversations as important as they give parents an opportunity to understand why the doctor made the suggestion. She also described how many families are happy to learn when the provider or the CHN takes the time to teach them. In general, parents feel more comfortable speaking with the CHNs as opposed to the doctor. During my observations there was usually more conversation in the room when the provider was not there. I have seen a young mother open up to a CHN about her mother passing away just two weeks earlier and not being able to see her before she died. I have seen parents bring in piles of papers that they share with the CHNs, hoping they can help translate the materials for them. I also observed that families use these opportunities to ask about the services provided at the hospital and clinic, or questions concerning the various agencies they interact with in order to seek care. Angela describes well the role the CHNs play in helping parents understand the relationship between services and the agencies that provide them:

> They will say, ‘Well I go to DES, I thought that I just needed to apply for food stamps. And for example, how the taxi driver who came to pick me up what does he do? What is the connection with [Medicaid/Medicare agency] as the entity which manage my health care benefits?’ So, we have to go through the structure to explain DES to go to [Medicare/Medicaid] to go to any other health plan and the health plan to a transportation to company discount cab, and then discount cab to the providers, etc.

For many families, it seemed as if it was not always clear who they would see in the clinic, and who does what, and what the relationship is between the various entities and agencies involved on their children’s path to care, especially when the CHNs are making many arrangements for them. According to Angela, the CHNs *help make these relationships more visible* to families so that they understand who does what. For example, one day I overheard Samira and Kriti talking about how many of their families think that the CHNs run their own taxi company since they send the taxis and the parents are not involved in the process of making these arrangements. The CHNs often have to help families understand that they do not have their own taxi company, and that the reason a taxi shows up at their house is because it is a service their insurance plan provides and which the CHNs arrange for them.

I also observed families use the discharge opportunity to ask about the services the clinic provides as well as the health center. If, for instance, a family is interested in or has a question about the connection between the taxi that comes to their house and their insurance company (like in the example above), then that would be a time to talk about the relationships between the various entities involved in their children's' care instead of forcing such a conversation when the family is not ready to hear the explanation. The CHNs seem to know that it is best not to overwhelm families with too much information, but rather, stick to what they think they need to know or what the parents think they need to know.

After the visit.

The work the CHNs do does not start and stop with the clinical encounter at pediatrics clinic. They also help families connect with specialist providers based on referrals made by the attending physician. During an interview, Reem described why this work is so important and necessary:

> Because they call them about the appointment and they don't understand what they are saying to them and they miss the appointment. That's why I go personally and make the appointment or on the phone sometimes and do it.

Reem describes how often referrals are made and the parents will get phone calls about scheduling a medical visit with a specialist provider but are unable to do so because they do not speak English. When this happens, they may ask for help from the CHNs. Often, as I have seen, the CHNs will take on this responsibility themselves by scheduling an appointment for the family at a location close to their home and at a time that is convenient for them. To take on this responsibility they gather information from the provider and the referral coordinator and make calls to the insurance agencies. And while there is no guarantee that families will follow through, they do their best to decrease the chances of them missing the appointment in ways that are within their control (e.g. scheduling the appointment, arranging transportation).

The CHNs also follow up with parents when test results are ready to share. These calls are especially important when there is a positive result. The urgency of these calls is heightened if the children are currently in school. Sometimes they call parents to explain what the positive result means and why it is important that they bring their child back to the clinic to be seen and treated by a doctor. Much like their persistent phone calls to insurance agencies and taxi companies to make sure families make it to the clinic, they are persistent with these calls as well; but their persistence does not stop with phone calls, they typically do more if they feel they need to. CHNs will often go to families' homes, they will call neighbors or relatives in these situations to locate parents. Samira recounted an incident where she had to go to a family's home:

> There's a day where we had a patient where newborn screening came back positive with something and we called, called, called the patient. They were not answering. Left a message. We called, they were not answering. So, we had to go to their house. There's two incidents like that. One we went because both of them were coming to the appointment, were not answering the phone, but we had to go to their home tell them it's important you come, your child needs to see the

> infectious disease doctor, or your child needs to see the thyroid doctor, this is the screening came back positive. [They ask], ‘What is positive? What is there?’ We have to evaluate more, we can’t tell you exactly what it is. You have to bring your child.

Samira describes going beyond a phone call. She actually had to go to the home in order to locate the parents because she was not getting any response from the parent and she felt the situation was urgent. In this incident the parent needed further clarification as they did not know what a “positive” result meant. Like so much of their work, when the CHNs make these phone calls (or home visits) they need to generate compelling messages, often in multiple languages to encourage parents to bring their children back to the clinic to get the care and serves they need. Once again, this demonstrates their linguistic and rhetorical flexibility to respond to new and different situations with uncertain outcomes.

Discussion

One of the strengths of the team of CHNs is their emic understanding of the local communities they serve and work alongside. The guidance and support they offer families are driven by a desire to help their “communities,” but also a desire to help families reach a place of greater independence. Their goal is not to keep families under the “wings” of the refugee clinic, but to see them fly on their own. As I have shown in this chapter, the CHNs in this study routinely make important connections between refugee families and the healthcare system. They guide families through multiple literacy practices; they facilitate a variety of interactions and procedures with people, agencies and texts at multiple and critical stages and gatekeeping junctures (e.g. front desk, medical consultation) on the path the care. They provide more accessible education and guidance for families to support their ongoing navigation of the healthcare system in ways that also help to humanize the experience.

The chapter also demonstrated how their work is situated, dynamic and full of new experiences, outcomes, encounters and people. As the opening vignette and the many examples of practices highlighted in this chapter show, the CHNs are often busy and on the move as they assist families in a variety of ways across contexts. Sometimes, as Angela described, it is as if they are everywhere and nowhere all at once. They may be on their way to help a parent get to the clinic from outside the facility, while on the phone trying to help another parent get to the clinic from home. They might be on the phone with a parent and a taxi driver trying to visualize the space in which the two are trying to connect. Much of their work is about connections—making them, keeping them and strengthening them. It is often characterized by uncertainties, but it is with patience, respect, compassion and understanding that they are able to do what they do and keep families coming back to the clinic. By examining the CHNs routine practices and the CHNs stated reasons for engaging in such practices, we begin to understand the crucial role the CHNs play in refugee families access to quality care and providers capacities to deliver that care, which I expand upon in Chapter 5 as I trace three types of advocacy they are involved in through their work.

CHAPTER FIVE
SEEING THE CONNECTIONS: EXPLORING THREE TYPES OF ADVOCACY IN CULTURAL HEALTH NAVIGATION

This chapter builds and expands upon chapter four by exploring three types of advocacy the CHNs work involves, while also surfacing more of what the CHNs know and how they know it. In order to offer a more nuanced understanding and depiction of the three types of advocacy work, I identify and analyze example incidents or events elicited during interviews with the CHNs that demonstrate what this work looks like in action. It is through my analysis and interpretive work of the incidents that I begin to note *what about them might be critical* (i.e. they are rendered critical through the analysis) and reflect a need for additional analysis and unpacking *with* the CHNs as is systematically examined in Chapter 6. In other words, this chapter expands upon chapter four while providing the contexts for understanding the findings presented in Chapter 6.

Fixing It: Eliminating Major Obstacles to Care

One type of advocacy work that the CHNs participate in is involved in "fixing" something for families. In some cases, this means acting on their behalf—that is they *do* for families, rather than show them *how* to do something. In other cases, they react to a situation *for* families without their direct involvement. When a CHN "fixes" a problem by acting or by reacting to a situation that needs an immediate response there is a limited amount (if any) of teaching or guiding through a particular process, practice or interaction. CHNS sometimes have to step in as a trusted resource and take care of something for families rather than focus on education and learning. According to the CHNs, there are a number of reasons that they do this, and I will explore their rationales further in Chapter 6; but here in this section, the focus is on what this kind of work looks like, under what circumstances it takes place and what needs the CHNs feel that it is meeting for families (and providers).

Based on my observations, acting on parents' behalf is not always possible or legal. For instance, a CHN cannot approve or give consent for procedures or practices (e.g. vaccinations) that parents do not consent to themselves. CHNs also cannot bring children to the clinic *for* parents or force parents to have their children seen by a specialist provider outside of the clinic, regardless of a provider's strong recommendations for them to do so. This is to say that there are some limitations to what CHNs can do for families without their approval or involvement. However, the analysis provided in this section will show how CHNs in this study routinely made decisions to "fix" something or take care of something for a family even when they understood that long term, the best use of their energy and time is spent on helping families learn to navigate the healthcare system more independently. In order to better understand what this work looks like, I highlight two examples of this type of work elicited during interviews with the CHNs (and in some cases observations as well) that help unpack this kind of advocacy work and the needs it is meeting.

Health insurance and access to care.

Health insurance is complex and can be a major barrier to care for refugee families. As all the CHNs pointed out during observations, the very concept of health insurance is new for most of the families they work with as are the various practices, processes and entities (e.g. agencies) involved in applying for and maintaining health insurance. In an interview, Angela talked about how they often have to provide "basic health education" when they can to help families understand, at the very least, the organizational structure and the relationships between the various entities families encounter:

> For example, I can point out the issue of how [Medicare/Medicaid] is organized. So, for example they will say, 'Well I go to DES. I thought that I just needed to apply for food stamps. And for example, how the taxi driver who came to pick me up what does he do? What is the connection with the [Medicare/Medicaid agency] as the entity which manage my healthcare benefits? So, we have to go through the structure to explain DES to go to [insurance agency] or any other health plan and the health plan to a transportation to company discount cab and then discount cab to the providers.

As I have seen, there is not always time for this kind of mini lesson, and even if there were it does not address the many unknowns and uncertainties regarding health insurance for families. In general, the CHNs are not expected to help with insurance-related issues and are reluctant to start. During my observations I asked Kriti why they are reluctant to help, and she explained that they do not have the time to help in light of their many other responsibilities. However, sometimes the many unknowns and uncertainties experienced by families when it comes to health insurance create challenges at the clinic—challenges that are more difficult to ignore, like *not having insurance.*

Sometimes, as both Kriti and Reem recounted during interviews, families are scheduled for an appointment but do not have insurance to cover the visit. Kriti, for instance, talked about an incident where she called to arrange for transportation for a family only to find that the insurance agency could not process the request because the patient's insurance had been terminated:

> The main is [states' Medicare/Medicaid], no insurance. They already had an appointment, no insurance. I call [insurance agency], it was denied. Before we make appointment, right? Transportation setup, no insurance, it was terminated since last month. So, I cannot set up transportation.

When Kriti called to arrange transportation, she discovered the patient was not insured, which meant she could not follow through with the family's request for transportation support. Reem's patient, on the other hand, had already arrived at the clinic:

> Yeah, one time one of my patients came here, I didn't know that her sons [insurance plan] is inactive because she came driving, usually we figure out when we schedule transportation they say she needs to activate her insurance, so I didn't know that...then when she reached her, she came from [distant location].

In this case, Reem had no way of knowing beforehand that the child's' insurance was inactive, which meant there were few if any preventative measures she could have taken to avoid the situation. According to Reem's description, the family was able to get to the clinic on their own (which is one of the goals the CHNs have for their families). On the other hand, getting the clinic on their own meant that Reem was unable to catch the child's' insurance status before the family made the long journey to the clinic. In contrast, Kriti *was* able to catch the insurance status a few days before family came to the clinic so there was more time to respond and/or to alert the family. In both cases, though, the CHNs faced the same problem—neither of the families had active insurance for their child's' visit.

Because I had often heard the CHNs talk about the fact that they really didn't want to have to help with insurance (during informal conversations and during interviews), I was surprised to find that instead of ignoring the situation, they both chose to do something about it. During the same interview, Kriti described what she did once she discovered the insurance was no longer active:

> So, I call the parent…we have important [appointment] for your kids, why you didn't go to DES office? You need to renew your insurance. 'I don't know how to fill out the form! Sometimes we went to the [resettlement] agency they help us, but we went there, I never see my caseworker. I went there twice already, so I don't know how to fill [out the form]!'

For Kriti, she had time to call the parent and to check to see what they knew or had done (if anything) about their child's' insurance. It starts with a reminder that the family has an important appointment scheduled for their child and is followed by a question about why they have not renewed their child's' plan. However, in Reem's case, the parent called *her* for assistance while at the clinic. Like Kriti's parent, the mother did not know how to apply or renew their child's' insurance plans. In both situations, the CHNs could have chosen to nothing more than what Kriti did above—that is, to find out what was going on and remind the parent to apply. However, in both cases, the CHNs decided to do more on behalf of their families. Reem described her thinking about the situation and how she responded:

> So, it is difficult to let her go back home without doing anything for her. Then I took her to the DES and in order to apply in order to activate or renew his [insurance], they give us a paper, they told her that he can be seen today, and she

> will not be billed for this today, and she will wait for just about one month for her to get a new one.

Reem expressed reservations about letting the mother go all the way home without doing anything for her or her child. Kriti's response was similar. Once she heard that the mother did not know how to fill out the application (knowing already that the visit was important for the child) she decided to step in and help. As she explained in the same interview, she often feels she has no choice:

> That's why I say we are not CHN…a social worker…without insurance they must pay, they don't have money, so the doctor need to follow up everything too. So, this is actually, this is social work from outside the clinic, but we still doing everything because we don't want to miss their health. This is related and connected all the health issues with the social work and the medical care is together, so we cannot ignore it.

Here Kriti described the difficult position the CHNs often find themselves and the tensions they encounter in their work—do they ignore what they see because it is not part of their job description? What seems to make these decisions so difficult and robust is that they *see* so much. I often heard several of the CHNs talk about their home visits and what they saw, and how difficult it was to walk away without doing anything--even if it meant just showing a parent how to use a washer and dryer to clean their clothes. The more they see, it seems, the more difficult it is to "ignore" things, and this may explain why Kriti described herself and the other CHNs as "social workers." Her observations about and understandings of the connections between one's health and social lives seems to make it more difficult to ignore certain things as other health professionals may find it easier to do.

In both cases, there was a need for support with the eligibility/application process, which as I have seen can take hours; it involves a lengthy application in English (that can be found online or in person at a local DES office) and an interview with a representative. The CHNs do not have *hours* to work with families and at no point did Kriti or Reem talk about teaching or guiding them through the application and interview process. Instead, they talked about stepping in and taking care of the application *for them* because they did not have enough time to teach them how to fill out the forms and could only help if they filled them out themselves. Because the application allows a third-party to act as an official representative in the process, the CHNs were often able to step in and “fix” the immediate problem or concern (e.g., filling out paperwork required for obtaining or renewing insurance). By bringing them to the office, obtaining the appropriate paperwork, responding to the questions, and either leaving the application with them or waiting to see the whole process through if they have time, the CHNs addressed the most urgent and important issue. However, *by doing and not showing or teaching*, the CHNs may be setting themselves up to be needed in the future to support this process. This is to say that the “fix it” approach does not address the larger problem this incident may represent, nor does it seem to help families apply on their own.

Responding to distress.

In addition to “fixing” insurance-related issues, the CHNs also often take care of transportation *for* their families rather than involve them in the process and show them how they might approach doing the task on their own. When they arrange for transportation it is usually on the phone and without the family's involvement, which means there is little to no teaching and learning taking place. Sometimes, as I saw during my observations, they even arrange transportation for each other's families. I noticed how this typically happened when a CHN was absent from work or if they were too busy (e.g. in an exam room) and a family needed to get home or to the clinic and could not wait. In other words, CHNs sometimes help each other by making phone calls to insurance agencies to arrange for transportation for families that are not within their cultural groups. I had never, however, observed a CHN actually *interact with a family member from a different cultural group that did not share a language* and take care of something for them, like transportation. As I learned throughout this study, there is much that CHNs do that people do not see; and the incident I examine in this section is another example of work that often goes unnoticed and undocumented.

During an interview, Samira told me about an incident involving transportation that she experienced with a parent that was not from her cultural group (i.e. Somali). Samira's memory begins with her walking back to the clinic from the emergency department. She first described what she saw, "I see this Burmese lady going back and forth, back and forth." She talked about how she noticed that the woman was pacing in front of one of the exits as I have seen many refugee families do when waiting for transportation. She said she felt the woman needed help—that the pacing back and forth near the door meant something to her. But, as Samira also made very clear, she did not know the woman. In light of all of these factors she *could* have kept walking back to the clinic. Instead, she described approaching the woman and initiating a very deliberate inquiry about transportation:

> I’m like, are you ok? She’s like, ‘Taxi.” Did you come with taxi? ‘Taxi.’ Oh, um, phone? [insurance plan]? I called [insurance plan]. No, I called [cab company], the taxi company. They’re like, we didn’t bring her there. And I called the other company that [insurance agency] is contracted with. They said we didn’t bring her there. So, I call [another insurance agency] and they’re like how did she come there? Oh, cause at first, I didn’t know. I said with taxi. And they’re like, no she didn’t come with taxi, how did she come here? I’m like, maybe somebody dropped her. I don’t know, I don’t speak her language, but she needs taxi to go back home. So, you know, I called the taxi company and I called [insurance agency] right away. Everything was settled...about forty minutes...and the glow when the taxi came. She was so happy she had me.

Samira’s inquiry begins with a simple question: are you okay? As an experienced CHN, refugee and mother herself, she has a sense that there is something that might be wrong. She does not actually learn if the woman is okay, but she does learn what she might need via a single word: taxi. Despite not speaking much English, many of the families know words like “taxi” or the name of their insurance agency. They also, as I frequently saw, know that their insurance ID’s have important information that may help them communicate, which is why so many of them seem to have their paperwork with them when they come. Samira knows this as well, in part because they tell their families to bring this information with them. She then requests the ID so that she can continue with her inquiry so that she can resolve the situation for the mother. When Samira discovered that no one was coming for the woman, she followed up with phone calls to the insurance agency to set up transportation. Samira did all of this with limited help and involvement from the woman; Samira did not teach or guide, she just did.

After telling me about what happened the day of the interaction, she told me what happened the following day because it stood out to her as a memorable. Her reflections also stood out to me as they helped show that other important things happened via this interaction:

> The next day I was walking from the hospital again, and she was going that way. She pointed, 'Look! Look! Taxi!' I'm like oh my gosh! I'm like yes. And then every time she sees me, she says the 'taxi person,' the one that helped me with the taxi. The only thing I can hear is 'taxi' so I'm like, is it the person that helped you with the taxi? Or is she the taxi driver? I don't care. All I know is I helped her and she's happy. Every time she sees me she says hi and she just gets that face, that happy face...When you help somebody even though they don't speak your language, but they get excited like okay now I can trust this person; she doesn't speak my language, but she helped me. Tomorrow I can ask her for help. I shouldn't be scared of her.

Samira described another encounter with the same woman where she saw first-hand what the woman took away from the exchange. Despite not learning how to arrange transportation, she learned that Samira was a safe resource she could return to for help. Samira used the word "trust" to describe what she felt this interaction helped facilitate; and trust, as I have often heard from the CHNs, is so important to the work they do. Recall, for instance, in *Chapter 4* how Casey talked about the relationship between respect and trust and how those that trusted her "listened" and were more willing to share information with her. Sometimes, however, as this incident demonstrated, trust can emanate from interactions where languages and cultural backgrounds are not shared. Sometimes, it emanates from the feeling that you are being seen and recognized in a way that makes you feel understood.

As Samira walked me through the full story and not just the first encounter with the woman, I started to wonder why she stopped. A possible answer to this question emerged later in the interview where we were talking about her experiences as a refugee herself, and how these experiences influenced the work she does:

> Well, if I had no experience with refugees I would be sucking at my job. Imagine you, you are American. I bring you a refugee person, what are you gonna do? How will you talk to them? It just encourages me cause I have a reason to go to work; I have a patient to help; I have a Somali person; I have a refugee person. [It] doesn’t matter if he’s Somali, Sudanese, anybody who’s needing help.

Samira’s comments resonate with those of the other CHNs I interviewed and observed. To Samira, it is not just about helping fellow Somali refugees; it is about helping people, but more specific to this context, patients. After we spoke about this, I started to pay closer attention to the entrances and exits of the health center. I saw a few interactions here and there where CHNs seemed to be interacting with parents or families from other cultural groups. One day, while I was leaving the clinic with Samira I actually got to experience one of these moments with her. There was a woman wearing a *pagne* or traditional Burundi “wraparound” looking out to the street quietly as her baby slept in a car seat by her side. It was past five o'clock and Samira had already clocked out for the day, but she stopped. She seemed to follow a similar inquiry process that started with, “Are you okay?” Within only a few minutes Samira had determined there was no one coming to get this mother and that she needed a taxi. I still vividly recall the smile on the mother's’ face when Samira handed her paperwork back and told her a taxi was coming.

While the incident illustrates another way in which the CHNs “fix” or take care of something for families and how important this work can be, it also shows us what is possible without sharing a language. Samira’s retelling of the entire story demonstrates how the CHNs tend to walk around the facility with a different set of lenses on that help them identify refugee parents and families in need. And it seems that regardless of the language of the family or where they come from, the CHNs seem to know how to approach them and determine what might be needed. These may seem like brief encounters that do not mean very much, but as Samira explained, they can set roots for trusting relationships that keep families coming back. Of course, it would be impossible to help in *all* situations where a language is not shared, but the CHNs often help other families with transportation *because* it is something they can take care of with minimal involvement from the parents. In other words, being able to “fix” things for families is sometimes the *only* way something can happen, and it does not mean that no learning whatsoever is taking place.

Guided Practice: Learning by Doing

In addition to “fixing” or taking care of things for their families, the CHNs also spend a considerable amount of time guiding families through practices, interactions and procedures. This type of advocacy work involves much more teaching, learning and scaffolding. Some of this kind of guided practice is visible to others (e.g. showing families how to use a medical device), but other times, it is not visible (e.g. it may be acted out in languages unknown to onlookers) and/or may go undocumented. In this section, I take a closer look at what this type of advocacy looks like in action through incidents I was granted access to during interviews and in some cases observations. These incidents capture work that I may have seen during my observations but did not actually know was taking place. In general, and in the incidents analyzed in this section, CHNs help families shift more quickly from sense-making to more agentive action in new cultural contexts (e.g. medical culture). One of the ways in which CHNs do this is by identifying moments and situations where contextualized, as needed teaching and learning is necessary and possible. Among the goals of this ongoing and situated work is to expand families and patient's communicative repertoires, but also increase their cultural competencies, particularly as parents.

The incidents that fall under this particular type of advocacy and that are explored in this section illustrate the fact that tensions exist between the parenting practices that refugee families bring with them, the dynamics that emerge between refugee families and health care providers, and the kinds of practices and dynamics that are privileged in the U.S. healthcare system. The CHNs told me that they often find themselves having to manage these tensions as they try to guide parents through new cultural contexts and as parent learn some of the ways they may need to change in order to accomplish certain goals in new "figured worlds." For instance, if parents want their children to go to school, they need to make sure they get the required vaccinations. As Angela described in an interview where we were talking about what the CHNs often need to teach refugee families, she explained:

> I will say even more crucial is I can say, for example, immunizations...because we have the cultural beliefs and practices which our refugees come with, and we help them. I help them understand that here things work different. Or not even here. For the best care, for the best health status of a person, we have to change. Not only those coming from my community. So, those timely immunizations, those annual checkups, they don't exist in daily practice over there.

As I heard from all the CHNs, vaccinations represent new cultural practices for many refugee families. The CHNs often need to help families understand why and how this practice (among others) is important and what purposes it serves within their children's' lives. According to Angela, this type of guidance is not just about teaching families about different practices and ways of doing things, it is also about making sure that children get the best healthcare available to them.

Parent-provider communication.

One experience or aspect of healthcare delivery that is likely new and/or different for many refugee families seeking care at the clinic is the medical consultation. According to the CHNs, refugee families may not be familiar with who is involved and what their roles are (e.g. medical doctor, medical assistant, nurse), what kinds of objects (e.g. stethoscope, thermometer) or practices are involved (e.g. physical examination, interview) how much time it takes and what the outcomes may be (e.g. more tests needed, referred elsewhere). Some parents may have little to no frame of reference for such exchanges and procedures and may not know what they are supposed to be doing or how they should be acting or when it is appropriate to speak. Often the diagnostic process as a whole is new for refugee families—as it was for the CHNs as well. Kriti recalled her first experience going to the doctor in the U.S. during our first interview:

> I remember I went one time I wasn't feeling well. I remember the lady treat me. I think at that time I had some infection, so they said, like, okay, you need to have blood drawn and blah blah and they said they gonna call two days and the blood work came back and they say you have infection, you need to have antibiotics for seven days. So, that really different. Like my country they just guess what you have, they don't treat you like here…because the first I asked the doctor to give me some medication, acting like people from my country because if you went to the doctor office in my country, they give you right away medication even they didn't know what is your disease, so here I have different experience.

Kriti's memory of her first experience with the healthcare system in the U.S. sounded similar to most of the other CHNs descriptions. Each seemed to expect a quicker visit with less talking and a speedy diagnosis and treatment plan that involved some kind of medication. According to the CHNs, many of the families they work with in the pediatrics clinic have similar expectations for the medical consultation, and these expectations do not include a lengthy dialogue with a medical doctor about their children. Angela described in an interview how parents tend to think that, "I'm not the specialist, the one who sees the problems, so meaning if the specialist who is the doctor says that this is a problem, then it is a problem. But if the doctor doesn't say anything it means things are the way they should be, so that is the belief." The CHNs, as I explore in this section, often have to help parents understand their *role* in the medical consultation and what it means and looks like to participate in this dialogue and that it is, indeed, a dialogue. This is to say the CHNs often have to scaffold these encounters as they unfold. Often this type of advocacy work goes unrecognized as it is acted out in languages most people at the clinic do not speak; however, during my interviews I gained more access to these conversations and the kinds of work the CHNs do in the exam room by hearing about some of the conversations they have with parents and the work they do with families in other languages.

One of the key findings of this study is that the CHNs play a critical role in facilitating communicative or interactional aspects of the clinical exchange between parents and providers. During an interview with Casey where we were talking about some of the challenges she experienced in her work, she talked about how she often has to help parents understand their role in the consultation:

> The provider asks questions, and they're like, 'No, you are the doctor, you know everything.' But I remind them, he's the doctor, yes, he knows, but you help him to know about your kids. If you don't help him, he will not help your kid. Because you are the mom, you are the dad, you know your kid best than the doctor. It is you who guide the doctor to know your kid and to help your kid. Because he's the doctor, if your baby has fever, cough, yes, he can do this, do this...but you are with the kid all day, you know how he is, you know everything about your kid. It is you who must...don't say, 'You are the doctor you know everything.' No, it's you, the parent.

Here, we see how Casey works to manage the different expectations that parents bring to the visit (e.g. the doctor knows everything), while also helping the parent understand that *they* are crucial resources in the healthcare delivery of their children. She tries to get parents to recognize that they are experts of their children's' lives (e.g. their habits, behaviors, attitudes, feelings), not the doctor. When she says, “It is you who guide the doctor to know your kid” she is letting parents know that the doctor needs their help—that he or she cannot diagnose and treat their child alone, even with their medical expertise. Casey went on to explain during the interview why this is such an important aspect of her work:

> That’s where I always want the parent to know their responsibility first and know how to communicate with the provider because they call me to come, they don't know why the are there, because in their mind, Casey called us to come here, we don’t know why. Okay, I called you because of this and this, and I explain this is a six month visit and also the doctor will ask what questions do you have or how is your child, and they say, ‘You can check yourself.’ But they don’t get that. That’s how, every time, I repeat.

Casey talked about how she often helps parents interact with the provider, but that sometimes she also has to help them understand what type of visit they are there for as the *type* of visit shapes the questions asked. Recall in Chapter 4 how Angela described a mother that had grown comfortable speaking in English during visits with her older children but needed support for her first newborn visit. Casey’ memory highlights the ways in which the CHNs have to manage some of the tensions between expectations and understandings parents enter the clinical encounter with and the realities of healthcare delivery in the U.S., which often include new practices, procedures, people and outcomes. I recall one incident where a parent brought her child in because she thought something was wrong with her skin. After the doctor examined the child, she told the mother she had dry skin and recommended using lotion and/or Vaseline. After the doctor left, the mother seemed upset and said, “We come all this way for a talk.” Much like Kriti’s first visit, the expectation was that the doctor would prescribe medication without all the “talking” and questions. But, as many of the parents learn through the CHNs, this is not how these interactions go.

Over time and across contexts, CHNs scaffold parent-provider communication during consultations (e.g. by helping parents understand their roles as parents in this new context) in ways that they hope will transfer to consultations when the CHNs cannot be present. With the support of the CHN, even parents with limited proficiencies in English learn how to communicate with providers as active participants in a dialogue about their children’s health. Often it is the mother who brings the child in for the visit and who knows most about what is going on in the lives of their children, especially newborns. As mothers participate in more consultations and diverse kinds of visits (e.g. newborn, one-month, one-year) they learn what kind of information (e.g. behaviors, diets) is valued and therefore what they need to look out for between visits. According to the CHNs, this is also true when/if fathers happen to bring their children to the visit. As I have seen, when a father does come, they often have to call the mother while in the exam room because they don't know how to respond to a question. In one consultation, I recall a father calling the mother to ask about how many times she was breastfeeding the child, if she was starting to use formula and how she was mixing it. The attention and care that tends to emerge from these scaffolded interactions have also been observed by the CHNs to impact family dynamics more generally. As Angela reflected during an interview:

> I see that most in our cultures the care for the kids is left for the women, and the dad is the breadwinner but is not really caring for the child. I see that even among them, some progressively are learning that the care for the child is a task for both the man and the woman, and whoever is available can bring the child to talk about how the child pees or poops. The dads are not shy to answer those questions. Some of the time at the beginning the dad will say, ‘Oh really? I don’t know because at home I don’t take care of the child, let me call my wife and ask.’ But the following time he will have paid attention to how things go at home.

Here Angela described how the medical consultation can encourage *both* parents to pay closer attention to some of their own parenting practices (e.g. how they are mixing formula, when they are feeding the child), but also more attention to their children's behavior and habits. In other words, the questions asked during the medical consultation, in some cases, may start to influence *how* parents parent. By the time a father brings their child in to the doctor the next time, he may be better prepared to participate on their own without the mother. Take for instance the following excerpt from a Somali family’s first visit to the clinic where only the father was present with his two sons. While the questions asked do not seem to pertain to the children directly, the excerpt offers a glimpse of how the CHNs guide parents through these interactions. I chose this example because the father spoke English, which made this kind of scaffolding more visible to me in real time:

> I am in an exam room with a Somali father and his two young sons. The father speaks enough English that he is able to interact with the provider on his own. The family has only been in the U.S. for a couple weeks. Samira is in the room to

help as needed. The resident is going through his first round of questions about the older son. At one point he asks the father, “Do you have any developmental concerns about your son?” The father looks to Samira and they speak in Somali. The father says, “No.” The resident asks, “What is the child's’ diet like?” Again, the father looks to Samira and they speak. He says, “Pretty much everything.” The resident then asks if the father is reading to his son. The father asks, “Do I read?” The resident clarifies by saying, “Do you read to your son in Somali?” The father says no. The resident asks if they lived in a refugee camp before coming to the U.S. The father says yes. “For how long?” the resident asks. “Seven years,” the father says. The resident asks if they ever got bloodwork done in the camp. The father says, “No.” The resident then asks if they received dental care. Again, the father looks confused and laughs. Samira says, “They do not have dentists in refugee camps.” The resident says, “Sorry, I just had to ask.” The resident asks how the father is doing and what his health is like. The father looks a little confused and turns to Samira. She says something to him in Somali and then he says, “I’m fine.” The resident asks if there are any problems with the mother's’ health. He says other than a “late period” she is fine. The resident asks, “What about your parents?” At this point the father laughs a little. He says, “They’re not here.” The resident says, “Yes, but I’m trying to get their medical history.” Samira again speaks with the father in Somali. After they speak, the father says that one of the parents is not alive and on the mother's’ side her mom has high blood pressure (Field Notes, July 11th, 2017).

Here we see how the CHN had to scaffold this encounter for the father. Every time the resident asked an unfamiliar or confusing question, he turned to Samira for support. As I have seen at the clinic and know from the scholarship on refugee health, obtaining medical histories is often difficult. Like this father, parents are not always clear how the medical history questions relate to their child or the visit and may be reluctant to answer (or know how). But here, Samira was there to explain why the resident was asking questions about family members. In this consult, she also helped him with some unfamiliar medical concepts such as “developmental concerns” and what such “concerns” might include so that the father could be on the lookout for them. You can see how much of the scaffolding in this excerpt is for the father, but in some ways, it is also for the provider. For instance, the resident asked about seeing a dentist to which Samira immediately informed him that there were no such services in a refugee camp; the resident may now understand why the father laughed when he asked the question, which may help with the kind of bi-directional trust discussed in Chapter 4.

During this conversation, as the CHNs often do, Samira had to help patch together a dialogue where her understandings (of families, providers, the healthcare system) were used as resources to effectively guide *both* participants through this exchange and the tensions and uncertainties that emerged in the process. This kind of advocacy work is so important to helping establish trusting relationships between parents and providers, which as the scholarship shows is crucial to delivering quality care (e.g. Colucci et al., 2012; Sheikh-Mohammed et al., 2006). At this clinic, however, it is the children who are the patients, and they have less say or control over how these interactions play out but are most vulnerable to the outcomes. According to the CHNs, it is this reality that makes the work they do during these consultations so important. As Kriti often reminded me—whether during my observations or in interviews, should they not help parents during these interactions (or in other situations), “The kid is going to suffer...it’s our patient.”

Understanding conditions and consequences.

The second incident illustrates yet another way the CHNs guide parents through practices and help them learn by doing. I focus here on how the CHNs often have to help parents understand their children's’ conditions and the ways in which they need to respond in a new cultural context. Like the previous incident, the CHNs are in a position where they had to manage and address some of the tensions between refugee families lived experiences and their parenting practices prior coming to the U.S., and the valued parenting practices embedded in the healthcare system. During an interview with Casey, she talked about an incident where she got very upset with a parent after trying on multiple occasions to get her to bring her children in for medical treatment. She first provided some background information, so I could understand the full story. She told me she was working with a mother and her two children, one of which had a hole in her heart and the other Dr. Day believed had tuberculosis. In both cases, Dr. Day made it clear to Casey that the children were in need of urgent medical attention, and it was Casey’s responsibility to make sure that the mother was aware of and understood her children’s’ conditions, the concerns of the doctor and the actions she needed to take. The problem, however, as Casey communicated to me, was that every time she tried to reach the mother and schedule an appointment for her children, she did not show up or arrived too late to be seen.

As Casey told me the full story, she talked about how she first tried to “fix” or take care of what she could on her end to make sure that the children would be seen, which included scheduling appointments at times that would accommodate the mother’s work schedule and scheduling transportation. In other words, she attempted to eliminate any obstacles that might prevent the mother from physically making it to the clinic. However, this type of advocacy work was insufficient in and of itself. The mother also needed to understand (and find such an understanding compelling) that her children needed to be seen by a doctor. Casey could not force the mother to bring her children to the clinic, but she could guide the mother through the steps she needed to take to understand and address the medical concerns. Casey described what she often would tell the mother:

> Every time I explain to her this situation, they need to see the child. If you don’t do this with this condition, you will see one day, they can come to take your kid, and don’t think it’s me or the doctor, because the doctor must report everything, because this is the situation where they must act now. You cannot wait. If they think the baby has TB they must protect other kids, if she goes to school, they must protect others at school, if your baby doesn’t grow right because of the hole in the heart, they must close that. You need to understand that if this is not...we are not here to play, we are helping you, and if we don’t help you, I don’t think you will get somewhere that can do everything how we are doing this.

This is one example of the kind of rhetorical work the CHNs do and are able to do when they share the same language(s) and know their families. One of the more compelling parts of Casey’ argument was where she talked about the potential consequences of the mothers' inaction—that is her children could be removed from her home. Several of the other CHNs talked about how many of their parents were afraid of their children being taken away from them because of suspected child abuse as they often hear rumors of this happening. In this situation, it may not be clear to the mother that medical neglect is a form of child abuse, and how her inaction could be characterized as neglect, which a provider is mandated to report. Unless the mother was educated on child abuse laws in this country, it is unlikely that she knows this is a possibility. This part of Casey's argument helped to communicate the urgency of the situation. Casey also made sure the mother was aware that the school, too, would likely take action to protect other children should her child have tuberculosis. As I have heard from the CHNs, for many refugee families, education is important and something they tend to want for their children and Casey knows this. She wanted the mother to know that her child's education may be affected by her inaction as well. Finally, she tried to make it clear that if she continued to miss appointments, she may lose her opportunity to seek care at this clinic. The CHNs often talked about how this was something they tried hard to avoid because they know that families will not get the same kind of resources elsewhere.

Unfortunately, Casey's efforts did not pay off in the way she hoped. She told me that one day after speaking with the mother yet again and scheduling an appointment at a convenient time for her, she showed up too late to be seen. It was at this point that she finally spoke with Dr. Day and said:

> I don't know if this mom she understands, because we speak, we share the same language, but I don't think she gets what we are doing here. Maybe

> she needs somebody to explain her more. Because I did all my best and it’s still the same.

Her reflections here suggest that sharing a language does not always guarantee understanding, nor does sharing a similar cultural background. This was frustrating for Casey because she felt she did all she could for this family to make sure the children were able to get the care they need, but none of the desired outcomes she was hoping for happened. When we spoke the mother *still* had not brought her children in and this worried Casey. During my observations, she often expressed worry about some of her families, and this was one of them. I recall another incident where she kept trying to get a mother to the clinic for a circumcision because there is a small window in which physicians will do this procedure, and the mother was about to miss the opportunity. The frustration and worry Casey described feeling was also expressed by the other CHNs, and often under similar circumstances—that is, they felt they tried their best to get a parent to bring their children to the clinic but were unsuccessful.

As another example, Reem described a situation where a mother had brought her son to the clinic on multiple occasions with concerns and complaints about his behavior. The mother expressed to Reem that she did not have time to rest or to take care of her other children because of the demands of this particular child. She talked about how she and Dr. Day had seen first-hand some of the child's behavioral tendencies play out during the medical consultation. She told me:

> I have a mom, her son, it is very clear he is autistic. The last time he is pushing this, hitting this, and he opens drawers, all the drawers. It is very clear he is abnormal, but mom, when the doctor tried to refer them to the Department of

> Developmental Disabilities (DDD), yeah, the mom said, no, I don't want something put on my sons record when he goes to school. I told her, how will he go to school if he's autistic? So, you have to take care of that early when he is still young, because now he is young. But if he grows older it will be more difficult, his case will be developed, and it will be more progressive. She said, 'I will go home, I will discuss that with my husband then I will call you back.' And since that time, she didn't call back.

Like Casey, Reem could not force the mother to have her child assessed, but she could try to help her understand why the doctor believed it was important that the child be assessed. Like Casey, she emphasized school and the importance of getting a diagnosis early so that the necessary resources could be made available for him. Reem told me that despite her many phone calls, the mother never did respond. At the time of the interview, she told me that Dr. Day had recently emailed her about the situation—asking if she had heard anything, but she had nothing to report. This frustrated Reem, especially after all the complaints she had heard from the mother about this child. She felt, much like Casey, that she was doing what she could to advocate for the child and the mother, but none of her efforts seemed to pay off. She explained that sometimes this made her feel like families wanted the CHNs "to do everything" for them without putting in effort themselves.

During my observations, I saw all the CHNs get frustrated at some point at a family that did not seem to be responding in the ways they hoped, particularly in the kind of urgent situations that Casey described. I recall one day speaking with Kriti when she was feeling frustrated by a family. She talked about how so many of her families are uneducated and how they tend to stick with their family and/or village. She told me how difficult it was to work with these families. She mentioned that she often tried to encourage these families (mostly the parents) to go to ESL and parenting classes, but that many of her parents would tell her they did not need any classes or training. “How do you get better if you don’t train?” she asked me. In this situation, she said, many of the kids end up “controlling” the parents and how this was especially true of the mothers. When I asked her why she explained that the mothers she works with tend to think they “need to be behind the men in the house when it comes to the children.” As all of this shows, there are clearly tensions between the parents and the CHNs as well. Sometimes, as Kriti expressed here (as did the other CHNs), they feel powerless and do not want to work with certain families. It can be extremely frustrating to put so much effort into someone, but see nothing come of it, especially when there are no clear answers as to why.

Future Planning: Scaffolding Self-Advocacy

As I discussed in Chapter 4, among the goals of the CHNs is to help families reach a place of independence (or greater independence). One of the ways the CHNs can proactively help families gradually make this shift is by preparing them for interactions and situations where they cannot be present, but where they may need to advocate for themselves and have difficulty doing so. With such priorities in mind, the third way in which the CHNs try to advocate for their families is by planning for the future and coming up with strategies and ways to help families communicate and advocate for themselves when they cannot be with them. This kind of advocacy work reflects forward thinking, unlike when the CHNs are having to react in the immediacy of a moment or crisis and try and “fix” a problem. It also reflects distinct practices and goals as the CHNs consider how they might support communication, interactions and actions without being physically present or even present by phone. This kind of advocacy work usually reflects a response to more global and long-standing problems experienced by families that cross cultures and communities. It may come in the form of education or it might involve coming up with communicative strategies that do not rely exclusively on language and therefore expand upon families' communicative repertoires. In what follows, I highlight three examples of the ways in which CHNs strive to scaffold self-advocacy and help families act and interact when they are not with them. Much like the other two types of advocacy, this work often goes unnoticed and/or undocumented and in some cases, unfinished because there is not enough time.

Connecting with resources and situated learning.

From my interviews and observations, I learned that one of the ways CHNs support refugee families when they cannot be with them is by providing community-based education and connecting families with needed resources in the process. The CHNs provide on-site, situated teaching and learning where families could draw on what they learn to make decisions and take action in particular contexts and in particular situations. The lessons tend to respond to identified exigencies in the CHNs communities and across communities seen at the refugee clinic. In an interview, Angela explained how this work came to be and the exigencies she felt it was responding to:

> I thought of it because first of all, initially, [the director of the clinic] said it's a good idea to give education to the parents like a sort of class...So we try a couple trials, but the issues were notably, and mostly, two issues, transportation and child-care. Because if the mom or the dad was willing to come even if he was

> already about to take the bus, he had a problem where to leave the kids, who to leave the kids with. And second, transportation wise, we can’t request a taxi because it was not a medical visit. So, I came up with suggestions so that instead of the patient coming to us, we go to them in the apartment complexes, which we did.

Here Angela talks about some of the issues that emerged when trying to offer classes at the health center, specifically within the family learning center adjacent to the clinic. However, what she and the team learned was that most families could not make it to the classes because of transportation and child-care. As a result, Angela decided that they should bring lessons *to* families where they live. During an interview, Angela reflected on how effective these classes were:

> And that program was helping a lot because we were not giving education to our patients only who live in the apartment complex, we were calling all the persons...immigrants who are interested in knowing a little bit about the care for a child. We were inviting them. And from there some were interested, and they even said we want to be a part of your clinic, so they were enrolling. The apartment complex managers were also interested because we were giving information which helps the kids get less sick and lowers the number of 9-1-1 calls coming to those apartment complexes. But also, we were asking them is there a health-related topic you want us to address during this conversation. And often they came up with something that had not been able to have the residents understand due to cultural or language barriers. But our CHNs who are doing interpretation at that time during the classes, they were passing the message on.

As Angela recalled, not only did the classes bring refugee families across cultures together for targeted lessons, but they also served as an invitation for others to join in a kind of multicultural and multilingual educational experience. During an interview, Samira echoed the need to deliver education to refugee families at their homes. She explained to me that "If you teach the person at their home, then they will try to make the changes...so I think it's just good to have somebody educating refugees in their home." What Samira described is the ways in which the knowledge passed on during these lessons could more readily applied when the CHNs are not there, since their homes are often where many health-related decisions are made.

As one example of community-based education, I highlight a lesson delivered at a grocery store that several of the CHNs brought up during observations and in interviews. As I would learn, all the CHNs seemed to look back fondly on this experience. Samira shared the most with me across interviews because she found it to be such a memorable experience that she wanted to continue. She explained, "There's a day we went to the store with the doctor to show them all the food, the difference, the good ones, the bad ones. They learned. They were very happy. It was good. And now it's not there. I want it back." As a bit of background, many clinical encounters are spent talking with parents about their children's diets—that is what they are eating, how much they are eating and when they are eating. After establishing diets, which for many families includes "junk food" such as chips, soda, premade meals and fast food, the doctor often talks about adjusting or changing the diet to incorporate "healthier" options such as fruits and vegetables. I often saw Dr. Day give parents a plastic plate with images that indicated the portions for specific food groups (e.g. fruits, protein, dairy)—that is a visual representation of what they *should* be feeding their children. Despite the efforts of the provider to help families adjust their children's' diets, I often saw the same families return without having made any changes (i.e. the child was still over or underweight). The lesson at the grocery store was meant to be one kind of a response to situations such as these and the problems they seemed to represent.

I learned from the CHNs that many families are not able to act on the dietary recommendations of the provider, even if they wanted to. For instance, as Samira described in an interview, many families she works with have no frame of reference for what "eat greens" or eat "more greens" means—a frequent recommendation made during medical visits. She also told me that parents may not be sure *where* to go shopping and purchase items the doctor recommended. These uncertainties can be life-threatening in cases where, for instance, a child has Type 1 Diabetes. During an interview with Kriti she described the many difficulties she experienced working with a family and their child who had Type 1 Diabetes. She recalled the countless conversations she had with both parents about the foods the girl could or could not eat and how it took years to make the kind of progress their daughter needed. But buying food also costs money, and there are so many grocery stores in the greater metropolitan area that knowing where to start (much like the healthcare system) may feel daunting; this may explain why, as the CHNS told me, parents often purchase premade food where and when they can. Thus, physically bringing families to a trusted (by the CHNs) and local grocery store by their homes was an important first step towards connecting with needed resources.

The next step was to help families make connections between what had been suggested and recommended by doctors to items at a grocery store so that families could begin to establish a visual frame of reference for recommendations. As Samira explained:

> Cause some of the fruits we didn’t grow back home. Strawberries, I never saw before. There were many other fruits and veggies...we used to throw them away or give it to the animals, but here it is food. Now we see it in the store. So, when you’re alone you don’t know about it, you’re like skip, skip, and when you see a provider showing you this is good for you, this is good for you and then you’re like, ok let me try it.

As Samira explained, many recommendations made by providers may be culturally specific and may not have meaning to the families that seek care at this clinic. Without helping families make these connections (i.e. between recommendations and actual products), families may continue to “skip” those recommended items. Samira described how helpful it was to have the doctor at the grocery store *with* the support of the CHNs so that they could help make those connections for parents—that is between recommendations and products. However, making these kinds of connections was not all that took place during this lesson as more was needed for parents to act on dietary recommendations.

The CHNs explained that while teaching groups of families in community-based settings (including during field trips to grocery stores) they and the provider responded to questions the families had while exploring the different aisles in the store. Angela explained during observations that while at the store, the provider and the CHNs worked together to delivery personalized lessons for families (since the families represented crossed cultures and languages). Angela also shared photographs of the event with me so that I could see what it looked like. I saw CHNs in isles talking with families and picking up and pointing to objects. There were many smiles. Samira talked more about this during an interview:

> And then they will ask, 'What is this?' I try to tell them oh this is this...or, 'You can eat this?' Well, it's not good for you, but you can eat this. They were like, 'It is a frog?' I'm like no, it's not a frog it's just eggs in a can. You know, just things like that. They had so many questions...There was a skinny boy, he was like, so can I eat this? If I eat this will I get weight? Will I be big? Or is this good for you? How much sugar does this have? The kid was curious, he just wanted to know everything. It was just an awesome experience. I should have written down questions they had.

Samira indicated wishing she had written down the questions families asked because there were so many. And the fact that they had so many questions suggests that there was a need for this lesson and that families were curious and wanted to know more about shopping for food and making "healthier" choices for their children and themselves. The CHNs also went over how to read labels with specific purposes in mind. Often Dr. Day will tell parents to decrease the amount of sugar or salt that they are feeding their children, but parents may not know how to tell how much salt or sugar there is or where to look. During the lesson, the CHNs helped families identify items or ingredients on a label as they discussed, for instance, how much sugar is "too much." In other words, the CHNs demonstrated ways to examine the content of food and what to look for if they wanted to eat "healthy" or respond to medical recommendations. Through this lesson, the families could also see in tangible ways how health and making health-related decisions extends beyond the walls of the clinic and can take place in many domains of social life. What seemed to be so effective and valuable about this experience, according to the CHNs, was how interactive it was (i.e. dialogic), but also how it brought important lessons to those spaces and places where health-related decisions are *actually* made.

Recognizing and responding to bias.

In the following incident I highlight some of the ways in which CHNs recognize and reflect on bias experienced by the families they work with and how they help them to better advocate for themselves, even without speaking English. Recall in Chapter 1 how one of the many challenges refugees face in the context of healthcare is discrimination or discriminatory practices and bias. Bias or discrimination may manifest in different ways like not involving patients in their own care or providing insufficient information with limited options. In an incident Casey described during an interview, she told me about how a parent (though she did indicate this happens other times as well) approached the front desk staff to register her child. She said the mother did not speak English but presented one insurance ID card. The problem, however, was that she did not present *all* the cards of the children scheduled to be seen. When Casey went to check the schedule, she wondered:

> Why didn't they register the other kid? Now he will be late. He's already late...they are already in the room. I tell Dr. Day...there's two there, they didn't register the other one and we must wait to repeat and sometimes I don't know what to do, but I told my patient they do their best.

By not registering all patients, the front desk staff created problems with the overall flow of the clinic since the appointment had been reduced in time. While talking about this incident and reflecting on what happened at the front desk she explained:

> Yeah, some providers okay, but some they don't want to deal with refugees, even if they speak English, they...it's not ignore, but sometime…Okay employee here, they say you are not American, you are refugee, you are from Africa. They just, in their mind they don't think you [refugee] understands what they are saying sometimes. I feel bad if they don't serve my patients as they could.

Here she described what she recognized as one of her families being treated unfairly *because* they were refugees or *because* they did not speak English and may not have been able to stand up for themselves. During an interview Samira echoed some of these concerns. We were talking about some of the ways she has to advocate for her families when working with other providers. She said, "Well, some people, some of the providers, since they think oh this person is somebody illiterate they might say things that can offend them and sometimes it's just that you have to be there and show them this is not how you talk to this person." Being "illiterate," not speaking English and being a refugee were often cited by the CHNs as being reasons why they felt some providers did not treat their families in the ways they believed they deserved. However, the CHNs cannot always be there to identify when this kind of treatment is happening *and* step in to do something about. Thus, the CHNs often look for ways to help families in these kinds of situations as they identify them.

For Casey, after seeing similar incidents play out at the registration desk (i.e. not all children getting registered), she decided to try to do something about it and help her families advocate for themselves when registering their children. She explained:

> I told them, show ID, if two patients, show them the two IDs for your kids, because they don't know how to say first name, last name. Show ID, and that's what they do. And because some situations I know this, I have experience with this, and I have seen this...that's why I know it happens if that person [front desk staff] is there, I know something will happen for my patient...but because I know already, I must be on top of my patient.

Casey's awareness and understanding of the situation helps her to come up with concrete and realistic strategy for parents who may not be able to speak to the front desk staff. In doing so, she explores other modes of communicating; if the parent cannot speak, then what else could they do in this particular encounter to make sure that all their children get registered? To help her increase her families' communicative repertoires in situations like this, she tries to get them in the habit of bringing and showing *all* insurance ID cards of children scheduled for the appointment. If there are two, they need to show two. If there are four, they need to show four. This means they need to be clear on whose card is whose, and which to show. Other issues may come up during this encounter but by encouraging this new practice she is addressing a repeated problem that has visible and tangible effects on the overall operations of the clinic, and the experiences of her patients; it also may make parents more cognizant of their children's' insurance cards and insurance more broadly, which may carry over to other contexts.

The distinction between responses to the encounter reflect two different approaches to healthcare delivery and communication. On the one hand, you have an employee that seems to dismiss what they know and see because they can or think they can—that is they assume the parent does not know what is going on anyway. In other words, *being* a refugee, *being* African, *being* a non-native speaker of English makes some of these families more vulnerable and susceptible to being dismissed and overlooked. On the other hand, you have an employee that goes out of their way to find out what is going on and what she can do to help—like how Samira did with the Burmese mother trying to get home. Casey observed a pattern over time during interactions between front desk staff and her families. Once she felt she understood what was happening, she decided to do something about it so that her patients got the care they needed, and the clinic stayed on schedule (as much as it can). This type of advocacy work often goes unnoticed or undocumented, but as evidenced here plays an important role in the healthcare delivery of refugee families and in the overall ebb and flow of the clinic, which is already difficult to manage.

Learning to draw on social networks as a resource.

Another way that the CHNs have talked about helping families advocate for themselves is by encouraging them to learn when and where to draw on their existing social networks. As I discussed in Chapter 2, in many ways, we are our social networks. While much of the scholarship suggests that refugee families tend to experience social isolation and a lack of social support, according to the CHNs, for the families at this clinic, isolation and lack of support do not characterize all families’ realities. The CHNs also told me how often families are more likely to listen to each other than those they interact with in the medical context—one of the reasons that they frequently mentioned a support group for mothers as a plan for the future. The CHNs are in a unique position to help families make these kinds of connections because of their insider knowledge of families' social networks—including their relatives, friends and neighbors. In this incident, Kriti tried to encourage a parent to draw on her existing social resources to address an ongoing problem where Kriti could not be present—even by phone.

Before exploring what happened, I provide a bit of background to help with context. The incident involved a Burmese mother and her young daughter who has Type I Diabetes. The family had been in the country for around seven years at the time, and Kriti had been working with them since they arrived. Kriti knew the family well—this included where they lived, their relatives, friends and neighbors. Kriti told me that over the years, and since the daughter was diagnosed with Type 1 Diabetes, the mother continued to have difficulty with the pharmacy and making sure her daughter had the insulin she needed. She explained that the mother did not speak much English but continued to go the pharmacy on her own to refill or pick up prescriptions. Every time, it seemed, there was a problem. During an interview, Kriti described the most recent incident with the mother at the pharmacy:

> Ok this is the last one she went to the pharmacy. The pharmacy explain to her, it's not ready, or come back two days. And she calls me, 'The pharmacy told me they cannot give me, what happened? You need to call the pharmacy, you have to call the doctor.' Ok, hold on, so which pharmacy? The same pharmacy? Okay so you have a problem last time? What did they tell you? 'I don't know, maybe the doctor didn't send prescription.' No, there was a bunch of refills, the doctor went

> to make sure he always have more refill, that's why we say before a week, before she run out you have to go get medication, so you don't need to be frustrated like this. She said, 'today is the last day. I don't have medication to give her tomorrow. They didn't give me, they said they need a doctor's' note or something.' And I went here, the nurses and I explain to this parent...the nurse call to the pharmacy, and the pharmacy said, no I told her come back tomorrow, we're not ready right now.

Kriti recalls a difficult conversation she had with this mother where she tried to establish what was happening. Her memory of the incident suggests that the mother was unclear about why she could not get her prescription when she needed it. Regardless of what actually happened and why the mother was having difficulty, there was clearly miscommunication between the mother and the pharmacy and also between the mother and the CHN. After getting many of these kinds of phone calls from this mother Kriti finally decided to do something to help her communicate in her absence. She described to me what she told the mother:

> I explain to her, if you go to the pharmacy you have to...they have been here like...if they are just new arrival, I accept that they have a problem. They have been here more than seven years, and I know this family because I have followed up since she [the daughter] was admitted. Home visits a lot of times. I knew the family well now. I knew who speak English in their house. I told her take your brother, they finish high school, or your sister. Go with them to pharmacy. One time and then you can understand well.

Here, Kriti demonstrates that she knows this family. She has worked with them for years—seven to be precise. And it is this amount of time that tells her that she should be able to do this on her own. She also knows who the family members know and who they interact with. She knows who speaks English and who has gone to school here in the U.S. and might be a valuable resource during these exchanges. She suggested to the mother that she take one of her family members with her—even if it is just one time to help her communicate and learn how to better approach refilling her daughter's prescription. This strategy is one way for the woman to draw on her existing social resources to help her when Kriti cannot be present.

Unfortunately, for whatever reason, the mother refused to take a family member with her to the pharmacy. After hearing this, Kriti became quite frustrated and communicated some of her feelings during our third interview:

> Sometimes, we really want to help you, it's for your kids. You need to take action too, you cannot sit down. You have to find a way for your kids. It's really needed. You have to find somebody who can take you there. That's why sometimes I'm really frustrated. Like sometimes I'm frustrated. I really want to help you, but you have to take action too, not only me. I'm trying to hook everything together, but you need to, how do you say? You need to pay for your kids too, you need to move forward. You cannot just sit home and call, 'Kriti, no medication.'

What seems to frustrate Kriti most is that she feels like she is the only one trying to help this child. She talked about how parents in general (though she was focused on this mother) need to take action for their children as well, not just her. They need to, as she put it, "pay for their kids" and to "move forward" rather than sitting home and calling her for help. The frustration Kriti expressed when reflecting on this particular incident resonates with similar reflections from other CHNs. For instance, Casey often talked about feeling as though families thought there was no expiration date to the support she offered. She explained, “In their mind they think it’s my responsibility to do everything for them, but every time I explain to them I’m here to help you, I will not be there forever.” And it is this final point that Casey makes that is important; the CHNs cannot always be around and available to help. Kriti knows this and tried to offer a possible solution; it did not work out and Kriti never did find out why, which characterizes many outcomes at this clinic.

The above examples examined in this section show that the CHNs cannot always be there for and with their families and how part of their job is to come up with communicative strategies to help families advocate and communicate when they are on their own (without CHNs or health care providers nearby). As I described in Chapter 4, the team has a number of projects they are currently working on that are aimed at helping families communicate without them. During observations, Angela described several of these projects—both as considerations and as works in progress. For instance, they are working on putting together visual representation of the front-desk registration prompts (see Appendix I). Angela also indicated that they are thinking of creating YouTube videos for parents without phones—one of which would be about how to measure formula correctly. It is very clear that they have communication and their families on their minds, but also their own limitations. As this section in particular has shown, the CHNs know that health-related decisions, interactions and activities do not take place exclusively within the clinical context. They also understand that a variety of social factors and contexts may shape experiences of health and literacy for refugee families, and they consider the work they do to support families' capacities to "communicate" and act without them just as important as what they do to help families in the clinic and during their visits where they are present.

Discussion

This chapter explored and examined three types of advocacy work the CHNs are involved in and under what circumstances (or in what contexts) it occurs. By doing so, I illuminated some of the dimensions of the context—or what Flower (2003) might call the "force field"—in which the CHNs operate and some the "contradictory agendas and conflicting voices" (Flower, 2003, p. 64) they have to navigate and negotiate on a regular basis. As my analysis throughout Chapters 4 and 5 shows, the CHNs tend to serve as valued and trusted linguistic and cultural resources that help families take part in practices that are needed to gain access to healthcare and by engaging in those practices, at times, for them. The example incidents in this chapter also demonstrate the ways in which the CHNs insider knowledge of their families enables them to see and hear things that other health professionals may not. As Kriti put it, they can more readily see the connections between their patients' health and the social complexities of their lives and how all of these factors may influence their experiences with health, literacy and access to healthcare. Sometimes, however, as we also saw, this may make it more difficult for them to "ignore" certain things they see or hear because they know it is often the children who will "suffer" or face the consequences. Subsequently, they may take on responsibilities that leave them feeling stretched beyond their capabilities and sacrifice learning opportunities for their families (e.g., helping with health insurance). This chapter also captures some of the tensions that the CHNs have to navigate on a regular basis in multiple languages, and the ways in which they often open up lines of communication and information sharing about health, healthcare and refugee experiences and realities in ways that *help providers and parents communicate more effectively*. We also get a sense of how important it is to the CHNs that they help their families communicate and self-advocate when they cannot be present and how they often consider ways to support families in this capacity.

CHAPTER SIX

COMING TOGETHER: INTECULTURAL INQUIRY WITH THE CULTURAL HEALTH NAVIGATORS

This chapter, in contrast to the previous two, invites you to look through the eyes of the CHNs as they make sense of and respond to three data-driven scenes. The three scenes include critical elements of incidents analyzed in Chapter 5 that were rendered critical through my analysis and interpretive work. Following the categories presented in Chapter 5, each composite captures one of three kinds of advocacy work which include "fixing" or taking care of something for families, guided practice and learning by doing, and future planning/scaffolding advocacy. The goal of bringing these scenes to the group was to support a broader engagement with them so that together we could begin to unpack what might be problematic or vexing about them. The CHNs were invited to read through and perform the three scenes during the group conversation by acting out roles in the scenes. While engaged in this activity, we periodically paused in order to reflect on the events that were unfolding at the time.

In this chapter, I examine the reflections, insights, and questions that emerged during the group conversation I had with the CHNs, and how our interactions and dialogue expanded and challenged our individual and collective understandings of the situated, context-dependent nature of their advocacy work. While acting out the composites and making sense of specific events/situations/challenges within them, we discussed some of difficulties and successes they encounter as well as the feelings (e.g., of frustration, sadness, curiosity, joy) that emerged, what decisions were made and why, and the way that their own lived experiences seemed to inform their practices and choices. In these ways, the group conversation provided an opportunity to make more explicit not only what priorities seem to influence the choices that CHNs make in particular unforeseen moments of situated practice but also the consequences of those choices for the health and well-being of the families they serve.

The primary goal of this chapter is to render more visible the processes by which situated practice is informed by experiential knowledge, and I explore the multiple ways that CHNs attention to locally relevant factors informs and influences the relationship between the two (knowledge and practice). Thus, building on the analysis of three different kinds of advocacy work provided in Chapter 5, this chapter describes and analyzes the ways that CHNs make sense of and value the choices they make in situated moments of interaction with families—moments characterized by uncertainty, ambiguity and complexity. By collaboratively examining the practices of the CHNs and the kinds of advocacy work they do, we jointly make sense of what they know, how they know it, and the ways that knowledge influences the care they provide to families with refugee children over time and across contexts (e.g., in the clinical setting, at the pharmacy, at home, in the community).

Scene One: Decisions, Decisions and Contradictions

During interviews and informal conversations with the CHNs they often talked about having to do work that they felt was outside the scope of their responsibilities, including activities and interactions they felt they should not have to facilitate (e.g. applying for health insurance, enrolling children in school, helping with domestic disputes). However, as the analysis provided here will highlight, drawing professional boundaries is not always easy for the CHNs, in large part because they have worked with the same families before and already know some of the challenges facing them. As I mention in Chapter 5, helping with insurance-related matters is not a responsibility the CHNs want to take on or feel that they should but nevertheless often demands their attention (and intervention). Confusion about whether a family has health insurance and/or how to use it often becomes a source of frustration for both families and the CHNs. As I observed and heard from the CHNs, parents tend to find out their child's insurance is inactive if the CHN is able to catch it beforehand while making transportation arrangements, or when they arrive at the clinic and try to register their child for a visit. When they find out that the insurance is inactive at the clinic, many parents seem confused about what they are being told, what action they are supposed to take or why action is even necessary. This creates uncertainty, often coupled with anxiety that their child needs to be seen soon, which usually influences parents to call the CHNs for help and/or support. It is in these moments that the CHNs often need to make difficult decisions as to how they will respond. The decisions are difficult because they often feel there is a need to respond, but doing so requires that they engage in activities that they have been discouraged from engaging in. The first scene is a composite of what I learned about how CHNs typically respond to such challenges from my observations of and interactions with them over time.

Several questions that emerged from my observations of CHNs practices and my conversations with them about those observations helped guide the writing of the scene and the focus of the conversation. For instance, I often wondered why many families showed up with no knowledge of their child's' health insurance status? I also wondered how and under what circumstances the CHNs decide to help with insurance-related matters despite it not being their responsibility? What factors and/or understandings influence their decisions? Finally, what do their decisions suggest about their underlying priorities and principles as CHNs? In what follows, my analysis of key moments of dialogue that emerged during the group conversation shows some of the ways that the CHNs make sense of what is happening in the scene as it unfolds, the decisions they make in the moment, and why they think those decisions are the best ones to make under the circumstances. By exploring the CHNs decision-making processes, the analysis provides a window into the situated ways that the CHNs draw on professional and experiential knowledge in moments of contradiction and uncertainty to the benefit of the families (and providers) they serve. To show how the CHNs make sense of what is happening as the scene unfolds, I explore the insights and theories elicited during our conversation (as the logics behind the kinds of decisions made) and consider the factors that the CHNs believe influence the practices and logics identified. This analysis reveals some of the ways that the CHNs knowledge, understandings and principles inform their practice, and how their lived experiences become interpretive resources for examining the larger problem this scene may represent.

Interactions and outcomes.

The scene begins with a mother approaching the front desk. She hands a couple health insurance ID cards to the front desk staff as the CHNs often tell them to do. The mother is informed that her insurance is inactive (who or which of her children is not clear) and that she needs insurance for the appointment. While the front desk staff repeats this information, nothing else is communicated to the parent. It also seems that the parent may not fully understand what is going on. In light of this information, the CHNs collectively try to determine what might be happening and why. Their observations and insights reflect shared and distinct understandings and theories that reflect problems and dilemmas inside and outside of the clinic.

When I first paused the enacting of the scene (i.e. after the mom finds out about her child's' insurance), a few of the CHNs focused on the interaction between the parent and the front desk staff. Samira pointed out that the mom did not seem to understand what was happening. Kriti noted that the front desk staff did not ask which language the parent spoke; Casey added that she did not greet her or ask how she could help her; and Reem wondered whether or not she asked the names of the woman's children. The observations and critique of this exchange emphasize how important interactions are on the path to care in the shaping of understandings and outcomes. Front desk staff are among the many gatekeepers of healthcare; their actions and interactions with patients and families are important, and the CHNs' questions and observations reflect this understanding. The CHNs know how important it is to establish the preferred language of patients so that they get the communicative resources they need. The CHNs also emphasize the need for a greeting, suggesting the importance of humanizing interactions for refugee families. Finally, the front desk staff does not ask the parent the names of her children, which the CHNs know is a valuable way to communicate in the absence of a shared language. Without seeking clarification by verifying the names of the patients, it may not be entirely clear to the mother who among her children does not have insurance, or if she even has shown the right ID cards. The lack of information communicated and generated during this exchange seemed to create additional work for the CHNs as they tried to figure out what was happening and why.

Reflecting further on this initial interaction, Reem reminded the group of the system they have in place for scheduling transportation and how this is often where they catch health insurance terminations or inactivity. Angela expanded upon this:

> Yeah, but. I think this is precisely for those that do not need our support with transportation cause there's different levels of need. So, when they don't...they may have received the letter, because [Medicare/Medicaid agency] send them a letter to remind them it's time for renewal and they may have this because they don't know the content.

Angela's comment shows that the CHNs recognize that even with this arrangement in place, there are needs that their current system is not meeting. There are different "levels" of need as families become increasingly independent. In the scene we were reading and discussing, the family seems to have fallen in between the cracks. Although the mother may no longer need transportation, this does not mean she no longer needs other kinds of support. As Angela pointed out, since families are often informed of their insurance status via mail, if the parents cannot read the document then they have no way of knowing that their child's insurance has been terminated, especially if they are still in the process of learning about how insurance works here in the U.S. The ways in which the CHNs attend to the specifics of the situation meets a number of needs of the families they work with but does not meet the needs of all the families that use the pediatrics clinic. For families that are able to get to the clinic on their own without the CHNs support, it is more difficult to catch or know if their child’s insurance is active for scheduled appointments, and this can create unexpected challenges for the CHNs at the clinic.

While trying to make sense out of and figure out what factors might have contributed to the situation this mother found herself in, the CHNs also considered factors outside of the clinic. As they discussed the cards the mother shared and the interaction between the parent and front desk staff, Angela pointed out that sometimes a patient may have multiple Medical Record Numbers (MRNs), and “what happens is just one letter change the health plan may think maybe it’s a new patient, a different patient and assign him an ID.” She explained that many of the names of the refugee patients at this clinic are unfamiliar to those outside of their cultural group(s), and just one misspelled name may result in health insurance policy changes or duplicates that fragment a patient's insurance plan or create plans for patients that do not actually exist. Complications also may arise when patients first and last names are similar to those of another family member. Angela recounted a story where a grandfather and grandson had the same first and last names but in reverse, and both had an appointment on the same day. Angela began the retelling of this story by saying, “Oh this reminds me of a case we had downstairs. It was a really hard one.” She continued to describe what happened:

> So, the taxi came, called both names. The grandpa goes in the taxi and comes here. The lady, the one that works downstairs at the front desk said I don’t have this patient enrolled. And after we checked and went through all this, we realized, how come grandpa came? And he was showing his ID and we realized that was the mix up.

In other words, the CHNs know that sometimes agencies and individuals they work with have difficulty with some of their patient’s names; but they also know that many of the families they work with may be indifferent to the last name and first name distinction, as this does not have meaning for them in their cultures.

While reflecting on the challenges the situation evoked in the scene, the CHNs also talked about policy and/or insurance company changes, and their efforts to make sense of this seemed to contribute to tension and disagreement among the CHNs as they tried to explain the main cause of this problem. Casey indicated she had experienced situations where a member’s policy number changed. The other CHNs, based on their experiences, asserted that this was not possible. However, rather than continue to insist that Casey was wrong, the other CHNs tried to figure out when or how this might happen by asking questions (which they often do). For instance, Kriti asked Casey whether the child or children she was referring to had special care needs. This question demonstrates Kriti’s knowledge of the potential for policy changes in these cases—and her willingness to pass along such knowledge to her colleague Casey. Samira suggested that sometimes when changing plans, the insurance company may accidently give the family that states’ Emergency Medicare/Medicaid insurance (i.e. temporary), which could result in two policy numbers. While the discussion did not result in any confirmation of anyone’s claims, it did generate a number of possible explanations while revealing several discrepancies in their understandings of insurance policies, and potential gaps in their knowledge.

Another interpretation that emerged during the group's conversation about this scene was that there may have been a delay in activation or reactivation of the insurance plan. While [re]activation happens quickly, other times it may take weeks or even a month before the new plan(s) show up in the system. This is to say that even if the family or parent did apply, it may seem as if they did not. Several of the CHNs recalled the discomfort they feel when they have to question families about whether or not they applied, even after they said they did. As Angela recalled:

> One day I was kind of upset and I talked to the person in [insurance agency] in like an upset way. I say, I don't understand. So, would this mean that my patient is not telling the truth? Because she says that she applied two weeks ago? And he said, when I go into the system, the patient is right, they applied, but it takes some time to process.

Angela's comments demonstrate her awareness of the potential for delays (perhaps as a result of her professional experiences as a CHN but also perhaps as a result of her personal experiences trying to navigate the healthcare system) as well as a willingness to investigate other avenues for inquiry before making any conclusions or assumptions. According to my observations and interviews, this stands in contrast to what other health professionals might do. As Kriti described during an interview, "So sometimes if you don't understand refugee people, the provider might get mad easily. 'Why this patient not listen to me? Why this patient didn't come to their appointment? It will be a lot of questions. Why, why, why?" In other words, providers may rush to conclusions without accounting for the full ecology of the refugee experience with the healthcare system.

CHNs are hesitant to make assumptions too quickly; if they were to immediately assume a family was lying, they may jeopardize their already fragile relationship and risk losing the family altogether—a concern that permeates their work.

Before making a decision and/determining the appropriate response to a situation, the CHNs tend to go through their own inquiry and/or assessment process which usually involves listening to and drawing on their multiple experiences (professional and personal) as resources. As demonstrated by the examples shared here, they often work through this process on their own, but during this group performance and conversation, they were doing so collectively. Many of the thoughts and questions and possibilities that may go through their minds as they process information and determine the appropriate response or action were rendered more visible (to me and to them) through the group conversation. As the scene continued to unfold and we paused at critical moments, the CHNs tried to make sense of what was going on together by listening closely to one another, exploring possibilities and asking questions.

Making decisions.

After we talked through the possible reasons why the family had difficulty with their insurance being processed when they arrived at the clinic, we reached a place in the scene where the mother asked for help from a CHN. Again, we paused our re-enactment of the scene to discuss what was going on and what sense they were making of the situation. I asked them to think about what they might do in this situation and why. All acknowledged that helping with health insurance was not among their responsibilities and yet not all of their responses reflected this delineation. In this section, I analyze three of the CHNs responses to this hypothetical situation in order to highlight the different kinds of considerations that influence their decisions about how to respond. I not only explore the logic(s) that they CHNs said were behind the decisions made, I also discuss the factors that seemed to influence such logics. I begin with Kriti's response (which was similar to Reem's) as she was the first to tell us all what she would do and why, which helped initiate an important dialogue:

> Because this insurance...if the insurance is not active, they need to be seen, the kids need to be seen. So, it is a sick visit, okay, if they apply today we told them, from my experience, you have to go today to Department of Economic Security, so it will be covered by today's date if they be seen. So, we're gonna see her today but you have to go after the visit, you have to go to DES office and apply the insurance. So, then she's [like] I don't know how to fill out the forms and so we went there to get the application form and fill out with her, everything and then I give it to her. Or sometime if they're not too busy I took them over there. If they're [DES] busy over there, then just take this one to your closest DES office...so it will be covered by today's date.

Much like many of the "fix it" responses examined in Chapter 5, Kriti wanted to address the situation immediately *for* the family, which involved bringing them to where they needed to go, acquiring the necessary paperwork and essentially filling out that paperwork for them. In addition, Kriti pointed out that she knows from experience that if she does not address the issue immediately that, "it will take forever to get back the insurance" for her families as they may not take action themselves. Ultimately, what seemed to be most important to Kriti was the children; if they needed to be seen, she would draw on whatever knowledge she has to engage in practices that would increase the chances that this would happen. Her response generated questions and comments from the other CHNs in the room. First, Angela asked, “How do you do that? It’s a huge form and they ask about income. Cause you have to fill that out.” In response, Kriti said she calls the husband to obtain income information. Samira then asked, “But what if the family does not bring or have the necessary paperwork?” At this point, Kriti acknowledged that, yes, often families do not bring in all the necessary documents but “the important thing is they have to go and apply by today’s date, so it will cover the visit.” When Samira responded saying they do not accept incomplete applications, Kriti said this is not her experience; she explained that if more information is required they contact the family, but they will accept an incomplete application. During this exchange and again later, while listening to the recording, I found myself wondering why Kriti chose to respond with so much passion/conviction, why the other CHNs had different ways of viewing the situation at hand, and how this variation might influence refugee families’ access to health care?

Kriti’s responses indicate that she chose to respond to this particular situation based on the time she has available, her understanding that it would likely take the family much more time to complete the paperwork (based on her past experiences as a CHNs), and the circumstances of the visit (i.e. the child is very sick and needs to be seen as soon as possible). Somewhere along the way she learned that in order to avoid a situation where the family receives a bill for the care, a patient must fill out the application the day of the appointment. She said she also understood that incomplete applications are accepted.

Casey, on the other hand, responded quite differently. When we arrived at the place in the scene where the CHNs were called upon to make a decision, and after the group had engaged in a dialogue about Kriti's response, Casey offered hers. Unlike Kriti, Casey' response (which resonated with Samira's'), is much less involved:

> For me, I do not have time to help them. To help them is to remind them of the appointment, if it is not active to remind them to go to apply but I'm not responsible to go to apply for them cause when it comes to food stamps they don't call me to go help them. How they fill the paper? Because they see that food stamp is important than to get insurance.

Based on my observations and what I know of Casey and her work, she is perhaps the busiest of the CHNs and sees the largest number of patients. Sometimes she cannot get to them all and providers must resort to using the language line. Thus, for her, availability and time almost always influence her decision-making. In this firm response, we see that Casey is interested in establishing boundaries with her families—boundaries that Kriti has not established. In her mind, to help her patients is to remind them of their appointments and let them know (if she catches it) to apply or reapply. She does not ignore the issue, but she is far less hands-on than Kriti and leaves it to her families to figure it out on their own. But her response is also grounded in her understanding of the application process as well. Casey has made a connection between the application for health insurance and food stamps. The forms that families must fill out in order to receive food stamps is the same benefits application form for health insurance. Casey's observation that families' do not seem to need help or reminding when it comes to filling out the same application for food stamps adds something else for the CHNs to consider together, and this is what we did together next.

For a moment the CHNs were quiet as if they had not considered this before; they seemed to wonder alongside Casey how families fill out the same application for food stamps but do not seem to be able to do so when it comes to filling out forms needed to process insurance. And yet, instead of jumping to conclusions about the families they work with (e.g. they are lazy, they don't care about insurance), the CHNs try to figure out why this may be happening. Yes, like Casey seemed to imply, it could be that families view food stamps as more important; but it could also be, as Kriti observed, because the application for food stamps is required every six months, whereas health insurance is every year. The lengthy gap may explain why families may not *remember* to apply; however, the time difference still fails to account for how some families are able to *fill out* the same form for food stamps, but not health insurance. The question Casey posed for the group remained unanswered during the conversation but may be a valuable question to pursue. Overall, like Kriti, Casey based her decision on her understandings of the application process for benefits, but also her limited availability and the need to establish professional boundaries. This is where Angela decided to share what she would do in this situation. Her response, in contrast to the other two, is more about creating and delivering a compelling and informative message to her audience with the goal of preventing the situation from happening in the future:

> But coming back to the group Casey and I were talking about, we give them the information. When we are together explaining it is their responsibility to go to DES and apply, try to do it tomorrow or in the next few days so that this visit is

> covered, but we don’t leave them pending neither. Like three days after or four days we call and say did you go to DES. And some will tell you, yes I went, and some will tell you they have different reasons, valid or not valid, not to have gone and you keep reminding and encouraging and go fill out the paperwork at the DES and in general they do it because they understand they don’t want the bill going to their home. It’s like a negative incentive but, yeah, and actually there’s something else we tell them... it’s about emergency. Because we tell them if you don’t have active [Medicare/Medicaid] and you run into an emergency, because emergencies you can’t predict them, this bill of the clinic is maybe a hundred or so, we don’t know how much because we don’t go into billing, but the emergency visit will be hundreds and sometimes a thousand, we don't want it to happen because you just didn’t take time. We know that you have to go early, you line up sometimes the whole day, but it is worth it.

While Kriti’s and Casey’s responses were more reactive to the immediate situation, Angela’s represents a more proactive stance. Her decision and response came after Kriti and Casey—both of which generated an important discussion about the application process and billing concerns for families (which all the CHNs share). Like Casey, Angela emphasized the fact that families should learn to go to DES to apply for health insurance—and she would assist families by encouraging them to do so. In addition, Angela *also* would try to help families understand *why* applying for and having insurance is important and why they should get into the habit of doing it themselves. In other words, using Angela’s terminology, she would try to “incentivize” the need for health insurance and therefore filling out the necessary applications in a timely fashion. To do so, she draws on some commonly used tropes like the unpredictable nature of emergencies and the potential for getting stuck with a very large bill. By trying to incentivize the *need* for health insurance, she seems to be seeking more ongoing and lasting changes in habits and understandings among the families she works with so that situations like this are less likely to happen in the future.

At no point did the CHNs try to argue that any one of their decisions was the "right" decision. However, while there may not be a "right" decision, there is value to be found in each of the decisions made. Consider Casey's response, for instance. To some, her "I do not have time to help" may be taken as cold and dismissive. To others it may speak to her realities as the most in demand CHN; she can't do everything. What she *is* doing is attempting to establish professional boundaries, which is something some of the other CHNs seem to struggle with, especially with health insurance related issues. Kriti, for instance, talked about boundaries during the third interview when thinking of advice she would tell a new CHN. While this was something she still admitted struggling with she explained that:

> You can limit your time because from my experience, in the beginning, I just want to help. I just answer my phone, even night time, or morning, early morning. I just wake up and pick up the phone. But you have to limit for yourself too. But that the thing I learned from my experience. You have to limit your time.

And so, despite making some adjustments over the years to help "limit" her time, there is still something for Kriti to possibly learn from Casey and her approach to situations like these. Kriti's response, too, is valuable. She decided to address the issue immediately.

She helped take care of the application process for the family so that they would not be billed, and their child could be seen by a doctor. While her response may not seem to demonstrate forward thinking, she is making sure the child has access to care and the family is encouraged to keep coming to the clinic. Angela, too, offers a valuable response. She presented an incentivizing message that she often delivers to families in order to help with understandings that might prevent situations like this from happening in the future. Again, the point of the conversation did not seem to be about establishing the “right” response, but rather, using the conversation as an opportunity to share information--including what they would do and why while also trying to understand each other’s decisions and perspectives which generated a number of questions and anchors for further inquiry. In sum, each of their decisions seemed to be influenced by their own personal and professional experiences. While no one response was agreed upon as “the response,” the CHNs were able to share different approaches, understandings and considerations that could be used as resources in the future.

Scene Two: Navigating the Exam Room

The next scene takes us inside an exam room—to an intimate experience between a doctor and parent(s) but where the children are the focus. The scene begins with a narration of what the CHN can see in the room. There is a mother and her two children. The children are playing loudly, making it difficult to hear the provider; the mother does not speak English, but the children do; the CHN has known this family for years and they are there for a follow-up visit concerning the children's weight; this has been an ongoing concern that the mother verbalized understanding and said she would address, but has not. The scene opens with the provider discussing the children's' diet with the mother as they often do.

In contrast to the previous scene, I was most interested in their ideas and perspectives on the possible stories behind this story in order to generate a more robust understanding of the situation or potential problem(s) it may represent. Much like the previous scene, the elements of this scene emerged from the data and coding of critical incidents and my analysis in Chapter 5. In what follows, I focus on three central aspects of the scene that got traction when I asked the CHNs to help enact and discuss the scene. By noticing what they seemed to find interesting and/or perplexing, and then pausing and asking for their interpretations and theories about what they could see and hear, I was able to shed light on what might be hidden or behind the scenes. It was in this scene in particular that their distinct and shared perspectives and understandings helped generate a more complex rendering of the incident that could prove useful in other contexts.

Interpreting parent responses and actions.

According to the CHNs, looking and being “healthy” is not the same for everyone, nor is being “overweight.” As Angela explained to the group, when some parents are told that their children are “overweight” during the doctor’s visit, they may not agree with this assessment:

> The other thing...the parents are advised not to buy those chips and sodas period so if the parents keep buying them...cause I don’t know if this is the chips from school which kind of cause them gaining weight cause you just have that ...so it means the parents...some parents from the perspective like we were talking, Casey, in our culture….that’s a chubby child is a sign of health...and the parents

> will say without telling the doctor he will say my child is healthy, I don’t want a skinny bony child.

Because Angela knows that parents are told time and time again not to give their children chips, soda, juice or other “junk food”—she believes that they may not consider the child's’ weight a problem. As she pointed out, for the families that she and Casey work, with being “chubby” may be a sign of good health; as Angela pointed out, these families “don’t want a skinny bony child.” Thus, it may be that the mother heard and understood the concern, but did not agree and therefore, did not feel compelled to respond. Reem, too, provided one such example with a father and his two children. When asked about the portions he was feeding his children during a medical visit, he responded with, “What are you talking about?” He then explained to Reem that his children eat what they want to eat and stop when they are done; there are no specific portions as food is not regulated in this way. Angela and Reem suggest that perhaps there are different cultural logics colliding in this exchange, and this may explain why the mother has not responded or embraced the advice provided during previous visits to the clinic.

After Reem shared the above example, Angela shared another possibility stemming from her personal experiences as a refugee herself as well as her knowledge of refugee families’ experiences in the camps:

> And one of the reasons could be...but maybe not necessary...one of the reasons, and I would understand perfectly, it makes me even emotional. You see, you’ve been living in refugee camps in deprivation, seriously, that’s being deprived of those good luxury things, they don’t have. I was looking one day on the internet, refugee camps where the people had to do a kind of strike because they went to

> office of UNHCR in the refugee camp...they say we don’t have enough food, which is true, and UNHCR just relies on what the different developed donor countries give, and if they don’t get enough they have to cut the ratio...no not ratio, maybe the portions they have to give to the families, so having your kids coming here, and having plenty of possibilities of food. I think psychologically for the parents it’s also hard to say, no I don’t give you this. Because as a parent, you was always living, if I could have more to give to my kids so that they feel good like other kids are, and some have been in refugee….when they had lived a very good life in their country of origin, some have been even in high government positions, or business positions but they lost everything.

As Angela described, many refugee families that come to this clinic have lived in camps for years where there were few resources (including food), and this may contribute to malnutrition when they enter the U.S. and subsequently a lack of restraint when it comes to the many high-calorie or high-fat foods they encounter after arriving in the U.S. Knowing this, Angela suggested that when they arrive, they may see they have more options than they once had and they no longer have to rely on others for daily for rations. As I discussed in Chapter 5, the plethora of options for buying food may be overwhelming at first, and parents may not know what to do with all the choices. When considering the experiences in the camps, some parents, as Angela noted, may find it psychologically challenging to say “no” to their children. They feel good being able to provide more; now they can do what they were unable to do for years and in some cases decades.

Reem, too, agreed with Angela. She added that, “When they came here they buy all these candies and they just feel happy they are giving these things, because I know for many Iraqi people before the war there were many economic sanctions, so all these important things were not available.” While candy and soda may be considered “junk food” by medical culture, and a commodity that is easy to come by, for many of these families’ items like chips and soda and candy represent all the things their children did not have growing up. Thus, refugee parents may be less concerned about what foods are “good” or “bad” for their children. This may be especially true for families that have just arrived in the U.S. As Reem explained, “So when they come here they are drinking soda as if it is water, then after that when they saw the doctors and they saw the bad effects of these sodas they stopped buying it, but in the beginning, they are so happy with that.” According to Reem, some families may begin by saying “yes” to just about everything because they can but will eventually adjust their children's’ diets over time as they learn more. Here the CHNs highlight the importance of being aware of where refugee families are coming from and what kinds of experiences they may have had that might impact choices made here in the U.S. By doing so they show how they not only apply what they know from past experiences (professional and personal), but also how they seem to learn from one another during certain moments in the conversation which this literate practice made possible.

The CHNs also talked about how families tend to receive mixed messages from healthcare providers and government agencies that provide nutrition assistance on what to feed their children, and it often falls on the CHNs to help parents make sense of what at times seem like contradictory recommendations. Casey pointed out how often families are told not to give their children *chips, soda* or *juice* by the doctor; and while soda and chips may make sense to some families, often they do not fully understand why they should not be giving their children *juice.* Many if not all of the refugee families seeking care at this clinic are enrolled in the states' Women, Infant and Children's (WIC) nutrition program, where they get eWIC cards they can use at specific locations to buy certain food products. When looking at the WIC programs' food list, however, there are number of specific kinds of juices listed. Refugee parents (like other parents) often buy juice because they believe it has nutritional value. Yet, when they come to the doctor's office, they are told that, "soda and juice are the same" and that they are both high in sugar and offer little nutritional value and should not be purchased for their children. This comes as a surprise to many parents, including refugee parents.

Kriti described similar experiences with mixed messages and/or understandings with her families regarding food:

> Most of my patients they say no chip at home. Okay, so the doctor say no chip, but the baby still the same. But they say, I didn't give chip at all and then like five minutes the kids pull the mom's bag and here was a lot of chips, not from here, from my country. And then she said, no this is not chip, it is from Asian store. They thought all of the Asian stores, all the things at the Asian stores are healthy. The doctor check. No, it is exactly like here. He read everything to them. It is not good.

In the example, the family was under the impression that because they purchased items at an Asian store that they were therefore healthier than food in U.S. However, during the medical visit, the doctor and Kriti took a closer look at the items and their labels and learned that they were similar to the kinds of junk food the doctor recommends not feeding children. Kriti recalled how surprised the parents were to discover this and how she had to explain that buying items at certain ethnic stores does not mean they are healthier. She also indicated that she had to emphasize how important it is to read the labels of food products, which is not always something parents can do. Both Casey and Kriti demonstrate their awareness of some of the mixed messages and recommendations their families may be encountering when buying food in the U.S. and how it may impact children’s health. While they do not always have time to go over how to read labels (which is something they did during the grocery store visit), they can help families make sense of what they are hearing so that they can at as more informed consumers.

Interpreting silence.

After the CHNs discussed some of the possible reasons behind the mother's’ response to the doctors’ concern, I noticed the CHNs wanted to share ideas about her response to her children's behavior in the room. The CHNs focused on how the children were making noise, opening up drawers, crawling around the floor and playing with any objects they could get their hands on. The mother in the scene, they thought, remained quiet and did not say anything to her children. As a collective, we wondered what might explain her silence. According to the CHNs, there are several possible explanations for silence in this context.

According to a couple of the CHNs, the mother’s noticed quiet may have to do with the family members’ experiences in the refugee camps. Angela, for instance, commented on how the lack of structure in the camps can impact parenting practices and attitudes that have been carried over to the U.S.:

> I would say maybe the parents may be trying but some are kind of…I wouldn't say lenient, like let things be whatever they are. And sometimes I think of it too...to understand how they were living in the refugee camps. And I see in the refugee camp, there was, I want to say discipline but that is not the word. I mean put order with the kid...the child wakes up in the morning. The parents, you have no plans, you have nothing to do, the whole year. So, it's not like you are...again, I don't want to use strong words, but when you are a family in [a city in Burundi] you wake up this time, you get up for school or like me the way I grew up mom was waking me up...first you go get that bucket, go fetch water and then you arrive, you get ready, I have already packed your lunch and you go, so it's kind of organized, but in the refugee camps.

Here Angela suggested that because of the lack of structure, parents may "let things be whatever they are" because they may not have had to *be* anything in particular while living in the refugee camps. From their home visits, the CHNs know that when refugee families arrive in the U.S., they often continue to live as they did in the camps. During my observations, I saw many exam room interactions like this one, especially when there are multiple children in the room. I recall children crawling on the floors and eating snacks crouched under chairs. I've seen mothers with their shoes off with naked infants on their laps. There have been many other noticeable kinds of behaviors in the exams rooms as well—those were the children never said a word as they sat silently beside their mother, only responding to the verbal cues to move to the exam table. The CHNs learn a lot from what they see in these rooms. As Angela explained towards the beginning of this conversation, “Yeah, because the kids are all over the place and it shows that, kids... the way they act in the office, even if it is a short time, I think it gives a picture of how they act at home.”

Another possible reason for this mother’s silence is what Reem described as “misunderstandings” (e.g., about acceptable parenting/disciplining practices in the U.S.). The CHNs know stories travel fast among, across and within refugee communities since many live within the same apartment complexes. This is especially true for new arrivals who are often overwhelmed by so much new in their lives and they do not yet know who to trust. Kriti explained that, “New arrival people, they hear all the information spread the whole community and how the parents are scared to even to yell at the kids, even like the kids are different here, the culture totally different.” According to all the CHNs, parents often hear stories of children being taken away by unknown entities (usually the Department of Child Protective Services) and sometimes they see it first-hand but may not know what they are seeing. There is also no telling how the stories are told and may alter from person to person as they spread. Fearful of losing their children, parents may feel powerless to act as parents as they are not sure what kind of parents they can be. As one father related to Reem during an exam “If I were in Iraq, I would know what to do.” The uncertainty parents experience may have implications for children's’ health and overall well-being in ways we may not fully understand, but which could be explored.

The CHNs are uniquely qualified to address parents’ uncertainties as they have experienced similar uncertainties and adjustments when they immigrated to the U.S. As

Kriti recalled during an interview, “I can tell totally different. I was born there [Burma], I grew up from there, my parents are from there, and when I came here, I saw it totally different.” Their migration experiences and the lessons they have learned along the way as CHNs make them better equipped to respond to parents’ questions about how to raise their children here. Parents’ questions may come during or after exams, on the phone, or during home visits. While each CHN may have different responses, they are all grappling with similar uncertainties and tensions. Reem, for instance, told the group that she often tells her families that, “Americans they don’t let their kids behave like that, there are rules, they should be disciplined, even inside the house there are rules.” She wants parents to know that they still need to set “rules” in their homes. Samira, on the other hand, indicated that she might ask, “How would you deal them if you were back home? And if she tells me what she does, and [if] I think it’s bad then I don’t want her to get in trouble, but if it’s a good option then I will tell her use the same way you would talk to them back home because they don’t just take away your kids without good reason.” Samira’s focus seems to be on placing existing practices in the new context to assess consequences and determine whether or not they are “acceptable” or legal in the U.S. Whatever the response, much like the parents, the CHNs do not have all the answer, but as seen here, try to do what they can to mitigate these tensions and make sure families are protected.

According to some of the CHNs, another reason that the mom may be silent and not responding to her children's’ behavior might involve her own experiences with domestic violence in her own home. Angela was first to bring this up after the mother spoke in the scene and said she did not want to share everything that was going on at home because she was having difficulty with her children:

> Actually, before the mom spoke, before I heard what she said, I was thinking that often the thing which can happen is domestic violence at the house...the moms who are under pressure because of the violence by their husbands, they don't put order in the house, so they let the kids do whatever. And we've had some strange situations. What put that thought in me is how she stays quiet. Often the moms that are victims of domestic violence they prefer the silence and even if you ask them at home if everything is ok they will say yes but reading by those expression or body language I would say that you know what's going on.

For Angela, the *mother's* silence in combination with the *children's* behavior may signal that she (and possibly the children) may be experiencing domestic violence in the home, which is one of the reasons the CHNs have emphasized looking at body language during medical visits. After Angela finished speaking, Reem talked about working with a family where a daughter was being physically abused by her father, but the mother did not want to say anything because she was afraid they might take the children away. That is why, as Reem explained, "Some of them, not all of them, they refuse to say anything." To which Angela immediately replied, "Which leads me to say that even with this answer that she gives, this may not be enough of the story." Angela went on to explains how mothers experiencing or witnessing domestic violence can feel a great deal of pressure to remain quiet as a way to avoid being found out by local or state agencies responsible for following up on reported cases of domestic violence. Angela said it may also explain why the mother does not "put order" in the house:

> The way the traditional [families]...the man is the head of the family, the one who decides everything, but often he will be at work, so it is normally up to the mom to put some order in the house for the kids to behave this way, but she will feel if I go too far, if the situation gets bad maybe after Department of Child Protective Services gets involves because the child has reported the family wrongly at school the dad will blame the mom.

As both Reem and Angela described, silence among mothers and a lack of order in the home (that shows up in the exam room) may signal that they are experiencing domestic violence in the home and are afraid to take action as a parent. However, as Reem's example also suggests, sometimes mothers (or children) are not silent with the CHNs (i.e. CHNs) and are willing to open up and share. I recall another story Reem told me during my observations where a mother confided in her that her husband was violent at home and had recently abandoned the family, leaving her and her three young sons to live from shelter to shelter. When I asked Reem why she did not say anything to anyone, she responded by saying, "It's not for me to tell." However, as the CHNs also shared during the conversation, they will try to "encourage" the mother (or children) to say something without, as Angela put it, "going into details."

The CHNs also talked about how most of the refugee parents that I observed in the clinic spoke no or limited English, while many of their children were either emerging bilinguals or fluent in English. In the second scene that I created to share and discuss with the CHNs, the mother does not speak much English, but her children do. While reading the scene out loud and digesting it, Casey identified a lack of competency in English as a potential reason for the *mother's* silence:

> Sometimes the children they don’t listen to the parents, especially the moms, because they don’t speak English, and they don’t listen, and they think we don’t understand what you are talking about because now they speak English...that’s how they don’t listen.

As Casey has observed, when parents do not speak English and children do, it can make parenting difficult. Children may assume that parents do not understand them. I observed the CHNs trying to mitigate this in the exam rooms by making sure that when a provider and child were speaking in English together that the parent was still involved in the conversation through interpretation. Kriti talked about how many of her parents did not speak English and the challenges they faced trying to parent their children as a result. For some parents, she told me, this made them feel like they would prefer to return to the camps. She recalled one memorable exchange with a mother her communicated this desire and what she said to her:

> I wish I could go back, even I don’t have food I don’t care. I have more peaceful mind. Cause here the kids...I don’t know how to drive, I don’t know how to speak English, I don’t know how to go by myself. The kids are like you don’t know anything. They look down to me. My own kids treat me like this. I can’t stand anymore.

For this particular parent, the feeling of powerlessness was so strong that they would rather return to the refugee camp then spend another day in a place where they were constantly reminded of what they lost, including their capacity to *be parents* to their children. According to the CHNs, this is truer of the mothers than the fathers, which is why they focus more of their efforts on the mothers. Kriti talked more about this during an interview:

> That’s why I really want to focus on the women group. They stay the whole day in their house, and then, of course they are taking care of the house, like housewife...cooking and preparing dinner for husband. But extra time, they have time too. Extra time just watching movie and then like, you have extra time. If you want to learn. They say I’m really busy when can I go to ESL classes? In the apartment they just walk to leasing office. They offer them [lessons] in the apartment. So just go there and come back, prepare dinner and you can do dishes and everything.

From what I have heard from the CHNs, and as Kriti illustrates, it is often challenging to get mothers to go to ESL classes, even when offered at their apartment complexes. But without English, they are unable to go to the store alone, they are unable to buy food, they are unable to speak with their children's’ teachers and know how their children are doing in school; they are unable to help their children with their school work; they are unable to offer guidance as to how to live in this country; they are, in a way, trapped until either their husband comes home, or their children come home to help. For mother’s in particular, this may be a recipe for diminished authority and agency to act as parents; and children may be less inclined to listen to them which means, in a way, they are raising themselves. For these reasons among others, the CHNs often try to encourage parents, especially mothers, to go to ESL classes if and when possible so that they do not feel trapped and that they can be more involved in their children's’ lives here in the U.S. As Kriti explained during the third interview:

> So that’s why the big things to go learn and at least ESL classes. Some parents, they have some knowledge from home. They were in school, 8th grade, 9th grade, they have some basic English from there, so I still say go to English class you can keep improving.

The CHNs know that many of their parents are struggling with how to be parents and raise their children in the U.S., and that not knowing English makes this even more challenging for them. By making these strong recommendations to their families, especially the mothers, the CHNs are trying to advocate for the family as a whole. They want to see parents be able to be parents to their children and for children to be children and not interpreters or translators to which their parents rely on in order to go to the store, for instance. As Kriti explains, this includes even those parents that know some English already—the goal is to keep “improving” because such improvements are not only important for the parents, but for their children.

The CHNs also talked about how many of the families that seek care at the clinic are quite large. From my observations, conversations and interviews with the CHNs, I learned that sometimes there are more than ten children living in a one or two-bedroom apartment. During less formal conversations, the CHNs talked with me about the expectation placed on women in many of their cultural groups to keep having children, even when it may pose a risk to their own health. During the conversation Angela weighed in on why and how this may be a problem:

> Another thing could be the size of the family plays a role. If you have, if it is a mom that has 2, 3 kids, it is easy to keep them in check, check them and make sure they do the right thing, but when they get 8, 10...it gets out of control and

> sometimes the parents don’t have any more energy...they say, ok let me focus on preparing their food, doing their washing their clothes, cause here they have clothes, too many clothes too wash, too many babies to feed, too many of this.

Angela talks here about the pressure and stress refugee families are under when resettling in the U.S. Recall from Chapter 1 all they have to do and learn and so quickly. All of this may render parents exhausted, making it difficult to keep their children “in check” or to “make sure they do the right thing” when they are overwhelmed and may not know what the “right” thing is anyway. Often, the CHNs offer emotional support by listening to parents who are feeling overwhelmed and exhausted. I recall during my observations overhearing a very long exchange between Angela and a mother on the phone. Sometimes while listening she had to place the phone further from her ear just to take a break from what she was hearing and breathe. After she got off the phone she said that the woman was a single mom who did not have a husband to talk to for emotional support and how there is not enough mental health support for most of these families. She explained that, “When they see they can talk to you they pour everything in their head. On the one hand it makes us mad, but on the other hand, when I cool down, I know they have never had anybody to talk to.” In other words, the CHNs often find themselves playing the role of the listener when stresses of life in their families’ homes becomes too much for some parents to bear.

Scene Three: Presence, Absence and Advocacy

The third and final scene captures important situations and challenges that occur outside the clinic walls. Although it is usually more difficult for the CHNs to advocate for families when they are not working with them in the clinical setting, it is outside of the walls of the clinic that many important interactions take place and decisions are made relative to children's health. As I have described elsewhere, the CHNs are often trying to figure out ways to help families communicate and self-advocate when they cannot be with them—hence, the numerous projects they have started but not finished (e.g. translated scripts of pharmacy prompts). While writing this scene, I attempted to capture recurring patterns from my observations of and interviews with CHNs in a composite sketch that I hoped would elicit some of their tacit understandings and unspoken assumptions. By sharing the scenes with the CHNs, I hoped they would recognize the kinds of issues depicted and want to discuss how they identify when there may be a need for greater support outside of the clinic. I also hoped they would want to help me better understand how they come up with ways to respond to those needs while advocating for families or helping families advocate for themselves.

The third scene takes place at a local pharmacy, where refugee families tend to encounter frequent difficulties. The scene opens with a mother trying to refill a prescription at the pharmacy, but the pharmacist tells her he cannot refill it for her. I give the CHNs a bit of background before the scene begins; I let them know that the CHN in the scene has known the family for years, but the mother does not speak much English, so she often experiences difficulty at the pharmacy. I also let them know that the prescription is for a chronic condition, but the dosage has just been decreased from one pill to two pills. After we started reading the scene out loud, I asked the CHNs to pause so we might try to make sense of this initial information at the pharmacy. As we continued reading through the scene (with everyone playing a different part), the CHNs generated additional and more complex understandings of what was going on, what kinds of responses might be necessitated, and why such responses would be helpful to the family.

Prescriptions and gatekeepers.

In this section, I share the CHNs initial interpretations of the situation at the pharmacy—that is before the CHN in the scene heard from or spoke to the mother. First, Angela suggested that the doctor may not have sent the prescription (e.g. he was busy). Casey added that if they go too early to pick up the prescription then their insurance would not cover the bill and the family would have to pay in full. Finally, Samira suggested that perhaps the mother took the wrong bottle to the pharmacy and/or did not know the name of the prescription(s). These initial responses reflect the various kinds of situations the CHNs tend to find themselves in and their awareness of three of the major gatekeepers involved in the process of writing and refilling prescriptions—doctor, pharmacy, and insurance agency. Their comments also reflect their understandings of the importance of the relationships that exist between CHNs and families and how each may shape the practices of the CHNs, the experiences of patients, and the families' interactions with providers. The noted that sometimes the doctor may not send the prescription, or they may not send it in when they were supposed to or said they would. When this happens, the pharmacy cannot do their job. Other times, like in this situation, there may be difficulties communicating; while the pharmacy may have records of medications in the system, if the parent does not know or cannot provide the name of the prescription and have no other way of establishing what medication they are there for, there is little the pharmacy can do. The conversation we had about the scene also helped me understand what happens when the parent, for whatever reason, tries to refill the prescription too early; in such cases, the insurance company will not cover the expenses, and the bill will fall upon the family. These gatekeepers, and the relationships between them may not be entirely understood or visible to refugee families, but they are to the CHNs. Because the relationships between these important gatekeepers may not be clear to families and because they may not fully understand the process of [re]filling a prescription, the CHNs are often called for help. From this conversation, I learned how the CHNs determine what is happening and where there may be miscommunication or misunderstandings so that they can contact the necessary gatekeeper (e.g. doctor). Sometimes they are able to get the family what they need, but sometimes they are not--all of which needs to be communicated to the family, so they can start to learn.

After the CHNs offered their initial interpretations of what might be going on at the pharmacy, they read the part of the scene where a CHN hears from a mother who is distraught because she is at the pharmacy, but the pharmacist will not give her the medication for her child. In the scene, the mother asks the CHN to fix the situation by speaking to the pharmacy or the doctor. After the head nurse speaks with the pharmacy, the CHNs learn that the pharmacist filled the prescription two weeks prior and that they informed the mother about the new dosage schedule (i.e. from two pills to one pill). The pharmacist explained that because she came early, they could not refill the prescription. It was at this point that the CHNs wanted to know if there was anything not included in the scene that might help explain what was included. In what follows I offer some of the ideas generated through the collective conversation—all of which inform the strategies they come up with later to address situations like this in the future.

Now that the CHNs knew that the medication had been adjusted and the mother was there early for her child's' prescription, they shifted to talking about medication and treatment plans—a common and often cited problem for many of the families and the providers that work with them. In other words, rather than focus on the interactional aspect of this scene, they focus on what it may represent (i.e. difficulties with medication). Samira presented the first theory which led to stories shared by the other CHNs:

> Or maybe her kids spilled it...I have like that situation where a mom says oh my kids spilled the medicine; can I get it again? No, you just got it the insurance will not cover it. ‘Can you talk to the doctor? Can you prescribe another one?’ They ask me such things, which I say well if you want to pay for it I can talk to the doctor, but the insurance will never cover for it.

Here we see how sometimes parents may not keep a close eye on prescriptions and/or may not realize that once a prescription is spilled or lost it cannot automatically be refilled. Angela also shared a story about a medication spill but described how the major gatekeepers responded differently because the child’s condition was life-threatening. She described it is a “miracle” to the group because usually, even if the provider is willing to refill the prescription, the insurance company still will not cover it. But, sometimes there are spills, prescriptions get lost and are not cared for in the ways they need to be.

Samira also talked about how sometimes medication is shared. She explained that, “Sometimes when they have a kid having the same symptoms as this one they would share, and they would finish before it is time.” Parents may discuss and compare symptoms, and sometimes this results in medication sharing. What this also tells us is that refugee families talk about health with one another and that it is social. Sharing medication (and symptoms) may also encourage families to seek out specific medications when they come to the doctor. As Casey explained, “Sometimes they brought the medication and they ask the doctor...can I have this medication? This is what my friend suggested.” I often observed parents asking for specific medications or medication in general during the medical visit. According to the CHNs, parents made requests so often that providers started to write prescriptions for over-the-counter medications like Tylenol so that the families felt like they were getting what they came for. Regardless of how and why medication is being shared or obtained, the implication is that treatment plans are not being followed and many parents do not seem to be fully informed about the complex pharmaceutical process and those involved.

Possibilities and limitations.

In this section, I discuss and present the CHNs ideas and strategies for addressing the situation at hand, but more specifically, what they said they might do to support families in their absence so that situations like this do not happen in the future. In this section, more so than the others, I account for the way in which ideas emerged through dialogue—as they shared ideas and identified their own limitations. First, they consider what they often do to support families when communication or interactions at the pharmacy is an issue and a parent is having difficulty refilling a prescription. Second, they consider what they have done when families have difficulty following treatment plans, which may result in complications at the pharmacy as well. Finally, they consider what they tend to do if none of their current strategies seem to be working. With a focus on planning for the future, these ideas and strategies strive to support families in the moments and interactions where the CHNs cannot be there. I should note, however, that regardless of what the problem might be, the CHNs usually need to speak with the doctor or head nurse in order to figure out what is going on. What they learn will shape their responses. Sometimes, this is where their efforts stop. Other times this is where they begin.

The first set of ideas and/or strategies respond to the interactional challenges between the family and the pharmacy, which make it more difficult to understand how the prescription process works and what is showing up on the pharmacists ends in relation to the families' understandings. In the following excerpt, you can see how three CHNs talk through possible responses to communication-related challenges at the pharmacy for both patients and providers:

> Casey: If it is a family I would suggest to use the downstairs pharmacy
> and after pick up come here each time.
>
> Samira: Or they can mail it to them every...when it is close to the refill time, if it is pills.
>
> Casey: But in this case she came early to pick up the medication.
>
> Samira: Yeah, but I'm saying to prevent that then we have her come to the pharmacy and not go to their pharmacy and then call for refill.
>
> Angela: But coming to the pharmacy when the day the doctor fills that, yes, but coming back for refill supposed to have transportation.
>
> Samira: So, have it mailed to them cause some patients they ask can you mail, and they do mail their medicine for them and they do mail to them when it is the refill time.

To avoid confusion, the first suggestion or response is to have the family come to the pharmacy at the medical center. This is viewed as a way to "prevent" what happened in the scene. According to the CHNs the pharmacy at the center has been much better at recognizing and responding to refugee family’s needs. The influx of refugee families has made them more attentive to language-related issues, prompting them to ask what languages they speak or prefer, and tracking down the appropriate CHN to help. If the CHNs are available, they may come downstairs to facilitate communication. By having the families go to the pharmacy at the center, the CHNs are better able to walk them through the process, provide language support and prevent miscommunications and misunderstandings. In other words, they would have more control over what takes place at this pharmacy and can be more involved in the process. But families are not always able to come to the pharmacy on-site, as Angela reminded the group, which means this would not work long-term or in all situations.

In light of this reminder (or passing on of knowledge), Samira suggested that they could have the prescription mailed to the family’s home automatically. If the prescription is scheduled to continue to be mailed, the family does not need to go or interact with the pharmacy or worry about when to call for refills. However, much like the “fix it” response, the family would not really be learning much about the process. The purpose, then, of this strategy is to make sure that families are getting their prescriptions on time, and that communication at the pharmacy and the process itself is not an obstacle. In addition to these suggestions, Angela talked about having parents call and hand over the phone to the pharmacist to help communicate:

> Actually, we have done when a parent was in a difficult situation with a pharmacy, I was asking them to go back online to call me and hand the phone to the pharmacist, so I can talk to them and understand the issue and how to solve it.

> But again it’s…. it’s a having ability here. If this situation happens at an all-day clinic and the patient is trying to reach Casey it will be difficult because she may try to answer, but when she has many calls, Casey, or maybe another person...when you have too many patients that’s the challenge.

Angela does two things here. First, she suggested a strategy she has already used. Second, she acknowledges its’ limitations from experience. What if this is an all-day pharmacy and the parents go during off hours? Or what if they are at the pharmacy and the CHN is not able to speak because they are too busy? While she sees this as a possible strategy, she also recognizes that in many situations, and in the long-run, it is not a solution to the interactional challenges experienced by refugee families and providers at the pharmacy. These options are also not likely to help those whose challenges reflect other problems--namely following treatment plans and understanding the concept of a prescription.

During the group conversation, some of the CHNs observed that sometimes communication with the pharmacy is not the primary problem or is not a problem at all. As all of the CHNs pointed out, the problem has more to do with following treatment plans and understanding what prescriptions are and do. Here a few of the CHNs talked about what they might do should following the treatment plan be the issue:

> Samira: To my mind, what comes is, okay this has happened, we can’t go back and fix it, but in the future, we’ll have them come to our pharmacy and know that she’s getting exactly, and I’ll teach how to use it.
>
> Casey: Yeah, education.
>
> Angela: Sometimes Dr. Day does, but normally it is the MA or…
>
> Samira: Or whoever, to show them how to use it before they leave the clinic, so this doesn’t happen, and you should use this pharmacy here.

As I have discussed elsewhere, often the CHNs feel responsible for educating families. If the problem reflects challenges following treatment plans, then it is important for the CHNs to address this issue on site when the prescription is prescribed. Again, Samira emphasized coming to the pharmacy within the medical center, but what she also stressed is education—that is teaching families "how to use it" or how to properly medicate their child or children. Making sure that parents are clear on how to follow a treatment plan by going over that plan with them in the clinic and sometimes with the doctor or medical assistant is one way to address this problem; and if they can couple that strategy with having them come to the pharmacy on site, then that would be even better as they could walk them through the entire process. It is case by case, however, and their lessons need to be tailored to the situation. Angela in particular described the situated nature of their work and the experiences of refugee families:

> It depends case by case, but roughly what we try to do is educate the families to…like for medication, if it is a medication that it has to be picked up at the pharmacy and we know it is long-term ...like that medication for seizures that I was talking about for our patient, that one we educate them on how to save the bottle so they can go get the refills and just bring the bottles, because those bottles for some at the beginning, there are so many things happening...especially for those…they will even let the child play with the label. We explain that the information that is on the label will be used later again or if it is an emergency. So, education is the key things we do.

What Angela highlights is how the lessons change depending on the family and the situation. It would be difficult to provide general education on medication and following treatment plans. She described a very situated approach to education involving medication. The lesson and the strategies employed or suggested need to align with the families' needs. Thus, saving bottles for chronic or long-term conditions may be a helpful communicative strategy to make sure they continue to obtain the needed prescription; this would be less effective of a response for a temporary medication, like an antibiotic. In this case, it's less about keeping track of bottles and refill times and instructions, and more about making sure they follow the plan and complete it. Samira talked about how sometimes she has the parent take a photograph of the prescription bottle so that she can read it and then go over the instructions. Again, it is case by case.

Sometimes education at the clinic does not address the problem. In the following expert of dialogue, you can see how the CHNs experienced some limitations while working with families in this capacity:

> Casey: Sometimes we need to talk with the patient before they take medication. We remind them do you remember how to take this medication?
>
> Samira: Yeah, that's why we have the doctor explain and label and everything.
>
> Casey: Sometimes we do, and they don't understand.
>
> Samira: Then how will they understand you if they didn't understand with you and the doctor?
>
> Casey: They come back here, and we ask them how you took the medication and they explain and sometimes we find that it is not how the doctor told them.
>
> Samira: Yeah, then that we can teach them. Although they will not understand if you told them and showed them before and they come back and still don't know...they have some learning issue we can't solve.

Sometimes teaching is happening, but learning is not. Samira's question represents an important moment in the conversation where she presses the pause button for all of us; if they are not "understanding" with the support of the doctor and the CHN, how *will* they understand? Should this be the case, as Samira pointed out, then this may reflect an issue that they cannot "solve." Her questions and observations seem to sit within a problem space that the CHNs often find themselves; they have done what they feel they can do to help, but their efforts do not seem to be paying off. Medication, in particular, is an ongoing challenge for all within the clinic.

I want to return to Samira's question for a moment: "Then how will they understand you if they didn't understand with you and the doctor together?" Again, this assumes that understanding is the problem, which may or may not be the case. It may be a combination of things that we do not fully understand. In light of these ongoing challenges and uncertainties involving medication, treatment plans and prescription systems that seem to cross all cultural groups, Angela described a current project that they hope will help:

> Plus, hopefully the project will able to proceed….with the [resettlement agency] they went back to their name Lutheran Services...they went back to their initial...so that lady we met, Dr. Day and I...we met for presentation with the teacher...she was doing like a training for the ESL teacher…they were ready to help us like teach the numbers on the syringe so they know how it is given so the person needs to know the English numbers...so that we partner so that when they teach English they teach those numbers and how to count those lines...when the

> project proceeds we hope to help get parents to give the right medication to the kids.

What Angela is described is a recent development. She and Dr. Day reached out to one of the local resettlement agencies—whom they have ongoing connections with--for help; and this help seems aligned with the limitations identified during the group conversation. Many of the families that seek care at this clinic do not speak English, and this includes being able to identify and read English numbers. Many families are also not able to read health-related devices like thermometers or syringes, which is why Angela once talked about creating YouTube videos to demonstrate. As CHNs, they know that families often attend ESL classes at their resettlement agency. These classes are intended to support refugees' acquisition of English. Following the CHNs logic, why not use this as an opportunity to cover numbers and measurements? Much like the lesson at the grocery store, this is an effort targeting *all* refugee families, not necessarily specific communities or groups. It reflects experiences across cultures with medication. It also reflects the CHNs known limitations—not necessarily what they are incapable of helping their families with, but which they do not have the time, resources or energy for when considering everything else they have to do.

Discussion

In this chapter, I invited readers to look at three different scenes through the eyes of the CHNs with me. By tracing and analyzing the group conversation, we begin to see how the CHNs assess certain situations and interactions and arrive at a response or decision to act (or not). This is to say that this chapter helped to make their sense-making and thinking patterns more visible, demonstrating the ways in which their ongoing experiences as CHNs and past experiences as refugees or immigrants shape and inform their current efforts and understandings on a regular basis. It was through the collective sense-making process that we also saw the ways in which difference and variety in terms of perspectives and interpretations can be valuable and generative resources instead of static assumptions or understandings (about their families, providers, etc.) that fail to account for the diversity they encounter or the unexpected experiences and situations that characterize so much of their work. Rarely did the CHNs insist on a particular way of knowing or doing something; instead, they listened and asked questions, presented what they thought and why and/or offered something for the group to consider. In other words, this chapter made some of their problem-solving and complex thinking more explicit while demonstrating the potential value of having intercultural dialogues such as this among and between CHNs as it may prove useful to the team, to each of CHNs as individuals and for other health professionals working at the clinic. The insights that emerged from this conversation help to illustrate how complex refugee families' lives are and how knowledgeable the CHNs have to be in order to provide the kind of support many of these families need.

CHAPTER SEVEN

TOWARDS A BROADER ENGAGEMENT: IMPLICATIONS OF STUDY

Implications for Practice and Pedagogy

As I have shown in Chapters 4 through 6, the CHNs' work can be categorized into three types of advocacy. The first type is where they "fix" or take care of something for a family or parent. In these situations, the CHNs do for the family rather than teach or show them how to do it for themselves, which means there is limited to no learning taking place. Examples of this type of work include the support the CHN provide families with transportation and at times for health insurance. The second type of advocacy is when the CHNs help guide families through certain practices, interactions or procedures. This type of advocacy involves teaching and learning by doing something together. An example of this type of advocacy is the scaffolding of parent-provider interactions that the CHN provide during medical consultations. The third type of advocacy is when the CHNs engage in future planning and try to come up with strategies and resources to help families communicate and advocate for themselves when the CHNs cannot be there with them. Examples of this type of advocacy include the grocery store lessen and teaching families to always carry their insurance information with them so that they are able to communicate with an interlocutor that does not share a language. This type of work looks to the future and seeks more long-term solutions to long-standing problems or issues that seem to cross cultures. Currently, however, my findings and analysis suggest that most of the CHNs time is spent on the first two types of advocacy.

In an ideal world, there would be more time for the third type of advocacy and more time in general for teaching and learning. In other words, the CHNs would have more time to guide and teach families, rather than rush through encounters and activities with little explanation. They would have more time to help families understand “why” things are happening the way they are, which is important for anyone to understand. As Angela explained, “Explaining the why is really a good way to give energy to the refugee families to start to do things better, to start to do things by themselves...we don’t have time but we need it.” For instance, it would be helpful if the CHNs had time to go over the forms families have to sign at the registration desk and why they are needed. It would also be ideal if the CHNs had more time to regularly connect with the communities served through community-outreach and education. The CHNs frequently communicated the value of bringing education to the contexts in which such education is relevant (e.g. grocery store, apartment complexes) and where health-related decisions are made. In this way, families are more likely to make adjustments and/or adopt new practices. Ideally, CHNs would also have more time to work on developing and co-constructing accessible and relevant resources for families to learn more independently—like the idea for a YouTube video on how to mix baby formula correctly. In short, to help refugee families gradually become more independent, there would need to be more time for teaching and more opportunities for learning both inside and outside of the clinical setting as well as resources to supplement what they are learning.

Ideal worlds, however, are just that—ideal. The reality is that the CHNs are not able to do much of what I have just described, despite their willingness and desire to do so; they spend far more time on the first type of advocacy because it is necessary for the families they work with. I wondered along with the CHNs during our final meeting together what some of the reasons were for the prioritization of the first two types of advocacy work. The first issue that came up was the number of patients they currently are serving at the clinic. Angela talked about how when they first opened the clinic in 2012 there were fewer than 200 patients. Since then their numbers have grown substantially. By the end of 2017, there were nearly 1500 patients—this despite the decrease in refugee admissions to the U.S. Angela talked about how many in the clinic speculated that the decrease in admissions would mean that the clinic's numbers would stabilize; instead, they talked about how the exact opposite was happening. Angela explained that since resettlement agencies have fewer new arrivals, they have more time and human resources to address more needs within refugee communities, including those that have been in the country for years. Angela connected this back to the clinic by saying that many agencies were discovering children in the community (and families) who had never seen a doctor in the U.S. She added that while some families may have made connections here and there for immunizations, there were so many refugee children that have not received "proper pediatric care." What this means for the clinic is that their numbers are likely to continue to increase. During the meeting, the CHNs informed me that numbers were already starting to increase and in the previous week alone they had made contact with thirty new patients. If the numbers continue to increase, there will be even less time for teaching and learning.

Another reason for the limited time for the third type of advocacy was that medical visits for refugee families are currently not long enough. Like most medical facilities, each appointment is scheduled for fifteen-minute slots. While this schedule may work for some facilities and patient populations, as I have observed and as the CHNs explained to me, this is not enough time for refugees. Appointments typically take much longer, and one of the reasons is because of all the interpretive work needed. However, longer visits do not mean that more teaching and learning is taking place, but rather, it often means that it just takes longer to get through the entire process (i.e. interview and examination). This is to say that there is only so much the CHNs can do in the time they have with families during the medical visit. As Angela described, "There is no way [it is enough time], unless you just want to brush on just a few things and then leave and the patient goes home with more questions and some frustrations," which describes how some families leave medical visits at the clinic. Sometimes, as Reem put it, "they don't get it in the room." When all the whys and hows are not addressed during the medical consultation, especially for more complicated visits (e.g. newborn), parents may leave the clinic with more questions than answers. As Samira recalled during the conversation, "I had a patient that was waiting for thirty minutes, I was in the [exam] room, just to ask me when is my [referral] appointment."

In addition to time and the steady increase in patients, the CHNs also talked about how so many of their families are new arrivals to the U.S. Therefore, most of their families need more of the first type of advocacy. Most new arrivals do not have a car or a license and have never been to a healthcare facility in the U.S. (other than the Department of Public Health for their screenings). In order to meet the most pressing needs of their families and the new patients that they encounter each week, they need to spend a lot of their time on appointment reminders and transportation arrangements. However, they also talked about how even those that have been here for longer and speak English (or some English) may grow dependent on the CHNs to make these arrangements for them, and part of this might be explained by the fact that they have never been involved in the process of making these calls and have never had to remember their appointments. Some families start to expect things from the CHNs. As Angela put it, some feel like, "You do for us, I don't want to do any effort." While this is certainly not true of all families they work with, it is true for some. While the CHNs could say no in these kinds of situations, they tend not to because they worry that the children will not be seen, which is a reality that is difficult for the CHNs to ignore. Thus, a potential pattern of dependency may emerge with certain families despite the CHNs stated goals of wanting them to be more independent.

It would seem that there is a very real tension between the CHNs stated goals for their families and the realities they face every day at the clinic. While they wish for their families to reach a place of greater independence—from the clinic and the CHNs, they are often not able to offer some of the services that may help families work towards this goal. For the above reasons, CHNs often find themselves spending more time "fixing" and doing things for families (like transportation and applying for health insurance) and less time on teaching, guiding, scaffolding and future planning for encounters and activities where the CHNs cannot be present. The questions is, if the CHNs would like to have more opportunities to teach their families and explain the why and the how *and* still have time for future planning and scaffolding self-advocacy, what can be done about this? What might help open up space and time for the CHNs to provide more guidance and scaffolding? What might open up space for them to come up with strategies and resources to help families (parents more specifically) do more on their own including learning? In what follows I offer few possible ideas that emerged from the final meeting/conversation with the CHNs as well as my findings and analysis. These recommendations or suggestions fall into four categories: 1) clinic operations 2) training and professional development 3) community capacity-building and 4) developing resources for learning.

Clinic operations.

When the CHNs and I spoke about the limited time they tend to have to work with families and the steady growth of the clinic, several suggestions were made to try and create more opportunities for teaching and learning. The first of these falls under the category of clinic operations as they have to do with how the clinic operates and reflect more internal system-level changes. The first suggestion made was to increase the number of “sessions” for the clinic. By session, the CHNs refer to periods of time in which the clinic operates. Currently, the refugee clinic holds five sessions—two on Tuesdays and Fridays and one on Mondays. For instance, on Tuesday, there is one session in the morning and one in the afternoon (the clinic is not open in the evening). The CHNs felt that it might be helpful if there were at least two more sessions (seven in total) in which the clinic was operating to accommodate the number of patients they have, while potentially opening up more time and space for teaching and learning. While refugee families could schedule appointments with the general clinic, they would not have access to the kinds of resources (e.g. the CHNs) and continuity of care (e.g. one medical provider) that they receive from the refugee pediatrics clinic. This is to say that refugee families typically only schedule appointments when the clinic is open. Despite the increase in patients, they have not increased sessions which may open up time and space for more teaching, learning and future planning.

Another recommendation made by the CHNs was to increase the allotted time for appointments. As I previously mentioned, refugee families' appointments, like most appointments, are scheduled for fifteen minutes. However, rarely do these appointments take fifteen minutes; and for every appointment that takes longer than fifteen minutes, the next is pushed back further. While this may be an issue at many clinics and healthcare facilities, it is particularly pronounced at this clinic for a few reasons. One is because interpretation is almost always required, and this takes time. Another reason is that more explanation tends to be required and families often bring in multiple children at once. What also contributes to the long visits times is that each family also has to visit with a resident (or intern) physician before they actually see the attending physician. I have observed visits that have took nearly an hour between the resident and the attending physician. This means families are spending a lot of time either participating in multiple exams or waiting to be seen. In addition, because appointments keep getting pushed back the CHNs often have to rush from one exam to another since they are involved in all aspects of the encounter (i.e. intake, consultation, discharge), which means that they rarely have time to work with parents after the visit to answer questions and verify understandings. If there were more time during the actual visit, it may create more opportunities for teaching during and after the exam, and the CHNs may not feel as rushed.

A third recommendation was for more part-time assistants or volunteers to help the CHNs. Part-time staff or volunteers could focus more on teaching and working with families after (or before) exams or during less complex interactions or activities like registering at the front desk or signing consent forms for immunizations. Angela described this in more detail during the final meeting:

> I think they need some more support, more part-time...because Casey has part-time with Lily but it's only eight hours. The reason I'm saying is sometimes they ask to be two places at same time, it is impossible. Reem or Casey is busy with a provider and there is one patient who is finished and who needs to go downstairs and doesn't know how she is going to speak to the pharmacist. So, it is impossible that they be in two places. And besides, actually, even when they try to manage that they have to go fast...okay I show quickly...there's not enough teaching time, related to your third advocacy time, there is not enough time to teach the person so that she has just to rush. So, if she had somebody who could take that time maybe down at the lab or at the pharmacy and then her she's helping and teaching, and the one that's in the room that would be helpful...in terms of human resources.

The CHNs often have to rush around or rush as they explain certain things to families because they are needed elsewhere and do not have the time. As Angela says, it is impossible to be two places at once. But what if there were someone there who spoke the necessary languages and could stay with the parent and answer questions and go over, for instance, the referrals made by the doctor to a specialist provider? If the CHNs had help, even in these small moments, it could go a long way towards helping families with the whys and the hows of what they are experiencing so that they can start to develop understandings that may help foster more independent activity.

Professional development and training.

We also talked about professional development and training as a way to create more opportunities for teaching and learning for refugee families. We agreed that training more providers to work with refugee families might help to cultivate a collective and distributed effort to support refugee families. This would mean providing more training for providers working with refugees in any capacity, including pharmacy and/or laboratory technicians, front desk staff, and medical assistants. It could also include specialist providers that the clinic frequently refers families to as these types of providers are often the least responsive to refugee needs (e.g. they often do not provide language support). If more providers already working with and making regular contact with refugee families were formally trained to work with them and knew more about their unique needs, families may be able to do more without the CHNs. These providers might also become resources for learning—both for refugees and other providers. It is not clear what such a training would look like or involve or how it might be developed, but it would make sense for the CHNs to be involved in some capacity. However, given their limited time and availability, a project like this seems unlikely at the moment. But it could, as the CHNs also discussed, involve those already doing great work with refugees. For example, the CHNs talked about a particular CVS pharmacy that many refugee families now go to because of how well they work with refugees. Just like the refugee clinic, the more refugees the pharmacy encounters, the more effective they become at meeting their needs. The same can be said of this CVS pharmacy, making them a potentially valuable resource for other pharmacies who happen to work with refugees.

Community capacity-building.

We also discussed community-capacity building as another way to create more learning opportunities while also helping families do more without the clinic and the CHNs. One of the ways in which the CHNs could work towards more capacity building is by utilizing who they call “ambassadors” in their communities. These individuals, often patients themselves, could be leveraged as resources for patients at the clinic. Angela offered the following description:

> When we have outreach, when we go out and teach in the community, we have some person as being a member of our clinic or not being a member of our clinic who get things right away, faster than others. And they will be even the ambassadors in the community; they will go oh, I learned from these people in that pediatric clinic that and, ‘You, my neighbor, you need to bring your child to this clinic.’ Not necessarily here, but for example, we talk about there are 13 visits that a child has to have before 5. So, that ambassador, I call them ambassador because they truly are and genuinely, they teach others. They say your child needs this visit at 9-month, 12-month, 15-month, etc. So, you need to bring your child to your doctor...at least...that going out in the community has many advantages way beyond recruiting people to come here or just that session of teaching immunization, it can go further...that would be them preparing for the future because those persons can fly with their own wings without us being there...if we have someone who can coach or is coaching our families.

Ambassadors are described here as people that tend to “get things right away, faster than others.” These are people that learn fast (for whatever reason) and take what they learn, and they share it with their communities. As Angela notes, this does not always mean telling families to come to this specific clinic; it may also mean that they pass on knowledge to families about the ways in which they can get their children the healthcare they need. By going out into the community more frequently they can identify more “ambassadors” that can help foster capacity-building through their own teaching and even recruiting of others to do the same. In other words, one ambassador may identify and apprentice or sponsor another to be a resource for their community.

If the CHNs were able to identify more “ambassadors” and train them to be a resource for specific needs, this could have a major impact on communities while working towards the CHNS stated goals. For instance, there might be an “ambassador” that is trained to help families apply for health insurance or set up transportation. There might have an ambassador that focuses on scheduling appointments and keeping those appointments. This is to say that the ambassadors could be leveraged to help distribute the labor involved with getting families to the clinic (i.e. the first type of advocacy). They might be used in other ways as well (e.g. understanding treatment plans, making referrals appointments), but it may more useful if they were helping with the first type of advocacy since it takes up so much of the CHNs time. What this would mean for the CHNs is that they would actually have a trusted resource to redirect families to if they need to in order to make sure the necessary questions get answered and the whys and the hows are clearer. This, of course, assumes that these “ambassadors” are willing to do this kind of work for free, which may not be the case. Regardless of whether or not pay would be needed, training more “ambassadors” within communities, and training them to work with families on specific tasks that tend to take up a lot of the CHNs time or which they do not have time for, could prove to be extremely powerful and transformative for these communities and the clinic.

Another idea related to the above is to create a support group for mothers. I often heard from the CHNs how mothers tend to listen more to other mothers, and that the care of the children in most of their communities falls upon the mothers. I have seen how the CHNs try to encourage mothers to speak with one another at the clinic, but there is currently no organized effort to make this a structured activity that could take place in the community with the guidance of either the CHNs or an “ambassador” in the community; it would depend on the goals of the group. It could be that more experienced mothers who have been living in the U.S. could become resources for new mothers in the U.S. It could be more of a gathering where mothers’ share experiences and recommendations. It could also be more focused on the different kinds of visits they are encouraged to take their children and what to expect and what kind of information they would need to know about their children. It could be structured or semi structured; topical or not. I cannot say what it would look like, but if more experienced mothers could work with less experienced mothers (at least as mothers within the U.S.) it might prove to be an extremely valuable experience that might lessen what the CHNs have to cover, but often have to rush through at the clinic. Like the “ambassadors,” such gatherings could be a place to talk about the hows and the whys of things left unexplained in a safe space with other mothers in their communities.

Building off both the “ambassador” idea and the mothers’ support group, we also talked about more community-based education, specifically education on child abuse/neglect laws in this country, which as I have shown in Chapters 5 and 6 are major concerns among refugee families and have a way of affecting children's’ health (e.g. dietary concerns). The lack of awareness and/or knowledge of child abuse laws in this country has many families afraid to do anything to their children; they are unsure how to parent. In other cases, parents keep doing what they did before resettling in the U.S. and sometimes this may be considered abuse. When child abuse is reported, families get a visit from child protective services (CPS). Often, as Casey explained, parents are told the agency is there to help. However, in many families’ minds this means the agency is there to give them something; instead, they are there to take one or more of their children away as a way to help *them* (i.e. the children). The misunderstandings and/or lack of understandings has made parenting difficult for families; in some cases, it has torn families apart. The CHNs do not have the time to teach families all about the child abuse laws in this country during medical visits, nor are they trained to do so. The implication being that there may be a need for professional development for the CHNs to learn more about the child welfare system so that they can, as Angela put it, “teach them how to avoid those situations” through community-based education.

Developing resources for learning.

As I have previously mentioned, the CHNs have many projects in waiting. Many of these projects are aimed at helping with some of the less complex encounters or activities at the clinic, like registering at the front desk. Having more time to work on these projects so that they can actually be used by families would be another valuable use of time. What might also be of value is possibly collaborating on the creation of resources for families to pursue their own learning independently on subjects of interest or necessity. Without accessible resources to supplement what takes place at the clinic (and outside), so much is left to the CHNs to teach, answer and respond to. If the idea is to open up more space for teaching and learning opportunities while working towards families' greater independence, having other kinds of resources to support learning would be helpful and would help, like many of these other ideas, distribute some of the labor. For instance, the CHNs have talked about creating YouTube videos on a range of topics so that parents who do not read even in their own languages can learn too and on their own. Developing resources could be a collaborative effort involving the CHNs, but not exclusively, as they would need input from refugee families and a "trial" or "experiment" in using them as Angela put it. At the time in which I was collecting data for this study, most of their projects were in folders on computers—incomplete and underdeveloped. Though it would involve a lot of effort and time at the start, these resources may prove valuable in the future once created.

Theoretical Implications: Theorizing Health Literacy

The findings in this study demonstrate how the CHNs act as literacy mediators or sponsors that facilitate the collective distribution of health literacy, supporting refugee families' capacities to act and make decisions on the pathway to care. Whether this support involves physically getting refugee patients to a facility or tailoring educational resources so that informed decisions can be made. CHNs are an integral social resource within refugee families' social networks for learning about and navigating the healthcare system. In some cases, as this study shows, the CHNs have become social resources for navigating other aspects of social life in the U.S. that intersect with health and healthcare (e.g. school, buying food). Sometimes, this creates a greater dependency on the CHNs--not necessarily because families lack resources, but because the CHNs have shown themselves to be consistent and trustworthy support systems that extend beyond the walls of the clinic. For refugee families, this kind of trusted support is not always easy to come by, nor is the emic understandings the CHNs bring to their work.

Consider, for instance, the graduation list the CHNs created and are still in the process of working on. The two macro skills or abilities (i.e. communication in the clinic and transportation) reflect the greatest needs of the families they work with. Under transportation they list things like being ready at one’s home at least 30 minutes before the taxi arrives, providing the name and date of birth of the patient being seen at the registration desk and using more words than body language when interacting with medical providers. They also even include knowing where to wait at the facility once a family has arrived via taxi service. To health professionals that work in other contexts and with other patients, this list may not make sense or have value to them or their patient populations. They may wonder why providing the first and last name (or child’s name) and date of birth would need to be listed as a skill that is needed on the path to care. The fact that this skill is listed, however, is among the many reasons the CHNs are perhaps the most powerful and effective sponsors of health literacy for refugee families. The know, for instance, that many families do not make distinctions between first and last names and may not be familiar with the expectations and conventions of healthcare interactions.

What the CHNs do to support refugee families, and what they list as needed skills to graduate from the clinic, reflect many foundational skills and understandings needed to begin to navigate the healthcare system more independently—some of which might be taken for granted by other health professionals. For some patients and providers, the content on the graduation list would be irrelevant. For instance, I do not need reminders to provide my name, address and birthdate when I register for a medical appointment because I have been to so many medical appointments in my life that I know this is an expectation during healthcare interactions; I know it is one of the ways that they confirm who I am. Many of the refugee families the CHNs work with at this clinic do not know what is expected when making an appointment or registering for one. They do not have a license or car and often do not know how to navigate the city, especially if they are new. For refugee families that bring their children to this clinic, knowing how to schedule transportation *is* relevant and important as it represents a necessary step towards being able to do more independently on the path to care that some might overlook, but which the CHNs do not; they both acknowledge the reality of this challenge and do something about it.

The findings of this study show just how locally specific and context-dependent the path to care is and what health literacy or being health literate means. Most of what the CHNs indicate as important for their families to be able to know or do shows how knowledgeable they are of the families they work with and the many taken-for-granted skills and/or understandings many health professionals may assume their patients know how to do without support. The CHNs know they cannot assume that a family will be ready for a taxi on time; they cannot assume that a parent will know to bring and show their child’s health insurance cards; they cannot assume that parents will be able to understand and sign consent forms for vaccinations (i.e. that the paper will speak for itself); they cannot assume that they know how to make appointments and what it means to make and keep them; they cannot assume that parents will know how to interact with the doctor; they cannot assume they will know why certain questions are being asked or what is expected of them during a medical visit; nor can they assume that families will know who is who and who does what (e.g. nurse, medical assistant). The more families show up and participate in the healthcare delivery of their children, the more support they get (in this case, for instance) from the CHNs and the more they learn about this figured world—the expectations and goals of certain actions, the roles of certain people (e.g. nurse, medical assistant), the various processes and procedures involved the healthcare delivery of their children, and how health and well-being are understood in this new context.

As my findings demonstrate, participation in the healthcare system is an important step towards being able to navigate a path to care within the larger healthcare system. I say “a” path to care because no path is exactly the same and people seek care for different reasons as needed. Participation, of course, takes time and labor—something that many refugee families may not have. The personal benefits of such an investment also need to be evident but may not be (e.g. applying for insurance). This, as I learned, could be for a number of reasons including other labor-intensive demands considered higher priority (e.g. employment). By connecting with and inviting families to participate in the healthcare of their children through their persistent efforts and support, the CHNs help initiate families’ socialization into this new cultural context.

Part of the socialization process, as I have shown, is about delivering compelling messages that help, for instance, educate parents and encourage them to bring their children to the clinic when there is a medical concern. Take for instance, in Chapter 4, where Kriti had to negotiate a way to explain a condition (i.e. kidney stones) with no direct translation. These ongoing exchanges, where the CHNs co-construct and negotiate ways of talking about health and illness become future resources for other families (when appropriate or relevant). As I have also shown, the CHNs efforts to rhetorically make things happen do not always work out the way they planned. In Chapter 5, for example, Casey talked about how challenging it was to try to get a mother to bring her children into the clinic despite the seriousness of their medical conditions. She described the approaches she took to help this mother understand what the conditions were and why it was so important that she bring her children to the clinic. As is sometimes the case, the message was not effective in the ways Casey hoped. However, like the other CHNs, she continues to try to develop strategies to more effectively communicate with and educate families. In this way, as an expression of multiple literacies, the CHNs are developing rhetorical strategies in multiple languages simultaneously.

With this said, the CHNs' own participation in the healthcare system as both patients *and* health professionals can be viewed as a way of strengthening their capacity to be resources for the families they work with. During our final interview, Kriti talked about her own learning and the ways in which working as a CHN has helped her better support her families:

> When I started here, I knew because I'm working with the Burmese community, so I knew about the community background, right? So, when I work here it help

> me a lot...improve when I talk with the doctor and when I explain between the doctor and patient. So, I got a lot of information from the doctor too. More knowledge from the doctor, so I can get more educated to my community. So, this is a big improvement for me...and sometimes, honestly, I didn't get, like, medical in the beginning right...So, I got a lot of knowledge. So, the patient confused, what is that? What can happen? So, I can explain more detail how they can see. So, that's why I got a lot of knowledge from here...it help me for myself, and for my community for the refugee patient too.

First, Kriti talks about how her knowledge of the Burmese community was an important and valuable resource as a CHN. Then, she talks about how working as a CHN has helped her learn more about healthcare and medicine in the U.S. Recall that to be a CHN one is not required to have specific educational or clinical credentials. Instead, they are hired based on personal and professional experience and knowledge of the communities being served. These interconnected experiences have enabled them to continue to make important capital gains while accumulating relevant knowledge that they can pass on to their families. Like the families they work with, the CHNs learn as they go. Every time they encounter a new situation and have to problem-solve, they develop ways of addressing similar situations in the future; they also may learn something new in the process. Take, for instance, the conversation about health insurance in chapter six. There were different understandings of the application process—all of which were learned through their experiences as CHNs. This is to say that the demands of their job present challenges but also create ongoing learning opportunities that help support the health literacy development of refugee families.

This study also highlights how health literacy development is socially and interactionally mediated. Whether they are refugee-background or not, people rarely make health-related decisions alone. The CHNs often talked about how fast word spreads among their communities and how experiences with the healthcare system are shared. Take, for instance, the ways in which the CHNs described how refugee families often share and compare information about symptoms they or their children are experiencing. This may result in medication sharing or parents who come to the clinic looking for specific medications after conversations with those they know and trust. Again, trust is key when it comes to the sources we go to for information, which may explain why many parents reach out to the CHNs for other needs—like the domestic violence issues talked about in chapter six. Often, refugee-background families call the CHNs for advice about what to do when experiencing domestic violence or domestic disputes in the home.

Many of the refugee-background families in this study have come to rely on the CHNs as they have repeatedly shown that they are trustworthy and valuable resources when it comes to the healthcare of their children. The CHNs also recognize how interactionally mediated, locally situated and context-dependent health and health literacy is, which is why they encourage interactions between families and hope to begin a support group for mothers as they have observed that many of the mothers tend to learn best from those they know and trust. They also encourage them to draw on their existing social resources like Kriti did in Chapter 5. Despite how individualized healthcare in the U.S. seems to be (i.e. our health is our own and we take care of it ourselves), we see in this study that this does not seem to reflect the experiences and realities of patients—at least those at this clinic. This became more visible as I observed exam visits where aunts and uncles or grandparents showed up to visits as well as the parents. For many refugee-background families, health and healthcare is a family rather than individual experience and endeavor. Having people you trust with you during a medical visit can bring comfort, especially if it is a new encounter. Moreover, when considering the lack of resources for refugee families to make sense of and learn about the healthcare system, people become the primary resources, and this includes the CHNs.

Up until this point, I have highlighted the importance of social interaction when conceptualizing health literacy, and the distributed and situated nature of health literacy development and practices. My focus has been on the work of *one type of health professional* and the ways in which they support their families access to and navigation of the healthcare system as trusted resources and sponsors. More recently, and in light of a "universal precautions" approach to health literacy that assumes *all* patients are at risk of not understanding information relevant to maintaining and improving their health, Brach et al. (2012) from the Institute of Medicine, has recommended we work towards more "health literate organizations." A range of accreditation, quality and health professional organizations have begun to recommend system-level changes to make organizations, rather than people, health literate—reinforcing the idea of health literacy as a social, distributed and collective effort. The implication is that if healthcare access and delivery are to improve, the responsibility cannot fall on any one person or entity and that efforts need to come from the top (i.e. leadership) and ground-levels. In other words, if health literacy is to improve at the local and organizational level, it needs to be a collaborative and collective effort that involves individuals and teams (like the care coordination team) at all levels—from the patients served all the way up to those in leadership positions.

While I can only speak for the clinic where I conducted my observations, I would argue that the hiring of CHNs is one way to work towards this larger and collective effort. One reason is that they serve as trusted mediators or liaisons between communities served (often underserved communities) and the healthcare system. With these connections they could potentially help identify patients who would be willing to participate in the design and evaluation of health information and services which is one of the listed “attributes” of a health literate organization. To do this, researchers have suggested establishing advisory groups and/or collaborating with the “target” community in the design and testing of interventions. The CHNs could also potentially help to obtain feedback on existing health information and services and involve patients in the development of new strategies, practices and resources on health and the healthcare system that do not essentialize the populations served. They could also potentially work with communities to create alternatives to written documents that permeate so much of the healthcare system and which privilege reading as the primary delivery system of meaning.

Pedagogical implications.

The are several pedagogical implications of this study. First, health literacy may not be some “thing” that can be formally taught in decontextualized settings. As the CHNs demonstrate through their work, so much is learned in the doing and as-needed on *a* path to care, which is rarely an individual endeavor. For this reason, all the scaffolding the CHNs do and guidance they provide for families in context as events and interactions unfold is so important and useful. Based on more sociocultural theories of learning, the more families can learn in the contexts in which information is relevant or where practices and interactions take place, the more effective it is likely to be in the long-run. This includes the many other contexts, places and spaces in which health-related decisions are made (e.g. grocery store, home). With that said, it may be beneficial for there to be more in context teaching and learning opportunities that account for and respond to families' needs (e.g. language support) and limitations (e.g. transportation). I would argue that these kinds of learning opportunities may be better suited for the situated nature of health literacy and how no path to care is linear, but rather, dynamic and often full of new experiences, interactions and people. Of course, there are experiences and expectations that seem to cross contexts, and it would also be valuable to identify those as well for learning purposes.

Another pedagogical implication of this study involves assessment. As I described in Chapter 1, health literacy is often measured using decontextualized tests such as the Rapid Estimate of Adult Literacy, which includes how many health-related words one can read aloud and pronounce correctly within five seconds. It is unclear what purpose(s) a test like this serves or what it helps us understand about what people know and how best to work with them. The findings in this study suggest that tests like this fail to account for the situated, social and distributed nature of health literacy and the complex ecologies in which health-related decisions are made and information is sought. They also fail to account for the dialogic nature of healthcare delivery and how different these experiences can be across contexts. Establishing a reading level, for instance, does not help us understand to what extent a patient is able to effectively communicate with a provider during different kinds of medical encounters let alone whether or not they are able to advocate for themselves. In Chapter 4, I discussed one such example where a mother had was comfortable interacting with a provider in English with her older children but found it difficult to do so with her newborn as there were more complicated and culturally specific questions.

Many current health literacy assessments also fail to account for the culturally specific content embedded in healthcare delivery and messages that many refugees (among others) may not be familiar with—making it difficult to make sense of certain information or interactions even if they do speak English. Health insurance, for instance, is very complex and culturally specific. For most of the refugee families at this clinic, it is new concept shaped by practices and procedures of which they are unfamiliar. The CHNs themselves, as evidenced in Chapter 6, are still figuring it all out and continue to learn by doing for their families. Other examples include some of the culturally specific questions asked during medical visits. For example, I often heard the doctor ask if a families' home was "child proof." The question assumes the parents know what this means and how to respond, which many did not. Finally, these tests do not account for language(s) spoken and the knowledge one might possess despite not speaking the dominant language (i.e. English). As I have shown, even if refugee parents do not yet speak English, with the help of the CHNs, they are still learning and doing. It is unfair, then, to assume that because they do not speak English they do not know anything at all.

Another pedagogical implication involves resources for learning. At this time, there are few accessible resources—other than the CHNs—for families to turn to when it comes to health-related questions and concerns. Again, I wish to use health insurance as an example. The majority of existing resources to learn about health insurance are at local DES offices or online and in English. For most of the families at this clinic, these resources are not accessible to them. Many families do not have phones let alone internet access; and even if they did have internet access, there is no guarantee they would be able to navigate the web in order to access the resources they need (most of which are in English anyway). Furthermore, there seems to be no resource(s) that the CHNs can direct families to for the support they would need to learn. I would argue that there may be opportunities here for more capacity building within communities served to further distribute the labor. As an example, it may be valuable to have more trained members or “ambassadors” as the CHNs referred to them, within communities served to support others with health insurance or collaborate in the design and testing of material resources families could access on their own.

Methodological Implications

One of the goals of this study was to learn more about what the CHNs know, how they know it and how what they know influences and shapes the work they do. In other words, I wanted to surface the local, situated and experiential knowledge embodied in their practices that had not been systematically documented and/or examined. While critical incidents and the critical-incident-interview technique have been used in pedagogical research and in research on interpersonal relations and interactions in the workplace, this study demonstrates how critical incidents (and listening for them) can also be used as a method of intercultural inquiry. As I have shown, most of the CHNs work involves having to negotiate and make sense of tensions and differences between cultural practices, beliefs and value systems in multiple languages. By adopting the critical incident interview technique, I was able to listen for and identify moments or incidents where the CHNs were doing this kind of internal mediational work and try to unpack what was happening and what might be critical or significant about the experience they were describing. By doing so, I was able to render the tacit as explicit and therefore subject to examination and analysis with the CHNs. This is to say that this method of inquiry proved to be very useful when it came to surfacing local “funds of knowledge” that reflected their intercultural understandings and sense-making.

I would also argue that this method of intercultural inquiry (i.e. the use of critical incident methodologies) is useful for making sense of the dynamic differences between individuals, groups, organizations and institutions. The critical-incident-interview technique prompts researchers to attend to tension and friction, which often is the site of difference. In other words, this technique draws our attention to difference--not as something stagnate, but as something relational (i.e. tension suggests that there is a rub between individuals, groups, etc.). While it is valuable to look for what is shared and similar, it is equally as important to look for what is not, especially in a context like this one where it can be an important and at times crucial interpretive resource rather than a prepacked assumption. By writing the data-driven scenes and bringing them to the CHNs, I was inviting them into an embodied literate practice where difference and variation were welcomed, challenged and used as springboards for exploring alternative perspectives. The goal of this literate practice was not to come up with “answers” or “solutions,” but rather, to make sense of situations in real time and for the whole group to see and explore together. For this reason, pausing at certain critical moments of the incidents was especially useful as it encouraged them to think on their feet as they often do in their work. It also facilitated a more robust conversation and more complex renderings of what was happening and why. Through this literate practice, the CHNs demonstrated a variety of ways of looking at and interpreting information, actions and things said (and not said). The findings in Chapter 6 are a partial testament to the value of this methodological approach to intercultural inquiry; the findings reflect possibilities and possible interpretive lenses for looking, knowing and inquiring which can get obscured on the path to “answers.”

This is not to say that “answers” and “solutions” should not be pursued. One of the underlying goals of this study was to support a broader engagement with the scenes in order to begin to unpack what made them problematic or vexing in the first place so that the CHNs and the clinic more broadly might be in a better position to pursue those “answers” and/or “solutions.” By drawing on a methodology of engagement, I demonstrate that sometimes in research, it is about supporting others as they find their own answers. As I have shown in this study, the CHNs already have too many responsibilities and are often needed in too many places. There is not usually enough time for the kind of systematic rhetorical and knowledge-work needed to reflect upon their experiences individually or as a collective. However, as graduate student pursuing my doctoral degree, I did have the time. I had the time to observe, trace and document what they do and listen as they made sense of their social worlds and their roles as CHNs. I was able to stand back and see and examine what they seemed to be doing and working towards together, how they communicated and talked about what they were doing and what they have learned along the way. In other words, and in the spirit of learning and attending to my study participants’ priorities, I took the time to observe, document, listen and do the kind of assembly work that Grabill (2013) calls for in order to support a broader engagement of inquiry *with* the CHNs. This assembly work was so important in this study because most of what the CHNs do (and how they do it) has not been systematically documented; as evidenced by this study, doing so takes time and labor, which is one of the reasons it may not happen as often as it should. This kind of assembly work was a crucial first step towards identifying and understanding what the CHNs do and are working towards together. Without having done the assembly work I did, (which first manifested as a robust inventory of their practices and reflections of those practices) I would not have been able to provide the nuanced and complex rendering of the work they do to support refugee families (and how the do it) as well as the experiential and situated knowledge that informs their efforts and which reflects the many tensions they (and their families) have to navigate and make sense of on a daily basis.

Much of what I have just described responds to and resonates with more recent calls within the critical humanities to not only reach further for knowledge—to the places where we as researchers tend not to reach (e.g. the margins of the margins), but to also reach out differently. The entire research and writing project has been an emergent epistemic endeavor involving dynamic and embodied intercultural inquiry. Even the research methods were in some ways emergent while deeply connected to the data. Sometimes this left me feeling unsettled as I wrestled with decisions along the way while trying to be responsive to what I was seeing, hearing, learning and feeling. This study demonstrates that there are different ways in which we might pursue knowledge—not as some fixed and sedimented "thing" but instead as something relational, often meeting at the intersections of difference. This is the space that the CHNs live and breathe in as CHNs and where their invention and inquiry work takes place on a daily basis. I therefore drew on methods that helped me to more effectively meet the CHNs at those intersections so that I could catch a glimpse of their dynamic thinking and ways of knowing.

Future Directions

Throughout this study I often used the word "agency"—sometimes when talking about communication, sometimes when talking about healthcare delivery and access to care, and other times when talking about parenting. What I mean by "agency" has not been fully theorized in this study, but efforts to do so are important when trying to understand what it means to act as an agent in the healthcare system rather than a passive participant. I still do not know to what extent the refugee families at the clinic felt they were capable of agentive action or how agentive action can be understood in this context. In the future, I hope to pursue a research agenda that would help me to begin to theorize agency in healthcare, health literacy and health communication. I encourage other researchers in these fields to do so as well as I view such efforts to be important steps towards improving communication in the context of healthcare delivery as well as the quality of the care received.

Finally, some researchers might continue to wonder, why refugees? Why CHNs working with refugees? Why [and] should there be more research like this? I would argue that the findings I have presented have much to offer in terms of thinking about how to improve access to care and health literacy for refugee families, but also for patients more broadly. For instance, as I indicated in my findings, some of the practices that the CHNs engaged in were adopted by the general pediatrics clinic because they found them to be useful to their patients as well. I would argue that the CHNs embodied sensitivity and experiential knowledge make them valuable interpretive resources for thinking about ways to provide more culturally and linguistically responsive care, and what that might look like in practice. This kind of sensitivity (and the awareness it brings) is important when working with anyone in healthcare (and in other contexts such as education). As a researcher interested in health literacy and communication in the context of healthcare delivery and access to care, I hope to keep looking for and learning from such exemplars.

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APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL FORMS

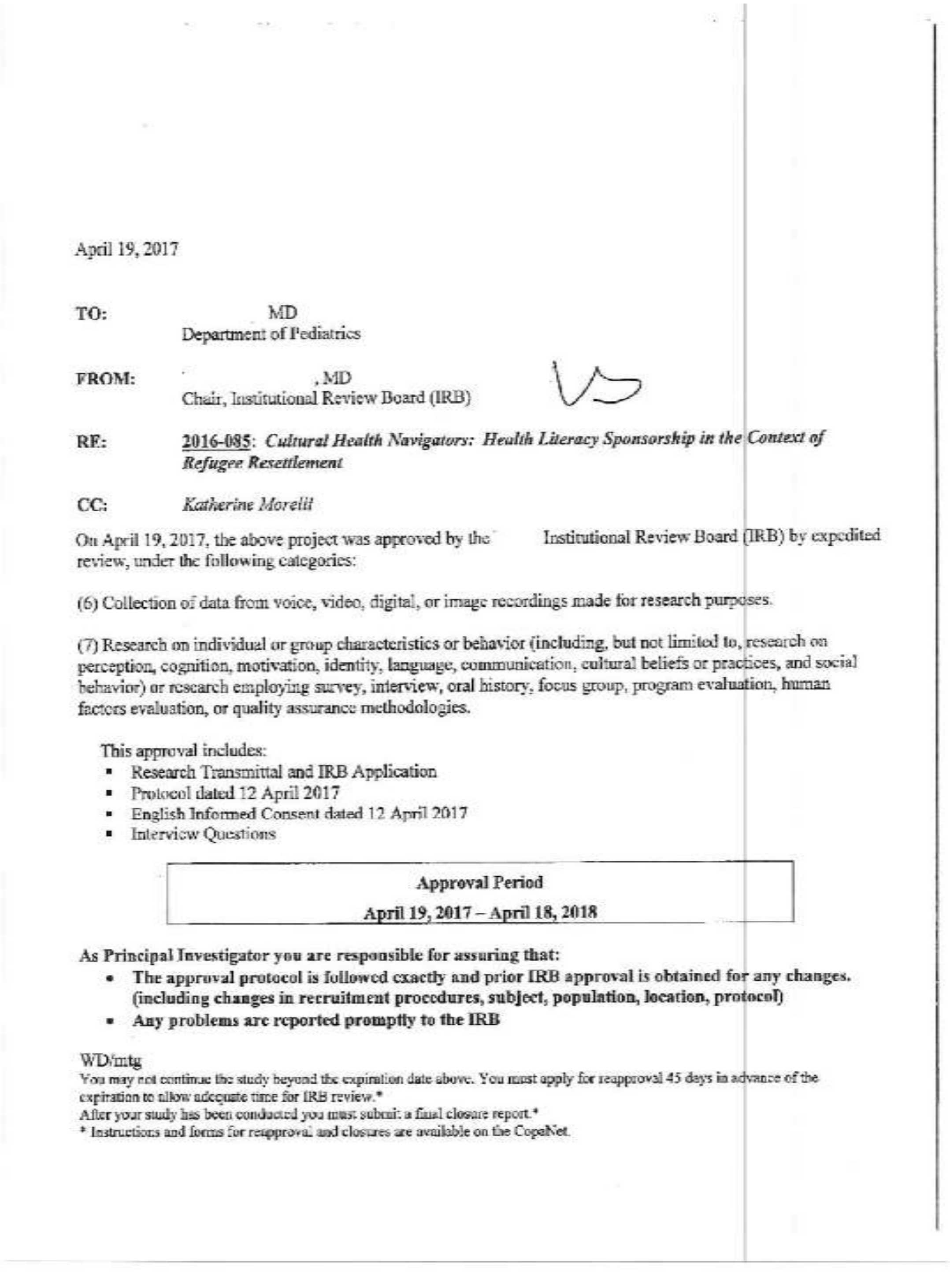
ASU Knowledge Enterprise Development

Doris Warriner,

On April 28, 2017, the ASU IRB reviewed the following protocol:

Type of Review:	Contextual review
Title:	Cultural Health Navigators
Investigator:	Doris Warriner
IRB ID:	STUDY 00006134

The above-referenced protocol has been given a contextual review and the IRB acknowledges that oversight is deferred to the [redacted] IRB. The ASU IRB understands that the IRB will provide review, approval, and continuing oversight as required by 45 CFR Part46, 21 CFR Parts 50,56, and 812 and in accordance with applicable Federal and State Laws as authorized by the Affiliation Agreement.



April 19, 2017

TO: MD
Department of Pediatrics

FROM: , MD
Chair, Institutional Review Board (IRB)

RE: <u>**2016-085**</u>: ***Cultural Health Navigators: Health Literacy Sponsorship in the Context of Refugee Resettlement***

CC: *Katherine Morelli*

On April 19, 2017, the above project was approved by the Institutional Review Board (IRB) by expedited review, under the following categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

This approval includes:

- Research Transmittal and IRB Application
- Protocol dated 12 April 2017
- English Informed Consent dated 12 April 2017
- Interview Questions

Approval Period

April 19, 2017 – April 18, 2018

As Principal Investigator you are responsible for assuring that:

- **The approval protocol is followed exactly and prior IRB approval is obtained for any changes. (including changes in recruitment procedures, subject, population, location, protocol)**
- **Any problems are reported promptly to the IRB**

WD/mtg

You may not continue the study beyond the expiration date above. You must apply for reapproval 45 days in advance of the expiration to allow adequate time for IRB review.*

After your study has been conducted you must submit a final closure report.*

* Instructions and forms for reapproval and closures are available on the CopeNet.

APPENDIX B

PARTICIPANT CONSENT FORM

INFORMED CONSENT DOCUMENT
AGREEMENT TO BE IN A RESEARCH STUDY

PROTOCOL NUMBER AND TITLE OF STUDY:

Cultural Health Navigators: Health Literacy Sponsorship in the Context of Refugee Resettlement

NAME OF PERSON IN CHARGE OF THE RESEARCH STUDY (STUDY DOCTOR/INVESTIGATOR):

Dr. [redacted]

TELEPHONE NUMBER(S), DAYTIME:

[redacted]

INTRODUCTION

You are being invited to volunteer for a research study. You must read and sign this form before you agree to take part in this study. This form will give you more information about this study. Please ask as many questions as you need to before you decide if you want to be in the study. You should not sign this form if you have any questions that have not been answered.

PURPOSE OF THE STUDY

The purpose of this study is to document and examine the work that Cultural Health Navigators who are working within the Pediatrics Clinic of [redacted] do to serve and support refugee families.

HOW LONG THE STUDY WILL LAST AND HOW MANY PEOPLE WILL BE IN THE STUDY

The study will last about three to four months and will involve observations of the work that Cultural Health Navigators do at the clinic, three to four individual interviews about what you do and why, and one or two focus groups with other Cultural Health Navigators. The focus groups will provide an opportunity for me to share findings and receive feedback and/or input from you. All Cultural Health Navigators working in the pediatrics clinic are hoped to be in this study.

WHAT WILL HAPPEN DURING THE STUDY

Before the study starts, you will be asked to sign this consent form.

Study Procedures:

During the weekly scheduled meeting with all Cultural Health Navigators at the Pediatric Clinic, you will be presented with this consent form. I will talk about this study with you. You will have a week to read this form and think about if you would like to participate. During a second meeting a week later, you will have an opportunity to ask me questions about the study and sign this form. If you agree to participate I will observe you at work in the Pediatric Clinic during the months of May, June, July and August of 2017. I will also schedule three interviews with you each month. The interviews will take place during work hours at the Pediatric Clinic. The first interview will be sometime in May or June. The second interview will be sometime in June or July. The third will be sometime in June or July. Each interview will take approximately 30 minutes. The interviews will include questions about the work you do at the clinic to support refugee families. The interview questions will also ask you about your past experiences with the clinic to support refugee families. The interview questions will also ask you about your past experiences with the U.S. healthcare system. I will also schedule two focus groups with all Cultural Health Navigators participating in this study. One will take place in June or July of 2017. The second focus group will take place in July or August of 2017. The focus groups will take place during work hours at the Pediatric Clinic. Each focus group will take approximately one hour. The focus groups will give me a chance to share my findings with you, and get feedback.

POSSIBLE SIDE EFFECTS AND RISKS

There are no foreseeable risks or discomforts to your participation.

POSSIBLE BENEFITS OF THE STUDY

You may receive a chance to be in a research study that may help others. This study could inform programs or policies that support the work that you do with refugee families in the pediatric clinic at [redacted] It may also offer insight on how other health professionals can meet the needs of refugee families and compliment your efforts.

ALTERNATIVES TO PARTICIPATING IN THE STUDY

Since this study is for research only, the only other choice would be not to be in the study.

CONFIDENTIALITY

Your records of being in this study will be kept private except when ordered by law. The following people will have access to your study records:

- The investigators
- [redacted] IRB

If the study results are presented at meetings or printed in publications, your name will not be used.

LEGAL RIGHTS

You will not lose any of your legal rights by signing this consent form.

CONTACT INFORMATION

If you have questions, concerns, or complaints about this study contact:

Dr. [redacted]
[redacted]

OR

Katherine Morelli
(860)-878-9966
kemorelli@gmail.com

If you do not want to talk to the investigator or study staff, if you have concerns or complaints about the research, or to ask questions about your rights as a study subject you may contact the IRB at [redacted]. [redacted] policy indicates that all concerns/complaints are to be submitted in writing for review at a convened IRB meeting to:

Mailing Address: **OR**	**Email Address:**
[redacted]	

APPENDIX C

PATIENT AUTHORIZATION FORM

INFORMED CONSENT
PATIENT AUTHORIZATION – FIELD OBSERVATION

NAME OF SPONSOR COMPANY:

PROTOCOL NUMBER AND TITLE OF STUDY: 2016-085

NAME OF PERSON IN CHARGE OF THE RESEARCH STUDY (STUDY DOCTOR/INVESTIGATOR): Dr. [redacted]

TELEPHONE NUMBER(S), DAYTIME: [redacted]

INTRODUCTION

Currently, a graduate student is conducting a research study. The study will examine the work of the Cultural Health Navigators. The study will involve observations of the work that these Navigators conduct at the clinic. The study may include audio recordings of the Navigators as they work with you the refugee. If you agree to allow the student to observe the Navigators as they discuss your specific case, you will be asked to sign this form. Please ask as many questions as you need to before you decide if you wish to allow the observer to attend your sessions with the Navigator. Your records will be kept private. You will not lose any of your legal rights by signing this form.

CONTACT INFORMATION

If you have questions, concerns, or complaints about this study or to report a study related injury, contact:

Dr. [redacted]
[redacted]

If you have concerns or complaints about the research you may contact the IRB.If you have questions about your rights, you may contact the IRB at [redacted] [redacted] policy indicates that all concerns/complaints are to be submitted in writing for review at a convened IRB meeting to:

Mailing Address: OR	**Email Address:**
[redacted]	

If you are unable to provide your concerns/complaints in writing or if this is an emergency situation regarding subject safety, contact our office at:

[redacted]

[redacted] IRB has approved the information in this consent form and has given approval for the investigator

APPENDIX D

CULTURAL HEALTH NAVIGATOR INTERVIEW PROTOCOL

INTERVIEW ONE

I would like to hear about your life before coming to the U.S.

1. Where were you born?
2. Where did you live before coming to the U.S.?
3. What year did you arrive in the U.S.?
4. What are your earliest memories of living in the U.S.?
5. When did you learn English?
6. Did you speak English often in your home country?
7. How many languages do you speak?
8. Could you talk about your experiences with healthcare before coming to the US?
9. When you first arrived in the US, what did you know about healthcare?
10. Do you recall the first time you visited a clinic or a doctor? What was that like for you?
11. What or who was most helpful when you had questions about health or healthcare?
12. Could you tell me how you learned about the US healthcare system?
13. Can you remember an experience that was particularly difficult for you when you first encountered the US healthcare system? What do you think made things difficult? Did anything make the situation easier for you?

I would like to ask you about living and working in [state]**:**

14. How long have you lived in [city]?
15. When did you become a cultural health navigator?
16. How were you hired?
17. Why did you decide to do this work?
18. How do you think being multilingual helps you do your job?
19. Did you receive any training when you began working as a cultural health navigator?
20. Could you talk about when you first started working as a cultural health navigator? What was that like?

INTERVIEW TWO

1. Can you describe some of the routines you have as a Cultural Health Navigator at the pediatrics clinic? What kinds of things do you do regularly?
2. Out of all of those practices that you just described to me, which ones are your main responsibilities?
3. Do you consider your job to be a challenging one? If so, what makes it challenging? If not, why not?
4. When you think about what you do as a CHN and the practices you described, what do you think helps refugee families the most?
5. I’ve noticed that you seem to know your patient's pretty well. Could you talk about some of the different ways you get to know them?

INTERVIEW THREE

Kriti

1. During the last interview you talked about how one of your main responsibilities is to make sure you say the “right” information between the provider and the patient. Can you say more about this? Hoping to hear more about what you mean by “right” information?
2. Last time we spoke, we talked about how refugee patients often have trouble understanding the culture here in the U.S. .and bring many challenges to the clinic. Could you talk more about this?
3. We’ve talked a few times together about how you encourage parents to try to “improve” themselves outside of the clinic because this would help you all here at the clinic as well. Could you give me examples of how you do this? I’d like to understand how your efforts help these families/parents improve themselves.
4. In many conversations we’ve had together, you’ve talked about how sometimes you’re asked to do things, by both patients and providers, that you don’t think are your responsibility as a CHN. Can you think of any examples? What do you think about this?
5. This question brings us back to the very first interview I had with you where we talked about your experiences coming to the US and with the US healthcare system. Could you talk about whether you think those experiences influence the work you do as a CHN?
6. If you could give a new cultural health navigator any advice, what would it be?

Casey

1. During the last interview you talked about how one of your main responsibilities is to help your patients navigate the healthcare system and to know how to seek help. [Can you think of any examples of this?] What do you think about this responsibility?
2. Last time we spoke you also talked about how patients sometimes share information with you that they don’t want you to share with anyone. You explained that if it is medically related you tell the provider, but if it’s related to culture you address it? Could you help me understand this? How do you decide when to go to the provider?
3. You’ve mentioned a few times how important it is to be in the exam rooms with your patients so that you can explain things to them and see how they react. Can you say more about this and how it’s important?
4. We’ve talked many times about how stressful it can be to reach or locate your patients and keep track of other places they go to seek care. How do you manage this stress? What strategies do you use to reach or locate your patients?
5. This last question brings us back to the very first interview I had with you where we talked about your experiences coming to the US and with the US healthcare

system. Could you talk about whether you think those experiences influence the work you do as a CHN?
6. If you could give a new cultural health navigator any advice, what would it be?

Samira

1. In our last interview you talked about how important it is to make things “clear” between the provider and the patient so that “neither get offended.” I’d like to hear more about this? What do you mean when you say, “make things clear”?
2. During the last interview, you also talked about how one of your main responsibilities is educating your patients. [Can you think of any examples of this?] What do you think about this responsibility?
3. We’ve talked a few times together about situations with providers that you felt were difficult for you and the patient, and you felt that you had to explain “the rules” to the provider. Can you explain this a little bit more? What do you mean by “the rules”? Why do you think you have to explain them?
4. Another thing you talked about in our last interview were the classes you all were offering patients in the community, and how you would like to do this again. When you think about these classes, why do you think these are helpful for your patients?
5. This question brings us back to both interviews I’ve had with you. You’ve mentioned that as a refugee, you “know that it’s important” that you’re here at the clinic for your patients. Can you tell me more about this and how your experiences as a refugee influence the work you do now as a CHN?
6. If you could give a new cultural health navigator any advice, what would it be?

Reem

1. In our last interview you talked about how one of your main responsibilities is to make sure you say “accurate” information between the patient and provider. I know sometimes this isn’t easy. Can you tell me more about this? What do you mean by “accurate”?
2. You’ve talked to me about a few situations where a patient told you something and you wanted to tell someone, but you felt that it was “for them to tell,” not you. Can you think of any examples? What do you usually do in such situations?
3. We’ve talked many times about how stressful it can be to reach or locate your patients and keep track of other places they go to seek care. Can you talk more about this? What makes it stressful?
4. In many conversations we’ve had together, you’ve talked about how sometimes you’re asked to do things, by both patients and providers, that you don’t think are your responsibility as a CHN. Can you think of any examples? What do you think about this?
5. This question brings us back to the very first interview I had with you where we talked about your experiences coming to the US and with the US healthcare

system. Could you talk about whether you think those experiences influence the work you do as a CHN?

6. If you could give a new cultural health navigator any advice, what would it be?

APPENDIX E

CARE COORDINATOR INTERVIEW PROTOCOL

INTERVIEW ONE

1. I know you work as the Care Coordinator in the pediatrics Clinic, but you also sometimes step in as a CHN. Can you tell me a bit more about these two different roles?
2. Can you describe some of the routine practices you engage in as a Care Coordinator?
3. When you think of the work you do at the pediatrics clinic, what do you think helps refugee families the most?
4. Do you consider your job challenging? What do you mean by that? Can you think of any examples?
5. You seem to know many of your patients and families pretty well. Could you talk about why this is important? And tell me a bit about how you get to know them?
6. You and I have talked about some of the projects that you've started working on in collaboration with the CHNs but have not been able to finish. Which one(s) would you like to continue working on? Why do you think this is important? Do you see any impediments to bringing that particular idea to reality?

APPENDIX F

DATA-DRIVEN SCENES FOR GROUP CONVERSATION

STORY ONE:
EXPLORING DECISION-MAKING PROCESSES

In this incident, I'm interested in focusing on your decision-making process. I'm especially interested in how and why you make the decisions you make and what are the consequences or outcomes of those decisions.

Narrator:

A mother and her three children arrive at the clinic for a follow-up visit. The family did not take a taxi to clinic but got a ride from a family friend. You called the mother many times about bringing her children in for the follow-up visit. It is often difficult to get her to come to the clinic, but now she is here. She walks up to the registration desk and shows her children's [insurance] ID cards. She doesn't speak much English.

***Front Desk Staff:**

Your insurance is inactive. Did you know it was inactive? You need insurance for this appointment.

Narrator:

The front desk staff gives the mom her cards back. The mother isn't sure what to do next and might not understand what the front desk staff said. She is still standing there.

Front Desk Staff:

No insurance. You have no insurance.

Narrator:

Now the mother seems to understand something is wrong but still isn't sure what to do next. She looks worried. She takes out her phone and calls you. You pick up the phone and say….

CHN:

Hello?

Mother:

They say no insurance! I'm here and they say no insurance!

***CHN:**

What do you mean no insurance? Do you mean it's not active? Did you go to DES?

***Mother:**

I don't know! Why do they say no insurance?! I showed my cards. I don't understand!

***Narrator:**

You know that helping with insurance is not one of your responsibilities, and you don't want it to become one of your responsibilities. You also know that it was difficult to get the mom to come to the clinic, and that the children really need to be seen.

***CHN:** ? ? ? ? ? ?

SCENARIO TWO:
EXPLORING PERSPECTIVES ON A PROBLEM

In this incident, I'm interested in your different perspectives and understandings of a situation/problem that I've heard about from many of you.

***Narrator:**

You are in an exam room in the clinic. You are working with a mom and her two children. The two children are playing loudly in the room. One is seven and the other is ten years old. The mom does not speak English, but the children do. You have known the family since they got here around two years ago. The family is there for a follow-up visit about a medical concern. The concern is about the children's weight. The doctor is concerned that they are overweight for their age and height and this could lead to problems later in life. This issue has been talked about several times during other visits. The last time they were at the clinic the mom said she understood the concern and was planning to do something about it in the ways the doctor suggested. However, today the doctor sees that the children have actually gained more weight since their last visit two months ago. The scene begins with the doctor asking about the children's diet.

Doctor:

Ok, mom, talk to me about what's going on. Have you made any of the changes we talked about last time? No more juice? No more soda?

Narrator:

While the doctor is talking with the mom the children are talking loudly with each other. One of them is opening drawers and looking inside them. The mom is quiet. Suddenly one of the children says while smiling and giggling...

Child 1:

Soda!

Doctor:

Ok, thank you, but I'm trying to talk to your mom right now, ok?

Child 2:

Chips too. We eat chips!

***Narrator:**

The doctor is trying to talk to the mom, but the children keep interrupting. They are still playing with items in the room and making noise. One of the children is crawling all over the floor. It is difficult to have a conversation with the mom. The mom is not responding to her children's behavior.

Doctor:

Ok, it’s really important that I talk to your mom right now, so I need you to be quiet, ok? Mom, is this true? Are they eating chips and drinking soda?

Narrator:

You know this mom well enough to know that she looks uncomfortable and tense. She looks at her children who are still touching and opening things in the room and talking loudly. She looks at you and says...

***Mom:**

I don’t want to tell the doctor about what’s going on with the family. I’m having a lot of difficulty with my children. They don’t listen. I don’t know what to do. I’m scared to not give them what they want. What happens if I don’t give them juice or soda? I think I’ll get in trouble. They may say something at school. They take kids away, don’t they?

SCENE THREE:

EXPLORING ADVOCACY OUTSIDE THE CLINIC

In this incident, I am interested in how you come up with strategies to advocate for families when you are not with them. I am also interested in how you help families advocate for themselves when they are on their own.

***Narrator:**

A mom you have been working with for many years is at the pharmacy near her home. One of her children has a chronic medical issue. The doctor recently adjusted the medication schedule from twice a day to once a day. She is at the pharmacy trying to get a refill for her child’s prescription. You have noticed over the years that this mom often has difficulty with the pharmacy and calls you for help. The mom does not speak much English, but she goes alone to the pharmacy. After her interaction with the pharmacist she calls you. She sounds very upset and frustrated.

CHN: Hello?

Mom:

I’m at the pharmacy and they say they won’t give me my medication. They say I need to talk to the doctor to get my medication. You need to call the pharmacy! You need to call the doctor! I need this medication today!

CHN: Ok, let me look into this and call you back

***Narrator:**

You talk with the staff nurse and she calls the pharmacy. The pharmacy tells you that they filled the new prescription two weeks ago. They say they told the mom about the new dosage schedule and that they could not refill the medication because it is too early.

***Nurse:**

It seems like we often have issues talking with this family and the pharmacy. We can't be there to help the family all the time. What are we going to do about this? Is there anything we can do to prevent this from happening in the future?

APPENDIX G

THE GRADUATION LIST

Communication in the clinic

1.Front Desk

- Questionnaire (check in)

2. In clinic

- Rooming patients
    - Clarify the name and address
    - Allergies to medicine
    - Pharmacy they use
    - Depression questions
- Discharging patients
    - Understanding the discharge instructions and the date to call to make the appointment
    - Call a month ahead of the indicated date to schedule the actual appointment
- Vaccinations
    - Signing the consent to give shots
    - Clarifying name and date of birth

3. Providers

- Understand what the doctor says
- Convey her message and community
- Able to ask to clarification questions like culture aspect i.e. how many wet diapers
- Uses more words than body language
- Doctor to remind the patient the dosages of taking medicine

4. Lab and Pharmacy

- Showing the card with name and address
- Requesting syringes
- Understanding the dosages
- Accepting/declining counseling
- Refill: know which medication you need refill for

Transportation

1. Setting up transportation (pick up process)

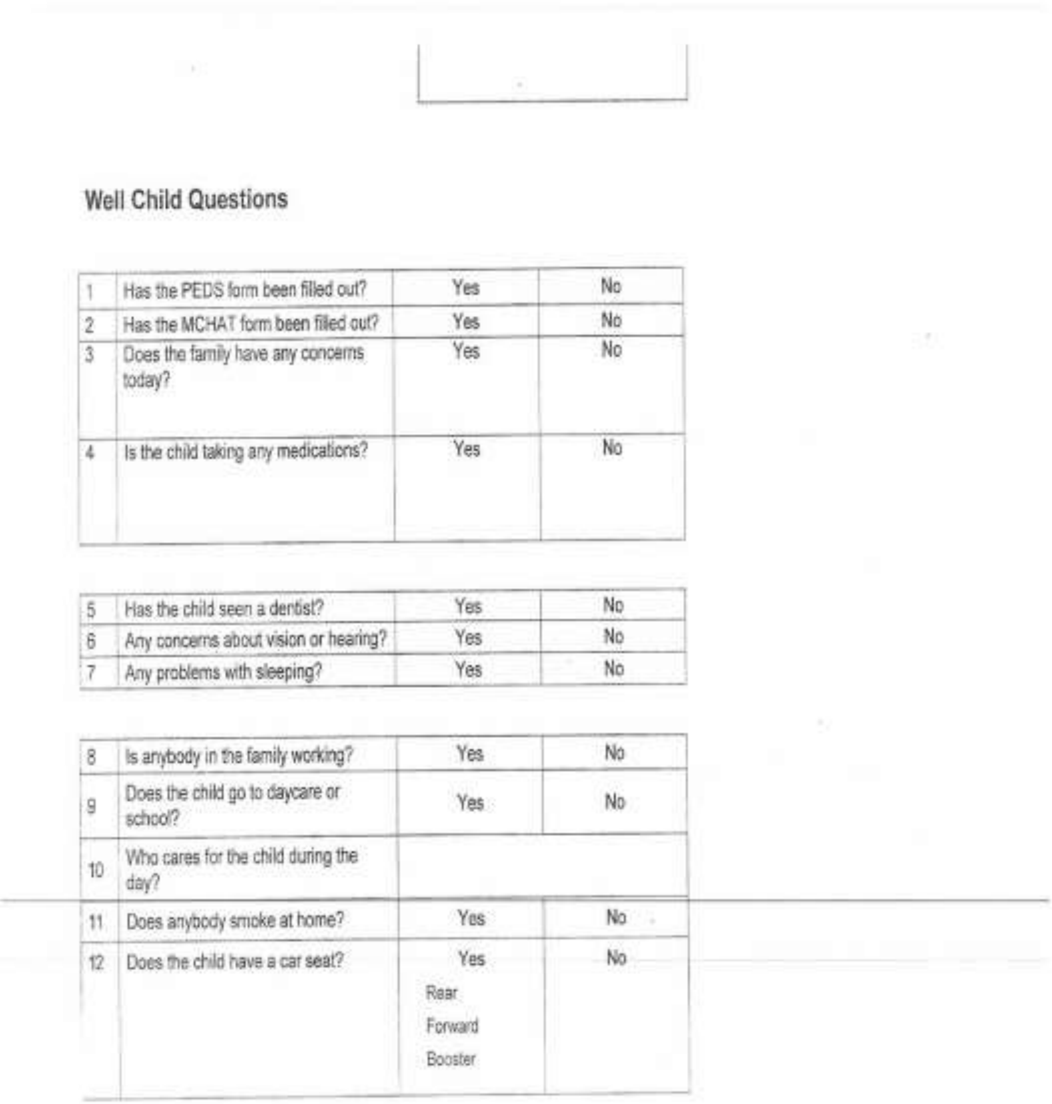
- Each health plan have different prompts
- Calling three days in advance
- Having the child’s [insurance]ID handy
- Name of data and time
- Appointment data and time
- Childs’s home address and phone number
- Providers’ name, address and phone number
- If the plan offers confirmation number please write them down the pickup and return confirmation
- If they don’t have a phone—request the driver to knock on the door or go to the leasing office
- Be there at least 30 minutes before the taxi came

2. Calling for a return taxi (return taxi process)

- For [redacted] call
    - Discount cab call [redacted]
- For other health plans
    - Call the health plan directly
    - Wait at the South entrance or at the Pharmacy when the weather is severe

APPENDIX H

WELL CHILD VISIT QUESTIONNARE

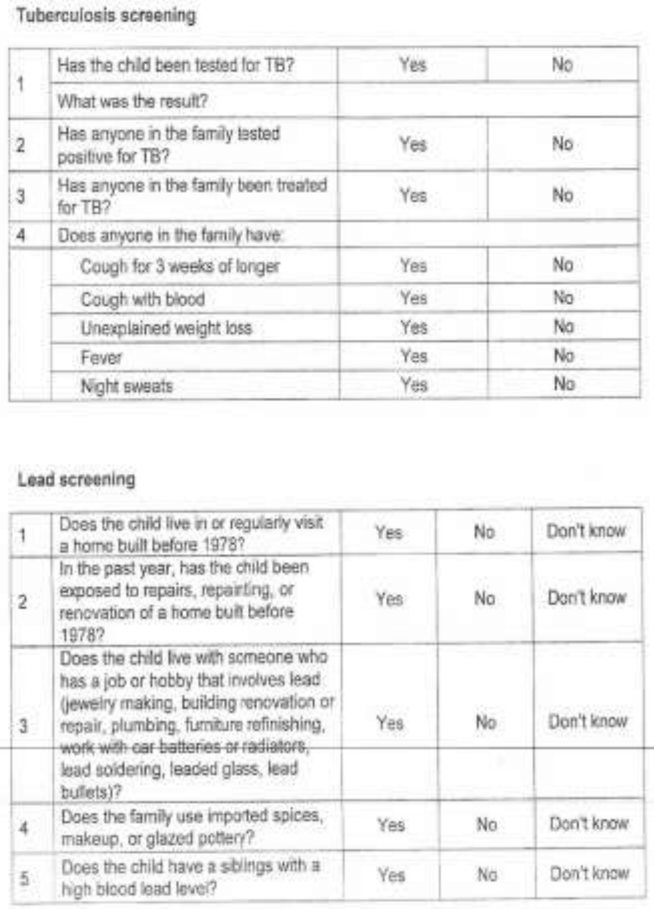


Well Child Questions

1	Has the PEDS form been filled out?	Yes	No
2	Has the MCHAT form been filled out?	Yes	No
3	Does the family have any concerns today?	Yes	No
4	Is the child taking any medications?	Yes	No

5	Has the child seen a dentist?	Yes	No
6	Any concerns about vision or hearing?	Yes	No
7	Any problems with sleeping?	Yes	No

8	Is anybody in the family working?	Yes	No
9	Does the child go to daycare or school?	Yes	No
10	Who cares for the child during the day?		
11	Does anybody smoke at home?	Yes	No
12	Does the child have a car seat?	Yes Rear Forward Booster	No



Tuberculosis screening

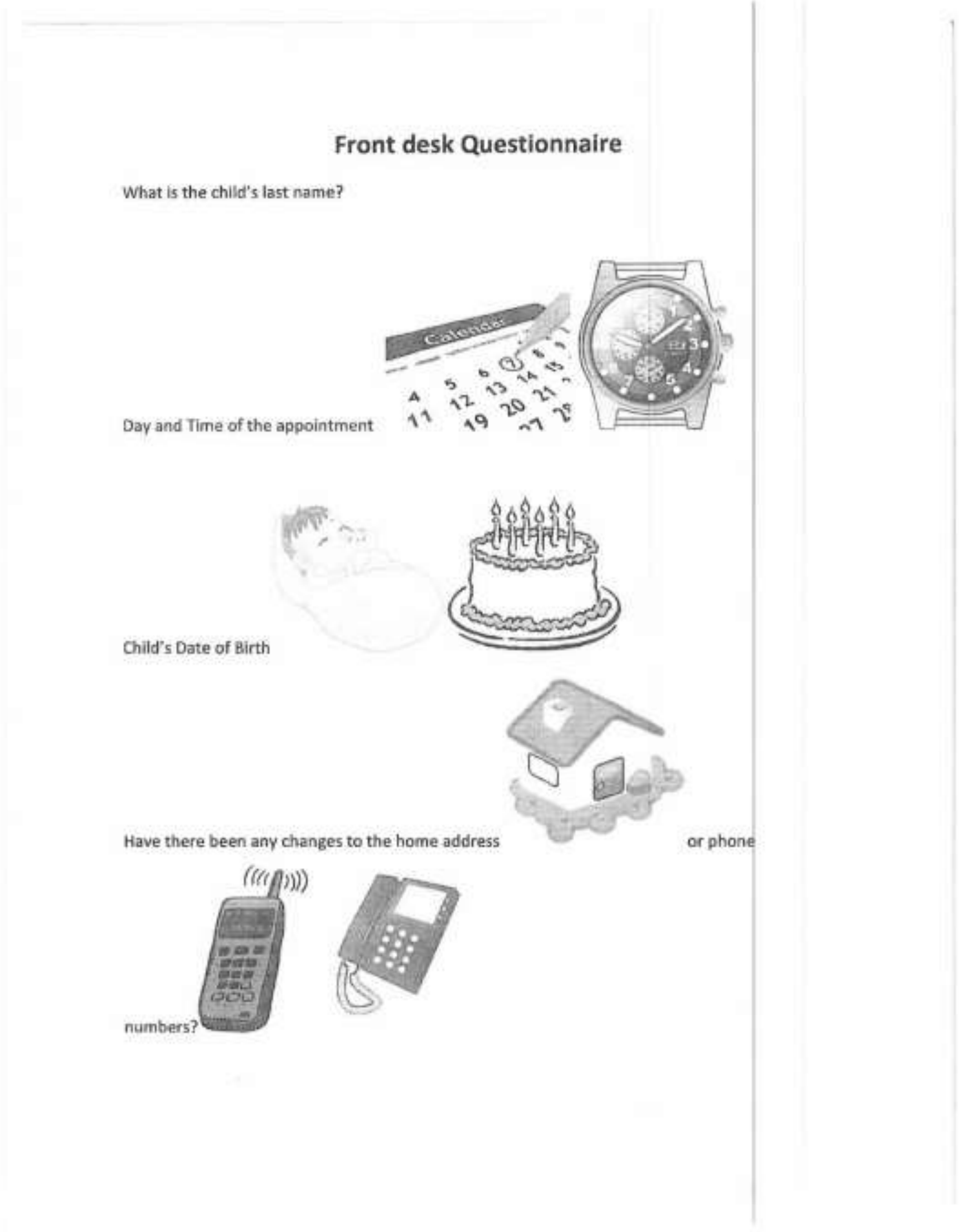
1	Has the child been tested for TB?	Yes	No
	What was the result?		
2	Has anyone in the family tested positive for TB?	Yes	No
3	Has anyone in the family been treated for TB?	Yes	No
4	Does anyone in the family have:		
	Cough for 3 weeks of longer	Yes	No
	Cough with blood	Yes	No
	Unexplained weight loss	Yes	No
	Fever	Yes	No
	Night sweats	Yes	No

Lead screening

1	Does the child live in or regularly visit a home built before 1978?	Yes	No	Don't know
2	In the past year, has the child been exposed to repairs, repainting, or renovation of a home built before 1978?	Yes	No	Don't know
3	Does the child live with someone who has a job or hobby that involves lead (jewelry making, building renovation or repair, plumbing, furniture refinishing, work with car batteries or radiators, lead soldering, leaded glass, lead bullets)?	Yes	No	Don't know
4	Does the family use imported spices, makeup, or glazed pottery?	Yes	No	Don't know
5	Does the child have a siblings with a high blood lead level?	Yes	No	Don't know

APPENDIX I

VISUAL FRONT DESK PROMP



Front desk Questionnaire

What is the child's last name?

Day and Time of the appointment

Child's Date of Birth

Have there been any changes to the home address or phone numbers?

Have you travelled outside the U.S in the past three

weeks?

Does Your Child Have medical insurance or AHCCCS

AHCCCS

ARIZONA HEALTH CARE COST CONTAINMENT SYSTEM

Member Identification Card

HEALTH CENTER NAME

Does Your Child Have a dentist

If No

Do you want to schedule an appointment?