WHY ARE YOU HERE? EXPLORING THE LOGIC BEHIND NONURGENT USE OF A PEDIATRIC EMERGENCY DEPARTMENT

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Caregivers often associate fevers with permanent harm and bring children to emergency departments (EDs) unnecessarily. However, families using EDs for nonurgent complaints often have difficulty accessing quality primary care. Mutual misconceptions among caregivers and healthcare providers regarding nonurgent ED use are a barrier to implementing meaningful interventions. The purpose of this project was to identify dominant themes in caregivers’ narratives about bringing children to the ED for nonurgent fevers. Thirty caregivers were recruited in a pediatric ED for participation in qualitative semi-structured interview from August to November 2014. Interview transcripts were coded and analyzed for themes.

Caregivers’ decisions to come to the ED revolved around their need for reassurance that children were not in danger. Several major themes emerged: caregivers came to the ED when they felt they had no other options; parents feared that fevers would result in seizures; caregivers frequently drew on family members and the internet for health information; and many families struggled to access their PCPs for sick care due to challenging family logistics. Reducing nonurgent ED utilization requires interventions at the individual and structural level. Individual-level interventions should empower caregivers to manage fevers and other common illnesses at home. However, such interventions may have limited impact on utilization outcomes among families with poor access to primary care. Afterhours primary care should be expanded to accommodate families with rigid work schedules and limited transportation resources.
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CHAPTER 1: INTRODUCTION

1.1 Background

Decades of “fever phobia” research has established that parents caring for sick children often associate even low-acuity fevers with permanent harm and bring children to emergency departments (EDs) unnecessarily (Schmitt BD 1980; Crocetti, Moghbeli, and Serwint 2001a; Poirier, Collins, and McGuire 2010; Rupe, Ahlers-Schmidt, and Wittler 2010; Sullivan and Farrar 2011; Wallenstein et al. 2013). Nonurgent use of emergency rooms is often a source of frustration for hospital staff (Fry 2012) and tremendous problem for insurers and health systems seeking to cut costs. However, families using EDs for nonurgent complaints often have difficulty accessing quality primary care. Berry et al. (2008) note that non-urgent visits may result from a combination of difficulty with PCPs and perceptions of higher quality of care in the ED. Parents bringing children with non-urgent conditions to emergency departments tend to have greater difficulty with PCP wait times (Brousseau DC, Bergholte J, and Gorelick MH 2004), and improved appointment availability and access have been associated with reduced non-urgent ED utilization (Brousseau et al. 2009). Chin et al. (2006) suggest that the preference for ED care expressed by parents of non-urgent patients does not constitute deliberate abuse of the healthcare system, but a failure of the primary care system to resolve simple problems. Salami et al. (2012) note that PCPs and EDs would like parents to be better educated about appropriate ED use, while parents want extended working hours from PCPs. However, the challenge of nonurgent ED utilization for fevers and other illness is likely not solely reducible to
caregiver\(^1\) knowledge or primary care access (Guttman, Zimmerman, and Nelson 2003), and mutual misconceptions among caregivers and healthcare providers regarding nonurgent ED use continue to impede the development of meaningful interventions (Salami, Salvador, and Vega 2012; Brousseau et al. 2011).

Fevers are a leading diagnosis among ED patients visiting Children’s Medical Center (Children’s) in Dallas, TX. Like many other hospitals, close to half of all ED visits are for low-acuity conditions. Nonurgent ED visits for fevers can present a problem for a number of reasons. First, the ED is not an ideal place to receive primary care. Trips to the ED disrupt a child’s continuity of care with their pediatrician, and they receive lower quality care overall as a result (Howard et al. 2005). Furthermore, the nature of healthcare finance makes even the simplest ED fever visits significantly more expensive for than a primary care office visit. Though this cost is primarily borne by insurers and health systems, caregivers of commercially insured children see some of this cost themselves through a copay or coinsurance. Additionally, Children’s has millions of dollars in government funding linked to reductions in emergency department utilization, among other metrics. Because the causes of medically nonurgent ED visits are presumed to be somewhat more mutable than those of urgent visits, they are a prime target for intervention.

1.2 Study Purpose

Although there is abundant research on nonurgent ED utilization, it does not easily lend itself to localized interventions. Existing research provides an excellent point of departure for new investigations, and Children’s staff were curious about their own patients and their

\(^1\) Throughout this document, the term “caregiver” is used to refer to a family member assuming responsibility for a child, usually a parent
reasons for coming to the ED. Even in a data-driven world, stories, especially those close to home, play a tremendous role in creating the will for new programs and policies in healthcare (Sobo 2009). Thus the scientific purpose of this study was to investigate how caregivers made decisions about bringing children to the ED with nonurgent fevers. This included an investigation of caregiver beliefs and practices as well as the structural factors that constrained their decision-making. The practical purpose was to identify ways to tailor parent education more efficiently and identify key primary care access issues affecting the use of the emergency department ED for non-urgent fevers. Thus, the study addressed four research questions:

- How do caregivers understand the severity of their child’s fevers?
- How do caregivers make decisions about coming to the ED?
- How does access to primary care affect the use of ED services?
- How do caregivers seek information when seeking care for their children?

1.3 Deliverables

Deliverables to Children’s included a variety of documents, verbal presentations, and action planning activities. Documents included a formal report and several issue briefs. Clinical staff and leadership team members were interested in the study results but did not generally have time to read comprehensive reports, and the issue briefs were created to disseminate results effectively among these groups. A formal presentation was made to a diverse group of leaders, management, and front-line staff on June 30th, 2015. One-on-one and small group presentations were made to interested individuals unable to attend at other dates. Research findings were also incorporated into the planning of an evaluation of the ED’s community
health worker program and the development of a parenting skills program using the low-literacy medical reference guide *What to Do When Your Child is Sick*.

1.4 Limitations

This study collected limited data on caregiver treatment practices, and is unable to provide a great deal of practical information on whether parents were treating fevers effectively at home. Data is not entirely comparable between all interviews, as some interview questions were altered significantly in the early stages of the research. Families with an expressed preference for speaking Spanish during health care encounters are also underrepresented in the study. Only 3 interviews were conducted in Spanish (with families who had a preference for it indicated in the hospital computer system). This represented just 10% of the study sample, whereas this group is roughly 20% of all ED patients. Additionally, data quality may have suffered in interviews where participants had an *unexpressed* preference for Spanish. Community health workers in the ED informed me that some Spanish-speaking families may indicate a preference for English even if they have limited language skills due to a perception that it will make their experience in the hospital less difficult.
CHAPTER 2: CONTEXT OF WORK

2.1 Fever Phobia

Schmitt (1980) coined the term “Fever Phobia” in 1980 to describe parents’ concerns about low-grade fevers and the aggressive approaches they took to treating them. Crocetti et al. (2001b) followed up on Schmitt’s work two decades later; surveys with 340 Baltimore parents at a hospital-based primary care clinic suggested that parents were still unnecessarily treating low-grade fevers based on fears that high fevers could cause permanent harm. In a similar study, Poirier et al. (2010) also found that inappropriate use of fever-reducing medications (i.e., using them for low-grade fevers) was common, as was unnecessary use of the ED for fever. Writing for a physician audience, Sullivan and Farrar (2011) note that parents tend to administer fever-reducing medications due to concerns about normalizing their child’s body temperature; they also emphasize that caregivers tend to view fevers as an illness in of themselves rather than the body’s response to infection. Thus, they describe a need to shift the focus of parental strategies from controlling fevers to comforting children. Wallenstein et al.’s (2013) survey study of “fever literacy” found that nearly 90% of caregivers erroneously believed that fevers could cause brain damage, used antipyretics unnecessarily, and sought professional medical attention for low-grade fevers. More than 80% of participants believed that a fever began at temperatures below 38 degrees Celsius (100.4 degrees Fahrenheit).

Fevers have been a source of fear and worry for parents, and it has been hypothesized that these concerns are more prevalent in parents of young children. A survey of parents attending a hospital-based primary care clinic found that 57% were “very worried” when their
children had fevers; additional, higher levels of worry were independently predicted by fewer years of education, Hispanic ethnicity, and having younger children (Rupe, Ahlers-Schmidt, and Wittler 2010). However, Morrison et al. (2014) found that fever visits to a pediatric emergency department were associated with low caregiver health literacy, but only if children were over two years of age. In a survey of Canadian parents at urgent care centers and emergency departments, concerns about causes of fevers and their seriousness were most prevalent; additionally, parents usually wanted information about febrile seizures and other dangers related to fevers (Enarson et al. 2012). A computer-based educational fever intervention piloted by O’Neill-Murphy et al. (2001) was able to moderately reduce parent anxiety related to fever and increase home management skills. Baker et al. (2009) created an 11-minute educational video teaching fever management skills and piloted it with 140 parents of children presenting to a pediatric ED with nonurgent fevers. Using a prospective randomized cohort design, subsequent ED visits were tracked in both the intervention and control groups. The intervention group showed significant increases in knowledge related to fever, but there was no change in the frequency or medical necessity of their ER visits.

2.1.1 Anthropology and Childhood Fever

Anthropological and other qualitative research on fever has been profoundly influenced by Kleinman et al.’s (1978) work on explanatory models of illness. Helman’s (1978) work on folk models of colds and fevers in the United Kingdom has also been influential in this area. Though much of the qualitative research on self-limiting viral fever (as opposed to fever related to tropical diseases such as malaria) has been not been conducted by anthropologists, this body of work has a distinctly anthropological genealogy.
In an interview study with parents in the United Kingdom, Kai (1996) found that fever was a leading concern relative to other acute childhood illnesses. Fevers inspired fears of potential further harm, irreparable damage, or death. Parents reported that they would continuously monitor fevers and attempt to keep temperatures low, but felt powerless if the fever continued to rise. Diffusing responsibility for the illness by consulting other lay people and medical professionals provided parents with a degree of reassurance. Typically, the need for reassurance overrode any concerns of possible embarrassment resulting from a potentially nonurgent physician consultation. Kai suggests that clinicians address parental fears and beliefs instead of viewing their visits as inappropriate.

In a focus group study of Caribbean women living in the United States, Yearwood (2007) observed that social networks played a crucial role in women’s decisions about treating childhood illness. Home remedies that had been passed down through families were commonly used to treat fever and other illnesses, but women also constantly experimented with new remedies learned of via word of mouth. Doctors were usually a last resort in the treatment of nonacute childhood illness, though many women did not have as large of networks for acquiring remedies and advice as they had had access to in their home countries.

Mikhail (1994) observed that Mexican-American mothers living in rural California regarded fever as serious and used a variety of home remedies and over-the-counter (OTC) treatments before seeking professional medical help. Schwartz et al. (1997) observed low rates of thermometer use among Mexican-American mothers in San Diego County; mothers typically used touch or visual observation to assess the acuity of fevers. Thermometer users were more likely to take their children to see a doctor. Krajewski (1991) notes that fever is occasionally
attributed to the evil eye in some Mexican American communities and may not always have a medical solution.

DeSantis (1989) compared illness concepts related to children under five in a sample of Cuban and Haitian immigrant mothers living in Miami. Cuban mothers had a more biomedical orientation towards health and healthcare (largely due to the national Cuban educational and healthcare systems) and used biomedical language to describe illnesses and preventive measures. Fever was often classified under a biomedical term such as pharyngitis. Fevers in particular were considered the result of spells from evil people, but they could be treated with a variety of home remedies such as teas, herbs, oil rubs, and warm baths. Use of these remedies was usually a first choice of care, and a physician would be seen if home treatments failed to produce results. Physicians were usually the first choice of care among Cuban mothers. However, Cuban mothers tended to engage in collective family decision-making about treatment for children's illnesses, and the input of grandmothers was especially important. Though family decision-making was not unimportant to Haitians, the Haitian population living in Miami was younger and consisted of fewer extended families.

Maternal treatment behaviors also reflected perceptions of the nature of illness and parental responsibilities. Cuban mothers took a variety of preventive actions with their children because illness was perceived to be the result of parental failures. Haitian mothers were more fatalistic and believed illness occurrence to be inevitable; however, they felt empowered to make efforts to control illness once it did occur. DeSantis notes that biomedical and ethnomedical sources of care were not mutually exclusive in either group, and cautions that a particular orientation towards either source of care does not necessarily provide insight into
parents’ explanatory models of illness. For example, use of biomedical treatment does not imply a biomedical explanatory model, and it remains important that providers investigate perceptions of disease etiology thoroughly. Moreover, DeSantis notes that fever in particular is a vague illness category and should be explored further, as it may not carry the same meaning among different cultural groups.

Turkish parents participating in Kalaca et al.’s (2006) focus group study of childhood fever in Istanbul described fevers as frightening for their children to have; parents, were, however, armed with an array of home remedies for treating them. Most mothers did not use thermometers and assessed fevers by touch. They differentiated “regular fever” from “measles fever”; the former was “hot” illness while the latter was a “cold” one (Kalaca et al. 2006:58). Like parents in other studies, Turkish mothers typically involved their social network in determining a diagnosis and appropriate treatment for their children. Similarly, Roma participants in Pavlic et al.’s (2011) qualitative study rarely employed thermometers but were still able to competently assess elevated body temperature and treat fever accordingly using remedies such as teas, compresses, OTC medications, and the placement of potatoes on beets on the skin. The authors further note that an anthropological method and historical approach can aid in establishing the efficacy of alternative treatments that are not necessarily congruent with standard biomedical practice.

In a qualitative interview study, Langer et al. (2013) compared childhood fever perceptions among Turkish and German mothers residing in Germany. As reported in other studies, fever provoked a powerful emotional response related to fear of losing one’s child and treatment actions were situated within a context of maternal duty. Both groups attributed
fevers to infections and climate; only Turkish mothers mentioned the evil eye, while only German mothers cited children’s emotional stress or overexertion. Mothers’ treatment actions included both *instrumental help* such as seeking professional treatment and using medication as well as *affectionate help* that addressed children’s emotional and spiritual well-being. Langer et al. note that culture appeared to shape mothers’ explanations and strategies, but did not alter overall patterns of concern and responsibility. Insight into mothers’ explanatory models could be employed to counsel parents more effectively and avoid any possible delays in treatment.

As Langer et al. (2013) suggest, the studies reviewed here demonstrate that fever provokes a diverse array of culturally mediated caregiving responses. However, common themes include fear related to the possibility of worsening condition (Kai 1996; Langer et al. 2013; Kalaca et al. 2006), use of home remedies prior to seeking professional treatment (Yearwood 2007; Mikhail 1994; DeSantis 1989; Pavlič et al. 2011; Kalaca et al. 2006), and collective diagnosis involving the input of family members, friends, and neighbors (Yearwood 2007; Kalaca et al. 2006; DeSantis 1989; Kai 1996). As Becker et al. (1993) observed in the case of asthma, caregiver perceptions and practices specific to fever may have an impact on how patients go about choosing their care. Though aspects of fever such as the need for reassurance (Kai 1996) are consistent with parent perceptions in cases of nonurgent use in general (Brousseau et al. 2011; Guttman, Zimmerman, and Nelson 2003), the parental fearfulness and uncertainty associated with childhood fever may add a dimension of immediacy which may lead to primary care being omitted from the sequence of treatment-seeking, particularly in afterhours settings. Additionally, the possibility that thermometer use is not particular
widespread in some communities may also contribute to the prevalence of nonurgent pediatric fever visits in the ED; however, it should not be assumed that failure to use a thermometer precludes accurate assessment of fever severity (Pavlič et al. 2011) and it may even be the case that thermometer use increases utilization of formal medical care (Schwartz, Guendelman, and English 1997).

Furthermore, the extent to which fever care decisions may be reached collectively in some communities and cultural groups should be considered carefully. Research on nonurgent ED use has focused largely the actions of individual family-level caregivers, and discourses of appropriate care tend to focus narrowly on the individual responsibilities of parents. Patient counseling aimed at individual decision-making may be ineffective in situations where group consensus or the opinion of a family matriarch plays a significant role in care for a child. Thus, behavior-change oriented interventions intending to reduce nonurgent pediatric ED use must be tailored to address the decision-making structures that actually shape pediatric care.

2.2 Non-Urgent Use of the Emergency Department

A key outcome measure in prospective fever phobia research has been non-urgent use of emergency departments. However, research on fever phobia has been narrowly concerned with the knowledge, perceptions, and beliefs of individual caregivers. Although ethnographically inclined research has broadened this scope to address the role of culture and social organization, structural aspects of non-urgent emergency department utilization have gone largely unconsidered in fever research. Fortunately, there is a large body of relevant research – qualitative and quantitative – concerned with the structural nature of non-urgent ED utilization, particularly as it relates to primary care access. The anthropology of nonurgent ED
utilization has been undertaken by anthropologists and non-anthropologists alike. Members of the latter group are often physicians or nurses with advanced degrees who have been trained in conducting ethnography. However, the label “ethnographic” is frequently applied to any study employing in-depth or semi-structured interviews as a research method, and some of these ostensibly ethnographic studies can hardly be considered anthropological in nature. Research involving anthropologists and other social scientists is consistently sensitive to role of historical, social, political, and economic contexts in shaping individual experience.

2.2.1 Applied Anthropology and Non-Urgent ED Use

Becker et al.’s (1993) study of how adult asthma patients make decisions about coming to the ED is one of the first and few applications of both anthropological theory and methods to the issue of urgency in the ED. Using a critical medical anthropology (CMA) framework, they considered the lived experiences of patients in relation to the institutional power of the ED and dominant discourses on asthma and individual health. Their study demonstrated that asthma patients take diligent measures to prevent episodes and make systematic decisions about when to seek care but still face a “no-win” situation at the ED (Becker et al. 1993:306). Despite their efforts, patients in the study spoke of frequent experiences of being chastised for either delaying treatment or visiting the ED before their situation constituted a medical emergency. Indeed, patients preferred to stay out of the ED whenever possible in order to avoid disapproval from clinicians and to satisfy the demands of broader biomedical discourses about the importance of self-reliance and individual responsibility in maintaining personal health. At the time asthma was widely understood within a discourse which constructed episodes as individual failure to control one’s self or environment; as a result, asthma patients were
frequently blamed for their own illness events. Self-care and ED avoidance thus became a way for asthma patients to escape stigma, but this put them at considerably higher risk of dying from their disease.

Though not an anthropologist, Malone (1995) adopted a social constructionist perspective to dissect the ways in which frequent ED use is framed in the various languages of clinical practice, public health, health policy, and health economics. For example, physicians labeled it wasteful and inappropriate, public health construed the issue as one of justice, and economistic perspectives emphasized a problem of inefficiency. Malone’s (1998) subsequent ethnographic research in an urban adult ED provided in-depth explanation of how indigent patients’ use of emergency services extended beyond medical treatment alone. Observation and interviews revealed the ED’s hidden “almshouse” role; though rarely discussed, the informal provision of services such as food, clothing, rest, and social relief created tremendous motivation for individuals experiencing homelessness, substance abuse problems, or mental illness to visit the ED. Malone’s study participants also identified as ED regulars who felt that they were known and had a meaningful identity at the hospital. Clinicians – particularly physicians – were largely oblivious to this hidden dimension of ED practice and framed visits squarely in terms of their medical legitimacy or appropriateness. Malone notes that social problems such as drinking and drug use were often characterized as individual noncompliance and obstruction of care; in this sense, complex social issues were reduced to medical ones.

However, Malone also addresses the policy context of ED experiences, noting that changing parameters for reimbursement had begun to stress the ED’s role as almshouse. This narrowing of role resulted in less tolerance for such admissions as patient loads increased and
provides a clear example of how economic and social pressures can transform “the moral boundaries of accepted ED practice” (1998:815). However, Malone notes that failure to address social problems can in fact result in negative health outcomes. Though “fast track” areas intended for rapid processing of low-acuity patients are becoming increasingly popular components of EDs in the United States, Malone suggests that frequent visitors might be better served by a “slow track” system in which social workers and clinicians work together to disentangle patients’ social and medical problems (1998:820).

Goepp et al.’s (2004) evaluation of a Baltimore community health education program intended to reduce nonurgent pediatric ED usage clearly illustrates the contribution that an anthropologist can make to this issue in an applied setting. Initially, the authors trained a community health worker (CHW) team to educate participating families about screening for acuity and choosing sources of care. However, preliminary evaluation found that participants were largely uninterested in these activities and felt that the program had not been designed with their needs in mind. Most participants wanted CHWs to assist them with accessing employment, nutrition, and housing services rather than guide their healthcare decision-making. With this in the mind, the program was redesigned in a participatory fashion. Input from CHWs and participants was used to formulate more relevant program objectives. The new program discarded the previous focus on behavior change and was accompanied by ethnographic research (conducted by an anthropologist on the team) intended to understand participant lives and develop solutions grounded in their realities.

The ethnographic component of the project found that participants were fearful and suspicious of primary care providers (PCPs) due to historical concerns about nonconsensual
experimentation, and families felt safer and better represented when CHWs accompanied them to these appointments. Additionally, the ED was not only preferable to families for its convenience but because PCP appointments were frequently missed if a higher-priority visit to a social services office came up at the same time. Goepp et al. conclude that nonurgent ED visits result primarily from forces that deter primary care use – in this case mistrust, incongruous priorities, and complex lives – and those that promote ED use, namely simplicity, availability, and institutional transparency.

Shaw et al. (2013) employed an interdisciplinary team of clinical staff, anthropologists, and sociologists to study decision-making processes of adult patients seeking primary care in a New Jersey ED. Social scientists on the team conducted semi-structured interviews with patients triaged as nonurgent, and analysis identified two key groups: those who were familiar with and had access to primary care options and those who had no knowledge of such services. The majority of patients had health insurance and fell into the former group. Most of these patients were enrolled in Medicaid and had been instructed to go to the ED by a primary care provider or had experienced barriers to accessing primary care. Several patients recalled long waits and impersonal experiences at Federally Qualified Health Centers (FQHCs).

An insightful contribution of Shaw et al.’s study is their investigation of how patients defined an emergency. Most patients decided to come to the ED once they had exhausted primary care and self-care options; however, this did not necessarily coincide with a perception that one’s condition was a medical emergency. Having noted the difficulty of defining nonurgent and appropriate visits (and deciding who gets to do the defining), the authors highlight some of the limitations of understanding “appropriateness” in terms of medical
urgency. In establishing appropriateness of ED use, measures of medical urgency obscure the ambiguity faced by parents caring for a child whose condition is not clearly emergent or non-emergent to a lay person.

Browne et al.’s (2011) ethnographic study of a Canadian ED explores perspectives on primary care access among Aboriginal patients triaged as nonurgent. However, the study situates their hospital experiences as historically mediated social suffering. Though chronic pain was the most common reason for patients to visit the ED, they rarely received medications due to staff suspicions of substance abuse and hospital policies preventing prescription of pain medication in the hospital’s nonurgent division. Geography and referral systems had a way of funnelling patients from an impoverished local neighborhood to the study hospital. Though a complex array of social and economic factors created the conditions under which aboriginal patients presented at the ED with chronic pain, this context was lost on hospital staff, who treated patients dismissively. However, the authors further suggest that these complex interactions are themselves situated in a history of colonization and oppression; rather than accept aboriginal poverty as an inevitable dimension of Canadian society, Browne et al. employ the concept of intersectionality to stress the interdependence of race, poverty, geography, and life experience in patients’ ED visits and politicize this conceptualization within a postcolonial framework. In this sense, social suffering is not simply an aspect of modern poverty but a historical product of centuries of domination and marginalization.

2.2.2 Ethnographically-Informed Clinical Research on Non-Urgent ED use

Chin et al. (2006) employed ethnographic interviewing techniques in a pediatric ED to better understand parents’ reasons for bringing their children in with nonurgent conditions.
Parents’ stories were largely incongruent with dominant narratives of nonurgent ED use, as most patients were insured and had been referred to the ED by their PCP. Parents themselves were angry and confused about being sent to the ED for the treatment of illnesses they themselves perceived as nonacute. However, some parents still found primary care to be complex and difficult to access, and others noted that work and difficult life circumstances (primarily poverty) could complicate the task of caring for children. Chin et al.’s findings contradict the portrayal of nonurgent users as uninformed abusers of the healthcare system and emphasize the importance of understanding the structural factors that encourage nonurgent ED use. They further frame nonurgent ED use as a “failure of the [healthcare] system as a whole to provide simple alternatives to simple problems” (Chin et al. 2006:26).

Berry et al.’s (2008) ethnographic study of nonurgent ED visits at a Wisconsin children’s hospital found that a vast majority of patients were insured, and most had come to the ED after experiencing problems with their PCP or getting a referral. Patients’ PCPs tended to have long wait times and unfriendly staff. Communication with PCPs was often ineffective. The ED, on the other hand, was fast and efficient. With no need for appointments, advanced diagnostic equipment, and highly skilled staff, the ED was perceived as having significant advantages over primary care. Berry et al. conclude that nonurgent patients cannot be directed to seek care with PCPs if their underlying concerns regarding quality and convenience of care are not addressed first.

Though not explicitly ethnographic, Guttman et al.’s (2003) interview study of nonurgent ED visits (adult and pediatric) identified an array of instructive themes in caregiver responses and thoroughly deconstructed the notion of appropriateness in emergency medicine.
Whereas several of the studies mentioned below contribute to the reification of constructed concepts such as “emergency” and “inappropriate” by neglecting to question them, Guttman et al. note that definitions of legitimacy may vary considerably among lay people, clinicians, and insurers. Even medical emergency is a concept subject to some degree of interpretation among healthcare professionals. Notably, over a third of respondents defined emergencies in way that was incongruent with their own reason for coming. These patients or caregivers had a biomedically accurate perception of emergency but chose to come to the ED anyway, contradicting the notion that patients come to the ED with nonurgent complaints because they fail to comprehend what constitutes and emergency. The authors note that reducing nonurgent visits cannot simply be about primary care access or education and suggest that guidelines for reimbursement might even be adjusted to correspond to lay understandings. In a qualitative study of nonurgent ED use in Denver, Koziol-McLain et al. (2000) also critique the classification of certain ED visits as “appropriate”, arguing that a definition based on a biomedical or purely physiological framework is overly reductionist and fails the capture the experiences of distress that may motivate a medically nonurgent visit.

Guttman et al.’s grounded theory analysis provides perspective of the rationality behind supposedly inappropriate visits. For parents, bringing a child to the emergency department was partially motivated by a desire for reassurance that was deeply related to fundamental notions of caregiver responsibility. Parents felt as though they it was imperative that they know that children’s conditions were not deteriorating and none were willing to take risks on a child’s wellbeing. Emergencies (and by extension appropriate uses of the ED) were thus defined broadly to include all potentially worrisome conditions that might trigger that aforementioned
desire for reassurance. The theme of reassurance also appeared in Brousseau et al.’s (2011) qualitative study involving parents bringing children to EDs for nonurgent conditions. Parents in this study placed very little trust in telephone advice and urgent care, and they were happy to pay more for the reassurance and reduction in anxiety that came with the superior diagnostic capabilities available in the ED. Though barriers to PCP access are routinely identified in studies of nonurgent ED use, Brousseau et al. note that PCPs in their study tended to err on the side of caution and would refer patients if they were unable to see a child or were uncertain about a diagnosis. Additionally, neither PCPs nor parents considered nonurgent ED use to be a problem, despite concerns about breaches in continuity of care (Howard et al. 2005; Guttman, Nelson, and Zimmerman 2001).

2.2.3 Clinical Perspectives on Nonurgent Utilization

Though much of the research on nonurgent ED use has focused on perspectives of patients, a number of ethnographic studies have turned their analytical lens on to ED staff. Person et al. (2013) notes that nurses participating in an ethnographic study were frustrated by perceived misuse of the ED and attributed this practice to patients lacking insurance perceiving the ED as their primary care office. Nurses participating in Wolf’s (2010) ethnographic study grew frustrated whenever they encountered patients with chronic pain or pain of significant duration, either of which they considered inappropriate for care in the ED. Although mistriage is generally rare, observed triage nurses tended to perceive nonurgency in patients who loudly expressed pain; though this was reaction to perceived manipulation on the part of patients, it may also have served to marginalize patients whose culturally mediated expressions of pain were not recognized. Staff participating in Chin et al.’s (2006) ethnographic study were also
frustrated by nonurgent visits, but tended to over-perceive their prevalence; these clinicians criticized nonurgent patients as having a “fast food” mentality regarding use of the ED (Chin et al. 2006:25).

Fry’s (2012) ethnographic study investigated emergency nurses’ belief systems in Australia. Nurses in the study felt that patients owed it to staff to take steps to control their pain prior to coming to ED, and doing so increased the chances that nurses would perceive their condition as legitimate. The acuity of patients who arrived having had the time to pack a bag or apply makeup was perceived less readily by nurses, who were frustrated whenever patients seemed to arrive with expectations. Additionally, nurses expressed strong beliefs to the effect that patients should not “waste time” (2012:123). Conditions considered to be trivial were considered a PCP’s responsibility and an inappropriate use of ED resources. Some nurses characterized such conditions as abuse of the system, and would shorten assessment procedures if they perceived a condition to be trivial. Fry notes that “a culture of ED care was manifested by notion of timeliness, appropriateness, and efficiency” (2012:124) and suggests that nursing beliefs do influence both notions of patient worthiness and clinical judgment itself. In this context, triage becomes a site for expressing values and judging patients.

In an interview study with physicians and nurses, Guttman, Nelson, and Zimmerman (2001) identify three major ideologies of the emergency department. The restrictive ideology dominates the other two and frames medically nonurgent visits as inappropriate because they delay care for other patients and unnecessarily tax the system. Staff subscribing to this ideology tended to over-perceive the prevalence of nonurgent visits. Even so, they preferred not to admonish patients and would try to educate them about the importance of seeing a primary
care physician before going to the ED. The *all-inclusive ideology* objects to the label of “inappropriate” and welcomes all patients. Clinicians following this ideology acknowledged the legitimacy of parents’ psychological need for reassurance, and were generally empathetic towards parental concerns. These participants viewed the ED as a multipurpose care site responsible for addressing shortcomings of the overall healthcare system; they either did not advise patients at all about ED use or gently educated them. Also, this ideological position was perceived as somewhat deviant, and participants avoided advertising their views on the issue. A *pragmatic ideology* was identified as the middle ground between these; these participants considered the ED a place for medical emergencies but acknowledged that certain realities made nonurgent visits unavoidable.

Guttmann et al. note that the dominance of the restrictive ideology privileges certain values over others, produces an exclusive discourse of appropriateness, and marginalizes some patients. However, they also make the interesting point that attempts to privilege patient worldviews vis-à-vis dominant biomedical conceptualizations can inadvertently perpetuate the structural problems that cause nonurgent visits by failing to problematize them in the first place; without acknowledging flaws in the primary care system or the social difficulties facing patients, any structural critique of the nonurgent utilization problem is conveniently avoided. The conflict generated by restrictive ideologies, on the other hand, may highlight structural problems more easily.

2.2.4 Deconstructing Nonurgent and “Appropriate” ED Utilization

On the whole, anthropological research on nonurgent ED use has avoided unconscious acceptance of dominant constructions of nonurgent visits and “appropriateness.” These are not
objective concepts; rather, their meanings are contested and discursively negotiated (Shaw et al. 2013; Guttman, Nelson, and Zimmerman 2001). Ethnographic research has noted that triage and other patient assessment processes, though grounded in physiologic data and medical training, are best conceptualized as interpretive processes that are also influenced by the ideologies and belief systems of clinicians (Becker et al. 1993; Fry 2012; Guttman, Nelson, and Zimmerman 2001). However, the most incisive critiques of the construction of nonurgency have come from non-anthropologists. Koziol-McLain et al. (2000) note that the biomedical-physiological bias in defining “appropriate” use obscures the legitimate role of social distress in ED use. However, others would assert that even this position overstates the extent to which “appropriate” care is biomedically defined. Though notions of appropriate care may be shaped by clinician values, the greatest influence on application of the designation may come instead from those with the power to reimburse (Malone 1998; Guttman, Nelson, and Zimmerman 2001). Policy definitions of appropriateness are defined only partially by medical criteria and vary by state (Guttman, Nelson, and Zimmerman 2001). Legitimacy is ostensibly based on the “prudent layperson” standard, which prohibits the use of final diagnoses to define reimbursement and requires that insurers pay for any care which a patient considered imperative for the preservation of their wellbeing (Guttman, Zimmerman, and Nelson 2003). However, even though the prudent layperson standard became federal law affecting many Americans via the Affordable Care Act (ACA) in 2010, individual states routinely find ways to limit reimbursement to conditions which are ultimately triaged as nonurgent (Kellermann and Weinick 2012).
In ethnographic and qualitative research by non-anthropologists, there is some evidence of the tacit reification of the concept of the nonurgent visit. Nonurgent ED visits are frequently analyzed without any significant consideration for the impact that specific illnesses might have on caregiver practice (for examples, see Berry et al. 2008; Howard et al. 2005; Chin et al. 2006; Brousseau et al. 2011). By overemphasizing the meaningfulness of the nonurgent designation, these studies make the assumption that nonurgent visits are collectively more alike than they are dissimilar; in practice, these studies are characterized by the reductionist juxtaposition of primary care barriers and advantages of ED care. Though this work has provided a thorough examination of quality of care and access issues, there is evidence that more particularistic considerations are relevant; these may include the specific characteristics and social construction of a disease such as asthma (Becker et al. 1993) or the unique forms of social distress facing indigent drug users accessing ED care on a frequent basis (Malone 1998).

2.3 Summary

Virtually all anthropological and ethnographic research investigating nonurgent ED visits has generated evidence contradicting the notion that patients use the ED for non-emergencies because they are uneducated or unscrupulous. On the contrary, there is abundant evidence suggesting that patients avoid the ER until they believe it is necessary (Becker et al. 1993), are referred by PCPs (Howard et al. 2005; Chin et al. 2006; Berry et al. 2008), or face significant barriers to primary care access (Guttman, Zimmerman, and Nelson 2003; Goepp et al. 2004; Chin et al. 2006; Berry et al. 2008; Koziol-McLain et al. 2000; Shaw et al. 2013). However, in addition to identifying these more pragmatic aspects of nonurgent ED use, some research has successfully elucidated the less obvious cultural logic behind utilization patterns. ED use must
be recognized as not only a product of material realities, but a process mediated by factors such as illness stigma (Becker et al. 1993; Browne et al. 2011), negotiation of identity and the need to belong (Malone 1998), historical mistrust (Goepp et al. 2004), and the need to perform culturally defined roles of parent and caregiver (Guttman, Zimmerman, and Nelson 2003). Browne et al.’s (2011) study may be unique in its attempt to link historical processes of violence and oppression to modern-day marginalization in the ED.

Concerns about nonurgent ED visits disrupting “continuity of care” are routinely emphasized in the literature (Berry et al. 2008; Howard et al. 2005; Guttman, Nelson, and Zimmerman 2001). The underlying idea is that patients will have better outcomes if they see the same provider on a routine basis, and unnecessary ED visits are thus harmful (or at least suboptimal health care). However, anthropological and ethnographic research has provided an alternative perspective on this issue. Though some studies have noted that patients would prefer to be treated by their PCP when possible (Chin et al. 2006), patient perspectives of what constitutes ideal care clearly differ from those of experts. Ethnographic evidence suggest that some families choose sources of care based on perceived advantages relative to other options regardless of the severity level for which the facility is intended (Goepp et al. 2004; Shaw et al. 2013). Moreover, other research suggests that neither PCPs nor parents consider nonurgent ED use to be problematic (Brousseau et al. 2011). What these findings imply is that discourses of what is supposedly best for patients may also function to quietly discourage particular “inappropriate” patterns of health care utilization, even if dominant models of care are incongruent with patient needs or ineffectively implemented.
In this research, I explore contradictions and unanswered questions within two bodies of research. Fever phobia literature has exhaustively explored individual parental perceptions and beliefs while largely ignoring the social context of health-seeking behavior. Researchers have consistently recommended educational interventions for the fever-phobic, yet the body of work investigating nonurgent use of emergency rooms maintains a healthy skepticism for initiatives promoting educational solutions to what may be structural problems. However, even within ED utilization literature there has been a failure to reconcile the interaction between agency (in this case, a family’s freedom to choose whether they go to the ED or not) and structure (the social and material realities that constrain their choices). This project investigates the phenomenon of ED utilization for child fevers under the assumption that structure and agency interact dynamically. This will provide needed context for fever phobia literature while offering a nuanced perspective on nonurgent ED utilization that simultaneously addresses the role of individual decision-making and structural constraints.

2.4 Conceptual Framework

2.4.1 Andersen’s Behavioral Model of Healthcare Utilization

In the mid-1970s, Andersen and colleagues developed a behavioral model of healthcare utilization (hereafter “the behavioral model”) that has been widely used in health services research (Aday and Andersen 1974; Andersen and Aday 1978; Andersen 1995; Andersen and Newman 2005). The behavioral model is an ecological framework outlining a relationship between use of the healthcare system and a variety of individual and structural factors. It theorizes utilization at different units of analysis and permits investigation of macro-level issues (e.g. factors influencing patient volume at a healthcare facility) as well as micro-level questions
(e.g. factors influencing utilization decisions about a single episode of illness). For the purposes of this research, utilization is examined at the episode unit of analysis.

In the behavioral model, “individual determinants” affect health resource utilization most directly. These individual determinants are a catch-all category for ostensibly non-structural issues, and are essentially a bundling of human agency and immutable demographic characteristics. However, the impact of individual determinants on utilization is mediated by the structure of the healthcare system and various societal factors. Health care system factors affecting utilization include accessibility of the health care system, volume and distribution of healthcare resources, and structure of healthcare institutions (i.e. how patients are shuffled through institutions once they enter them). Societal factors include developments in medical technology and norms created by health care policy, particularly policies related to healthcare finance.

The individual determinants of healthcare utilization are the most developed component of the behavioral model and deserve further attention. The model assumes that an individual’s use of the healthcare system is driven by her predisposition to use services, her ability to use services, and the severity of her illness. Thus the major domains within the individual component of the model are predisposing factors, enabling factors, and illness level.

Predisposing factors affect a person’s inclination to use healthcare services. They include demographic factors (such as age, sex, and marital status), factors related to a person’s position within social structure (such as education, occupation, and religion), and beliefs (primarily values, attitudes, and knowledge related to health and healthcare). Enabling factors allow a person to access healthcare, and they include family resources (such as insurance
coverage or income) and community factors (such as local supply of healthcare resources and local norms related to health and healthcare). Illness level is the most explicit influence on whether health services are used. In the model, illness level can be understood as a patient or caregiver’s perception of their illness as well as a medical provider’s assessment of it.

2.4.2 Adapting the Behavioral Model to Qualitative Research

The behavioral model’s etic conceptual organization presents a challenge for researchers wishing to take an emic approach to understanding healthcare utilization. The model is a near-comprehensive inventory of factors related to healthcare utilization, but its concepts (e.g. “predisposing factors”) and their various sub-concepts (e.g. “demographic characteristics”) were developed using quantitative methods such as path analysis and multiple regression. For research aiming to model and predict issues such changes in patient volume over time, this is not a problem. However, analyses of the cultural logic underlying healthcare utilization at the individual level are likely to suffer under the constraints of such a rigid preordained structure. The model presents a particular challenge in its unintentional obfuscation of the relationship between structure and agency, a key dynamic in nonurgent ED utilization. As an example, the model defines “occupation” as an individual factor influencing disposition towards the use of health services; however, occupation could easily be construed as an enabling factor if it determines a parent’s ability to take time off work and access primary care during the day. As is, the model does not easily accommodate multiple dimensions of single concepts (such as occupation, which can measure both a person’s relative position in social space as well as the flexibility of their schedule) or relationships between concepts (for example, the relationships between health beliefs and perceived illness level).
2.4.3 Theorizing the Logic of Caregiver Practice

Andersen’s behavioral model provides a helpful inventory of individual and structural factors worth considering in ED utilization research, but describes their interrelationships with a broad brush (e.g. by relating structure and agency in terms of a limited supply of healthcare resources constraining an individual’s capacity to seek timely care). Yet, experiences with the healthcare system can clearly have a lasting impact on individual subjectivity (Becker et al. 1993; Goepp et al. 2004; Browne et al. 2011). A Bourdieusian framework allows for a richer conceptualization of the relationships between caregiver subjectivity and structural constraints. Bourdieu’s mutually constitutive concepts of habitus and field have particular relevance for theorizing the cultural logic of nonurgent ED use. Habitus describes individual subjectivity and can be understood as an ever-developing system of perceptions and dispositions that an individual forms throughout the course of their life (Bourdieu 1977). Habitus is an individual’s system of logically organizing the world as they experience it, and it guides every action they take. Habitus is significantly shaped by “fields,” which are broadly defined as social situations or structures in which individuals pursue economic, cultural, and symbolic capital. Fields can be any number of concrete or abstract settings ranging from a national economy to a small office workplace; however, their relevance here is that they constrain and shape the habitus of individuals within them (Bourdieu 1977; Bourdieu 1989). For example, we might deploy these concepts to delineate ways in which the structure of the US healthcare system shapes caregiver habitus. Poor access to routine primary care might fail to equip caregivers with effective home treatment skills and engender a habitus predisposed towards nonurgent use of the ED. At the
same time the constraints of other fields – such as the rigid schedules of wage labor in the economic field – might engender a similar predisposition toward nonurgent ED use, but for entirely different reasons.

Habitus is historically embodied over time and represents a “dialectic of the internalization of externality and the externalization of internality” (Bourdieu 1977:72). This is particularly beneficial for relating individual preferences for healthcare with structural aspects of healthcare accessibility. Most ED utilization literature conceives of poor access as structural barrier that acts upon subjects (i.e. patients) at the moment they interact with the healthcare system. Not only does this way of thinking diminish the role of subjectivity in healthcare decision-making, it precludes the possibility of relating the internalization of structure (e.g. learning over time that primary care not going to be there when you need it) to situations in which individuals appear to disregard the established rules of the system (e.g. not calling your PCP and coming straight to the ER).

In the behavioral model, healthcare institutions are a neutral actor. In a Bourdieusian framework, they are not. The ability to decide what is and is not “appropriate” use of the ED smacks of what Bourdieu described as symbolic power. Wielders of symbolic power can impose legitimacy and influence what is considered “common sense”, and often do so as a means of protecting the status quo (Bourdieu 1989:21). In the case of nonurgent ED utilization, discourses of “inappropriate decisions” may reflect the exercise of symbolic power to distract from inadequacies of primary care or the fact that hospitals are ill-equipped to deal with the social distress for which their assistance is now routinely sought (Koziol-McLain et al. 2000).
CHAPTER 3: METHODS

3.1 Study Site

Children’s Medical Center (Children’s) is a not-for-profit pediatric hospital in central Dallas. It serves the greater Dallas area and functions as a major safety net hospital for children in Dallas County. The Children’s ED had nearly 130,000 visits in 2014. The majority of patients seen in the children’s ED are insured through Medicaid. Roughly 20% of families typically indicate that Spanish is their preferred language (this preference is charted in a child’s medical record), but anecdotal experiences of staff\textsuperscript{2} suggest that this figure underestimates the need for Spanish-language interpretation and translation.

The Children’s ED is divided into two areas, the main emergency department and Fast Track. Upon arrival at the hospital, patients are triaged and assigned an acuity level ranging from level 1 to level 5. Level 1 patients require immediate life-saving attention, while level 5 patients are able to wait several hours to be seen and require few hospital resources. Level 4 and 5 patients are less acute and generally do not require resource-intensive care. At Children’s, these patients then are moved to Fast Track after triage. Fast Track is staffed by physician assistants and nurse practitioners rather than physicians. Fevers are one of the most common conditions seen in the ED (along with ear infections and upper respiratory infections) and were selected as a focus for the study for this reason.

\textsuperscript{2} And the author of this thesis
3.2 Preliminary Investigation

While developing the design of the study, I spent roughly 20 hours shadowing three different community health workers (CHWs) working in Fast Track. The role of these individuals was to consult with patients who had visited the ED three or more times within a rolling 12-month period and address any needs they had related to navigating the health care system. They would typically consult with families near the end of their visit to the ED and provide them with information about nurse advice lines, reenrolling in Medicaid, or finding a primary care provider.

Field notes collected during CHW shadowing significantly informed the recruitment and data collection process. CHWs and nursing staff provided advice on when and where to interview families during their visit, and observation of CHW interventions with families shaped the development of interview questions.

3.3 Sampling and Recruitment

Participant selection was conducted using the ED trackboard, a list of current ED patients generated using the hospital electronic health record system. Trackboard listings include a patient’s age, gender, triage level, preferred language, medical complaint, and location in the ED. Trackboard information was used to screen for eligible research participants but was not recorded. Caregivers were eligible for an interview if their child was between the ages of 3 months and 10 years and was presenting with a chief complaint of fever. Initially, children with multiple complaints were to be eligible; however, the very first interview participant was far more concerned about her child’s cough and had very little to say about his
fever. To avoid this, subsequent participants were required to have no complaints other than fever.

Participants were recruited using a convenience sampling method (Bernard 2006). However, as data collection progressed I attempted to recruit participants that diversified the existing sample in terms of child age, child ethnicity, time of visit, preferred language, and frequency of ED utilization. In this sense the sample was somewhat purposive, as I deliberately pursued participants whom I believed might have a story that differed from those I had already heard; however, this was always mediated by the pragmatic reality of conducting qualitative research in an emergency room. Asking nursing staff for half an hour with their patients could be a significant request and a truly purposive sample would have been difficult to obtain within a reasonable time frame. This was particularly true with Spanish-language interviews, which took much longer to complete due the need for an interpreter. Additionally, these interviews were fraught were technical difficulties due the use of a video interpreting service; poor wireless connectivity resulted in multiple disconnections from the service, which lengthened the process and once resulted in using multiple interpreters to complete one interview.

Participants were approached for an interview after the trackboard indicated that their child had been seen by a medical provider. Usually, this meant that the child had been diagnosed and was awaiting medication or discharge from the ED. At this point, I entered the patient’s room, introduced myself, and explained the purpose of the study. If the family expressed interested, I walked them through the study objectives and explained what their participation entailed in more detail. If there were multiple caregivers, they were given the choice of whether one or both of them would participate in the interview. Informed consent
was obtained verbally. The interview process was paused if a nurse or provider needed to see
the patient and resumed upon their leaving the room.

3.4 Semi-Structured Interviews

Thirty caregivers were recruited for semistructured interviews. Semistructured
interviews allow for the systematic collection of qualitative data while retaining a degree of
open-endedness (Bernard 2006). This type of interview also gives the interviewer significant
control over the pace and overall length of the interview, which was essential for conducting
research within the rigid structure of the ED. Typical interviews were around 25 minutes long;
however, the shortest was barely 13 minutes and the longest was almost an hour. Interview
questions were based on a review of relevant literature and observations made while
shadowing CHWs. Interviews used a series of open-ended questions complemented by more
structured probes. Overarching topics included the present trip to the ED, concerns about
fevers, primary care providers, information seeking, and use of afterhours healthcare services
such as urgent care and nurse advice lines. Routine probing generally addressed specific
dimensions of overarching topics, such as access to primary care and using the internet to find
health information.

The interview questions were piloted with four different parents prior to beginning data
collection and the protocol was modified based on their input. However, it was still necessary
to modify interview questions and probes during first dozen interviews as unexpected topics
emerged. Additionally, a few questions consistently produced redundant or irrelevant
information and were dropped from subsequent interviews to save time. Interviews were
recorded and transcribed verbatim.
3.5 Data Analysis

Interview transcripts were analyzed using a grounded theory approach, in which text data is analyzed for themes and themes are then conceptually related in a theoretical model that is “grounded” in the data (Bernard 2006; Glaser and Strauss 2009). However, given that data was collected using a theoretically informed, semistructured instrument, it would be disingenuous to claim that ideas from the literature did not have some degree of influence on the data analysis process. Concepts such as access play a significant role in both emic and etic conceptualizations of primary care, and disentangling them can be challenging for an analyst who is steeped in both. Theoretically, the structured nature of the interview protocol likely precluded exploration of some unanticipated topics. However, it was flexible enough to accommodate unexpected issues such as concerns about the Ebola crisis or the narratives of parents whose children who had actually experience febrile seizures (rather than the expected nonacute fever).
CHAPTER 4: RESULTS

4.1 Participant Demographics

Thirty families (40 caregivers) participated in the study. Eighteen of the children being seen in the ED (60%) were male and 12 were female (40%). Twenty-seven interviews were conducted in English, and 3 were conducted in Spanish using an interpreter. Nearly two-thirds of children in participating families were under 3 years old (see Table 1). Twenty-one children (70%) were accompanied by their mother with no other caregivers. Six (20%) were accompanied by both their mother and father, and 3 (10%) were accompanied by additional non-parent family member. Eighteen of the children were Hispanic (60%), 10 were African American (33.3%), and 2 were Caucasian (6.7%). Twenty-six children (86.7%) were insured through Medicaid, and four (13.3%) were insured commercially. Fifteen children (50%) would have been considered “frequent users” of the ED based on parent self-report (i.e. they had visited the ED 3 or more times in a twelve month period).

Table 1: Age of Participants’ Children

<table>
<thead>
<tr>
<th>Age in years</th>
<th>n (%)</th>
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<tr>
<td>&lt;1</td>
<td>8 (26.7)</td>
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<tr>
<td>1-2</td>
<td>5 (16.7)</td>
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<tr>
<td>2-3</td>
<td>6 (20)</td>
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<tr>
<td>3-4</td>
<td>4 (13.3)</td>
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<tr>
<td>4-5</td>
<td>2 (6.7)</td>
</tr>
<tr>
<td>5+</td>
<td>5 (16.7)</td>
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4.2 Overarching Theme: Reassurance

Families’ pursuit of reassurance about children’s wellbeing emerged as a central theme during data analysis. Many aspects of managing and interpreting children’s illnesses were ultimately related to the need for reassurance, while the utilization of different healthcare
resources depended largely on whether they could supply reassurance in a timely and persuasive manner (see figure 1).

Figure 1: Relationships Among Themes

For most families, visiting the ER was primarily a way of getting reassurance that their child was going to be OK. However, caregivers were typically not panicking about their child’s condition, nor were they unconcerned. Instead, they were in a sort of limbo, an uneasy liminal state between crisis and nonemergency. Reassurance could vary in terms of both supply and demand; some healthcare providers had greater capacity to provide reassurance (in terms of both access and persuasiveness).

Although criteria for obtaining reassurance varied, parents generally wanted to know what was going on in their child’s body and what should be done about it. Establishing the cause of illness was usually the linchpin of reassuring parents. Parents were usually interviewed
after a physician assistant or nurse practitioner had seen their child; if they had received a clear diagnosis, they were usually no longer worried. If a cause could not be established or temperatures did not decrease, parents continued to worry. When asked whether her concerns had been resolved, M19 said “No, because I have to wait and see whether it goes away or not. Like she [the PA] said, it's the first day, so we don't know what's wrong with him. So it doesn't take my concerns away cause I don't know what's wrong with him.”

What differed among families was the extent of the diagnostic testing they wanted and whether or not they expected medication. A handful of parents felt that the diagnostic technologies available in the ER were necessary to properly establish the cause of their child's fever. They insisted on blood work or x-rays, and this had contributed to their skipping over their pediatrician. M09’s son had recently had pneumonia and she fought hard to try and get her son a chest x-ray. She was quite surprised when the PA refused, citing a poor risk-to-benefit balance. M13 was expecting a “thorough exam” involving blood tests and x-rays and had bypassed her pediatrician’s office because they lacked the necessary equipment.

I was expecting them to do a thorough exam. I really expected them to draw blood to make sure there wasn't nothing, no infection going on. You know, if something's inside of her, you never know what could be going on. One thing I don't like is how they [start with] the simple stuff and rule that out. And if they rule out strep throat, then, and it's negative, I want blood drawn, because, my mind is not gonna be eased, cause y'all could send me away from here, and it's fever still going on, and something else could go on - then here come the seizures and all that.
For some parents, receiving medication was an important component of obtaining reassurance. These parents were either unaware of or rejected the idea that viral infections had to go away on their own and could not be treated with medication. When medical providers refused to give them medicine while children still had symptoms, parents felt like their doctors were not doing their jobs. M29 disliked going to her son’s pediatrician, saying “I don’t like to take him over there, cause every time I go over there, they tell me that it’s a virus, they never give him medications, and that’s why I don’t like to take him over there - it’s always a virus.” In a similar story, M20’s daughter had had a lengthy episode of diarrhea but received nothing from her pediatrician, who had told her that the illness would go away on its own. However, when she had come to the ER she did receive medication, leading her to question her pediatrician’s competence. She asked, “So if there was something for her to drink or give her, then why did she not give me that?” She went on to declare that she would change pediatricians if something similar happened again. It was unclear whether the medication she received in the ER had any curative function or was intended to make the diarrhea more bearable; however, the salient aspect of M20’s story is not that her physician failed to cure the diarrhea, but that she failed to adequately perform the role of appearing to treat it to the participant’s satisfaction.

On multiple levels, reassurance was relatively inexpensive. Families insured through Medicaid paid nothing for their ER visits, and privately insured families were more than willing to spend a few hundred dollars for the co-pay. Every family participating in the study reported having insurance of some form. Additionally, the opportunity cost of missing a day of work to
see the PCP was much higher than that of missing dinner at home to come to the ER. Furthermore, the CMC ED defies stereotypes about emergency room wait times. Even at peak evening times an ER visit could take just a few hours, whereas attempting to get a walk-in clinic visit could mean waiting all day with no guarantee of being seen. One family was even pleasantly surprised by how quick their visit had been. If families were unsure about whether to go the ER, they had little to lose by doing so. As M17 said, “Yeah, I always used to wait - especially because she doesn't have diarrhea or vomiting or something like that - but... [my friend] just said just go immediately. You're not gonna lose anything [laughs].”

4.3 Treatment Experience

Here, treatment experience refers broadly to caregivers’ subjective experience of managing fevers at home. Analysis focused on aspects of treatment experience with the most salience for deciding to come to the ER rather than systematically inventorying treatment practices. Thus, aspects of treatment experience were prioritized if they were implicated in the escalation of a child’s care from home treatment to a healthcare setting. Relevant themes tended to be classifiable as either a concern about fevers or a challenge related to treating them. Concerns shaped parents’ perceptions of the severity of their child’s illness and of what diagnostic procedures or treatments were needed. Challenges were issues that complicated the process of caring for sick children.

4.3.1 Concerns

Parents’ concerns could usually be categorized as related to bad signs, unknown causes, or feared outcomes.
4.3.1.1 Bad Signs

Bad signs were red flags that alerted caregivers to danger. Unsurprisingly, the most common of these was high temperature. However, explanatory models of what constituted a “high fever” varied widely, as did attitudes about what this meant. Though most parents considered a high fever to be somewhere between 101 and 104 degrees, there both extremes both high and low. M25, a 22-year-old mother of a 3-year-old boy, said, “I would say when it's above 94. Yeah. Yeah I would say that it's above 94, when a fever starts.” M03, a 30-year-old mother with a two-year-old son, referred to 103 degrees as a “slight fever.”

Several parents admitted that while they were aware of what medical professionals might have considered a high fever, temperatures lower than this were enough to bother them. As D29 explained:

I know that a fever is kinda considered 104, that's pretty much where they kinda draw the line for a fever, but when you get above that, the 101 range, that's pretty much where I kinda start getting real concerned as to what's going on.

M07’s 18-month-old son had had a febrile seizure at his babysitter’s house and been transported to the ER by ambulance. His mother had had to rendezvous with him at the ER and was distraught. The incident had dramatically changed her notion of what constituted a high fever, and to her, a high fever had become “anything over 100, 100.1. If it's 99ish, I'm not as concerned, but if he has 100 I'm on the way somewhere [laughs].”

Some parents used specific temperature cutoffs as a guide for action, but high fevers were also a dynamic concept that described parents’ growing discomfort with escalating temperatures. High fevers could be understood not only as numbers from a thermometer
reading, but in terms of the ebb and flow a child’s temperature. Rapid increases in
temperature, resistance to medication, and unpredictable changes made the high fever a
threatening adversary. M15 lamented her inability to control her 2-year-old son’s fever, saying
“Yeah, and once it hits 100, he start crying a lot. And then gets worse. And didn't stop, 101, 102,
103, and we can't control it, so... we need to do something.” Fevers’ uncontrollability made
them a danger, as M09 describes below:

    Around two so he sort of woke up with a fever and normally I'd wait the full 24 hours
and see if I can control it by substituting the Motrin and the uh Tylenol every four hours
or as long as he can bear it... but, um... it's, it's like the fever kept escalating..... it didn't
seem like what I was doing at home was helping.... at the end of the 24 hours it was just
getting out of control. It hadn't even been 24 hours and it's going that high. 104 is sort
of scary cause that's beyond 103 normally you don't seem em that high.

    Though almost every family interviewed had taken a thermometer reading when they
first noticed their child was not feeling well, perceptions of a high fever were often
accompanied by a colorful description of how the child actually felt to the caregiver’s touch.
D03 described his son’s body as “insanely hot.” M08 defined her son’s fever as high because it
was over 103, but added, “plus he was like burnin’ up, his body was real hot.” Understanding
fevers in these terms implicated children’s discomfort in the definition of illness and also was an
important piece of evidence that parents used to establish that their children were sick.

    Unusual behavior was another important sign that parents relied on to evaluate the
severity of their child’s condition. Unwillingness to eat, drink, or play were frequently a cause
for concern among caregivers, particularly in conjunction with obvious signs of unhappiness.
M02, whose daughter was 18 months old, stated that her biggest concern was “that she was
not taking liquids down. And not really eating like she usually does... and she was like, fussy, she
was real fussy.” Similarly, M15 said, “and that's another thing, he doesn't wanna eat and it
worries me. I mean, if we can control the fever, I'm fine with it. But if I can't control the fever and he doesn't wanna eat, that's what we worry about.”

If children appeared to be in pain, unusual behavior was even more worrisome. M1 was most concerned that “he's been crying, [as though] he is in pain, that's why I brought him in.” M01 reported seeing the sadness in her son’s eyes and was concerned that he was refusing most of the foods and drinks he normally enjoyed. These issues and her son’s cough actually concerned her far more than his fever. She said:

He don't wanna drink the pedialyte so that worries me, because if I just stay home and just do the medicine but he don't wanna drink the pedialyte, so he won't eat that much, he's losing weight, so I just decide to come here and see what they can do with the cough, and will give him something different to make him feel better... everything he swallows it bothers him, so that's why I just decide to come here.

Parents were similarly concerned with children not being themselves. M14 said, “I don't like to see him like that - he's usually a really bubbly person, he's a chatty cathy, he wants to talk talk talk, and he's just not himself.” Parents wanted children back to their normal playfulness, and for some this was a more important benchmark than temperature. M16 said, “To me, once my child - it's not really the number [on the thermometer] - once my child starts getting hot, starting to being not [himself], that's what I’m worrying about.”

Certain behavioral cues such as shaking and twitching were among the most worrisome signs, as they spoke to parental fears about seizures and made managing fevers far more frightening. Witnessing involuntary movements eroded caregivers’ sense of control and contributed to their decision to escalate care from home treatment into the professional sector. M13 said, “I noticed while she was asleep she was shaking in her sleep, so... yeah. It's time to go to the ER.” M02 had a similar story, saying” When she was asleep, she started like,
twitching. And that scared me, so I told my husband we had to take - I wanted to bring her in last night, but it was already late, so I had to give her some Tylenol and she went to sleep.”

The third major sign was duration of a fever. Caregivers often made the judgment that a child’s illness had gone on too long before finally deciding to seek care in the professional sector. For most families, this was a time period of roughly 24 hours. If a fever had begun the day before, persisted through the night, and not disappeared by morning, it became a problem. D15 said, “So I call [my wife], hey, we need to get to the doctor because it’s been all night, and today we supposed to be having, he supposed to be good by, the afternoon, but he wasn’t.” Some families were willing to spend a day waiting out a fever, but usually no more. As M25 said:

...you know what I actually did, I waited this time to see - the whole day, to see if it would go down, that’s why I done took him in the morning, to the, but when I got off work, my mom told me that he still had fever so I was like ugh I’m gonna take him, get him checked, because, it’s been since last night, and I thought it was gonna go away this morning, and it didn’t...

Parents usually had to deal with a constellation of bad signs, with some being prioritized over others. The importance of these various red flags depended on caregivers; sometimes a high temperature alone warranted a trip to the ER, while other parents were more concerned with whether the fever persisted or how their child acted. Importantly, parents’ processes of interpreting and acting on these signs were not always consistent. M09 explained how an usually high temperature overrode her usual policy of trying to control a fever for 24 hours:

So, normally I pretty much know how to control his fevers and I know like after 24 hours if I can’t get it under control bring him in - but - a hundred and three is already high, a hundred and four is, to me, considered red zone all the way. So, for me to bring him in.
4.3.1.2 Unknown Causes

For most parents, bad signs were a problem inasmuch as they were indicative of a malicious unknown cause of illness. More than anything else, parents wanted to hear that their children were OK; failing that, they just wanted to know what they were dealing with. Concerns about causes varied considerably, ranging from highly specific hunches to feelings of powerlessness about the unknowability of a child’s illness.

Caregivers in six of the families could be described as having a hunch about what was causing their child’s illness. These parents had recognized familiar symptoms from past episodes of illness and sought confirmation (or disconfirmation) of their suspicions in the ER. They also had more specific expectations about treatment they might get in the hospital. M10 came to the ER with her son “to see if he was, if he was having a virus. Because he was, uh, vomiting and then he had a slight fever so I figured you know they'll give us some antibiotics for the virus.” Although some of these parents were concerned about the danger of febrile seizures and high temperatures, they generally did not see unknown causes as potentially catastrophic. M14 suspected that her son had strep throat and simply came to get him checked out: “I know there's a lot of strep throat going around, I know there's a lot of viruses, and you really can't do anything with viruses, but because his fever was 104 I decided to bring him. Maybe he has strep - so I just wanted to get him checked for that.”

In an inversion of the hunch scenario, some parents observed a constellation of signs that led them to conclude they were dealing with a distinctly unfamiliar situation. After a period of observation, these parents had ruled out common culprits. M06 said:

We just kept checking her fever, and we just continued giving her Tylenol, and today I noticed that ... the fever was still there so I [brought] her in today because it felt like
something else was going on... other than just like maybe, teething or something like that.

In this situation, familiar devils were preferable to unfamiliar ones, as M13 described:

That's why I said if this is strep, then it's... [scoffs, as if it's nothing]. Yeah, it's a little - I think it's a little deeper, but, if it's strep we'll take it. You know. I'll take the easiest thing and go with it. But I just wanna make sure there's nothing else major going on.

The “unknownness” of fever causes was a problem because parents took fevers to be a sign of more serious infections than those typically associated with other routine childhood ailments like colds and sniffles. Many parents were far more curious about the causes of fevers and ways to prevent them than remedies or fever treatment tips. Regarding what she would like to know more about, M09 said:

“Like the causes of a fever... I know it's caused by some type of infection or something but... uh just knowing the cause and the different ways to prevent fever - which, I don't think, that's, the doctor, or, you know, a scientist has even established - ways to prevent them.”

These parents were more interested in understanding and limiting the risk their child was exposed than learning about ways to manage fevers at home. However, they ascribed a certain inevitability to kids getting sick. As M26 said of fevers, “I want to know how to prevent em but I know that's impossible... [laughs].”

4.3.1.3 Feared Outcomes

In addition to signs and causes, dangerous outcomes were the other major dimension of caregiver concerns about fevers. This was what generally set fevers apart from lesser concerns such as colds and runny noses. Febrile seizures were by far the most common concern among parents, and contributed significantly to concerns about high temperatures and duration of
fevers. The fear of seizures made children seem like ticking time bombs, particular when temperatures continued to rise in spite of medication. Parents perceived a positive association between temperature and risk of a febrile seizure, and this lent a great deal of significance and urgency to parents’ need to keep rising temperatures under control. M12 said: “I would say around 103.0 and it wasn't coming down after giving Tylenol and Motrin after four hours or whatever, then I would bring him to ER because they can have seizures and stuff like that. So that's kinda, worrisome [laughs].” In a variation on this theme, a few parents also associated fevers with irreversible harm such as a brain damage. M14 said, “I know you can get some, brain damage if it goes for a long time, depending on how high it is, can it come, can it be irreversible, does it stay that way, or... what.... especially in young kids like him, and in infants.”

The threat of seizures made going to ER an easy decision for parents. The potential risks of not going to the ER grossly outweighed the cost of going (a co-pay for the commercially insured and no cost for the publicly insured), and the risks of not going conflicted with parents’ need to feel like responsible caregivers. Though parents were generally unaware of the prevalence of febrile seizures, they considered the outcome severe enough to make even the slightest risk unacceptable. D03’s account captures the dilemma faced by parents:

“I have no clue what kind of treatment you're gonna get. I didn't - that's kinda the thing where you think, ‘Why even take your kid in with a fever’, because, you know, what are they gonna really do for em other than give em Tylenol. But then you also don't wanna stay at home, and [laughs], you know, and something really really bad happens, they have a seizure, something like that, where you're stupidly waiting around because you don't wanna take a kid with a mild fever to the hospital, you know? So, like... more of the fear of self-loathing if you don't do the right thing, I think [laughs]. It's an issue [laughs].”

Seizures were a fearsome bogeyman for parents whose children had never experienced them, but were a much more real concern for families who had. Children in several participating
families had experienced seizures previously or had one on the day of their visit. Firsthand familiarity with seizures made them even more frightening, and neither of the two families whose children had experienced febrile seizures in the past had been able to normalize the experience. M22, who had come all the way to Dallas from Waxahachie after a bad experience in the local ER, shared the story that informed her contemporary skittishness about high temperatures:

“He actually had a seizure back in January. I had a bad experience. I went up [to the Waxahachie ER] when his temperature was like 103, and that was cold and flu season so the emergency department was really full, and they wasn't able to give him you know, the quick attention that he needed. So when they finally went to just take his vitals and seat [us] back in the room, it was 105.7 - and it was 103 when I went - but as I sat in the emergency room it kept rising... and after they gave him some Motrin they never really came back to check the vitals again to see if the temperature was going down, and by the time they got us back in the room - I wasn't even in the room 10 minutes - he started to have a febrile seizure... and that was the whole reason I went to the hospital, because I read up a lot, you know, as far as children and toddlers and sickness, and I already knew if your child's temperature gets really high it, that can happen, so, when stuff like that gets close to that temperature I kinda freak out, and just rush to the doctor. Just see what it is, so... yeah, I was really upset that time cause I went just to make sure nothing would happen to him, and then I sat there so long something did happen to him, so... that's why I'm like, any time he has a high temperature, I'm, straight to the doctor now, cause it's really scary.”

4.3.2 Challenges

For every family, certain challenges complicated their experiences of managing illness at home. The major categories of challenges of were novel problems, technical knowledge and skills, and the presence of other illnesses such as asthma.

4.3.2.1 Novel Problems

A persistent theme in caregivers’ stories was the novelty of the challenges they were dealing with. Novel problems were often challenges that had never been dealt with before, for which caregivers usually felt unprepared; at the very least, they were unusual observations that
made the situation somehow different from a ‘normal’ episode of illness. Novelty had several dimensions, one of which was deviation from normalcy. Parents often emphasized that their children were healthy and rarely got sick, and that the sudden onset of illness had been a surprise. M19, whose son was seven years old, said:

“...Well that's the thing... he's not the type of- my son doesn't really get sick, so I kinda freaked out ... whenever something's wrong with him, like, I freak out, cause I'm not used to... like, me and my brother were not the type that kinda ever got sick either, and I don't know if it's because of what my mom would, you know, the stuff that she would so, so I freaked out, I didn't know what else to do.”

Parents used words such as “never” and “always” to demonstrate that the events of the last few days were a sharp departure from business as usual. As M18 stated regarding her daughter’s crying, “She was just being fussy all night and I didn't know what was wrong with her cause she never cries, never.”

Signs that were being observed for the first time were another type of novel problem. Record-breaking temperatures were an example of this. While discussing the potential for fevers to become “damaging”, M03 remarked to her husband, “I mean I don't think he had ever had a fever that high, right?” Similarly, M16 was dealing with the first fever she hadn't been able to control - her son was four - and said, “If he has a fever, and its controlled, I see him cooling down, and him starting to act like himself, then I'm like OK, well he's fine, he looks fine. But if it's something like - I mean this never has happened before, so it was something like, go, just go [to the ER].” Parents often felt that these first time challenges were better handled by an expert, and escalation into the professional sector usually followed.
Several caregivers spoke openly about how being new parents made caring for sick children frightening and stressful. M24 clearly described how her own inexperience influenced her willingness to use the ER to obtain reassurance.

“Being a new parent, every thing is crucial to me. I think when you done this for years and years, then you can detect what really is serious and what really isn't... but since I'm a new parent and I'm all new to this, then to me... I took her to the hospital for a bump on the head. When she ran into the wall. [As opposed to] someone who's been down that road before, who knows to put a ice pack and keep it moving and monitor... so it just depends on what the situation is, me at this point I'm taking em for everything.”

This kind of risk aversion was not limited to first time parents. Several mothers of infant children had other children who were adolescents, but the large age gap meant they were reliving the stressful experience of being a new parent. M07 commented, “I can be really honest with you when I tell you that even though I have the two older kids, with him, because, they're so far apart in age, um, I'm very scary with him, like every thing will make me worry.”

4.3.2.2 Technical Knowledge and Skills

In narratives about coming to the ER, parents frequently implicated limitations of their capacity to treat fevers at home. Most parents made an attempt to treat fevers at home before bringing children to their PCP or the ER, and they escalated their child’s care into the professional sector when their own efforts had failed. Most families were alternating Motrin and Tylenol to control fever temperatures while using other techniques such as baths, wet towels, or popsicles to comfort their children. Inability to bring down temperatures to desired levels with medication was typically the sign that home treatment had been unsuccessful. M29 said, “Yesterday I was able to control the fever with medication. Today I wasn't able to do it. Even with the Advil.”

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Unsurprisingly, a number of parents were interested in learning additional strategies for managing fevers at home. Specifically, they wanted vetted techniques for controlling temperatures that could complement their limited Motrin/Tylenol arsenal. Many parents had been made aware of various home remedies for fever through friends or the internet, but were unwilling to “experiment” on their children. When asked about what more she might like to know about fevers, M14 replied, “How to handle them better just besides trying to break them with the medicine, I think a lotta people know that, but is there anything else we can do about that? I know I had a coworker tell me to put him in cold water, but... I don't know how true that is. I just wanna know more about it.”

A few parents also wanted guidance on when it was necessary to bring a child to the ER, particularly what temperatures were dangerous. And in M13’s case, what do for any of the many contingencies that might arise:

“I think I need a better knowledge of OK when is it time to bring a child into the ER, especially after giving medication. So, do you bring ‘em in if the fever don't break, or do you just continue with the medicine throughout the whole day, if it's breaking, cause it - like I said, it'll break for about a hour, with medication, but then it spark - it spike right back up! ...but my thing I'ma ask, I don't know who I ask, but - what's the temp? That alerts us, OK, we need to go to the ER.”

4.3.2.3 Other Illnesses

Chronic illnesses or recent acute illnesses heightened parents’ concerns about fevers. Even low-grade fevers could be a cause for concern, as they occasionally indicated complications related to an ongoing illness or chronic condition. Several of the children in the study had asthma, and two were recovering from pneumonia. Combinations of these factors made it difficult for parents to understand the risk their child was facing, as M09 explained
while sharing her thoughts on the relationship between her son’s asthma, pneumonia, and allergies:

But 9 times out of 10, she [grandma] does the physician, and I do the hospital... cause I have to come and make sure that they doin' what they supposed to be doin' with him. Just because of history. ... the history of like pneumonia. History of asthma. History of allergies. All those three things trigger each other. So they all play a part... cause you never, like, him getting pneumonia recently was random, cause it's like, he's not having a asthma attack or he hasn't been sick with extreme allergies, so you sort of wonder where that pneumonia came in to play at.

4.3.2.4 Access to Medication

Many families were aware that fevers could be controlled more effectively by staggering alternating doses of Motrin and Tylenol, and most had been advised to do so by healthcare providers. Two families had been unable to follow this advice for financial reason. M13 remarked, “...they say alternate like Motrin and Tylenol, but I didn't have any Tylenol, didn't have any cash money to go to the store at the time, so I had to wait until her father got off, so... we got Tylenol, but, you know I just... wanted to bring her in...”

4.4 Primary Care Providers

Primary care providers were discussed at length during interviews. Although the relevant interview questions were loosely based topics deemed significant in the literature and mainstream health care quality paradigms, aspects of primary care with salience for obtaining reassurance also emerged organically during conversations with parents. Overarching themes were accessing primary care, relationships with pediatricians, and perceptions of pediatrician competence. Families’ processes of choosing doctors were also discussed at length, as this was often related to whether they had a competent, accessible physician whom they liked.
4.4.1 Accessing Primary Care

The nature of families’ experiences with primary care necessitates making a distinction between the dynamic process of accessing primary and the static notion of primary care access. Most families had theoretically reasonable access to primary care in the sense that they could usually secure an appointment within 24 hours, did not need to spend exorbitant amounts of time waiting to be seen by their doctors, and owned at least one family vehicle to which they enjoyed near-exclusive use. However, the actual task of accessing primary care could be quite complicated, as it required concordance between PCP and family availability. Table 2 explains examples of the steps involved in accessing primary care and potential challenges associated with completing them.

Table 2: Stages of Accessing Primary Care

<table>
<thead>
<tr>
<th>Step in accessing primary care</th>
<th>Common challenges</th>
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<tbody>
<tr>
<td>Establishing the need for professional help</td>
<td>Parent work obligations force them to monitor child remotely (making risk assessment difficult) and/or late in the day (when same-day appointments cannot be obtained)</td>
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<tr>
<td>Obtaining an appointment</td>
<td>Available appointments may be “too far out” (depending on the family’s assessment of need and actual availability of appointments)</td>
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<tr>
<td>Making preparations for an appointment</td>
<td>Negotiating time off with supervisor, finding childcare for other children</td>
</tr>
<tr>
<td>Traveling to the appointment</td>
<td>Vehicle needed by working family member(s) or children need to be picked up from school</td>
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Facing or anticipating one or more of these challenges (usually more) could lead families to go straight to the ER rather than their PCP. Families had often chosen not to consult with
their PCPs, and this was usually because they anticipated not being able to obtain the reassurance they desired from their PCP on a satisfactory timeline. The idea of anticipating barriers is crucial for discussing the “appropriateness” of non-urgent emergency room utilization. Most families did, in a sense, come to the ER because it was faster and more convenient than their PCP, with whom they usually had no contact prior to their visit. However, it would be misguided to characterize caregivers as having a “fast food mentality” about health care (Chin et al. 2006:25), given that the focal point of parental habitus was worry rather than convenience. The major aspects of accessing PCPs were appointment availability, family logistics, and time commitment.

4.4.1.1 Appointment Availability

Six families had PCPs with whom scheduling timely appointments was unambiguously problematic. Usually this meant that scheduling a sick visit took more than 48 hours. All were insured through Medicaid. For example, M11 had been given an appointment more than a week from the time she had initially called and decided to come to the ER four days before the scheduled date because she uncomfortable with making her two-year-old son wait that long. She did not consider the situation a crisis, and came to the ER purely because timely primary care was not an option. M08 reported that getting a walk-in visit usually meant waiting all day at the clinic, and M04 described a frustrating week-long wait for sick visits. M18’s clinic had difficulty honoring some of the appointments it made:

“Today I didn’t decide to go to the clinic because it’s always packed Mondays. Yes, it’s always packed Mondays so I really don’t like showing up while it’s packed, and yeah, they set up appointments for and they sometimes don’t wanna take you. Yeah. Since it’s so packed or busy they be like, oh you know, we can’t take you right now, so you know, try to send her to the hospital or something. So that’s why I brought her in today.
However, a majority of the families insured through Medicaid and (all families insured commercially) were reasonably satisfied with their ability to get a timely appointment. Most could get an appointment within 24 hours (although “tomorrow” was considered unreasonable in some cases), and it was not uncommon to obtain same-day appointments or walk-in visits by calling early in the morning or even just before 3 o’clock. These families often credited their PCPs’ willingness work them in. Although M24 wished her pediatrician was “a little friendlier”, she was pleased with the appointment scheduling, saying “Now that she’s wonderful in, because I called this morning, and she does walk-ins just like that [snaps fingers]. She gets us in, just like that, she told me to come within 30 minutes, so she’s good at that.

The four families with private insurance had no complaints about appointment availability, and spoke highly of how good their PCPs were about accommodating them (often the same day). M07 said, “They see me immediately. If I call in the morning, and I tell them what’s going on, they, uh, make, they... are really good at always squeezing me in somehow, that same day.”

4.4.1.2 Family Logistics

Parents who were working or in school had to navigate these obligations when seeking medical care for their children. Sympathetic supervisors and the ability to trade or drop shifts at work were crucial factors in this. Most working caregivers were capable of negotiating with their employers; though they tended to assert that their children were a priority and that they always leave work if necessary, they were grateful for the flexibility. M14 explained:

Where I work I’m pretty flexible as far as you know with my supervisor, my boss, he understands that I have kids, and he understands that their health is first, and, like today, I was not in even 10 minutes and I received the phone call and I told my boss “hey you know my son is sick, he has a fever” and he said that was fine, make sure
everything's ok and keep me updated. And I walked out! And it's not like - and I'm blessed in that aspect, because I know there's a lot of places where they're really strict on them, and they don't want anyone to go out.

The nature of some parents’ work (or the disposition of their supervisor) made it more difficult to access primary care. For several families, the combination of unsupportive supervisors, multiple children to transport to and from school every day, and job hours that closely overlapped with PCP business hours created frustrating barriers. M10’s supervisor expected her make appointments after getting off work at three in the afternoon, but this was rarely possible because she had to go straight from work to children’s schools to pick them up:

In a way- she [my supervisor] kinda isn't supportive. Because she expects to be there. And she expects us to make our appointments after work, but it's very impossible to do that most of the time, and especially with small kids, and that's just what I've explained to her when I first started working: "I've got small kids. I mean, I can't wait after work if they're sick within the time I have to go to work, I have to go, or I can't make it in." My job is from 8 to 3... The clinic is 8 to 5...And by the time I get out, I still gotta my kids up from school, and they'll be closed by then. And the last visit that they take is um, till four... So it's kinda like... hard. Stressful, too. [laughs]

M10 acknowledged that she was at least partially protected because she was able to use sick days to take her children to appointments or the ER. M24’s employer had instituted a system in which employees were allotted a limited number of points upon being hired. Points were deducted for every unexcused absence, and medical absences could only be excused if evidence of a hospital admission could be provided, which she described as “messed up.” However, she was not particularly worried because she felt the points were relatively abundant relative to what she anticipated needing. Although M06 was returning to and old job with an understanding supervisor, she was worried that delaying her daughter’s care any longer would compromise her first day back. She came to the ER to head off the possibility of having to leave
work the following day, but explained that normally she would be up early in the morning to call the doctor to set up an appointment.

Most families had access to one or more personal vehicles for transporting children to health care providers. Only one participant reported using the bus as routine source of transportation to the pediatrician’s office, and even she had been able to obtain a ride to the ER from her mother. Problems with transportation tended to arise when parents had to manage traveling to work, children’s schools, and PCPs at conflicting times. Families with one vehicle typically had to devote their car to family members who were working, meaning stay-at-home parents sometimes had to wait for working family members to return home if palatable public transportation was not available. M21’s sister and mother had both been having car trouble, so she was sharing her vehicle with them. When asked if this made getting her daughter to appointments difficult, she had this to say:

Yeah, right now, it’s difficult, because... um, recently, like a few days ago, my niece spilled soda in my mom's gear shift, so, it locked up... so now it’s just down to one car- well 2 cars - my dad, he goes to work at 3 in the morning, I have to be at work -me and my sister work at the same job, but she has to be there at 7 in the morning and I have to be there at 11. My mom has to be at work at 3. So I had to drop my mom off at work today, to come bring her here and then I have to go back... So, yes.

Families with difficult schedules were occasionally able to seek help from friends and family members with transportation and childcare. M08 usually planned visits to her clinic or the ER based on when friend or family were not at work so that they could watch her three older children. M16’s parents occasionally took her son to his doctor on her behalf. However support was sometimes limited than this; M02, M10, M29 and several other mothers had had to bring all of their children with them to the ER because there was no one available to watch them. M10 had tried to obtain help from others with getting her children to appointments but
found it difficult: “...it's kinda hard to get somebody to do it for me, because... I mean, I'm a single mother, doing everything by myself, and it's hard to pay people gas if I don't got it, I mean they're offering for gas, and the father works all day - me and the father are no longer together - the father works all day. And it's hard for me to get him to take him.”

The hours that clinics were open were generally poorly matched to families’ illness management timelines. Regardless of whether families had been monitoring a fever for a few days or if it had materialized out of nowhere while a child was at daycare, many families did not establish that professional help was necessary until mid to late afternoon on the day of their visit. This was in large part because parents were at work, and typically made “reassessments” of their child’s condition at the beginning and end of the day. This often left them in a situation where they felt that same-day attention was needed but could not realistically get it from their pediatrician because it was already between 3 and 5 in the afternoon. M25’s mother had been relaying information to her while she was at work, and made she made her reassessment when she got home:

Well when my mom called me, like around one, that the fever was still going on, and around two, an hour later, I asked her again and he still had fever and she said yes, so... when I got off, when I got home, he still had fever. And it was just, take him to the ER, because his clinic that he goes to, they close at 5. So I was like, I'm not gonna make it over there.. it was just, take it to the hospital.

4.4.1.3 Time Commitment

For some families, the time commitment associated with visiting their PCP made the ER an attractive alternative. M08 had spent the better part of entire days waiting at a previous PCP’s office, saying “you can't never get in like the same day... The way you go you gotta wait like, bout, 5-6 hours... [I want a new doctor] to be like, fast, that won't take all day, and like a,
good doctor.” In addition to being an inconvenience, long waits could be a stressful delay in obtaining reassurance that a child was OK. M06 was pleased with her PCP in most respects, but couldn’t avoid lengthy wait times even with an appointment. For her, this was a deal-breaker: “It's just a long wait. The baby can have fever, something could be wrong, and you're waiting two or three hours to be seen... I've just gotten tired of it, and [I'm] ready to look for another doctor.” Notably, the extent to which time commitment was a problem depended entirely on the disposition of the parent. M20 considered a brief visit preceded by a 45 minute wait to be “a long time,” but M10 said, “Walk-ins, I can, it's... good, the doctor appointments, I'm in and out. So I'm not in there no more than two hours. So Yes - I'm very happy about their doctor.

4.4.1.4 Other Access Issues

One family had been forced to switch from a beloved doctor available to them through Medicaid after breaking through the income eligibility ceiling and being switched over to CHIP. Only two families did not have current pediatricians, and both of them had had considerable difficulty accessing previous pediatricians.

4.4.2 Perceptions of Competence

Competence was another important dimension by which PCPs were evaluated. Children had not usually had adverse outcomes in which PCPs could be implicated, and for these families competence was roughly equated with apparent thoroughness. Doctors earned parents’ respect by appearing to “check everything” and taking extra steps to diagnose children (for example, by ordering additional tests). M11 emphasized her pediatrician’s consistent thoroughness: “Well I like his doctor, ‘cause she checks everything... for example, his ears, his
eyes, they will check him everywhere like that, even though it's not a physical she will check
everything. For a sick visit.” M25 had switched to a new pediatrician, and liked that the new
doctor would order blood work in order to find out what was “actually” going on with her son.
“I don’t like the guessing,” she said. M30 appreciated her doctor’s analytical approach, saying,
“He's very attentive to details, every time we go there, he's always analyzing why this medicine
is not working for her, maybe we need to change doses, maybe we need to add a medicine.”

Parents relied on observable evidence to assure them that PCPs were doing their jobs.
Some parents struggled with the notion that tests or prescriptions were not necessary when a
child was still showing symptoms. Although pediatricians were generally a respected and
authoritative source of guidance, parents wanted every possible step to be taken; when
informed that tests or medications were not necessary, parents felt as though the work of the
PCP was incomplete. M14 was displeased that her PCP had refused to do blood work at a
recent visit, and their explanation as to why did not address her underlying concerns:

...and then I know when I did a checkup for him, they didn't draw any blood, it was kinda
just, come in, come out, and I said, I asked him, you don't draw blood or check their
blood? Cause you know sometimes they're anemic, or you know, just because it's not
visible here doesn't mean it's not in his body, and it's, they said no! They weren't gonna
check his blood. So I didn't like that.

In these situations, perceptions of causes of illness and the nature of parents’ need for
reassurance was closely linked to ideas about competence. Parents who were especially
concerned about underlying causes of children’s illnesses needed more exhaustive diagnostic
procedures (and sometimes a prescription) to be reassured. Incomplete understanding of viral
illnesses (particularly vis-a-vis antibiotics) exacerbated this in a few cases. However, the
explainations parents received as to why such steps were unnecessary were often unsatisfactory, leading them to question their pediatrician’s judgment.

In cases where PCPs had seemingly failed to manage a child’s health effectively, efficacy became a crucial aspect of competence. Getting a second opinion that contradicted their doctor could severely damage trust in PCPs. M20 had begun to consider finding a new doctor after her PCP refused to prescribe medication for her daughter’s diarrhea, particularly since the child’s grandmother had successfully treated the diarrhea at home with arroz con leche and the ER had been willing to provide medication. M26 became deeply distrustful of her PCP’s judgment after a missed ear infection and disagreement about a flu shot, but was reluctant to switch due to the length of time her child had been with the pediatrician:

I can’t call the doctor like that cause she’s not really a good doctor... one time, we had like a little.. altercation where he had a ear infection and she had told me the ear infection was clear... two days later, he had a fever.... Me and him come up here, you know, we up here, it's late at night, I'm like, dang, you know, what could be wrong with him? Everything was going away. And then the nurse [said], "he has a ear infection." ... I'm like... your work [the pediatrician’s] is not worth anything... cause I'm relying on your expertise to help me, with my kid, to make sure he's ok, but... I don't trust you now, so... and then one time he was sick, he was sick like, had a runny nose and stuff, and she still wanted to give him a flu shot. And I'm like, you don't give a child a flu shot when a child is sick. No, you supposed to wait till he's in good health and then give him a flu shot, cause that's like you putting the flu virus while he's sick, it's gonna make him even sicker. So. It was just like, I need a new doctor. But I want to stick with her kinda cause I kinda knew her from birth, that's the doctor that was at the hospital ....I'm just kinda nervous to take her word, because, you know, one ear infection could be something bigger, you know, one thing could be bigger than the next... you know, and then it was like, you wasn't on top of it.

4.4.3 Relationships with Pediatricians

Having a good relationship with pediatricians was an important component of establishing them as go-to sources of guidance. One aspect of the family-physician relationship was duration; families valued having a doctor who their children had come to know and could
continue to grow up with. A long and established relationship was important enough that faults such as limited appointment availability could sometimes be overlooked. M17 had built a relationship with her children’s pediatrician over many years, and trusted him completely. She reported, “I love her doctor... he's the doctor for my three kids, I met him since six years ago, and he's really nice. The only problem with him is if I got an emergency, he's always busy, he's full all the time - but that's the only problem that I had with him.”

Communication skills and willingness to devote enough time during visits were also important aspects of physician-family relationships. Taking the time to explain things was an important quality of “good” doctors, and was part of what separated doctors who were accepted from those who were adored. M12 described her pediatrician:

She's wonderful. When I was pregnant with him, I did like the prenatal interviews and stuff like that... and since he's been born, she's just wonderful. She actually sits there - even though she knows that I'm a nurse, she still sits there and explains things, and says, [let me know if you have any questions], and if I do, she'll answer them truthfully, she doesn't keep anything back... she's all around wonderful.

Being able to see that a pediatrician truly cared about their child also separated great doctors from good ones. Relationships with these types of doctors went beyond amiable rapport and were characterized by strong bonds of trust. Through diligent work and charismatic communication, these doctors demonstrated to parents that they truly cared about their children. They exuded compassion and were readily trusted. M22 provided superlative praise:

What makes her the best? I can tell she cares, and she's not just seeing patients ... she remembers him, remembers what he goes through, you know, they have, it feels like I have a personal relationship with her - which I know I don't - but that's the way it feels when I go there, so, that means a lot to me. You can just really tell when people care about what they do.
The extent to which rapport with PCPs was important differed among families. M06 had a good relationship with her physician, but wait times had become intolerable; several families liked their physicians enough that they were willing to put up with poor availability of sick visits. Though families sometimes tolerated imperfections such as lack of warmth or excessively brief office visits, inability to form the sort of relationship they wanted could be a problem. Though family 27 had a competent and accessible physician, both parents felt that their current pediatrician was not showing sufficient interest in their daughter and this concerned them deeply. M27 shared, “He's friendly... [laugh] but we need somebody that's more - I not gonna say knowledgeable because to have a degree, you have to meet the qualifications - but I guess someone that's more, have an interest, [going to] take an interest in what's going on with our child.”

4.4.4 Choosing a Doctor

Families’ approaches to choosing a doctor provided insight into what they valued and how they started the process of establishing relationships with new pediatricians. Most families had chosen their pediatrician via referral from a trusted family member or friend, or by meeting the pediatrician through providers involved in the pregnancy or delivery. Doctors who were known to family members or close friends were trusted more readily. One teen mother who had been pushed out of her pediatrician’s patient roster when she became pregnant was overjoyed at the opportunity to begin taking her own child there. Family networks were a good source of reliable information about potential PCPs, and these referrals often came with the guarantee that candidates had done a good job of caring for someone in the family’s social network. M10 found her doctor through a friend whose child had also been born prematurely:
I chose it because one of my 14-year-old son, he was born premature and a friend of mine told me about the doctor cause she had a premature baby and she-, he went there, and she told me about the doctor. And both of our boys grew up together. They both were premature babies and they went there. And that's the way I found out about it.

OB-GYNs and doctors aiding in birth also referred parents to pediatricians, and occasionally a participating on-call physician with a pediatric practice even took on the role. This was most common if parents had waited until the last minute to choose or if plans to see a specific pediatrician fell through. M07 explained how she chose her doctor:

By accident, actually. His- what was gonna be his pediatrician had retired, like, the month before I went into labor with him. Um, and I had not had time to really find another pediatrician, and he happened to be the one who has on call for him when I had the baby, when I had him. And then I met him cause he came to check on him later, uh, he had done his circumcision also. And he just came to check on him, and we just started talking, he told me where his office was, and I, I went, and I just... never left, I guess [laughs] as far as pediatricians goes.

Last minute retirements and confusion at clinics sometimes undermined parents’ attempts to select the specific doctor they wanted. Because a pediatrician was usually needed immediately by the time these hitches emerged, it was not uncommon for parents to initially settle with a physician they hadn’t intended to work with. M20’s sister-in-law recommended a specific doctor to her, but when she came to the clinic the physician was not taking new patients. The clinic gave her other options and she chose from a list.

Though a few parents discovered a beloved doctor by accident, the haphazard method of choosing a PCP generally produced suboptimal results. More than a third of families had switched doctors at least once or were in the process of doing so when they were interviewed. For those in the process, the ER was an interim source of primary care. The family’s first doctor had often been a poor match for their needs, and families generally attempted to switch before
their child turned two. Switching doctors could be a difficult and frustrating process, regardless of whether a family had Medicaid or commercial insurance. Parents who had decided to switch spoke about doing so tentatively, and were usually in the early stages of doing internet research if they had even moved beyond contemplating the change. Though several parents had switched pediatricians without incident, others had horror stories about transferring records or trying out a new candidate. Families tended to settle for a doctor that could meet their needs and was good enough, if not perfect. M03’s story about trying to change pediatricians exemplifies this:

We’ve really learned to like her... we don’t like that she doesn’t, like, have afterhours, or weekend hours, so we were like, we’re gonna change to somebody else, and um... then we tried that and it was a disaster... like he [Dad] went to a new person and it was like a three-hour wait, and they made, like, they wouldn’t let them, they wouldn’t let him use their restroom to change him, so he had to go to like, a random guy’s restroom without a changing table and change him on the floor - at Baylor, actually! Yeah, it was, so, now we really appreciate her, even though she doesn’t have the weekend or the after hours [mom and dad laugh]. I mean like, today I called her, the daycare called me at three, I called her right after, and I was in there by 4:15. So now like if she makes us wait half an hour, an hour, we don’t mind at all, after that horrible experience.

4.5 Information Sources

Information sources refer broadly to people and resources that parents consulted for information about their child’s health. Interviews addressed sources sought during episodes of illness as well as sources used when children were well. Information sources mediated the process of obtaining reassurance in that they influenced caregivers’ sense of how urgently reassurance was needed as well as perceptions regarding where and when reassurance ought to be obtained. Family advice or a Google search could dramatically affect caregiver dispositions about going to the ER, or they could be peripheral background noise with little
impact on treatment or healthcare utilization decisions. This depended on the nature of the information source and the attitude of the caregiver in question.

4.5.1 Family

Family members, especially grandmothers of sick children, were a go-to source of information for caregivers, though not necessarily the most authoritative one. Family members played various roles in providing information, advice, and support. At their most active, family members were directly involved in home treatment and decision-making about seeking care. These individuals were often recognized for their experience raising children, medical training, or track record of treating illnesses successfully with home remedies. M02 deferred to her mother for many tasks related to caring for her children:

“[My mother-in-law] just tells me, uh, cause she raised like six, she has six kids, so she tells me what to do, and like - she can tell me what to do to the kids what she did to hers when they were sick, and then she'll tell us to, uh, if she sees that, if we call her and tell her that it's not going down, she like, she gets on us to tell us ‘you take em to the hospital.’ So I bring her then.”

The day of her visit to the ER, M19 had consulted with her mother about whether to go to her pediatrician or to the hospital, citing her training and knowledge: “I told her, like should I go to the doctor or should I go to the hospital and she's like just go to the hospital, so I just came straight over...my mom, like, she's all into home remedies, and you know, she was a nurse in Mexico, so she kinda knows everything.”

Though caregivers’ parents were almost always involved in some capacity, they sometimes had more circumscribed roles. M26 was skeptical of the home remedies her mother recommended and distastefully declared, “that's old southern stuff.” She went to share the
story of taste-testing a remedy her mother - who was present during the interview - had wanted to give her son for colic when he was younger: “

It's gross... I tasted some... after I took it, I was burping, and it's, this smell was still comin' out [pantomimes fumes coming from her mouth]. It was horrible, I'm like, he is not takin' that... that's why I don't let her do any home remedies. [So what's your beef with the home remedies?] I don't know nothing' about em! I, I have to see, I have to see it, like... you can't just tell me something works, and then... expect me to believe that, to let somebody do it on my own child.... my only child! I can't trust that! I can't be responsible for that.

D27 had moved to the United States from the Caribbean, and grown up relying on home remedies to compensate for inadequacies in the local health care system. After coming to the United States, he felt that his mother’s home remedies should only be used after pediatrician-approved treatments had been exhausted.

“I trust that the doctors here know what they’re doing, compared to remedies back home, cause actually before we came in here we were in the waiting area, I called my mom back home and she said, have you bathed her with rubbing alcohol? And I said no, I haven't tried it yet. Yeah. So, I'm just basically going on what the doctor said... the reason why I haven't tried is um like I say is because, you would typically want to go with what the doctor says rather [than] your home remedies, right? So that's pretty much what I've been going based on. But if we go home, and the temperature comes back, I'm probably gonna try what my mom says.”

4.5.2 Healthcare Providers

For many families, the pediatrician was the preferred source of information, if not the most readily accessed. Parents tended to view the PCP as the gatekeeper to higher levels of care, such as the ER, even if this was not always realized in practice. Most explained that in an ideal situation they would call the doctor to establish a course of action before seeking information anywhere else. Seven families had actually been advised to go to the ER by their
pediatricians. Though M06 had not sought pediatrician advice on the day she was interviewed, she said this unusual and differed from her typical process:

“Well first I call the, the pediatrician to see, you know, is this, you know, and emergency do I need to bring her in, take her to you know, the hospital - Children's, and... they kinda tell me like no, you know, they'll put me on hold and they'll ask a nurse, just somebody there, and they'll get back on the phone and let me know whether to bring her in or just keep an eye on her for another 24 hours, or whatever the case may be.”

The families who went to the ER based on recommendations from their PCP had received this advice in a variety of ways. Most were advised over the phone, though a few parents whose children had ongoing conditions had been given guidelines regarding when to go to the ED at a previous office visit. M20, whose daughter was 5 months old, had seen her doctor a day earlier and called in for guidance on the day of the interview:

Well um she started having fever. Well it started with a cold, I took her to her pediatric, and she said it was a cold and that they couldn't give her nothing cause she was still too little, so, just to keep on giving her Tylenol, and that was it. Oh, and she told that, in case she got a fever to call and they'll see if they could take her. And then well I called in and told them how much she had, and they told me just to bring her to the ER - which it was 101.

Over the phone, families usually spoke to a medical assistant rather than a nurse or physician, and were sometimes advised to go to the ER simply because the clinic was full (as opposed to going based on medical need). Calling the office did not necessarily mean that families got a clinical opinion on whether their child needed emergency care, and some families may not have understood this.

4.5.3 The Internet

Most families used the internet to locate health information, but of all available sources it may have been the least helpful for making important decisions about treatment and healthcare utilization. Parents valued it as a way to learn about their child’s health, but some
had difficult putting their trust in the information they found. Parents were sometimes embarrassed to admit how often they used Google to find health information, and several caregivers burst out laughing after sheepishly confessing, as though they anticipated disapproval.

On one level, the internet was an exploratory tool that helped parents answer questions. It was usually used in early in the process of managing an illness as opposed to the point where it was considered a crisis. In the initial stages of a child being sick, parents would attempt to diagnose their children and figure out an initial course of home treatment. Parents often searched for information about how to recognize common ailments such as teething or ear infections; alternatively, they would search for the symptoms they had observed and attempt to match them to whatever illnesses came up. These deductive and inductive approaches were not mutually exclusive; however, the accounts of M06 (whose daughter was 8 months old) and M14 (whose son was 3 years old) demonstrate their respective differences:

I just go to Google... [I’ve searched for] how I do I know if the baby's teething, or how do I know if the baby has an ear infection, or what are signs of you know throat infection... I just read on it and if it tells me like, just to continue giving the baby Tylenol or call your doctor immediately then that's what I do. Or [if it’s] something that might just go away.” (M06)

He was complaining about his belly, so I typed in ‘reasons for 3 year old stomach aching’ and there's so many... a while back, we Googled, why do kids snore, why do they kind of bubble at the mouth. (M14)

A major selling point for the internet was the vast wealth of practical information it could provide in an instant. Many parents were frequent visitors to websites such as BabyCenter and Parenting.com, where they had access to vast repositories of information
covering innumerable topics. M17 praised the helpfulness of a smartphone app she used for information:

I just look for that, what, what the baby have, and it can tell me, what [to] do, or if I can use some medicine, can I give it to her, or what is necessary to call the doctor or what is necessary to go to ER... yeah, it's an app, it's an app - I think it's My Health, or something, it's on my old phone, I just switched phones, and yeah - but it's just really, I love that app. It's helped me a lot! ... I used it once for, I think it was diarrhea... and I called, I just, first I read it and called the doctor just to be sure... And then the other, it helped me for the, when she was teething, it helped me a lot too. I mean it help a lot! It's a lot of information.

Notably, M17 felt it was necessary to verify what she found with her doctor. This part of her story touches on the internet’s greatest weakness: its inability to supply to the definitive reassurance that a credentialed expert could provide. Parents valued the expertise of physicians and it was important to get their opinion in person. M26 explained:

I mean, I'm still up here though... I'm still at children's [laughs] so I mean... it's probably helping me a little bit, but... it's making me not panic as much, but I still find myself up here at Children's, you know... I just need that, that expert opinion, to, you know, make sure everything is OK. Some reassurance.

Other parents were cognizant of the possibilities of drawing stressfully false conclusions through internet research. They recognized that it often led them to assume the worst and diagnose their children with life-threatening illnesses. Moreover, distinguishing fact from fiction could be difficult, and parents felt that making decisions based on unverifiable information - or “myths and legends” as D30 described it - was too risky. M07 felt that calling her pediatrician saved her time and stress by providing better information faster. Though she was willing to use web-based information to make decisions about her own health, she refused to take such risks when it came to her children:
I do [use the internet]... but I'm really bad at diagnosing myself, so I try not to do it with him [laughs] or my daughter and my older son... I'd rather just call. Typically for the kids no, for myself yeah... I do the Medical MD app... and everything that they say to look for I have, so [laughs] so I don't do that with the kids, cause, then I'll be like ‘Oh my god, they have this and they have that.’

Despite its inferiority to information from pediatricians or trusted family members, parents occasionally used the internet to fill gaps in what these sources were able to provide.

For parents who were unable to get satisfactory answers to all of their questions during visits to their pediatrician’s office, the internet was a tool to round out their personal knowledge base.

M14 acknowledged the limitations of the web, but felt that additional research was necessary.

Honestly? I Google it. I put it on the internet. It's kinda sad, but it's true - I have quicker and more, elaborate results on the internet than calling the PCP. The PCP it seems like nowadays they're just to a minimum of time that they can spend with these children and it's more the nurses that are with them than the doctors; they come in, they come out, and I think the longest I've ever had a doctor stay in there with us is about 15 minutes. And that's it.... I mean I Google everything, everything, everything. And I mean you can't rely too much on the internet, but I have a better chance getting a response on the internet than I do calling his PCP - cause sometimes I'll talk to the MA or the nurse, and then they'll wanna wait a day to bring him in- what if my child doesn't have a day to wait?

The internet was also a tool for understanding the implications of illness, e.g., how long it might last, what other illnesses it might be related to, and whether a doctor needed to be consulted. In this respect, it helped families get a grasp of what they were dealing with. Though the internet was used to establish when it was important to call the doctor, no one spoke about the internet dissuading them from seeking professional help. Parents almost never concretely implicated the internet in stories about going to the emergency room, though M30’s story about her daughter’s asthma attack was a rare exception:

Yes [the internet is helpful]. For example, let me tell you, last time that she had an asthma attack, I wasn't sure, I was trying to decide to come here or not, so I searched, you know, what is the danger signs, with having an asthma attack, and I found that they
have a lot of uh recommendations - when to go the emergency room, for example, when she, the patient has blue lips and blue nails, and that time she was really sick, and that was what immediately called my attention because she was really turning colors and I decided to come to the emergency. So yes - it was very useful for me, and I learned a lot of things from the internet.

Health literacy sometimes played a significant role in the use of web-based information. Though many parents were computer savvy enough to access information online, they lacked the skills to critically interpret it. When M23’s cousin suggested that her 1-year-old son might have hand, foot, and mouth disease (HFMD) the two of them Googled it and immediately panicked. Even though HFMD can be handled easily by a pediatrician or even through home treatment alone, they thought it was a serious illness that necessitated a trip to the ER. M24, whose daughter was 22 months old, was interviewed in early October 2014, roughly one week after Thomas Eric Duncan died of Ebola in Dallas. They had been hearing about Ebola everywhere, and their perspective on what Ebola cases in America might mean for their family had been largely shaped by cable news:

It's all over the news, it's all over the internet, it's all over everywhere... and um before we got here I was so nervous, cause when they called and told us to bring her to the ER, we took her temperature again and it was like 102, so they called the paramedics, and they acted like they didn't even wanna get close to her... so that's how I know it's affecting more than just us, it's affecting the whole community.

4.5.3.1 Establishing Trustworthiness

Parents had a number of methods for establishing whether internet information was trustworthy. A common method was for parents to compare what they found with what they already knew and look for concordance; if what they found did not sound right, they concluded that it probably was not. As M10 explained: “I go by what I already know. And if that's pretty
much telling the same thing that I already know then I go by that. So if it's something else new that I don't know about then of course I'm not gonna trust it.”

In a variation on this theme, parents would look for consensus among different websites and among commenters’ posts on parenting forums. M14 would search for a topic and compare the websites that came up to see if they had a consistent message: “I’ll browse more than one. And I'll see, say I Google 5, usually, it's three or four, but the more I Google I try to see if the other one says exactly what the other website would say, or if they're similar in any ways.”

Parents also used well-known brands and trusted domains as a guide. WebMD, Wikipedia, and BabyCenter were popular websites. Google was the only search engine mentioned (although it is possible that parents were using the word as a generic verb for searching the internet), and parents usually performed a Google search rather than going straight to specific websites. Parents also looked for URLs ending in “.gov,” “.edu,” and “.org,” which they perceived as more trustworthy and more likely to be informed by research studies and other sources of expertise.

A few parents chose websites based on their popularity, believing that the best information would be at the top of the list of search results. M21 said, “I kind of don't go back past the first page. So whatever's, I only look on the first page, I never go to the second page. If a page is after that... cause I figure, like, the most viewed is on the first page, so that's why I look on the first page.” Similarly, M24 said, “I usually go with the first one that comes up, pops up, you know, they be in order, so... I figure like, the best one should be first. That's how I look at it.”
4.5.4 Nurselnes

Children’s promotes the Medicaid nurseline as a key tool for reducing nonurgent utilization of the ED. However, only half of the participating families were aware that nurse lines were available to them, and even fewer actually used them. Several parents had used nurse lines during their pregnancies or their child’s infancy but had stopped using them for reasons they were unable to articulate. Parents acknowledged their benefits, but rarely mentioned them without prompting. M20 was familiar with her nurse line and had occasionally used it:

Mm... well... it’s OK I guess, I mean it does help, on what- I mean, I, they tell you how to do it, and you're not sure if you're doing it right or if you're not doing it right... but it's good that you get to call somebody and they could walk you through something. And then that's when they tell you, oh it's too bad either take her to the ER or these are, they give you different type of stuff you could do with them.

However, parents who did appreciate what nurse lines had to offer did not necessarily see the service as an option in crisis situations. While discussing nurserline use, a few participants burst out laughing when it dawned on them that they might have called the nurserline prior to their visit. M13 had found the Medicaid nurse line helpful in the past, and enthusiastically explained how the service was available 24 hours per day to walk her through challenges and help decide when it was necessary to see the pediatrician or go to the ER. However, when asked if she had ever considered calling them for the current fever or similar illnesses, her response was this:

No, no. No... maybe you know, now that I'm thinking about it [laughs] maybe [laughs louder] maybe I shoulda called them today! You know? Or last night? But I'm thinking the fever woulda broke... and it did break, so I shoulda really called them... I mean, everything is a learning experience.

Other parents were more explicitly exposed to the idea of using the nurse line during a potential emergency. They felt that calling a phone service in the middle of a potential crisis
situation conflicted with the need to get timely care for their child. These parents were worried about spending too much time on hold when they could be traveling to a hospital instead, and were skeptical of benefits that a nurseline could plausibly provide. M26 felt that calling the nurseline delayed the inevitable: “Yeah, I was thinking about calling that line though, but... they couldn't give me a prescription, or nothing, and they couldn't see him - physically - tell me what I should do, and everybody gonna tell me to go to the emergency room. Cause the fever was so high.”

M26 was not the only parent to voice concerns about telephone triage. Several caregivers rejected the idea that a child could be adequately “checked” through the phone. They felt that a visual and tactile inspection was necessary to understand what was happening to a child, and thus felt that a nurseline had little to offer them. M16 explained:

To me it's like for somebody to tell me something over the phone, it's like, how would they know? Only just based on the information they know? Or the education they know. But they haven't seen it. It's like, I'd rather let somebody see it than not see it. Cause a lot of things do change when you see it to not seeing it.

4.5.5 Other Sources

Healthcare providers, family, and internet were by far the most common sources of health information, but families had a few other avenues for information and guidance. Friends and colleagues were occasionally consulted for advice related to treatment and healthcare utilization, but usually only played a significant role if they had medical training (for example, M12 was a nurse and many of her colleagues had relevant expertise. One mother referred frequently to her What to Expect book as an alternative to Google, which she disliked because
of the way it facilitated misdiagnosis of her child. However, no other caregivers mentioned using books as an information source.

Six parents had received education or training in various health professionals that informed their treatment of fevers. These parents had taken coursework to become medical assistants or phlebotomists and learned about fevers and their potential outcomes (such as seizures) in the process. However, this was not particularly empowering and actually may served to further frighten parents by introducing them to a greater array of possible threats. M16 said, “I go to school, I went for phlebotomy, and that's what they told me [about febrile seizures], well that's what I remember, you know, always make sure, you know fever, you know - and more with the kids too, I was scared, I was scared, I was like, no.” M26, who had studied to be a medical assistant, said that seizures made her nervous because she had learned that if children's bodies overheated they could suffer seizures or brain damage. Only the nurse felt that her training and experience made her a more effective caregiver.

Cause I mean like... doctor's visits' cost, and emergency visit cost, more frequent - you know, cause parents that don't have that information they're either at the doctor all the time or the ER all the time, so that's money that they're having to spend all the time just for these visits, and then being a nurse at home you can just kinda treat what you can at home, and if it gets any worse then call the doctor, or go to the ER when you think it's necessary... so yeah, it's a money-saver [laughs].

Finally, parents occasionally cited their own experience or gut feelings when asked about sources of health information. More experienced parents - who were relatively few in number - occasionally referred to their years of practice, and often had little to learn from friends or family if they asked at all. Other parents spoke of a 'parental instinct' that they used for guidance. M14 conceptualized in this way:
... it's just a mom thing. Mom's have - I don't know if it's an instinct, I don't know if it's the feeling, I don't know what it is... it's just the mom thing... cause that, I mean, I have that MA training but sometimes I still call my mom and you know, my sister in law, but... really my mom. And she didn't have any training. I guess it's - you just learn.
CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

The perceptions and concerns of parents in the study were not inconsistent with what has been documented in fever phobia literature. Moreover, their use of the emergency room reflected the access challenges and preference for convenience observed in ED utilization research. What my findings suggest is that the narrative around these issues ought to change. Research studying these phenomena has produced explanatory discourses that primarily reflect the perspectives of clinicians, researchers, and healthcare administrators. However, my results provide a window into the articulation of a counter-discourse (Escobar 1995) among family caregivers that contradicts dominant medical constructions and understandings of fever phobia and nonurgent ED use.

5.1 Fever Phobia Revisited

Past fever phobia research has consistently constructed caregivers’ aggressive treatment of low-grade fevers in children as resulting from a lack of knowledge about the physiologic function of fevers or fears about implausible outcomes such as brain damage. In my sample, many parents were certainly overzealous in their treatment of fevers (or non-fever temperatures), and their tendency to associate rising temperatures with dreaded outcomes has been consistently observed in previous studies (Kai 1996; Langer et al. 2013; Kalaca et al. 2006). However, parents were primarily fearful of febrile seizures, which are relatively common in children. While some research has reported fears about fictional fever outcomes such as brain damage (Wallenstein et al. 2013), only a handful of parents in my sample thought that brain damage or other permanent harm might come to their child as a result of their fever.
A question that emerged during data analysis was whether fevers had a special significance for parents that other conditions did not. As parents discussed common childhood illnesses, they tended to associate fevers with more serious issues – such as bleeding or broken bones – rather ostensibly minor issues like the common cold. Fevers often indicated underlying infections, a word that connoted a fundamental wrongness in a child that needed righting by a healthcare provider. Although it is tempting to make a quick link between this perception and nonurgent use of the ED, most parents did not feel that the ED was necessarily a more appropriate venue for treating fevers than their PCP’s office. However, fevers were frightening and disempowering in a way that undermined parents’ confidence in treating them at home. While fevers were not usually a reason for proceeding straight to the ED, they were certainly a reason for seeking professional assistance in the first place. If the ED was a first stop in the healthcare system, this was usually due to logistical factors (such as work schedule or access to primary care) rather than parents’ perceptions of severity.

Notably, parents’ aggressive treatment of fevers was not driven purely by lack of technical knowledge about fevers. It is driven – perhaps to a much greater extent – by the concern that fevers can do real harm to children and even the fear of losing a child (also observed by Langer et al. 2013). Thus, the disadvantages of actively pursuing reassurance – such as embarrassment at the ED (see Kai 1996) or taking a day off work – seem trivial. While technical knowledge (such as when to bring a fever to the ED, or how to augment antipyretics with other remedies) may play a role in empowering parents to treat fevers at home or changing their mental models of fevers, changing treatment and healthcare utilization behaviors must begin by addressing caregivers’ deep-seated concerns.
5.2 Rethinking Nonurgent Use of the ED

Qualitative research has begun to tilt the discourse on nonurgent use of the ED from questioning the behavior of patients towards questioning the structure of healthcare (e.g. Guttman, Zimmerman, and Nelson 2003; Chin et al. 2006; Brousseau et al. 2011). These lucid explanations of patient and caregiver perspectives have clearly implicated failings of the healthcare system and likely sounded the death knell for the notion of “appropriate” use of the emergency room. My findings were largely consistent with these studies: parents brought children to the ED because PCPs were inaccessible, or because the demands of a family’s life required meant that the ED was the only logical place to seek care (at the time). But at the same, it was a desire for reassurance – not convenience – that truly motivated treatment-seeking behavior.

However, while past research has done much to legitimize the narratives of patients and caregivers attending the ED for nonurgent conditions, it has often stopped short of proposing solutions. ED utilization has had a tendency to document what might be referred to as barriers to “appropriate” use of healthcare services. The literature has a deep preoccupation with barriers such as long waits at PCPs, lack of transportation, and limited financial resources. However, tacitly focusing on barriers presents a number of problems. First, it privileges the identification of obvious problems over more nebulous ones. Many families in the study did not have easily identifiable barriers. A few had truly inaccessible PCPs or lacked personal transportation. However, most had a personal vehicle and a PCP who could see them within 24 hours. Many could even leave work if they needed to. However, successfully seeing a PCP –
even a theoretically accessible one – could still be a challenge due to any number of logistical variables.

Even a general focus on problems (e.g. with the healthcare system, with family logistics, etc.) can lead us to ask the wrong questions. While we have abundant evidence documenting ways in which healthcare is failing families, we have much less detailing what families actually want and need. While families in the study valued building relationship with their pediatricians, their desire to obtain reassurance that a sick child was not in danger grossly outweighed concerns about “losing out on quality and continuity of care” (Howard et al. 2005:430). Recommending that families find Patient-Centered Medical Homes (PCMHs) seems tone-deaf for those willing to tolerate limited access to continue a years-long relationship with a trusted family doctor.

In obesity research, structural concepts such as “food environment” and “food desert” have entered mainstream public health discourse as individualistic conceptualizations of health and wellbeing have been replaced by the social determinants of health and other ecological frameworks. Individual habitus has largely been reconciled with the material and social realities that constrain individual choice. A similarly rich theoretical approach is needed to adequately understand healthcare utilization. This demands a deeper understanding of healthcare consumers in relation to the health care environment in which they seek reassurance regarding the wellbeing of their children. Although, parents in the study often technically “chose” to come to the ED to seek reassurance, they did so within a context of constrained agency. Work schedules, administrating the lives of multiple children, and sharing transportation could make the ED a highly logical choice. Moreover, historical interactions with the healthcare system
often led parents to bypass their PCP and come to the ED. Past interactions – such as
misdiagnosis, unsatisfactory treatment, or referral to the ED – had shaped parental habitus and
could also make the ED a preferable choice. These types of choice might easily be recognized as
failure to understand the respective roles of PCPs and EDs; however, a habitus/field approach
creates a useful framework for capturing nebulous barriers such as these.

A Bourdieusian approach also helps clarify the extent to which treatment-seeking
habitus is shaped by priorities and experiences across multiple “fields.” Experiences within in
the healthcare field have only modest impacts on parental habitus; they may shape preferences
for certain sources of care, but parents have little to gain in the way of capital (e.g. economic,
symbolic, cultural) by playing by the rules of the field and “appropriately” using the ED. They
have much more to gain by privileging the rules of the economic field (e.g. not leaving work), as
this sustains the flow of capital that provides for the family. Thus, taking the risk of enduring a
lecture from a frustrated clinician might simply make economic sense. But most importantly,
any gains or losses here likely pale in comparison to the symbolic capital that hinges on
adequately fulfilling parental duties.

Future research on nonurgent use of the ED must shift its focus from documenting
problems – and even legitimizing patient and caregiver narratives – toward understanding how
health systems can best serve the interests of families. This requires a deeper understanding of
their needs and values as consumers of healthcare. Fixing barriers should give way to the
redesign of systems to better provide timely, meaningful reassurance.
5.3 Implications for Health Education

5.3.1 Recommendation 1: Tailor Fever Education to Caregiver Concerns

In order for health information to be persuasive, it must address caregivers’ foremost concerns directly. Anecdotally, I have heard nurses bemoan parents’ failure to understand that fevers are the body’s natural response to infection and are generally not dangerous. This may be an important aspect of acclimating parents to the banality of childhood fevers, particularly regarding aggressive use of fever-reducing medications. However, caregivers’ main concerns were not derived from inaccurate mental models of fevers, but fears about seizures. Because of this, caregiver concerns cannot simply be dismissed. Nor can they be educated out of existence. Instead, caregivers need to be introduced to an audience appropriate and persuasive message about the risks of febrile seizures. A febrile seizure risk message would ideally address both the probability of a seizure occurring and the danger of such an occurrence. Because febrile seizures are actually somewhat common, a risk message might stress that most episodes are harmless. However, crafting a persuasive message would likely be challenging; parents consider seizures of any form to be a catastrophe and this might be a difficult perception to change. Thus, parents do not need traditional education as much as they need a persuasive reframing of what they already know.

This is not to say that traditional education does not play a role here; it plays a crucial one. As risk-minimizers (or more accurately, reassurance-pursuers), parents may benefit from education about how long fevers should be managed at home before seeking medical attention. Teaching caregivers more about monitoring and treating fevers might make their treatment more effective and their decision-making more judicious. Because parents associated
higher temperatures with greater risk of seizures, educating about the relationship between temperatures and seizure risk may be important for reducing caregiver stress and inappropriate antipyretic use.

Education must also be responsive to heterogeneous caregiver concerns. Some parents feel empowered when equipped with new strategies for treating fevers, while others benefit from knowing their enemy. Parents’ need for reassurance is driven in part by their sense of control over their child’s health, and strengthening this must focus on what parents themselves find empowering. Fortunately, tools to aid clinicians in understanding caregiver concerns already exist. Arthur Kleinman’s concept of explanatory models (1978) has been adapted into many instruments for eliciting health beliefs. Simple open-ended questions about caregiver fears, perceived severity, and treatment expectations may be enough to provide clinical staff with the information to address concerns directly.

5.3.2 Recommendation 2: Empower Parents to Overcome Unforeseen Challenges

While a tailored risk message may be needed to mitigate fever phobia, reactive educational interventions are unlikely to keep families out of the ED. Frequent ED users at Children’s do not usually return for fever at every visit (unless a child is actually chronically ill). Instead, they may often come with novel problems each time. Education must build parents’ capacity to cope with unfamiliar challenges so they do not feel the need bring “a bump on the head”, as M24 reported, to the ED. Preparing families to be confident caretakers of sick children in advance may be crucial, as many of the information sources they access for assistance directed them towards the ED. Family members are no less averse to risk than parents themselves, and internet searches tend to exacerbate rather than alleviate caregiver
concerns. Furthermore, PCPs do not always perform the role of gatekeeper, and several referred parents to the ED simply because no appointments were available. Classes for new parents may be one approach to empowering caregivers to cope with novel illnesses and uncertainty.

5.3.3 Recommendation 3: Rethink Education about Using the Healthcare System

Children’s currently uses a team of community health workers to educate families about using the healthcare system, enrolling in Medicaid, and finding a primary care doctor. They target families who use the ED frequently for low-acuity conditions. However, my results revealed other forms of support that these families may need. My results bore strong similarities with Shaw et al.’s (2013) observation that adult patients came to the ED not because they sensed they were experiencing an emergency, but because they felt that available self-care and primary care options had been exhausted. They also were not inconsistent with Doobinin et al.’s (2003) observation that convenience had more relevance for use of the ED than perceptions of severity (though the use of convenience here would inaccurately connote self-interest). Of the caregivers who were not advised to come to the ED by healthcare providers, only two came straight to the ED without attempting any home treatment. Also, only two (different) caregivers deliberately bypassed their PCP because they believed the ED was a more appropriate venue. In short, parents came to the ED when they felt were out of options, not because they felt it was medically appropriate.

If PCPs were bypassed, it was because parents did not anticipate getting reassurance on a satisfactory timeline. Yet at the same time convenience is not the only factor driving their use of the ED. PCPs could be bypassed because it might take days to be seen, or even because they
were mistrusted. Some parents expected that they would be told to go the ED; some actually were. Caregivers who did not call their PCP had internalized previous experiences of not receiving reassurance; thus, it would not seem logical to them to suddenly put faith in that provider because it was the “appropriate” thing to do. This is not to say that all caregivers had bad PCPs; several adored their pediatricians and were perfectly content to keep seeing them for well-child visits despite struggling to access them for sick care. Additionally, working caregivers did not usually have convenient access to time off and sick children could be a serious economic threat to the family. Seeing the PCP during the day meant no pay. Caregivers who did not work usually relied on someone who did for transportation, meaning accessing primary care during the day could be difficult for them as well. Reassurance was intrinsically valuable and waiting for it was difficult; however, time could also be money.

Ultimately, families bypassed PCPs not because they misunderstood the importance of primary care, but because they expected – not unreasonably – that they had something to lose (or at most, little to gain) by waiting until they could see their pediatrician. In the reassurance economy, EDs have a distinct comparative advantage. Thus, education emphasizing the importance of PCPs may be doomed to fall on deaf ears. By doing so, health systems imply that an institutional preference regarding how health services are used is more important than caregivers knowing that their child is OK. A persuasive educational message is one that actually offers competitive alternatives for families. For example, helping families locate and transition to a PCP offering accessible afterhours services.
5.4 Implications for Health Systems

5.4.1 Recommendation 4: Organize Healthcare Resources to Meet Families’ Needs

In lieu of looking for ways to keep families out of the ED, an alternative approach might be to pose the question, “how do we provide reassurance to families when they need it?” To use the language of Andersen’s behavioral model, this is may be problem of organization rather than resources. This is to say that the supply of healthcare resources might be sufficient to meet the demand, if one could find the other at the right time. However, time was crucial when it came to families’ access to primary care. Due to various schedule constraints, caregivers would often not establish the need for professional medical help until late in the day. At this point, even PCPs who were quite accessible could not accommodate families who felt they needed same-day care. Although educating caregivers may prolong the time they are willing to treat illnesses at home before seeking professional reassurance, there is no imaginable productive (or ethical) intervention premised on persuading families not to seek medical help for their children. The most obvious (and probably most difficult) solution is to expand access to afterhours primary care. Most families’ pediatricians were only open until 5pm. Although the independent afterhours primary care market in the Dallas area is slowly expanding as night clinics such as PediaMed expand their offerings, these services were largely unknown to parents. If caregivers had even considered the possibility of urgent care or night clinics, they tended to feel that these services were not appropriate for children.

5.4.2 Recommendation 5: Improve Nurse Advice Lines

Nurse advice lines were a poor source of reassurance for most families, if they were known at all. To most caregivers, they felt inappropriate for the situation or lacked any tangible
value. However, they still represent a cost-effective opportunity for potentially modifying families’ sense of need for reassurance and funneling them toward care that is more cost-effective for health systems. Expanding services available through nurselines, such as the ability to schedule a primary care appointment in the middle of the night, may incentivize their use among some caregivers.
CHAPTER 6: REFLECTION

At the end of her interview, M13 asked: “This questionnaire. Does it really serve a purpose? I mean, does it go anywhere?” For me, this was the ultimate test. Could I really live up to my ambitions to do applied anthropology? I told her – thoroughly – about the report I was going to write and the changes I hoped it would make. It was an earnest answer to an earnest question, and in my mind, a promise I am still trying to keep. Literally every decision maker involved in the creation and approval of my applied thesis project changed roles between the beginning and end of the study. Fortunately, I changed roles with them (as a student-cum-employee), but this meant trying to create continued relevance for my project as my clients and I moved from the confines of the ED to a more public health-oriented arm of our organization.

Fortunately, participating in the reimagining of a children’s hospital as a pediatric health system proved beneficial, as it helped me rethink the context and potential implications of the study. As I resituated my work within a population health context, the anthropology of the ED became the anthropology of healthcare more broadly. I believe the study ultimately benefited as a result, as otherwise I may have constrained some of my conclusions to what I thought the ED might feel fell within their scope of practice. Instead, I felt empowered to draw broader conclusions that drew upon my theoretical training in both anthropology and public health more deeply.

For me, a powerful part of conducting this research was having to question my own biases and draw conclusions that contradicted my hunches. Early on in the project, I overheard a physician-researcher in another department deriding qualitative data as something that
people collected so they could “hear what they wanted to hear.” Though my own convictions in the value of anthropological methods were never shaken, throughout the project I became increasingly sensitive about the systematicity of the work I was doing, particularly my data analysis. I became almost paranoid about drawing invalid conclusions, and revisited my coding numerous times to second-guess myself (though Glaser and Strauss might call this appropriate application of the constant comparative approach). My analysis still feels imperfect. Did I choose the right codes? Did I really put aside my preconceived theoretical ideas? Although I know better than to wallow in pseudo-positivist angst over what remains a highly interpretive process, if anything I am more committed than ever to continuing to improve my methodological skills.

However, my concern has given way to excitement as I share my results with staff. On the surface, I often tell my colleagues what they already know. However, what is familiar to them is strange to me, and I package and deliver my observations accordingly. I frame them in new ways, pose new questions, and explore unconsidered possibilities. My findings have been used to inform the development of new programs, and I continue to disseminate this information to staff. My research has also been an empowering learning experience. Insights from the process have deepened my understanding of the “fields” (in Bourdieu’s sense) surrounding my work and enabled me to participate in them more actively. While using my findings to benefit the hospital and the families we serve continues to be my priority, this project has also been a tremendous source of personal and professional growth.
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