



Identifying Key Drivers of Frequent Urgent Care Visits at the Massachusetts General Hospital Chelsea Healthcare Center (MGH-Chelsea)

Citation

Jackson, Nicole. 2015. Identifying Key Drivers of Frequent Urgent Care Visits at the Massachusetts General Hospital Chelsea Healthcare Center (MGH-Chelsea). Doctoral dissertation, Harvard Medical School.

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Glossary of Abbreviations

CCC = Crimson Care Collaborative

CCC-Chelsea = Crimson Care Collaborative at MGH-Chelsea

CHC = Chelsea Healthcare Center

CUC = Chelsea Urgent Care

ER = Emergency Room

MGH = Massachusetts General Hospital

MGH-Chelsea = Massachusetts General Hospital Chelsea Healthcare Center

PCP = primary care physician

PC-C = Primary Care Checklist

Section 1: Introduction

Frequent users of the emergency room (ER) are commonly defined as patients who visit at least four times in a one-year period (Althaus et al; Pines et al 2011). Although patients falling in this category are only 4.5-8% of all emergency department patients, they constitute 21-28% of all ER visits (LaCalle & Rabin 2010; Pines et al 2011). Since the 1980s, researchers have attempted to characterize the population of frequent ER users (Nelson et al 2011). Studies have shown that there is substantial geographical variation in the demographic characteristics of this population. For instance, there is discrepancy on whether frequent ER users tend to be old or young, white or non-white, socioeconomically disadvantaged or not, with or without a primary care provider, and have a high burden of chronic diseases or not (LaCalle & Rabin 2010; Nelson et al 2011; Obrien et al 1997; Padget & Brodsky 1992; Pines et al 2011). **However, what appears to unify the experiences of most frequent ER users is the co-existence of multiple medical, psychiatric, and/or psychosocial problems, and a high utilization of health services both within and outside of the ER** (Nelson et al 2011; Obrien et al 1997; Padget & Brodsky 1992; Pines et al 2011).

We view the heavy use of emergency medical services as problematic for three reasons. First, the ER is not an appropriate facility for patients to rely on for care when suffering from multiple illnesses. Opportunities for continuity and coordination of care are scarce because, each time frequent ER users present to the ER, they have different complaints and are often cared for by different physicians, or even by different ERs. Given the high volume of patients that an ER cares for, in addition to the episodic and often urgent nature of most patient visits, ER clinicians may not have the skills, time, or infrastructure in place to obtain a complete medical history, and to subsequently address all of the complex needs of this medically- and socially-complex population that keeps them returning to the ER (Nelson et al 2011; Padget & Brodsky 1992). Second, many health care providers are concerned with how avoidable visits to the ER may interfere with the care of patients who are acutely ill and require immediate attention, especially if those avoidable health concerns can be managed at other facilities. In particular, literature holds that increases in avoidable visits drive the increase in overall ER visits, leading to ER overcrowding, prolonged waiting times and heightened stress and frustration among ER staff (Obrien et al 1997). Third, ER visits increase the likelihood of additional laboratory testing and hospital admission, especially for chronically ill patients, which costs hospitals a considerable

amount of money (LaCalle & Rabin 2010; Nelson et al 2011; Pines et al 2011). Increases in ER visits may therefore contribute to unsustainable increases in healthcare spending at the hospital level. Given these three reasons, **it is in the best interest of patients, ER staff and hospital directors to redirect frequent ER users to care pathways that enhance continuity and coordination of care and adequately address both the medical and psychosocial needs of these patients.**

We were interested in evaluating the population of frequent urgent care users at the Massachusetts General Hospital Chelsea Healthcare Center (MGH-Chelsea). There is no available literature on frequent urgent care users or consequences of its overuse, so we could not assume that frequent ER use and frequent urgent care use results in the same individual or societal consequences.

The American Academy of Urgent Care Medicine offers a useful definition of urgent care medicine: “the provision of immediate medical service offering outpatient care for the treatment of acute and chronic illness and injury.” Urgent care providers are similar to emergency room providers in that they are prepared to address complaints affecting patients of all ages and genders. However urgent care facilities are best for acute medical problems that are lower on the severity spectrum, since they tend to have limited resources for extensive laboratory testing and advanced imaging, limited capacity to observe patients for an extended period of time and an inability to care for critically ill patients¹.

However there is reason to believe that the frequent users of Chelsea Urgent Care are equally medically and socially complex as the general population of frequent ER users and that continuity and coordination of care is similarly compromised in this population. First, 32% of visits to Chelsea Urgent Care in 2010 consisted of repeat visits (Kashambwa, Rutendo, Tauheed & Anwisy 2012), a similar statistic seen among ER visits. Second, a significant percentage of Chelsea residents live in poverty and are foreign-born (“Chelsea (city) QuickFacts from the US Census Bureau”) and many of whom are undocumented and/or unemployed or underemployed, and without significant social support. Third, there is no ER facility in Chelsea, MA and the nearest ER is at an inconvenient distance from Chelsea. With a large socioeconomically-disadvantaged population in Chelsea and a urgent care facility that functions like an ER, there

¹ AAUCM.org [Internet]. American Academy of Urgent Care Medicine; c2015. Available from: <http://aaucm.org/about/urgentcare/default.aspx>.

are still compelling reasons to redirect frequent urgent care users in Chelsea to more comprehensive care pathways.

Given the heterogeneity of the frequent ER user population, we will characterize the population of frequent urgent care users at MGH-Chelsea through questionnaires to better understand the demographic, clinical, and psychosocial backgrounds of our patient population, as well as patterns of health care utilization. Furthermore, an investigation into how such patients manage their illnesses will allow us to elucidate the reasons for frequent urgent care visits from the patient perspective. Most research papers on this topic rely on data collected from the clinician perspective (Nelson et al 2011; Padget & Brodsky 1992), which do not produce sufficient comprehensive analyses to identify risk factors for frequent urgent care use.

Nelson et al (2011) performed a literature review that attempted to convey the journey of frequent ER users from their decision to obtain care in the ER through their clinical assessment, health care provided, and long-term health outcomes. This paper revealed the scarcity of qualitative studies in the literature on frequent ER users. The vast majority of studies used data obtained from the clinician perspective. Only three out of 45 studies in this review article obtained data from the patient's perspective, with one using qualitative methods, and two relying on ethnographic methods to collect data. Limiting data collection to patient records and provider opinion lacks vital insight from patients on what drives emergency room use (Padget & Brodsky 1992). This project will contribute a patient perspective on drivers of frequent urgent care use.

This project has the following aims:

- Aim 1: To characterize, through questionnaires, the frequent users of urgent care at MGH-Chelsea according to various demographic, clinical, behavioral, and social characteristics.
- Aim 2: To conduct a qualitative investigation of the key clinical and social drivers of frequent urgent care utilization among the aforementioned patient population through semi-structured interviews.
- Aim 3: To construct a narrative of the common themes driving overall frequent urgent care use through semi-structured interviews.

Section 2: Methods

Study Population: To be eligible for the study, patients must have had ≥ 2 visits to Chelsea Urgent Care. Most of the subjects were recruited from the population of patients that visit the Crimson Care Collaborative at MGH-Chelsea (CCC-Chelsea) per referral from Chelsea Urgent Care. The Crimson Care Collaborative (CCC) is a Harvard Medical School student-faculty medical practice initiative that currently has five sites around the Greater Boston and Cambridge area. CCC-Chelsea was launched in October 2011 with an aim to improve primary care for frequent users of the CHC's urgent care and post-incarceration populations in Chelsea, MA.

Recruitment for Semi-Structured Interviews: Recruitment for the preliminary qualitative study began after receiving IRB approval on July 17, 2012 (notified July 31, 2012). 109 MGH-Chelsea patients were identified who had visited Chelsea Urgent Care or the Massachusetts General Hospital Emergency Department at least twice. Recruitment letters were sent to all of these patients in their preferred language, which included information about the study, and the researcher's contact information to make an initial interview appointment at the CHC. 11 patients responded to the recruitment letter. Appointments were scheduled from August through December 2012. Interviews were conducted either in-person at the CHC or over-the-phone, during which time patients provided verbal consent, participated in a 1-2 hour interview and answered questions from a standardized questionnaire. All study volunteers received \$40 compensation for their time.

Data Collection: Questionnaires: Information collected on the questionnaire included age, sex, race/ethnicity, country of origin, primary language, immigration status, education level, insurance status, marital status, household size, employment status, household income, house ownership status, mode of transportation to the clinic, distance from clinic, basic survival needs (e.g. food, income), use of federal assistance programs, number and type of medical and psychiatric diagnoses, usual source of health care when ill (e.g. urgent care, pharmacy, primary care provider, hospital ER), frequency and nature of visits to Chelsea Urgent Care, and frequency and nature of hospitalizations. Some of this information was gathered from a previously-collected intake survey and from the patient's medical record. ***Semi-structured interviews:*** Interviews solicited information about the patients' psychosocial, cultural, and

socioeconomic contexts, how they manage their illnesses (including perceptions of the severity and complexity of their illness, and social support), reasons for visiting urgent care (including the kind of care they receive at these facilities), reasons for being without a primary care provider, opinions on their quality of care, and health literacy. Spanish-speaking patients were interviewed with the assistance of an over-the-phone medical interpreter. Interviews were tape-recorded with the patient's consent.

Data Analysis: Responses to questionnaires were described in terms of frequency of response or mean response and standard deviations. Each interview was transcribed into a Microsoft Word document with assistance from Dragon NaturallySpeaking software. Each transcript was reviewed multiple times and coded until a consistent code structure emerged. The code structure was reviewed and approved by the mentor. The themes were used to generate sixteen working hypotheses regarding frequent urgent care use at MGH-Chelsea.

Section 3: Results

Characteristics of Study Population

This study population consists of predominantly middle-aged men of Hispanic/Latino descent between the ages of 50-75. Most are originally from the United States, but other popular countries of origin included Guatemala and Honduras. Over a quarter of patients are undocumented immigrants. Most have a high school education or less, work less than full-time, have a household income of <\$30,000, and rely on public health insurance (Medicare, Medicaid/MassHealth, Free Care) to access health care. More than half of these patients receive federal benefits and a bit more than 1/3 endorsed both food and financial instability.

There is a relatively large burden of ongoing respiratory, psychiatric, musculoskeletal, and cardiovascular problems in this patient population. Almost half of the patients are current cigarette smokers. Most urgent care/ER visits are due to chest pain, joint pain/swelling, dyspnea, back pain, cold-like symptoms, and cough.

See the tables and figures in the Appendix for a composite look at the demographic, clinical and social characteristics of this study group, as well as the characteristics of each individual volunteer included in the study.

Patient Narratives

Volunteer #1

Volunteer #1 – Illness Narrative

Volunteer #1 is a 22-year-old English-speaking Latina female who grew up in the U.S. She has a history of bulimia, depression, anxiety, vitiligo, and acne, although her primary focus is on her mental health. She owes the onset of her bulimia at the age of 17 not specifically due to desires to be thin, but rather from a desire to have control over her social circumstances. She has been exposed to many challenging relationships involving close loved ones who she believes contributed to her bingeing behaviors. One seminal relationship was her father inflicting physical and emotional violence onto her mother. As the oldest child in the family, she had to support her mother emotionally and financially. The emotional stress caused her to literally become sick to her stomach. She recalls her first experience with bingeing:

:

It kind of just turned into like, you feel like sometimes you're so emotionally distraught, you feel physically sick, and then you eat, and then it's like "Well, if I feel nauseous, why not throw up?" And that's how it all kind of started, you know? "Oh, I feel sick. If I throw up, I'll probably feel better." Like one of those. And then it just formed into a habit because it was like a sense of control...a sense of just like, you know what? I ate something but I don't have to digest it. I don't have to gain the weight. I don't have to let the whole process happen. I can just disrupt it and take it out and it was kind of my only control.

She was also in an emotionally abusive relationship with her ex-husband, who she had dated for three years and was married to for 6 months. She had been binge-free for a period of time, but after her former husband returned to the United States after two military tours overseas with post-traumatic stress disorder (PTSD), the dynamics of their relationship changed:

...when we moved back to Boston, it became a problem where he wasn't able to, kind of, take care of us like he wanted. His masculinity became threatened, and with the PTSD, he never sought help for it. He knew it was there. We all knew it was there, but it was kind of like you didn't acknowledge it because it was such a soft spot with him. And he started, kind of like, it was more like, instead of like a husband and wife, it was like a lieutenant and another soldier. I became another soldier...and there were times, when you know, if the house wasn't clean or anything, he wouldn't come home. He was out with other people, um, you know and he would say things that were really wrong. I had to clean up after him and his family whenever they came over. Stuff like that. And it just literally became like I was under his rank. It was hard to get out of that situation.

It transformed into a stifling relationship, where she never felt comfortable being her true self:

You'd be surprised, you take something away from someone and how much they feel less of themselves. And something so little as having holes in your ears! It's just who I am. It just got to a point where even certain emotions weren't okay with him... Like if I was, say I was sad and I was crying, he wasn't okay with that. I shouldn't be crying, I should be happy...He wasn't very good at comforting at all. It was more, kind of like, when you see a father who was very stern, and when a child is crying, they don't know what to do but say like, "Buck up." It was kind of like that.

Since she couldn't open up to him emotionally, he never understood the psychological backdrop of her bulimia. His influence perpetuated her behavior. He normalized her purging behaviors whenever she developed a stomach-ache after eating too much: "I felt like since he was suggesting it, it's okay." Ever since then, bingeing and purging became a habit, almost like a reflex, that she has had difficulty breaking: "Like I want to throw up. Like my stomach wants to throw up. And there's been times when I didn't even make myself throw up. It just...it happens!"

Volunteer #1 acknowledges the unhealthy nature of all of these relationships, and how they need to stop so she can heal psychologically: "...it gets to a point where my dad did it to my mom, my mom did to me, and then I was about to allow my husband to do the same. And the cycles gotta break..." She worries that her symptoms will continue to worsen if she doesn't take the necessary steps to take better care of herself.

Volunteer #1 – Chronic Illness Management

Since engaging with healthcare, Volunteer #1 has learned about four approaches to managing her eating disorder: a healthy diet, anti-depressant, therapy and attending her primary care appointments. She believes that all of these are important in order to become healthy, but she admits that she hasn't been the best patient.

Maintaining a healthy diet is difficult for her. She doesn't know how to incorporate three daily meals into her busy and erratic schedule. It is also difficult for her to overcome the uncomfortable feeling of food in her stomach. She acknowledges that this feeling can be mitigated by eating smaller portions. She also rarely has an appetite, so she uses marijuana to help stimulate her appetite. Her anti-depressant is also supposed to stimulate her appetite, although she hadn't been taking it. It has helped that a few of her friends and co-workers check in with her regularly and ensure that she has at least kept herself hydrated. Eating out with close friends also provides a safe and structured environment for her to take in some food.

With regard to her anti-depressant, she didn't understand its use at first. She thought it was exclusively for her mood, although she didn't think that she was clinically depressed: "I just figured it was it was one of those...oh, you're feeling sad, here's a drug." Since she disagreed with the clinician's assessment of her mood, she opted not to take the anti-depressant. However now that she understands that the purpose of the prescription is to stimulate her appetite (she just had a doctor's appointment prior to the interview), she plans to take it, especially now that she has reached a low point in her illness trajectory:

I got to learn how to eat better and manage better because I'm busy all the time, but it's not going to do me any good if I'm tired, or in a hospital or passed out somewhere. It's not going to help. Especially now that I'm a lot busier, I have to be able to rely on my body to function. And it's a scary thought wondering if it's going to function or if I'm going to be in the middle of a sale and I pass out, or on the T and I pass out, or God forbid if something were to happen.

Volunteer #1 also acknowledges the role that psychotherapy has in understanding the relationship between her thoughts and her bingeing and purging behaviors. She reflected on an exercise that one of her therapists had her do, which forced her to write down all of her thoughts, to reflect on whether or not those thoughts were rational and to postulate where those thoughts were coming from. This exercise empowered her to feel as though she had control over the thoughts that were causing her to feel sadness, shame and anxiety. However she only worked with this therapist for one month. She has not found another therapist since then who she developed a connection with, and who treats her with compassion:

You'll see, I won't show up... with the last therapist I just really didn't feel a connection with her. I felt she was just impervious to how I felt. And she was just cold and stern. And it's like, as much as I can tolerate people's personalities, at the same time, me myself, as a person, want to be treated like one, not just as a patient or number like oh, here's this case file.

She also needs a therapist that will help her identify tangible solutions, rather than just exploring her emotions. The lack of guidance from her providers has been frustrating. Guidance is what she needs to better manage her eating disorder:

It's like, you get to a point where you know what you need to do. But where do you look for [it]? Where do you go? It's the same if you're going to the store and you're looking for a specific item. It's like, you know what you want, but you're not really sure, so you're going to ask a salesperson looking for their advice because they're the expert. That's how I feel like when I do come to my appointments...

Volunteer #1 – Experiences with Primary Care

Volunteer #1 usually has very good access to primary care. She recalls seeing a pediatrician throughout childhood. She never had problems accessing health care while married to her ex-husband because his military insurance would pay for it. There was a period of 3-6 months that she did not have a primary care doctor. She was living with her husband on a military base in upstate NY. In preparation for filing the divorce, she had been traveling back and forth between upstate NY and Chelsea. At the time of the interview, she had only been settled back in Chelsea for about 3 months. She had signed up for a primary care doctor, but had never gone to any appointments: "Access has always been there. It's just whether I use it or not." She was connected to a primary care doctor at the Crimson Care Collaborative at MGH-Chelsea after her visits to urgent care.

She is very satisfied with her primary care doctor. She sees the role of her primary care doctor as one that coordinates care: "...she does look into different outlets and stuff like that and she was very, very good about trying to get me to see a therapist, which is awesome." Although she is satisfied with the efforts her primary care doctor has taken to get her a therapist, she is disappointed that she has not found a good therapist. She believes that PCPs can have a role in facilitating the connection and assuring the quality of their referring specialists:

Sometimes I feel like [while] we're here maybe they would benefit from just like checking in with their own therapist and [inaudible voice]...making sure they're not disconnected from their career. Because sometimes it stops becoming a passion and it's just your job, it's just your career at that point. So it'd be nice to know that they still care enough about the person as an individual.

Volunteer #1 is also requesting more guidance from her providers regarding how to manage her bulimia, specifically how to overcome her specific obstacles related to healthy eating and finding a good therapist as detailed above.

Volunteer #1 – Experiences with Urgent Care

Volunteer #1 had three visits to the MGH Chelsea Urgent Care: two in April 2011 and 1 in February 2012. She had reached a breaking point with her bulimia and was desperate to seek help from health care professionals for the first time. She was on a downward spiral: she continued to rationalize her behavior, but found herself unable to stop as she physically felt sicker:

It was, like, it was normal, when you play pretend. It's not like you're ignoring it, because you're doing it yourself. It's a physical action, but you pretend like... and there are plenty of people who do it, but you pretend like it's okay to do it. And you're like, "Oh, well you know what I ate, so if I throw this up, it will totally balance out." And you convince yourself that it's okay! And especially with me, that's a hard thing to do because I know better than that! After convincing myself, "No, it's fine, you know, you'll be okay," and I get to the point where I know I'm not okay, but my body doesn't think so anymore.

She presented to Chelsea Urgent Care feeling incredibly sick. The chief complaint recorded in the chart for the first two visits were: "2 day h/o nausea, vomiting and diarrhea" and "abdominal pain, nausea, myalgias, malaise, decreased appetite x 1 wk." It appears that the provider was concerned about gastroenteritis or flu-like symptoms. Unfortunately Volunteer #1 was unable to disclose her concerns about her bingeing and purging behaviors because her ex-husband had

insisted on joining her for those visits. As mentioned earlier, she never felt comfortable discussing such issues with him because he was not at all sympathetic. She visited urgent care because she wanted help, but she had to pretend that she had no inclination as to what was causing her symptoms. She reflects on how she was feeling:

Well for those couple months, it started getting really bad. It wasn't the same feeling. Like when you purge, it's a specific feeling physically, not emotionally or anything, but it started to hurt more. It started to hurt my throat more. I was just in a lot, a lot of pain, and my periods weren't regular and it's probably because I wasn't getting the right nutrients that I needed and stuff like that. Being unhealthy, you're going to have unhealthy symptoms. I just physically felt sick, terribly sick. And that's when I knew... and every time I went, they had to give me IVs because I was dehydrated, but like you said, they look at it as the flu or something like that, but that's what it was. I was just really, really weak. It was just one of those unbearable feelings after a while. You don't know how you're even walking at that point with no energy.

She did not have a primary care doctor at that time. She was trying to manage her bulimia on her own, but she was declining clinically. She delayed medical care until the physical pain and weakness was no longer tolerable. She could have "prevented" the visit by talking herself out of it, as she had done many times before:

There have been instances where I wanted to get help, and it's shameful...because like you gotta admit that something's wrong and you're hurting yourself, and that's something not everyone wants to hear coming out of their own mouth.

However, if she had done that, she believes she would have only gotten worse. Although she was unsuccessful with conveying her concerns at the first two urgent care visits, she was successful at the third visit in February 2012 because she went alone this time. The chief complaint at that visit was: ""binging and purging" --> "hurt more than usual" day prior after vomiting." Her expectation and hope was that she would be stabilized and then informed about next steps in order to better manage her bulimia. It was at this visit that she was connected with an on-site therapist and with her current PCP at CCC-Chelsea.

She chose to visit Chelsea Urgent Care rather than another healthcare facility because of convenience. She does not own a car, and needed to get to the closest healthcare facility immediately. She also had prior suboptimal experiences at another healthcare facility and strongly prefers MGH-Chelsea because the providers appear to be more personable and invested in the unique needs of their patients:

There are instances where, if I could drive, maybe I would have driven myself to another hospital. Even going to another urgent care facility like the one in Everett...it wasn't the same as coming here, because the doctor actually talked to me and was like "Alright what's going on?" Not like, you go over there, they're a lot more "busy bodies" and it's more like "Look at the chart, look at the chart," and "Oh, the signs are okay." It's kind of intimidating, especially because I was younger, and you're just looking at an older adult who is all about the charts and the stats and it's like, they can't be bothered with my problems.

She goes on to describe the kind of care that she received at Chelsea, and how that created a safe space for her:

Well, I expected them just to take tests, to see where I was at physically, if I needed any fluids in me, they'd do so. Just like the standard...same with the other urgent care...it's always the same standard I'd expect from them: "We'll get you comfortable and figure out what's wrong with you. We'll get you comfortable first, stabilize first and figure out what's going on." Here, they did that. But they also had that personal interest in helping the person. Even when you have someone being professional, taking your vitals and everything, being friendly always helps make the person more comfortable. You don't have to be stiff to be professional. You can still do it with a smile on your face or something. So I think from that experience, and plus for me personally, I feel more comfortable when it's all women. And in this hospital, there are a lot of women...and that experience really allowed me to open up and say something that time.

Volunteer #2

Volunteer #2 – Illness Narrative

Volunteer #2 is a 48-year-old Caucasian male who has a history of insulin-dependent type 2 diabetes, hypertension, hyperlipidemia, obesity, cigarette use, osteoarthritis and migraines. He also has many psychiatric diagnoses, including bipolar disorder, paranoia and claustrophobia. He has been engaged in his health care for just over one year at the time of the interview. Prior to that, he had been "on the streets" and "just didn't care" about his health. His diabetes was uncontrolled and he was hearing voices. If it wasn't for his fiancé, who urged him to seek health care, he wouldn't have sought help. His diabetes has improved since connecting with health care providers, but is not well-controlled to his liking. He did not want to discuss his homelessness, his obesity or psychiatric conditions with the interviewer, but did admit that his psychiatric conditions are now stable. Throughout the interview, he stated that he was an impatient person, and wanted to end the interview as quickly as possible.

Volunteer #2 – Chronic Illness Management

He appears to be quite knowledgeable and engaged in his diabetes management. He was able to list his medications (glucophage, metformin and insulin), the doses and the frequency of administration. He takes all of his medications as instructed. When asked, “What would happen if you stopped taking your medications?” he replied: “I wouldn’t be around today.” He clearly understands the life-saving significance of his medications. He rarely misses a dose because he takes his medications at the same time at night. Volunteer #2 is aware that there is a designated safe range for one’s glucose and that his medications are designed to help keep his sugars stable. He knows that there are certain symptoms associated with both high and low blood sugars. He is accustomed to feeling symptoms of hyperglycemia, which includes thirst and frequent urination. There is nothing he can do about these symptoms, to his understanding, other than trying to decrease his blood glucose. He has never felt hypoglycemia, but he described some of those warning signs: “frequent urination, sweats, chills, shakes.”

He is quite confident about the type of diet he is supposed to adhere to: “salads, low-sodium products, low in carbohydrates...” while avoiding fried foods and white bread. Despite his best efforts, his glucose has been averaging in the 300s, and he is unsure why. To him, this is uncontrolled. He has been in touch with his PCP and his “diabetes technician” over the phone, reporting his sugars on a daily basis and adjusting his insulin dose under the direction of his diabetes technician as needed. Although he is not satisfied with his current control of his diabetes, this is much better than before he connected with healthcare over one year ago. Back then, he had no interest in his health.

Volunteer #2 denied chronic hypertension, as his blood pressures have been monitored and they have been within normal range. He was not interested in sharing his experiences with obesity or his psychiatric conditions, but he was willing to share that his psychiatric conditions were being managed through medications and regular visits to his psychiatrist and counselor. If he doesn’t take his medications regularly, he experiences auditory and visual hallucinations. The voices he hears tell him to hurt himself. He does not have any hallucinations while on the medications.

Volunteer #2 – Experience with Primary Care

Volunteer #2 has been connected to primary care for just over one year. Prior to that, he had no primary care doctor and he was not managing his medical and psychiatric conditions proactively.

He highly recommends his primary care doctor to others. All of the services that his PCP provides are helpful. His PCP's role is primarily in chronic disease management, education and prescription medication management: "She's been able to help me by getting me on the right track with my medications, telling me how to control my diabetes, what to expect what not to expect..." He has no further suggestions on ways to improve primary care at MGH-Chelsea.

Volunteer #2 – Experience with Urgent Care

There were three urgent care visits that he was able to reflect on, all within the past year. The first was in August 2011. He had developed a rash after using a new soap. The rash went away on its own after he discontinued use of the soap.

The second visit was in October 2011, when he developed sudden onset chest pain. He "wasn't feeling right" and thought it would be best to be seen by a doctor immediately. They didn't find anything wrong, although Volunteer #2 expected there to be a more thorough investigation into the etiology of his chest pain. He received no explanation for his chest pain, although he suspected it was due to his smoking.

The third occurred in April 2012, where he went in for bilateral hip pain. He had been having hip pain for a long time and he decided to go to urgent care once it became unbearable. He found out that he had developed bursitis in both hips. He received cortisone shots, which resolved the pain. He was very satisfied with his care.

He also had a visit for "left ear pain, sore throat, neck pain x 3 days", but he did not offer any reflections on this visit.

He chose to come to Chelsea Urgent Care rather another healthcare facility partially due to convenience (he lives in Chelsea) and partially due to poor past experiences with the Whidden Hospital. If he had taken the ambulance, he would have been taken to the Whidden Hospital and this would have been against his wishes ("I have no use for them").

Volunteer #3

Volunteer #3 – Illness Narrative and Chronic Illness Management

Volunteer #3 is a 48-year-old African-American male with a number of ongoing, unresolved health problems that he is trying to seek help for. He has a history of anxiety and PTSD, which he believes was triggered by exposure to murders in his childhood neighborhood of Roxbury, MA, in addition to sexual abuse inflicted by his stepfather. He becomes very emotional and angry when reminded of the sexual abuse, but he also thinks that it is therapeutic to discuss his feelings. He categorizes his anxiety as “severe.” He feels like he is on edge all the time and is unable to think straight. He has difficulty dealing with the chaotic urban environment of Boston, especially when taking public transportation. He wants help processing all of these feelings. He often reminded the interviewer that he is a “gentleman” and an “American citizen,” and he “don’t want no trouble.” He often feared that he would be punished for expressing his thoughts about his care.

For his anxiety, Volunteer #3 has been to a number of healthcare facilities, including Boston Medical Center, BIDMC, and most recently, MGH-Chelsea. He spoke on numerous occasions about a few providers at the Behavioral Health Clinic at Boston Medical Center, who he believes had sleep apnea. He was very disturbed by their odd behavior of spontaneously falling asleep and did not trust that they would give good care. He also went to the Beth Israel Deaconess Medical Center in order to address his mental health, but his opinion was that that “they’re not good people to address mental health” despite being the “best doctors.” He had been given medications for his anxiety, but they did not work. In fact, he believes he suffered some unfortunate side-effects from the medications: “I took the damage, I was damaged by the medications...” He could not articulate what specific side-effects he had suffered from. He is trying to proactively manage his anxiety through patience, prayer and avoiding coffee. However he admits that he needs more help than that and he has not found it yet. When asked about what his providers have offered regarding how to manage his anxiety, he replied: “They don’t say nothing! They fall asleep. They said nothing. I came here.”

Volunteer #3 has also had a sensation of a lump in his throat that has been associated with a cough. This has been going on for two years with no relief. His providers have thought that there may be an allergic component to this, or perhaps asthma. During one part of the

interview, he disagreed with this assessment, but he later offered that allergies, sinus infection, and asthma were all possibilities. He has tried taking Benadryl, and an inhaler, and has undergone an examination that sounds akin to a laryngoscopy: “And they did the thing with the camera to see what it is, but it’s been two years... She said it would go through my nose and you could see, you get to the end of it...” Nothing has worked. He is very frustrated that there is no reasonable explanation for his symptoms and no effective resolution.

He has had ongoing hip and back pain that he is attributing to wear-and-tear from playing basketball. Imaging studies were performed at an outside institution, but the records have not reached the office of his primary care doctor yet. Much of the care that he has received for the hip and back pain seemed to take place in an urgent care or emergency room facility, although it is unclear. He wasn’t experiencing any hip pain at the time of the interview, although he later admitted that this pain is chronic: “Throughout the day, it’s gonna happen.” Sometimes the pain gets so severe that his mobility is compromised and he has to seek care immediately. Similar to some of his other ongoing medical problems, he feels as though he has not been well-informed about the diagnosis or management of his condition: “I want to know. Just let me go, I’ll buy the pills, whatever you want. I want to know how bad it is in case I can’t walk.”

For acid reflux, he takes Prilosec. He does not note ongoing symptoms from his acid reflux. He is a cigarette smoker and he wants help cutting down. A problem not reflected in his medical record, but which he mentioned in the interview, is weight problems. He repeatedly expressed a desire for Ensure to keep his weight up, since he believed he was underweight. Upon probing into the nature of his weight problem, if it is due to a reduced appetite, poor access to food, or other factor, he replied:

Because I need them to stabilize me. That’s why. If they stabilize me, then I won’t have to need Ensure... As far as me, communicate, I need a social worker, that’s why. So that’s why I’m unstable. To be a gentleman and protect myself as a gentleman, that’s what... Because my thinking is not at the level it’s supposed to be to be comfortable as a good gentlemen. I don’t trust people because they’re full of shit.

When asked again about why he believes he is losing weight, he said, “Because I don’t have the therapy I need! They’re not delivering!”

Volunteer #3 – Experience with Primary Care

Volunteer #3 currently sees a primary care doctor at CCC-Chelsea. He has only assumed care here for the past two months. He decided to try establishing care at MGH-Chelsea due to his dissatisfaction with care at other institutions. He always had a primary care doctor and has never had trouble accessing one. He believes that primary care is important for everyone, especially as one ages, and thinks that finding a primary care doctor for oneself is the responsible thing to do: “If something happens, I’m at that age... It’s important for anybody to have a primary care doctor.”

When asked specifically about his experience with primary care, his feedback was always positive: “They are great! They do their job! Listen, there’s no problem, they did their job.” However during other parts of the interview, he remarked that “primary care don’t work” and that his goal is to find a primary care doctor that can adequately evaluate all of his medical problems and identify solutions to them: “I want a primary care [who] would do things accordingly, okay...” He even alluded to the fact that he is so dissatisfied that he may be leaving this institution soon to find another provider who can do the job: “they treat me bad here... they don’t want to address it and I don’t want to come back here after this.”

Volunteer #3 – Experience with Urgent Care

Volunteer #3 has had three visits to the MGH Chelsea Urgent Care, one in 2007 for “severe lower back pain x 3 days”, one in 2008 for “sore throat, cough yellow phlegm, nasal and head congestion, ear pain x 3 weeks” and one in 2012 for “cough x 3 weeks.” He reflected the most on his experience visiting urgent care for lower back/hip pain. He has chronic back and hip pain, but he has episodes of worsening pain that require him to seek immediate medical attention. He had made the decision to come to Chelsea Urgent Care for help because he was having difficulty walking (“I had a limp!”). He received Flexeril, which did not alleviate his symptoms. He had visited Boston Medical Center in the past with such severe back/hip pain that he was “bent over” and received a cortisone shot. He also visited BIDMC for his hip pain. Although there have been many providers involved in his care, he never felt well-informed about what was going on:

I want someone to see the x-ray so they can help me. There’s something going on here in my hip. Five doctors come back, Beth Israel, it’s the best in the world. When you send

five people back, this something interested in. I want to know what it is, they never told me, like yeah I'll be back.

He was also interjected about an unfortunate past experience at the Whidden Hospital: "There is a racist hospital...up here the hill in Everett, up there on the hill. You know that the hospital there? Oh God racist..."

Volunteer #4

Volunteer #4 – Illness Narrative and Chronic Illness Management

Volunteer #4 is a 54 year-old Spanish-speaking male who is originally from Honduras. He has lived in the United States for the past six years, and has held temporary jobs for the past three years. Money has been very tight, and it has been difficult for him to afford basic necessities. He brings home an average of \$50 per week. Sometimes he picks up cans for extra income. His roommates, all friends from Honduras, will often offer money for bills or food if his income has been particularly low.

The primary medical condition that Volunteer #4 has is what he describes as "asthma." He has been having symptoms of "asthma" for the past year. At baseline, he often has a "sensation in the throat," "discomfort in the nose," and symptoms similar to a cold or the flu. However, at times, when his symptoms flare, he describes symptoms of exertional fatigue, dyspnea, and tachypnea: "I breathe very quickly...I feel like, tired, and you know, like I can't run." Volunteer #4 has also been a cigarette smoker for the past 30 years who smokes 1-4 cigarettes per day on average. When asked about his understanding of the relationship between his smoking and his asthma, he replied: "What I know is that, when I have asthma, I usually don't smoke. I'm actually not very well, so [I] don't smoke, but then after, when it goes away, then I start smoking again."

He is not actively managing his "asthma" right now. He has only interfaced with health care once for his "asthma," which was in the context of an urgent care visit. He has not seen his primary care doctor yet for this condition, although he is assigned to one. He was instructed to use an inhaler daily to control his symptoms, but he has not been using it for two main reasons. One, the inhaler has been very difficult to afford with his financial instability. He did take the inhaler for a short period of time after the urgent care visit and then stopped because he could not afford to purchase a new one. It costs him \$40, and he does not always have this amount of

money available to spend on medications: “There is no money, you really can’t buy anything, you can’t do anything about it”. Two, he admits that taking his medications was not a high priority:

Yeah, I just wasn’t taking it seriously, I wasn’t doing what I should and I felt the symptoms, for example, the itching in my nose was only getting worse...I feel like I should’ve been using the inhaler more often and I wasn’t.

Now that his symptoms have worsened and he has experienced severe flares that warranted medical attention, he has come to understand the role of inhalers in preserving his lung function. During our interview, he became interested in having a conversation about how to properly use his inhaler. He also expressed motivation to purchase and begin using his inhaler again on a regular basis, especially with the stipend he was given for his participation in the research study: “The thing is that now you gave me \$40. So I’m going to use the \$40 for the inhaler...if my health requires it.” He also agreed to make an appointment with his primary care doctor after the interview in order to gain clarification on how to best manage his asthma.

Volunteer #4 – Experience with Primary Care

Volunteer #4 is currently assigned to one of the primary care doctors at CCC-Chelsea. He had only visited his primary care doctor on one occasion (February 2012) prior to the interview. He admits that he does not know this doctor well. He tends to only seek health care when he is acutely ill, when the symptoms are not manageable with over-the-counter medications. He would like to see his primary care doctor more often, but access is difficult due to his financial circumstances:

Sometimes... I don’t have the money to pay for the visit. You know, I just don’t go and other times I’ve gone and I’ve received the bill and I don’t have any way to pay it...the thing is that I don’t go to the doctors if I don’t have no money.

When asked about what resources he needs from primary care to help him better manage his asthma, he instead offered that it is his personal responsibility to proactively manage his health: “Well for now what I’m going to do is take more seriously the use of the inhaler...the medication...because I wasn’t taking it very seriously.”

Volunteer #4 – Experience with Urgent Care

Volunteer #4 has sought medical attention at the Chelsea Urgent Care twice in 2012 because of his asthma-like symptoms. He recalls that his cold-like symptoms had been lingering for months, but his symptoms were worsening to a point where he could no longer tolerate them. Nyquil was not helping and he had difficulty sleeping. When he came on both occasions, he was given oxygen. He decided to go to Chelsea Urgent Care rather than another healthcare facility for convenience: “It’s the only hospital that’s nearby.” Review of his medical chart revealed that he had also sought care in September 2006 for “neck pain radiating to lower back since motor vehicle accident” and in January 2012 for “diarrhea x 5 days.”

Volunteer #5

Volunteer #5 – Illness Narrative and Chronic Illness Management

Volunteer #5 is a 61-year-old Spanish-speaking female who is an undocumented immigrant from Guatemala. She has lived in the United States for the past nine years. She has a history of hypertension, coronary artery disease, diabetes, hypercholesterolemia and osteoporosis. She also has a history of two heart attacks, for which she is now being followed by a cardiologist. She believes that she had these medical problems when she was living in Guatemala (“I wasn’t feeling bad but it was advancing, getting worse and I started to feel bad”), but she was diagnosed in the United States. She cannot recall exactly how long it has been since her diagnoses.

In order to manage her diabetes, she exercises, eats healthy and avoids juices. She takes medicines every day for her diabetes and monitors her blood glucose levels: “The diabetes sometimes is 90, 95, 100, 110. I check and everything.” She is aware of the life-saving value of her diabetes medications. She is also able to report on the consequences of high and low blood sugars: “If you see how I feel when it’s low, I feel dizzy... When it goes up, you feel like your blood is on fire and you start sweating.” She takes medications for her cholesterol and blood pressure daily and she takes calcium supplements once weekly for her osteoporosis. She does not have any difficulty taking her medications because she incorporates them into her normal routine: “I get up at six, I eat breakfast and I take them.” This task is made easier for her because she obtains her medications for free with her health insurance. She reports that she abides by the

doctors' instructions because it is a priority for her to be healthy: "I do what I'm asked to do because it's for my own good health."

Volunteer #5 – Experience with Primary Care

Once Volunteer #5 arrived in the United States nine years ago, she recalls that it was very difficult to obtain health insurance, especially since she was an undocumented immigrant. It took her a long time, although she cannot recall exactly how long she was without insurance. However she believes that she received help with obtaining insurance when she came to MGH (unclear if the ED or urgent care) when she was acutely ill. She was informed that she was eligible for Medicaid. Now that she has health insurance, she does not have any difficulty accessing care. A social worker assists her in understanding the health insurance enrollment process and to ensure that she continues to be enrolled.

Volunteer #5 currently sees a primary care doctor at MGH-Chelsea. She applied for a primary care doctor once she was informed in the emergency room that she needed to have one. The application process was not easy for her, but she did get help. She is very satisfied with the primary care services that she receives because she is treated well by her providers. Her doctor helps her with her chronic illness management by prescribing and adjusting medications. When asked about ways that her primary care experience can be improved, she added that she needs help with obtaining food. She explained that she is unemployed and the only person who works in her household, consisting of herself, her husband, and two nephews, is her husband. Her husband's income is inconsistent because he works temporary jobs: "My husband works. Some days he works, some days he doesn't and we can barely make enough for the rent... because some days he works two or three days." If money is tight, and there is not enough money for food, they can usually afford to purchase beans. She has not informed her primary care doctor about her financial difficulty.

Volunteer #5 – Experience with Urgent Care

According to her medical record, Volunteer #5 has made a total of 10 urgent care visits: 1) August 2006: rash x 5 days; June 2007: 2) vaginal itch x 5 days; 3) July 2007: abdominal pain radiating to L lower back, dysuria and hematuria; 4) April 2008: painful lump on L side of

abdomen x 4 days, now draining yellow stuff; 5) April 2008: re-evaluation of abdominal abscess; 6) May 2008: knee pain/swelling; 7) May 2009: urinary frequency and dysuria x 4 days; 8) May 2009: persistent dysuria and vaginal itch; 9) May 2010: substernal chest pain x 24 hours; 10) 11-10-2011: mouth sores and sore throat. The visits that she was able to reflect on the most included her visits for chest pain, sore throat and vaginal itching.

Her visits for chest pain were terrifying. On the first occasion, she describes it in detail:

“I was not able to sleep and my nephew saw me crying and he asked what was wrong. I said, ‘I’m going to die,’ and I took an aspirin and Motrin and then (inaudible) and he called my daughter and my brother took me to the hospital.”

She had only been in the country for about one year when it happened. She was informed by the providers at the hospital that she had a heart attack. She had another episode of chest pain approximately five months prior to this interview and she was afraid that she was having another heart attack. She decided to go to urgent care because she knew that her primary care doctor would be unavailable. The providers in urgent care did not find anything. However she was given a pill that goes under the tongue (presumably nitroglycerin).

She recalls that her last visit to urgent care was for a sore throat. She recalls that it was late and her primary care doctor would like be unavailable, but she was unable to articulate why she was not able to wait until the morning to see the primary care doctor for the sore throat. She also commented on the fact that she would need an appointment to see her primary care doctor, but she would not need one to go to urgent care.

She also remembers a time when she was having vaginal itching. The itching was unbearable, which is why she decided to come in to urgent care. She thinks she may have had an infection because it went away with a prescription. She does not recall details about her other urgent care visits dating back to 2006. She reports good service at Chelsea Urgent Care.

Volunteer #6

Volunteer #6 – Illness Narrative and Chronic Illness Management

Volunteer #6 is a 34 year-old English-speaking female of Puerto Rican descent. She was born and raised in Brooklyn, lived in Puerto Rico from ages 12 to 22 and then returned to live in NYC, Framingham, MA and Chelsea, MA. She currently lives in a recovery home in East Boston due to her history of heroin and crack cocaine use. She has been clean since January 17, 2012.

Her history of substance abuse began at age 25. She recalls that she lost a tremendous amount of weight while abusing drugs. At age 27, she attempted to quit by attending methadone clinic. She took methadone for two years and benefited from the counseling sessions that they provided. She graduated from the program, but quickly relapsed three months after coming off of methadone. She believes that the methadone program was unsuccessful for her because it did not help her deal with her addiction:

I feel like the methadone was not good at all. Like right when you get off of methadone, your body still wants to choose methadone but you can't... you'd have so much free time on your hands, you don't know what to do with yourself. And if you're an addict, the only thing you want to do is be an addict, so you're gonna eventually go use.

She went back to using drugs, and lived for some time in a drug house. However after her drug home was raided, she became homeless for 2.5 years. Within the past year, she got into legal trouble and expressed a desire to become clean. She was imprisoned for approximately two months, where she withdrew from drugs. Upon discussion with her probation officer about her situation ("I didn't want to go back on the street because I was homeless and I wanted to get clean, because I just couldn't do it by myself"), the decision was made to send her to the recovery home in East Boston on March 20, 2012. She is expected to complete 18 months at the recovery home. The recovery home has been wonderful for her because it ensures a safe, drug-free environment for recovery and also imposes meaningful structure on her everyday life. So far, she has been able to return to school to complete her GED, apply for jobs and work on obtaining custody of her three kids, all purposeful activities that prevent her from feeling an urge to use throughout the day.

In addition to her history of substance abuse, Volunteer #6 has a history of depression, hepatitis C, obesity, chronic hip/back pain and cigarette smoking. She has suffered from depression ever since she was 15 years old. Her symptoms can become quite severe: "I'm sad, I don't want to live. Sometimes I get to a point where I'm just... don't want to live at all." She does not like to take medications, but she acknowledges that Zoloft has kept her stable, so she takes it daily. She also manages her depression by seeing her primary care doctor and psychiatrist regularly and training herself to think positively and cope with her emotions:

When I first got here, I would cry and cry and cry...and like, it was probably part of my detox... I wanted to use and I couldn't use, you understand what I'm saying? And I had to deal with all these emotions that I did not want to deal with. But being in the house, like,

I know how to deal with emotions now, you know what I mean? I'm not perfect, don't get me wrong, but I do work daily on it.

She was diagnosed with hepatitis C in 2006. Her virus levels have been undetectable, and upon discussion with her hepatologist, they have decided to hold off on therapy for now. She had gained a lot of weight since abstaining from heroin and cocaine, so she is working on losing weight to further improve the health of her liver. She is working with a nutritionist to strategize how to lose weight, including eating smaller portions, exercising and drinking plenty of fluids. She has been smoking cigarettes ever since she was twelve years old. She has been encouraged to quit smoking, but she is not ready for this yet. For her chronic pain, she takes ibuprofen as needed.

Volunteer #6 tries the best she can to follow the doctors' instructions, but it can be challenging to implement the prescribed dietary and exercise plans, given the environment that she lives in. For instance, the groceries are purchased for the tenants in the recovery home and the purchased food options are not always the healthiest. She is kept on a strict schedule, with limited amount of time outdoors, so she has difficulty fitting exercise into her schedule. Nonetheless, she is honest with her providers about what she can and cannot do and makes adjustments to the best of her ability. Now that she is sober, she has a renewed motivation to stay healthy: "...right now, now that I'm sober, I can get right, you know what I mean? But when I was using, I can't, but now I can."

Volunteer #6 – Experience with Primary Care

Volunteer #6 has always had a primary care doctor. There was a period of approximately two years, when she was using heroin and cocaine, that she did not see her primary care doctor: "No, I didn't want to see the doctor because I was using. When you use, you don't want to do shit!" However she has never had any trouble accessing healthcare, even with her travel back and forth between the Northeast of the United States and Puerto Rico. She attributes her ease in transition to her prior familiarity with the healthcare system and the plethora of social assistance in Massachusetts.

She sees her primary care doctor as a source of emotional support and as a person that helps her to coordinate care:

I talked to her about how I feel and about my substance abuse and my past history, as well as deaths in my family and how depressed I get, you know what I mean? My primary care doctor... because every time I tell her that “I feel this, I feel that,” she is always looking forward to seeing me, first of all, and second of all, getting the help that I need... So I look forward to seeing her when I have to see her because I know she’s helpful to me.

Volunteer #6 – Experience with Urgent Care

Volunteer #6 has visited Chelsea Urgent Care twice in the past, in 2007 and 2008, for nasal congestion, but she cannot recall the circumstances surrounding these visits. However she is able to reflect on three recent visits to the emergency room at the Neighborhood Health Center in East Boston. Most recently, she had a bad cold and she was very concerned about the severity of her symptoms.

I was very congested and I was coughing up a little bit of blood and my nose started to bleed so... which is why I went... because my lungs were hurting and my chest was killing me... like I couldn’t stop coughing and every time I would cough and cough and cough and cough, like it was hard for me to breathe... my nose was killing me, my face was kind of swollen, and my throat was killing me.

She needed immediate medical attention because she “couldn’t hold it” any longer. She also went to Neighborhood Health due to a recurrent foot fungus that was incredibly painful, and for shoulder and neck pain.

On all three occasions, she decided to go to urgent care because her PCP was not available at the time and she was unable to get an appointment with another provider in the practice. She would prefer to go to Chelsea Urgent Care instead of East Boston, since her medical records from her primary care visits are at MGH Chelsea, but her recovery home prefers for its tenants to go to East Boston due to its close proximity to the house.

She has been very satisfied with her care. All of her needs were met. She was given antibiotics, cough medicine and an inhaler after her most recent visit for the bad cold and her symptoms have been resolving. She was given a fungal cream for the recurrent foot fungus that she went to East Boston for. The shoulder pain that she went to East Boston for resolved without any intervention. She assumes that she slept on it wrong. She does not believe that her visits could have been prevented: “No, I think I had to go.”

Volunteer #7

Volunteer #7 – Illness Narrative and Chronic Illness Management

Volunteer #7 is a 43-year-old Spanish-speaking male from Honduras with a history of hypertension, presbyopia, right-sided hearing loss and dental problems. His vision is now corrected with reading glasses. He has also undergone evaluation for his hearing loss, which is associated with vibrations and ringing in his ears and exacerbated by loud noises. His workup thus far has been unremarkable. His hearing loss is presumed to be hereditary in nature. Although he has to be extra attentive in conversation, his hearing loss does not significantly diminish his quality of life. Since he works in construction, he has been encouraged to protect his ears from loud machinery to prevent further hearing loss.

His most active ongoing medical problem is his hypertension. He was first diagnosed approximately five years prior to this interview. He was asymptomatic at the time of diagnosis. His primary care physician in Honduras prescribed him enalapril for management of his hypertension. He continues to take enalapril 20 mg here in the United States.

His blood pressures are usually well-controlled on this dosage. However he recalls a few specific occasions when his blood pressure was not well-controlled. This includes a hospitalization in Honduras four years ago for dengue, and on two occasions, when he experienced facial paralysis that was presumed to be viral in etiology. He also recalls his blood pressure was elevated when he learned of his mother's death 2.5 years ago. He notes distinct symptoms when his blood pressure is uncontrolled: "I get headaches, I feel dizzy and I feel like this heat on my face." On average, he experiences these symptoms four times per year, but he believes the frequency has decreased lately.

Volunteer #7 believes that his blood pressures have been uncontrolled in the past due to a variety of unfortunate circumstances. He came to the United States 2.5 years ago with a temporary supply of his blood pressure medications, but without access to a primary care doctor in the United States, he soon ran out: "I brought medications from my country, but then I ran out and I had no way...I didn't know how to control the pressure." He also has had significant financial difficulty since living in the United States. He is only able to obtain construction work three days per week, on average, and he does not produce enough income to sustain himself and his family members in Honduras:

I'm alone here in the United States, you know. My family is back in my home country and sometimes I don't have enough money to pay for my house, send money for my family members...sometimes I can't adjust to all the things and to take care of our home.

He prioritizes paying for his rent, but in return, he often lacks basic necessities, such as food or new clothes. This causes a great deal of stress: "There are days that I get desperate. I feel like I just need to leave because I'm without my family and I have a lot of financial limitations." When he runs into such financial strain, which occurs approximately twice per month, he is able to ask for help from some friends. He believes that the stress and anxiety caused by his financial circumstances contributes to his historically uncontrolled blood pressures.

Volunteer #7 understands that his hypertension is best managed by both taking his medications and sustaining a healthy diet. He was initially denied free care when he first applied and he could not afford his medications. However now that he has free care and he has a primary care doctor, he is able to obtain his medications and attend his doctor's appointments with minimal difficulty. He keeps his medicines next to his bed so he remembers to take them first thing in the morning before going to work. With regard to his diet, he has already discussed nutrition with his primary care doctor. He believes he could make more of an effort to improve his eating.

Volunteer #7 – Experience with Primary Care

Volunteer #7 has been seeing a primary care doctor at CCC-Chelsea for 1.5 years. He was first introduced to this PCP after his urgent care visit. He had been in the United States for eight months at that time. He was informed that he needed to have a PCP and was given an application form. He admits that he was not looking for a PCP and he was not proactively managing his hypertension once his medications had run out.

He views his PCP as the gatekeeper for his medications: "She's helping me...one thing is, she's giving me the prescriptions so I can actually go and get the medications." His PCP has also counseled him on diet. He is satisfied with the care he has received and he has no specific suggestions for improvement.

Volunteer #7 – Experience with Urgent Care

Volunteer #7 recalls that many of his CUC visits were related to his blood pressure. His first visit was in September 2010 for “constant left sided chest pain that radiates to left arm with left finger numbness x 2 weeks.” He had just learned the news of his mother’s passing and he remembers having chest pain and a headache. He did not have a regular PCP at the time. He had been prescribed enalapril six months prior, but he had only been taking it for the two weeks prior to his urgent care visit because he had difficulty with obtaining the medication. The prescription for enalapril was sent to a pharmacy in Revere by mistake and he had no means of traveling to Revere to pick up the medication. He was finally able to resolve the issue by obtaining a new prescription and filling it at a local pharmacy in Chelsea.

In March 2012, Volunteer #7 presented to CUC for “headache x 3 days. Ran out of blood pressure meds, needs a prescription/hx- HTN.” He had run out of his blood pressure medications 15 days before his visit and he did not have health insurance. By this visit, he had already attempted to apply for free care, but it was denied. He admits that he was not able to access healthcare to get a prescription because of his lack of insurance. He presented in July 2012 due to concerns about his blood pressure: “headache, back pain for the past 5 days. Dizzy while standing. Increased work. History of well controlled HTN, but patient is worried about BP.”

Volunteer #7 decided to go to urgent care when he did because he was feeling sicker, and “short of breath, like I was drowning.” This was not a new feeling, but he felt that the sensation was “intense,” bothersome and related to his blood pressure. He is unsure what could have happened if he did not go to urgent care when he did. However he does believe that his visits could have been prevented if he was able to take his medications and if his psychosocial circumstances were not interfering with his blood pressure control. When asked about why he chose to go to urgent care over primary care, he admitted that he did not know he could call his PCP. He is very satisfied with the care he received at CUC.

Volunteer #8

Volunteer #8 – Illness Narrative and Chronic Illness Management

Volunteer #8 is a 64-yo Caucasian male with a history of emphysema, a lung mass, arthritis and psoriasis. He was born in Maine and has lived in various areas of Massachusetts and

New Hampshire before settling down in Chelsea for the past 15-20 years. He continues to work, which include cleaning and carrying carpets.

His most active and ongoing medical problems are his emphysema and cigarette smoking. He was diagnosed with emphysema within the past 6-7 months, after an urgent care visit for difficulty breathing. Since then, he has been taking Advair twice daily and Spiriva once daily. Whereas before, he had difficulty breathing while lying on his side or flat on his back, he has noticed that his breathing has improved since implementing these daily treatments. He “cheats a few times” with his medications, especially given occasional bouts of dizziness when he started taking these medications, but he is generally able to take his medications as prescribed. He incorporates his medications into his schedule by taking his morning inhalers within the first 30 minutes of waking up and by keeping his inhalers on his bureau so they are within reach. His best guess is that his lung function would worsen if he stopped medications. He was given an emergency inhaler (albuterol) if his symptoms worsen. He has never needed to use it. He has not had a flare-up of his COPD symptoms since his urgent care visit in April.

He hopes that he may be able to decrease the frequency of his COPD medications if he quits smoking. He has smoked daily for the past thirty-three years. He first began contemplating quitting approximately 3-4 months ago. He was not thinking about it at the time of his new COPD diagnosis, but with every puff of his cigarette since then, he becomes increasingly frustrated by his habit. He was able to quit for the first time a few weeks ago for 4.5 days and he recalls that his lung function improved significantly in that short period of time. He is usually unable to climb several flights of stairs without stopping at each landing due to shortness of breath, but in the few days that he abstained from smoking, he was able to climb all three flights of stairs without stopping! However he had an “uncontrollable urge” to have a cigarette, and then shortly thereafter, resumed smoking after purchasing a pack of cigarettes. He feels guilty that he returned to smoking so quickly, since he knows that smoking counteracts the effects of his COPD medications. He figures that, if he has quit before, he can do it again! He anticipates quitting by the upcoming weekend. He vowed: “By the time I see [my PCP], I’ll be smoke-free!” He admits that he needs to find a way to break his smoking habit: “I light up out of boredom... I gotta find something else.” The next time that he develops an urge to smoke, he wants to try exercising. He also has a few nicotine replacement methods ready, including the patch and electronic cigarettes (“Affinity”). He also may “bum a cigarette” from his neighbor, if he truly

cannot control the urge, instead of purchasing an entire pack of cigarettes. His PCP is aware of his smoking cessation efforts, and has provided various resources, including a referral to group therapy for smokers who are trying to quit.

Other medical problems include arthritis in his knee and psoriasis affecting his elbow and hand. For the latter, he takes cortisone injections.

Volunteer #8 – Experience with Primary Care

His current PCP is the first that he has ever had. He did not have a pediatrician or a family physician as a child, either. In the past, he had sought medical attention in the emergency room setting for acute conditions, such as laceration repair or other injuries. He did feel winded from smoking cigarettes and have a chronic smoker's cough, but he did not seek medical attention for his breathing because he was still able to physically function. From his perspective, he was perfectly healthy and did not need his own PCP. He was asked about his access to primary care at the urgent care visit in April and was referred to CCC-Chelsea since he lives in Chelsea. He was also uninsured at the time and received assistance in applying for MassHealth. His first PCP visit was one week after his April urgent care visit.

Volunteer #8 admits that his lack of a primary care doctor for the majority of his life was more influenced by his perception of his own good health, and lack of need for one, rather than his lack of health insurance. However now that he has a primary care doctor, he admits that he would rather have one, so that if he ever needs anything, he has a provider to turn to. His primary care doctor is most concerned about his lungs. He does not complain about his knees or skin. He respects all of his healthcare providers and finds all of them to be very helpful and resourceful. He has no further recommendations for improvement: "The doctors are doing all they could. Now it's all on me!"

Volunteer #8 – Experience with Urgent Care

Volunteer #8 has had four visits to CUC, all in 2012. The first was in April 2012 for "cough for over 1 month-difficulty sleeping due breathing-tired all the time." He believes that he caught a bad cold from his boss that was not going away. He also developed shortness of breath for 1-2 weeks that was particularly bad at night when he was trying to sleep. At first, he could

not lie comfortably on his sides, but then he could not breathe well on his back or sitting up, either. He tried taking Nyquil and ibuprofen, thinking that he would be able to heal himself, but these over-the-counter remedies did not help. He was concerned about his worsening lung function and decided that it was time to seek medical attention. At MGH-Chelsea Urgent Care, he received a chest X-ray scan to evaluate his lungs and was given prednisone and Combivent for his symptoms. He felt immediate relief from the prednisone and Combivent. He was referred to a primary care doctor at CCC-Chelsea and was instructed to continue the Combivent until his PCP appointment the following week. Their assessment was that he likely had either bronchitis and/or COPD. He was also instructed to return to the emergency room in 2 days for a CT scan to evaluate a lung mass that was seen on chest X-ray. He then returned the following day to learn the results of the CT scan. He was told that the doctors will need to sample the lung mass to reach a diagnosis. Volunteer #8 is unsure what would have happened if he had delayed going to the doctor, but he knew that the visit needed to happen. He decided to come to MGH-Chelsea due to convenience, since he lives in Chelsea.

His third visit was in June 2012 for “right shoulder, right lower back and left wrist pain after a fall three days ago.” He did not intend to seek medical care for it, but rather to heal on his own. However he became concerned about a broken bone once he felt that “something was loose.” The urgency of his concern led him to seek urgent care rather than his primary care doctor. He obtained an X-ray and was sent to Boston Medical Center to have a specialist look at it. He was told that he had a fracture and was given a splint. He returned to the CUC three days later due to concern about redness that was developing by his elbow. He was told that this was normal. He does not believe he could have prevented this visit either, due to concern about losing circulation or sensation in his fingers if the fracture was not properly cared for. All of his concerns were addressed at his urgent care visits, and he was able to follow the doctor’s discharge instructions.

Volunteer #9

Volunteer #9 – Illness Narrative and Chronic Illness Management

Volunteer #9 is a 63 year-old Spanish-speaking male from Honduras. He first came to the United States in 1970 (at age 21), but established residence in the United States in 1984 (at age 35). However he continued to go back and forth between the United States and Honduras. Since

coming to the United States, he has had various temporary jobs in different states (e.g. florist, unloading boats, etc.). At the time of the interview, he had been residing in Chelsea for over one year. Volunteer #9 has an extensive medical history, including type 2 diabetes complicated by peripheral neuropathy and retinopathy, hypertension, hyperlipidemia, congestive heart failure, dyspepsia, Bell's palsy, atypical chest pain, vitamin B12 deficiency and inactive TB. He also reports a history of two strokes in 2001, for which he was taken care of at MGH. From his perspective, his most active, ongoing medical problems are his hypertension, diabetes and his stomach discomforts.

Volunteer #9 was diagnosed with diabetes at age 38 in the United States. He sought medical care because he felt constantly tired. He was determined to be a bit overweight and to have diabetes. His diabetes was initially diet-controlled. He started taking diabetes medications 10 years ago. However he was not taking his diabetes medications properly because he did not feel that he was well-informed about his diabetes. He wasn't aware of how diabetes affects the body, for example. He only took his medications when he had symptoms that he attributed to diabetes. He did not understand that he needed to take them on a daily basis. He became informed about his diabetes when he returned to Honduras, spoke with a specialist, and encountered a Honduran patient with diabetes who shared a wealth of information with him. He also collected educational booklets from doctor's offices when he returned to the United States. He was diagnosed with hypertension 10 years after his diabetes diagnosis.

He currently takes his medications 95-99% of the time as prescribed. He organizes his daily medications each night, and he has a glucometer to check his blood sugar, but he occasionally forgets to bring his medications and glucometer with him. He has always been able to afford his medications, even when he was without health insurance. He is aware that his diabetes and blood pressure medications are vital to his health. He expressed concern that, if he stopped taking them as prescribed, he may faint or have another stroke.

Volunteer #9 also has ongoing "chest pain" that has led to several emergency room visits and one hospitalization. He feels that his providers have misunderstood his symptoms in the past. Whenever he has "chest pain", as written in the medical record, it truly feels as though his stomach is swollen, bloated and full. He feels like the food that he eats gets stuck. There have been nights where he cannot lay comfortably on his back because his stomach is so full that he feels as though the stomach contents will rise back up. It feels like everything in his stomach is

turning. Belching or passing gas provides relief. This uncomfortable sensation in his stomach sometimes rises to his chest, causes chest discomfort and makes it difficult to breathe: “the inflammation does not let me breathe.” Cardiac and GI workup to-date have been negative. He takes omeprazole daily, but it provides minimal relief. He has been working on this problem with his PCP.

Volunteer #9 – Experience with Primary Care

Volunteer #9 has established continuous care with a PCP at CCC-Chelsea for just over one year. It has been difficult for him to establish care with a PCP for long periods of time due to his work. He has been seen by doctors in Maryland, Texas, Tampa and Chelsea thus far. He has also been seen by doctors in Honduras when he returns. Nonetheless, he has never had difficulty accessing healthcare or a primary care doctor when he needed to. He has also always been able to obtain his medications, even during those periods where he did not have a PCP. He obtained health insurance in 2012, around the time that he established care with his primary care doctor at CCC-Chelsea.

He feels well taken care of by his PCP. However his biggest concern is the proper resolution of his stomach problem.

Volunteer #9 – Experience with Urgent Care

Volunteer #9 has had five visits to urgent care in the past year, all due to complaints of shortness of breath, bloatedness or chest pain. From his perspective, these were all circumstances where his chronic stomach bloatedness became so severe that they compromised his breathing and caused chest discomfort. He believes that his symptoms may have been related to his high cholesterol or his diabetes, which were previously out of control before he understood how to take his medications.

In November 2011, he visited the MGH-CUC after moving to Chelsea just three weeks before. He complained of a “headache in back of head 10 out of 10 w/o change in vision, SOB or chest pain and tingling in chin x 2 months, "lumps" on the base of his feet b/l that sometimes cause pain while he is walking and b/l knee pain x 1 year, requests atenolol refills.” According to the chart, his providers prescribed atenolol, encouraged continuation of metformin and glyburide,

and gave ibuprofen for pain. However Volunteer #9 cannot recall specifics regarding the visit. In December 2011, he presented to CUC for an atenolol refill, since he would run out prior to his PCP visit the following month. In January 2012 his chief complaint was “complaints of SOB. Develops it with minimal exertion (DOE). Feels a sense of heaviness in his chest, especially after meals. Feels like belching a lot but nothing comes out.” A few days later, he returned to CUC for “chest pain x 1.5 hrs while sitting at rest, SOB, nausea.” In July 2012, he presented for SOB x 3 days.

He was hospitalized at Massachusetts General Hospital after one of his emergency room visits for chest pain. The tests that he had performed included an EKG and cardiac catheterization. He was not given precise information about the outcome of the test, but his understanding was that the cardiac evaluation was negative.

He preferred to come to MGH-Chelsea for all of his urgent complaints because this was the medical facility that he had heard about in the area.

Volunteer #10

Volunteer #10 – Illness Narrative and Chronic Illness Management

Volunteer #10 is a 53-year-old Spanish-speaking gentleman from the Dominican Republic who has a history of high blood pressure, glaucoma, kidney stones, allergies and chronic back pain. His most active problems are his hypertension, chronic back pain, and glaucoma.

He was diagnosed with hypertension in the Dominican Republic 15 years ago. He often feels symptomatic if his blood pressure is elevated. His symptoms include dizziness, headache and a sensation of suffocation. He feels symptomatic on average 1-2 times per week. It generally does not impair his functioning.

Volunteer #10 has identified several circumstances that appear to raise his blood pressure. He identifies work as a factor that exacerbates his hypertension, as he has always done strenuous manual labor that requires many hours of standing on his feet and heavy lifting with few breaks. His blood pressure rises with stressful familial circumstances or when emotionally upset. He believes that the weather plays a role in modulating blood pressure. There was one frightening occasion in the Dominican Republic two years prior, where he almost fainted after

working outside in near 100°F weather conditions. He was found to have dangerously-elevated blood pressures. He was subsequently rushed to the hospital and treated. He notes that the temperature in the United States is not as extreme, which he believes has had a positive effect on his blood pressure control. He has not had life-threatening blood pressures in United States.

He was initially started on enalapril 10 mg daily and has increased to enalapril 20 mg daily. He takes his medications every day to keep his blood pressure stable (“like I don’t have anything”). He may remain asymptomatic if he misses a day or two of medications, but he begins to feel more fatigued by day three. For this reason, he tries his best to take his medications daily with breakfast. However he occasionally goes 2-3 days without medications because his prescription refills are at MGH Revere, an inconvenient location for him. He would prefer if his prescription refills were at the Walgreens near his home in Chelsea. He has not received other instructions for managing his blood pressure.

Volunteer #10 has chronic lower back pain, which is aggravated by his work. The pain is alleviated somewhat by ibuprofen, but he is very concerned about the effect of ibuprofen on his stomach long-term. He tries to mitigate these side-effects by taking ibuprofen with food, but he would prefer to take another pain medication if he could. He is not aware of other options.

Volunteer #10 has been diagnosed with glaucoma, which has had noticeable effects on his vision. He notes that light bothers him, his eyes are “tired” and red, and his vision has been compromised. He is very concerned about losing his vision (his “mirror of life”) because he is relatively young and wants to maintain his ability to work. He has been seen by an ophthalmologist, who says that his only option for preserving his vision is laser surgery. However unfortunately, his insurance (FreeCare) does not cover the expense of the surgery. The surgery would cost him \$2000 per eye, which is unaffordable for him. He does not know what to do about this situation.

Volunteer #10 – Experience with Primary Care

Volunteer #10 was referred to his current PCP at CCC-Chelsea after receiving care from the CUC. He is very satisfied with the service he receives from his PCP and is happy that he is treated well. His only suggestion is to allow patients to have easier access to their PCPs for urgent complaints. There is often a 1-2 month waiting period to see his PCP, which he believes is unacceptable. Even if he called the office with the hopes of speaking to his doctor directly, he is

usually placed in contact with an alternative provider. It is unclear to him if his concerns are relayed to his PCP. This is in contrast to his experience with primary care doctors in the Dominican Republic, where he would be able to see his own doctor within 1-2 hours after requesting to speak to him or her, unless the doctor was out of the country or in surgery.

He believes that the poor access to PCPs contributes to poor patient satisfaction and an unwanted reliance on urgent care for more immediate concerns. He cites his wife as an example – she suffers from chronic back pain and has not been able to make an appointment with her PCP when her pain flares. As a result, she tries her best to self-mediate with over-the-counter medications. This is insufficient to control her pain and she has been miserable.

Volunteer #10 – Experience with Urgent Care

Volunteer #10 has had a total of five urgent care visits. His first two visits were work-related injuries. In July 2010, he “cut middle finger [of] left hand with a piece of equipment while working at TD Garden,” and in June 2011, he sustained an “injury to his right foot while working at airport, swelling and pain to right ankle with decreased ROM.” His visit in February 2012 was to obtain refills on all of his medications. In May 2012, he had an exacerbation of his chronic back pain: “2 days h o left LBP with no radiation.” In September 2012, he had “right sided flank pain x 3 days” that was determined to be kidney stones.

With regard to his approach to urgent care in general, Volunteer #10 states that, if he is ever in acute pain, he requires immediate care. The same is true if his blood pressure became acutely elevated and he was either very symptomatic or concerned about it. He would not be willing to wait the 1-2 month period to see his PCP via appointment. This is why he chooses to go to urgent care rather than seeing his PCP. He believes that this sentiment is shared among most patients.

Volunteer #10 notes that it was the urgent care doctor who filled his prescriptions at MGH Revere instead of a pharmacy closer to home. Since his medications are for chronic diseases, the physician prescribed refills for one year. However it has been difficult for Volunteer #10 to travel to MGH Revere for his prescription refills. As a result, he occasionally goes 2-3 days without his daily medications. He has not discussed this issue with his PCP.

Volunteer #11

Volunteer #11 – Illness Narrative and Chronic Illness Management

Volunteer #11 is a 72-year-old Caucasian female with many chronic medical conditions, including emphysema, lung cancer, acid reflux, osteoporosis, bilateral rotator cuff tears, osteoarthritis and a history of squamous cell and basal cell carcinoma. Her most active medical condition is her emphysema.

She has been smoking cigarettes for the past fifty years and she believes that, in this stage of her life, she will likely die due to her lung disease. Her emphysema is manifested by a chronic, productive cough that is exacerbated by long lengths of talking and with hot weather. Physically, she is much more limited as a result of her emphysema. She cannot walk as far and has more difficulty breathing. This has been frustrating to her. She has been on supplemental home oxygen since January 2012, performs pulmonary rehabilitation and takes Combivent (ipratropium bromide/albuterol) four times daily and Flovent (fluticasone) daily. She would not be able to tolerate missing a dose of her inhalers. Just a few hours after a missed dose, she may experience chest congestion or tightness that would then prompt her to take her rescue inhaler. She has been given a nebulizer at home as a substitute for the Combivent if her lungs felt more congested than usual. She finds that the effects of the nebulizer last longer than the Combivent. However, if her symptoms continue to be bad after a nebulizer and she is concerned, she has been instructed to seek immediate care at Chelsea Urgent Care. She has a history of frequent urgent care and emergency room visits for COPD exacerbations, but she has not had any such visits since beginning supplemental oxygen.

Volunteer #11 was diagnosed with lung cancer and is now status-post radiation therapy. In the spring of 2010, a chest X-ray showed a lung nodule that was concerning for cancer. A CT scan and PET scan confirmed the suspicion for lung cancer. At the time, she was receiving care at Tufts Medical Center. She came to MGH for a second opinion. This was a terrifying time for her, between the new cancer diagnosis and the imaging machines that made her claustrophobic and anxious (“I saw my life flashing in front of my face”). Her radiation therapy was performed in May-July 2011. She has been receiving periodic CT scans since then to confirm resolution of the lung cancer. There was a concern about a recurrence vs. infection vs. aspiration pneumonia in August 2012, but this finding spontaneously resolved. To her knowledge, she is currently cancer-free.

Volunteer #11 has chronic acid reflux, manifested by a sensation of indigestion and a “crappy taste in the mouth.” This is exacerbated by acidic and fried foods and drinks, such as wine, orange juice, and fried clams. To prevent her symptoms, she sleeps with her head elevated, takes pantoprazole daily and tries to avoid foods that may worsen her reflux.

She also has osteoporosis. She believes that this was likely exacerbated by her smoking history and radiation history. She has experienced some complications of osteoporosis, including a vertebral compression fracture and a pelvic fracture after a fall. She takes calcium supplements and tries to eat calcium-rich foods, such as yogurts and cheeses, to strengthen her bones. She also takes a medication recommended by her gynecologist to decrease her risk of breast cancer and improve the condition of her bones.

Her bilateral rotator cuff tears and arthritis are also chronic conditions, but she is not actively managing them. She was diagnosed with basal cell carcinoma in 2000 and squamous cell carcinoma in 2011. Both skin cancers were successfully resected.

Volunteer #11 – Experience with Primary Care

Volunteer #11 did not have a PCP as a young adult because she did not have any chronic medical conditions. She did have a gynecologist, an ophthalmologist and a dentist, though, which in her opinion, was all she needed. There was only one episode of shoulder pain in her young adulthood that brought her to medical attention. She was diagnosed with a type of thoracic outlet syndrome. Otherwise, she did not need a general doctor. She obtained her first PCP at Tufts Medical Center in 1987 and has had one ever since then. Her opinion is that everyone should have a PCP.

She has had a PCP at MGH-Chelsea for less than one year. She ended up transitioning from Tufts Medical Center to MGH-Chelsea for her medical care because her PCP was retiring. She had great difficulty trying to find a new PCP, and was not assisted with the process even when she visited CUC for urgent complaints. Luckily, an employee of MGH-Chelsea, who happens to be the husband of a friend that lives in the same building as Volunteer #11, was able to help her identify a PCP at MGH-Chelsea who was accepting new patients. She was never without a PCP during that transition period.

She has viewed her primary care physicians as helpful in different ways. If she has any question or concern about her health, her PCPs have generally been accessible by either telephone or email. They have also been resourceful. She has received help in smoking cessation. She tried Wellbutrin, but had to stop the medication because she was losing too much weight.

She also believes that PCPs should have a role in assisting patients in navigating the healthcare system. However she cites an example of a time when she was referred to a gastroenterologist at the Brigham & Women's Hospital for constipation. She was scolded by that gastroenterologist for not bringing her medical records with her. She feels that this was rude and unfair because she was never told that she needed to bring her medical records with her to the appointment. She wishes that her PCP had made her aware of this. Furthermore, the gastroenterologist did not seem attentive to her medical history (kept saying she had a C-section rather than an oophorectomy), which caused her to lose confidence in him as a physician.

Volunteer #11 – Experience with Urgent Care

Over the past year, Volunteer #11 has had twelve urgent care visits. Many of these visits were due to an exacerbation of her chronic emphysema. She states that she “doesn’t panic easily,” but there are a few warning signs that make her concerned. This includes discolored sputum production (e.g. brown, gray, green), chest congestion that cannot be “coughed out” or relieved with the nebulizer or persistent chest pain/tightness. Anxiety sometimes causes chest discomfort, so she tries to calm herself down and/or take Tylenol to relieve her symptoms. She also understands that the emphysema makes her more susceptible to pneumonia, so she has a relatively low threshold to seek help (“at some point, I can’t be my own hero”). She may wait only a day or so before heading to Chelsea Urgent Care. She would prefer to see her PCP for urgent complaints, but she usually cannot schedule a same-day appointment. Since she cannot wait for the appointment, she would seek care from the CUC. She alludes to the distinction between an urgent care vs. a primary care facility: “Urgent care is not for routine check-ups!” She notes that the CUC has reduced their hours, so if they are closed and she needs immediate medical attention at night, then she would have to go to the MGH ED. She prefers to go to CUC over other facilities because she lives in Chelsea. She is also bothered by the extended waiting period to see a physician at the MGH ED, where she can receive similar care at the CUC. She tries her best to avoid going to the MGH ED if she can. If she had delayed seeking medical

attention for these COPD exacerbations, she supposes that she either could have gotten pneumonia or the symptoms would have resolved without intervention.

Other urgent care visits were due to “bleeding from her mouth after eating some cheese and crackers” in September 2011; “fall on left hand and bilateral knees, RHD” in October 2011, “oral bleeding” in April 2012, and “a fall on her oxygen cannula ending on her buttocks; she reports left hip/groin and coccyx pain” in May 2012. She is generally satisfied with her care, but she is disappointed with the conditions of the waiting room at the CUC. There are often a lot of sick children in the waiting room, including kids who are coughing, vomiting or have a runny nose. She feels that this is an infection hazard, especially for patients like herself who are more susceptible to infection. She is unsure what the best solution would be, but she wonders if patients who are so visibly sick should wear a facemask while in the waiting room to prevent spreading their infection to nearby vulnerable patients.

Section 4: Discussion, Limitations, Suggestions for Future Work and Conclusions

Discussion

This research study was designed to report on the demographic, clinical and social characteristics of a sample of frequent users of urgent care at MGH-Chelsea. This sample population has common chronic ambulatory medical conditions, such as diabetes, hypertension, tobacco abuse, and anxiety. Although this population frequents urgent care and the emergency room with an average of 5 visits per volunteer, there were relatively few hospitalizations in this group. This suggests that this population is not as ill as one may expect. It also implies that urgent care visits in this population are usually not leading to hospitalizations. Therefore, there might be room to consider the role of primary care in reducing “unnecessary” urgent care and emergency room visits.

Another objective of this study was to describe drivers of frequent urgent care use in this sample population through themes and narratives. Each volunteer’s narrative offered a glimpse into their unique societal and clinical context and how their contexts influenced their experience with using primary care and urgent care services. Two main themes emerged from the narratives: (1) engagement in healthcare for preventive health and chronic disease management; and (2) decision-making around seeking healthcare for urgent medical problems. Subthemes included engagement vs. disengagement in healthcare for the first theme, and for the second theme, the nature of the urgent medical problem, where to get help and reasons to get help (see Table 5 in the appendix).

Engagement in healthcare for preventive health and chronic illness management

Patients who were engaged in their healthcare described the various ways that their primary care doctors assisted them, including medication management (e.g. prescribing new medications, adjusting doses of current medications), monitoring of key chronic disease indicators (e.g. blood glucose and hemoglobin A1C for diabetics), evaluating concerning symptoms, education about chronic disease, coordination of care (e.g. referrals to specialty care, following up on specialists’ recommendations, identifying resources), behavioral modification (e.g. smoking cessation, diet, substance abuse) and offering a supportive and trusting patient-

doctor relationship. These patients expressed a general knowledge about their respective medical conditions and why they are taking their medications, which most owed to the work of their PCPs. Many also emphasized that the relationship with their doctors was incredibly important. What made their doctors so effective and trustworthy was their demonstration that they cared about them as a person and considered their unique needs. Most patients also expressed that their PCP was the primary contact person for any questions about their health, including urgent concerns.

In contrast, most patients described moments in their lives when they were not engaged in healthcare. For some, this was due to a lack of interest or an under-appreciation for the value of a PCP. Two patients explained that, when they were young and healthy, they did not see a need to have a PCP and only sought medical attention for urgent or emergent concerns. Homelessness, substance abuse, stifling relationships and stress were circumstances described by patients where they were temporarily disconnected from healthcare due to either a lack of internal motivation to seek care or as a result of normalizing their unhealthy behaviors. Poor health literacy also prevented some patients from engaging in their health in a productive way, including limited understanding about their disease, confusion about the indication for and use of prescribed medications and limited understanding of how their behaviors relate to health outcomes. An awkward patient-doctor interaction was off-putting for many patients and often led to a cycle of trying to find a trustworthy doctor. A lack of access to healthcare was problematic for many patients. Some patients described not having a PCP because they moved frequently and could not establish care for long periods of time. Some patients could not afford their co-payments or the medications that their PCP prescribed. Other patients describe difficulty traveling to the pharmacy to purchase their prescriptions because they are far away. Navigating the United States healthcare system for the new immigrants in the group was very confusing. It often required a visit to urgent care (or several) to get the appropriate connections to obtain health insurance and a PCP.

An interesting observation about this phenomenon of “engagement” vs. “disengagement” in this sample population is that patients who were operating outside of the healthcare system were usually disengaged from healthcare, but in contrast, patients who had a PCP were *not necessarily* fully engaged in their healthcare. In other words, once patients gained access to healthcare, there could still be factors that limited complete engagement in one’s healthcare,

including issues related to health literacy/education, financial hardship, fragile patient-doctor relationship and lack of internal motivation. As the discussion proceeds below, many of these factors appeared to contribute to urgent care visits. I would argue that a patient's ability to engage in his/her own healthcare should be constantly evaluated by providers to ensure effective chronic illness management, excellent rapport between patient and provider and patient satisfaction with care.

Decision-making around seeking healthcare for urgent medical problems

Nature of urgent medical problem

Many patients sought urgent care for new, urgent complaints unrelated to their medical history (e.g. new injury, upper respiratory symptoms, vaginal itching, and acute pain). Many patients also sought urgent care services for issues related to a chronic medical problem. Some patients were seeking answers to a chronic problem that was not adequately addressed in the primary care setting. For other patients, their chronic medical condition became acutely worse. Patients with a history of cigarette smoking, COPD, cardiovascular disease, chronic pain, and mental illness (e.g. depression, anxiety, eating disorder) appeared particularly at-risk of having periodic exacerbations of their chronic illness that resulted in urgent care use. Although some of these urgent care visits were likely due to the natural history of their disease, many were directly related to the patient's inability to manage their own illness. Reasons are overlapping, but include lack of health literacy surrounding their chronic illness (e.g. relationship between smoking and asthma/COPD, proper use of inhalers, downstream consequences of diabetes) and poor medication adherence (e.g. financial insecurity, poor health literacy, lack of access to pharmacy, running out of medications prior to connecting with a PCP). Interestingly, many of the factors contributing to urgent care visits are related to "disengagement from healthcare," as described in the section above.

Where to Seek Care

To the frustration of most patients, primary care is not easy to access for urgent concerns. Patients decided to seek urgent care rather than their primary care doctor because they wanted immediate attention. Sometimes, the clinic was already closed for the day when the symptom arose. Many patients commented that, although they would prefer that their PCP handle the

complaint, requiring an appointment to see their PCP is actually a barrier for urgent concerns. It may take anywhere from 1 week to 2 months to get an appointment to see their own PCP, which is often too long of a wait for an urgent complaint, such as acute pain or a medication refill. Furthermore, a few patients remarked that it is even difficult to access their PCP through the telephone. It is apparent that patients at MGH-Chelsea place a value on having ready access to their PCP at all times, but the system, as it stands, makes it nearly impossible. In contrast, one does not need an appointment to be seen in urgent care. This makes urgent care facilities more favorable for urgent concerns.

Patients preferred Chelsea Urgent Care over other nearby facilities because of convenience, rapport with providers at MGH-Chelsea, and the excellent quality of care. Most patients in this study reside in Chelsea and do not own a car, and are therefore limited by geography. MGH-Chelsea is the closest medical facility to their home; many patients would not know where else to go to meet their healthcare needs. Some patients commented on the community feel of MGH-Chelsea and how this is favorable to bigger institutions that may compromise the intimacy and personal connection that MGH-Chelsea is able to achieve. Most patients receive all of their primary and specialty care from MGH-Chelsea and therefore would prefer to go to an institution that already has their medical history on-record. Some patients have had great experiences with particular urgent care physicians at MGH-Chelsea and look forward to seeing them again for future urgent care complaints. Some patients have had very unfortunate experiences at outside hospitals in the area, and for that reason, try their best to go to MGH-Chelsea for all of their needs.

Reasons to Seek Care

Patients had a variety of expectations upon arriving to urgent care. Most patients expected a thorough, expedited evaluation and stabilization of their concerning symptom. Their symptoms were intolerable and they were not willing to wait. Their usual interventions, including over-the-counter medications and currently prescribed medications, were not working and they were expecting an intervention. This included a few patients who had ongoing symptoms that were not satisfactorily worked up in the primary care setting. There were a few patients who needed medication refills, and would not have been able to obtain their medications quick enough if they had waited for their scheduled PCP appointment. For other patients, urgent

care was their last resort to get help. It was the mechanism that they would use to get connected with the necessary care pathways to get well.

Limitations

Study Design: This study was designed to construct working hypotheses about drivers of frequent urgent care use in the patient population at MGH Chelsea. However, this was not designed to be a comparative study between frequent urgent care users and non-urgent care users, so it is uncertain whether or not these conclusions are unique to frequent urgent care users.

This study yielded a relatively small size sample size (~10% of eligible population). The sample size was limited by the rate at which interviews were able to be scheduled, and the short time-period for data collection. As a result, this study may not have captured all of the opinions about chronic illness management, primary car, and urgent care that may inform what the drivers of urgent care use are in the patient population at MGH-Chelsea.

Although an attempt was made to understand patient's decision-making regarding their healthcare, the questionnaire did not specifically ask patients about use of urgent care or ER services outside of MGH. However, during the study, it became apparent that some patients have sought healthcare from several health facilities. Therefore health care utilization patterns were not entirely captured through this study.

Data Collection: Interviews were conducted in a semi-structured format, allowing volunteers the freedom to tell their stories. This also allowed the interviewer to probe deeper about certain pertinent issues to understand the patient's unique context. However patients differed in their ability to reflect on the questions posed. Some were incredibly reflective, while others had difficulty understanding the questions and/or were terse in their responses. Psychiatric co-morbidities affected the ability of some volunteers to engage in the interview. A few patients were tangential speakers and were difficult to redirect. One patient reminded the interviewer that he was impatient and wanted to finish the interview as quickly as possible. Volunteers were also not consistently asked every question on the questionnaire, out of respect for volunteers' time and recognition that they addressed the subject in a prior response. Using translation services imposed particular challenges on time, as interviews tended to take twice as long as expected. It was a challenge to inquire about volunteers' urgent care experiences, as there was limited time to comment in-depth about all urgent visits. Furthermore, recall of specific urgent care visits was

variable. Sometimes it became necessary to focus on volunteers' approach to urgent care rather than specifics about each urgent care visit. All of these factors may have affected the quality of the data collected.

Data Analysis: Due to time-constraints and the small size of the primary research team (n=1), the researcher was unable to develop a code structure through the independent review and coding of transcripts by a second investigator, and then the review of transcripts with the code structure and resolution of discrepancies by a third investigator. It is therefore possible that the themes derived from this study are not sufficiently complex.

Conclusions

In semi-structured interviews with patients at MGH-Chelsea about their urgent care use, two main themes emerged: (1) engagement in healthcare for preventive health and chronic disease management and (2) decision-making around seeking healthcare for urgent medical problems. The dynamic concept of engagement vs. disengagement from healthcare appears to be important for understanding factors influencing how patients are able to manage their chronic illnesses and what drives urgent care visits related to chronic diseases. Patients also emphasized that primary care doctors are not easily accessible for urgent concerns, resulting in urgent care visits for chief complaints that could be addressed by a PCP.

The themes and narratives generated from this research have generated the following working hypotheses about frequent urgent care use at MGH-Chelsea:

1. Patient engagement in healthcare appears to contribute to improved management of chronic illness and patient satisfaction with their healthcare.
2. Patients can become disengaged from their healthcare for a variety of reasons, including lack of internal motivation, financial hardship, poor health literacy, stifling relationships, a fragile patient-doctor relationship and poor access to healthcare due to lack of a PCP or health insurance.
3. Patients who are less inclined to engage with healthcare on a regular basis may only be willing to see a doctor urgently for acute concerns.
4. Insufficient patient education about chronic illness or medication regimen may contribute to suboptimal chronic disease management.
5. Suboptimal chronic disease management may lead to exacerbations of chronic disease that requires urgent/emergent evaluation.
6. Patients prefer to see or speak to their PCP first for all of their questions and concerns.
7. Patients have difficulty bringing urgent concerns to the attention of their PCPs.
8. Significant wait times for appointments prevent patients from seeing their PCP in a timely fashion.
9. It is difficult to reach one's PCP over the phone in a timely fashion.

10. A proportion of urgent care visits appear to be occupied by ambulatory-sensitive problems that could have been addressed by a primary care doctor.
11. Patients may choose to seek urgent care for an expedited and thorough evaluation and explanation of their ongoing symptoms.
12. Convenience is a compelling factor in deciding where to seek urgent care.
13. Patients tend not to be satisfied with their healthcare if they do not bond with their provider or have a bad interaction with their provider.
14. Patients tend to avoid healthcare facilities where they have had poor interactions with providers in the past.
15. Urgent care is a location to get connected with primary care providers and apply for health insurance.
16. Some urgent care visits can be prevented by (1) regularly assessing and addressing factors contributing to patient disengagement; and (2) ensuring timely access to PCPs for urgent concerns (e.g. evening clinics, same-day appointments, improving telephone and email access to PCPs, etc.)

Suggestions for Future Work

To further refine the concerns of frequent urgent care users at MGH Chelsea, the study may benefit from either a larger sample size with a formal qualitative analysis or a by-person factor analysis. By-factor analysis consists of reading 23 polarized statements written on a slip of paper that represent the spectrum of opinions about drivers of frequent urgent care use obtained from the semi-structured interviews. Participants would be instructed to place each statement on a spot on a quasi-normal grid that corresponds with their level of agreement (see Figure 2). This would contribute a quantitative analysis to the data that may strengthen the claims made from the qualitative analysis.

To take a step further, a comparative study could be constructed comparing frequent urgent care users and match-controlled non-urgent care users. Results from such a study would contribute to the design and implementation of a Primary Care Checklist at the Chelsea Partnership Clinic. We envision the PC-C to be a novel clinical protocol that screens patients for key drivers of urgent care use, assesses the severity or risk level of drivers for which patients screen positive, and triages those patients to appropriate care pathways (e.g. primary care-based intervention or outside referral). Checklists have been used effectively in multiple contexts to improve patient care and standardize a range of complex, error-prone processes (Byrnes et al 2009, Dubose et al 2008, Lingard et al 2008). While the use of checklists and screening tools is prevalent in the health care setting, it has historically been focused on monitoring processes and addressing singular clinical issues as opposed to *strengthening systems* and *streamlining a*

comprehensive set of services. Because checklists have conventionally been specialized, their use in primary care has not been adequately explored. We hope that the implementation of the PC-C at CCC-Chelsea could serve as a model for improving the health of vulnerable populations at the level of primary care through reducing urgent care visits and improving patient satisfaction and health outcomes through comprehensive and holistic health care.

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Tables and Figures

Individual Patient Characteristics

Table 1.1. Volunteer 1: Demographic Information

Age	Sex	Race/ethnicity	Country of origin	Primary language	Immigration status	Highest education level attained	Insurance status
22	F	Hispanic or Latino	USA	English	Legal resident/U.S. citizen	Some college classes	Masshealth/Medicaid

Table 1.2. Volunteer 1: Clinical Information.

Smoking status	Starting age	Frequency of smoking	Alcohol	Illicit drug use	Health care - 1st choice	Urgent care/ ER visits	Number of hospitalizations (past year)	Reason for hospital visit
Non-smoker	N/A	N/A	1-2 cocktails/weekly	Marijuana – 3x weekly since age 15	Urgent care	3	0	N/A

Table 1.3. Volunteer 1: Social Information.

Marital status	Household size	Number of children < 18yo	Employment status	Household income	Housing status	Mode of transportation to clinic	Distance from MGH Chelsea	Food instability	Money instability	Safe in relationship	Domestic violence	Federal benefits /assistance
Separated	3	0	Full-time	\$15,001-30,000	Rent home	Walk	<30 min	No	No	Yes	Yes	Yes

Table 2.1. Volunteer 2: Demographic Information

Age	Sex	Race/ethnicity	Country of origin	Primary language	Immigration status	Highest education level attained	Insurance status
48	M	Caucasian	USA	English	Legal resident/U.S. citizen	High school	Masshealth

Table 2.2. Volunteer 2: Clinical Information.

Smoking status	Starting age	Frequency of smoking	Alcohol	Illicit drug use	Health care - 1st	Urgent care/ ER visits	Number of hospitalizations (past year)	Reason for hospital
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					choice	ER visits		visit
Current cigarette smoker	19	1 pack per day	No	No	PCP	4	3	Hernias, tonsillitis

Table 2.3. Volunteer 2: Social Information.

Marital status	Household size	Number of children < 18yo	Employment status	Household income	Housing status	Mode of transportation to clinic	Distance from MGH Chelsea	Food instability	Money instability	Safe in relationship	Domestic violence	Federal benefits /assistance
Engaged	2	0	Disabled	\$15,001-30,000	Rent home	Walk	<30 min	No	No	Yes	No	Yes

Table 3.1. Volunteer 3: Demographic Information

Age	Sex	Race/ethnicity	Country of origin	Primary language	Immigration status	Highest education level attained	Insurance status
48	M	Black or African-American	USA	English	Legal resident/U.S. citizen	Some college classes	Medicare & MassHealth

Table 3.2. Volunteer 3: Clinical Information

Smoking status	Starting age	Frequency of smoking	Alcohol	Illicit drug use	Health care - 1st choice	Urgent care/ER visits	Number of hospitalizations (past year)	Reason for hospital visit
Current cigarette smoker	21	6-7 cigarettes/day	3-6 beers per week	Marijuana in the past	Urgent care	3	0	N/A

Table 3.3. Volunteer 3: Social Information.

Marital status	Household size	Number of children < 18yo	Employment status	Household income	Housing status	Mode of transportation to clinic	Distance from MGH Chelsea	Food instability	Money instability	Safe in relationship	Domestic violence	Federal benefits /assistance
Single	1	0	Unemployed	<\$15,000	Rent home	Walk	<30 min	Yes	Yes	N/A	No	Yes

Table 4.1. Volunteer 4: Demographic Information

Age	Sex	Race/ethnicity	Country of origin	Primary language	Immigration status	Highest education level attained	Insurance status
54	M	Hispanic or Latino	Honduran	Spanish	Undocumented	Less than high school	No insurance (self-pay)

Table 4.2. Volunteer 4: Clinical Information

Smoking status	Starting age	Frequency of smoking	Alcohol	Illicit drug use	Health care - 1st choice	Urgent care/ER visits	Number of hospitalizations (past year)	Reason for hospital visit
Current cigarette smoker	24	2-3 cigarettes/day	Socially	No	Urgent care	5	0	N/A

Table 4.3. Volunteer 4: Social Information.

Marital status	Household size	Number of children < 18yo	Employment status	Household income	Housing status	Mode of transportation to clinic	Distance from MGHC Chelsea	Food instability	Money instability	Safe in relationship	Domestic violence	Federal benefits /assistance
Single	5	0	Working unstable jobs	<\$15,000	Rent home	Walk	<30 min	Yes	Yes	N/A	N/A	No

Table 5.1. Volunteer 5: Demographic Information

Age	Sex	Race/ethnicity	Country of origin	Primary language	Immigration status	Highest education level attained	Insurance status
61	F	Hispanic or Latino	Guatemala	Spanish	Undocumented	Less than high school	Medicaid/Free care

Table 5.2. Volunteer 5: Clinical Information

Smoking status	Starting age	Frequency of smoking	Alcohol	Illicit drug use	Health care - 1st choice	Urgent care/ER visits	Number of hospitalizations (past year)	Reason for hospital visit
Non-smoker	N/A	N/A	No	No	Primary care	10	0	N/A

Table 5.3. Volunteer 5: Social Information.

Marital status	Household size	Number of children < 18yo	Employment status	Household income	Housing status	Mode of transportation to clinic	Distance from MGH Chelsea	Food instability	Money instability	Safe in relationship	Domestic violence	Federal benefits /assistance
Married	4	1	Unemployed	<\$15,000	Rent home	Walk	<30 min	Yes	Yes	Yes	No	No

Table 6.1. Volunteer 6: Demographic Information

Age	Sex	Race/ethnicity	Country of origin	Primary language	Immigration status	Highest education level attained	Insurance status
34	F	Hispanic or Latino	USA	English	Legal resident/U.S. citizen	High school	Medicaid/MassHealth

Table 6.2. Volunteer 6: Clinical Information

Smoking status	Starting age	Frequency of smoking	Alcohol	Illicit drug use	Health care - 1st choice	Urgent care/ER visits	Number of hospitalizations (past year)	Reason for hospital visit
Current cigarette smoker	12	12-14 cigarettes/day	No	Past history of IV heroin and cocaine	Primary care	2 (+ 3 at a different urgent care facility)	0	N/A

Table 6.3. Volunteer 6: Social Information.

Marital status	Household size	Number of children < 18yo	Employment status	Household income	Housing status	Mode of transportation to clinic	Distance from MGH Chelsea	Food instability	Money instability	Safe in relationship	Domestic violence	Federal benefits /assistance
Separated	2 (in recovery house of 30)	3 (some one has a temporary custody)	Unemployed	<\$15,000 (only source of income is food stamps)	Homeless/living in recovery home	Shuttle		No	No	Yes	Yes	Yes

Table 7.1. Volunteer 7: Demographic Information

Age	Sex	Race/ethnicity	Country of origin	Primary language	Immigration status	Highest education level attained	Insurance status
43	M	Hispanic or Latino	Honduran	Spanish	Undocumented	High school graduate or GED	Free care

Table 7.2. Volunteer 7: Clinical Information

Smoking status	Starting age	Frequency of smoking	Alcohol	Illicit drug use	Health care - 1st choice	Urgent care/ER visits	Number of hospitalizations (past year)	Reason for hospital visit
Non-smoker	N/A	N/A	No	No	Urgent care	3	0	N/A

Table 7.3. Volunteer 7: Social Information.

Marital status	Household size	Number of children < 18yo	Employment status	Household income	Housing status	Mode of transportation to clinic	Distance from MGH Chelsea	Food instability	Money instability	Safe in relationship	Domestic violence	Federal benefits /assistance
Married	8	2	Working unstable jobs	\$15,001-30,000	Rent home	Walk	<30 min	Yes	No	Yes	No	No

Table 8.1. Volunteer 8: Demographic Information

Age	Sex	Race/ethnicity	Country of origin	Primary language	Immigration status	Highest education level attained	Insurance status
64	M	Caucasian	USA	English	Legal resident/U.S. citizen	Less than high school	MassHealth

Table 8.2. Volunteer 8: Clinical Information

Smoking status	Starting age	Frequency of smoking	Alcohol	Illicit drug use	Health care - 1st choice	Urgent care/ER visits	Number of hospitalizations (past year)	Reason for hospital visit
Current cigarette smoker	12	1-1.5 packs per day (12-14 cigarettes daily)	6 beers daily	Past use of LSD, Acid. None currently	Primary care	5	0	N/A

Table 8.3. Volunteer 8: Social Information.

Marital status	Household size	Number of children < 18yo	Employment status	Household income	Housing status	Mode of transportation to clinic	Distance from MGH Chelsea	Food instability	Money instability	Safe in relationship	Domestic violence	Federal benefits /assistance
Single	4	0	Work part-time	<\$15,000	Rent home	Walk	<30 min	No	No	Yes	No	Yes

Table 9.1. Volunteer 9: Demographic Information

Age	Sex	Race/ethnicity	Country of origin	Primary language	Immigration status	Highest education level attained	Insurance status
63	M	Hispanic or Latino	Honduran	Spanish	Legal resident/U.S. citizen	High school	Individual private insurance

Table 9.2. Volunteer 9: Clinical Information

Smoking status	Starting age	Frequency of smoking	Alcohol	Illicit drug use	Health care - 1st choice	Urgent care/ER visits	Number of hospitalizations (past year)	Reason for hospital visit
Non-smoker	N/A	N/A	None	None	Primary care	5	1	Chest pain

Table 9.3. Volunteer 9: Social Information.

Marital status	Household size	Number of children < 18yo	Employment status	Household income	Housing status	Mode of transportation to clinic	Distance from MGH Chelsea	Food instability	Money instability	Safe in relationship	Domestic violence	Federal benefits /assistance
Single	1	0	Temporary	\$15,001-30,000	Rent home	No response	No response	No response	No	No response	No response	Yes

Table 10.1. Volunteer 10: Demographic Information

Age	Sex	Race/ethnicity	Country of origin	Primary language	Immigration status	Highest education level attained	Insurance status
53	M	Hispanic or Latino	Dominican Republic	Spanish	Legal resident/U.S. citizen	College graduate	Individual private insurance

Table 10.2. Volunteer 10: Clinical Information

Smoking status	Starting age	Frequency of smoking	Alcohol	Illicit drug use	Health care - 1st choice	Urgent care/ER visits	Number of hospitalizations (past year)	Reason for hospital visit
Non-smoker	N/A	N/A	2-3 cups of wine/week	None	Urgent care	5	0	N/A

Table 10.3. Volunteer 10: Social Information.

Marital status	Household size	Number of children < 18yo	Employment status	Household income	Housing status	Mode of transportation to clinic	Distance from MGH Chelsea	Food instability	Money instability	Safe in relationship	Domestic violence	Federal benefits /assistance
Married	4	0	Work full-time	\$15,001-30,000	Rent home	Car	<30 min	No	Yes	Yes	No	Yes

Table 11.1. Volunteer 11: Demographic Information

Age	Sex	Race/ethnicity	Country of origin	Primary language	Immigration status	Highest education level attained	Insurance status
72	F	Caucasian	USA	English	Legal resident/U.S. citizen	Graduate school	Medicare and private insurance

Table 11.2. Volunteer 11: Clinical Information

Smoking status	Starting age	Frequency of smoking	Alcohol	Illicit drug use	Health care - 1st choice	Urgent care/ER visits	Number of hospitalizations (past year)	Reason for hospital visit
Past cigarette smoker	18	1 pack per day	2-3 drinks (Scotch) /week	None	Urgent care	12	1	Fall – pelvic fracture

Table 11.3. Volunteer 11: Social Information.

Marital status	Household size	Number of children < 18yo	Employment status	Household income	Housing status	Mode of transportation to clinic	Distance from MGH Chelsea	Food instability	Money instability	Safe in relationship	Domestic violence	Federal benefits /assistance
Married	2	0	Retired	>\$60,000	Own home	Car	<30 min	No	No	Yes	No	No

Characteristics of Study Population

Table 1. Demographic Information

Age	Mean: 51; Median: 53; Range: 22-72 Distribution: 1 0-25 years old (9%) 4 25-50 years old (36%) 6 50-75 years (55%) 0 75-100 years old
Sex	4 females (36%) 7 males (64%)
Marital status	4 Single (36%) 1 Engaged (9%) 4 Married (36%) 2 Separated (18%)
Race/ethnicity	3 Caucasian (27%) 1 Black or African-American (9%) 0 Native American 0 Asian or Pacific Islander 7 Hispanic or Latino (64%)
Country of origin	6 United States of America (55%) 3 Honduras (27%) 1 Guatemala (9%) 1 Dominican Republic (9%)
Primary language	6 English (55%) 5 Spanish (45%)
Immigration status	8 Legal resident/U.S. citizen (73%) 3 Undocumented (27%)
Education level	3 Less than high school (27%) 3 Some high school (27%) 1 High school graduate or GED (9%) 2 Some college classes (18%) 1 College graduate (9%) 1 Graduate school (9%)
Health insurance status	2 Medicare (17%) 4 Medicaid/MassHealth (33%) 2 Health safety net (free care) (17%) 0 Employer-based private insurance (0%) 3 Individual private insurance (25%) 1 No insurance (8%)
<i>*One patient had two insurance policies</i>	

Table 2. Social Information

Employment status	3 Working a paid full-time job (27%) 1 Working a paid part-time job (9%) 2 Working unstable jobs (18%) 4 Unemployed (36%) 1 Retired (9%)
Household income	5 <\$15,000 (45%) 5 \$15,001-30,000 (45%) 0 \$30,001-60,000 (0%) 1 >\$60,000 (10%)
Food instability	4 Yes (36%) 7 No (64%)
Money instability	4 Yes (36%) 7 No (64%)
Domestic violence	2 Yes (18%) 7 No (64%) 2 No response (18%)
Federal benefits/assistance	7 Yes (64%) 4 No (36%)

Table 3. Clinical Information

Number of ongoing medical/psychiatric conditions	Total = 64 Mean per person = 5.82 Range (per person) = 3-12
Number of urgent care/ER visits	Total = 57 Mean per person = 5.18 Range (per person) = 2-12
Tobacco use	5 Current smoker (45%) 1 Past smoker (10%) 5 Never smoked (45%)
Illicit drug use	1 Yes – current (9%) 3 Yes – past (27%) 6 Never (55%) 1 No response (9%)

Table 4. Top Diagnosed Chronic Medical and Psychiatric Conditions

Condition	Number of diagnoses
Cigarette smoking	7
Hypertension	5
Anxiety disorder	4
Type 2 diabetes	3
Depression, hip pain, osteoarthritis, COPD, chest pain of undetermined cause, GERD	2

Table 5. Identified Themes for Volunteer Narratives.

- 1. Engagement in healthcare for preventive health and chronic illness management**
 - a) Disengaged
 - b) Engaged
- 2. Decision-making around seeking healthcare for urgent medical problems**
 - a) Nature of urgent medical problem
 - b) Where to get help
 - c) Reasons to get help

Figure 1. Chief Complaint at Urgent Care/ER Visits

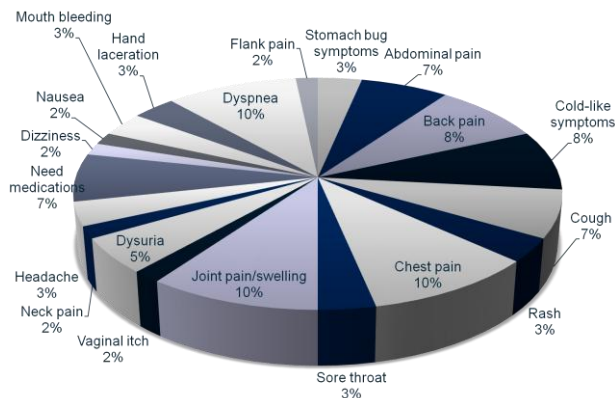


Figure 2. Quasi-normal grid for by-person factor analysis

Strongly disagree		Neutral			Strongly agree	

Appendix I: Mailed Recruitment Letter

Dear [patient's name],

This letter is to tell you about a research study being conducted at Massachusetts General Hospital by Dr. Rebecca Berman, MD and Dr. Marya Cohen, MD MPH at MGH Chelsea Healthcare Center. Dr. Berman and Dr. Cohen are assessing the use of urgent care and the emergency room services among patients seeing a doctor through MGH Chelsea's Tuesday evening Crimson Care Collaborative clinic. All such patients who have been to the Tuesday evening clinic and MGH Chelsea Urgent Care are being informed about this research project, in case they would like to participate.

In this research study, patients will be asked to consider coming to MGH Chelsea for an hour-long interview about their experience with finding and using healthcare, including Chelsea Urgent Care, to take care of their medical problems. Your feedback will be used to help improve the health care we give to patients like you. If you choose to participate, you will receive \$40 for volunteering your time. All of your responses will be kept confidential; they will not be added to your medical record. Please note that your participation is entirely optional. Your decision to participate or not participate will not affect the medical care that you receive at MGH Chelsea.

If you would like more information about the study, or if you do not wish to participate in this study, please contact the research assistant, Nicole Jackson or Dr. Cohen or Dr. Berman, by email (Nicole_jackson@hms.harvard.edu) or by phone (860-798-6423). Your participation is voluntary. Whether you participate or not will have no effect on the medical care you receive at MGH. If we do not hear from you within 2 weeks of receipt of this letter, our staff may call you by the end of the summer to see if you want to learn more.

Thank you in advance for considering this request.

Sincerely yours,
Dr. Marya Cohen, MD, MPH
Chelsea Healthcare Center
617-889-8580
mjcohen@partners.org

Dr. Rebecca Berman, MD
Internal Medicine Associates Team 2
617-724-8400
rberman@partners.org

Appendix II: Phone Script

- 1) *Hello, my name is [INTERVIEWER NAME], and I am calling from the MGH Chelsea Healthcare Center. May I please speak with [PATIENT'S NAME]?*

DO NOT MENTION CRIMSON CARE COLLABORATIVE OR PURPOSE OF THE STUDY TO ANYONE OTHER THAN THE PATIENT NAMED ON THE SAMPLE RECORD.

If respondent is on the phone:

Continue with to #2 below. If respondent is unavailable:

- Schedule a call back time with the person on the phone.

-If voicemail: Do not leave message, call back another time.

- 1) *I am a medical student working with Dr. Rebecca Berman and Dr. Marya Cohen at MGH Chelsea on a research study about how patients at the Tuesday evening clinic use urgent care and the emergency room.*

[You should have received information about the study in a letter sent from Dr. Berman and Dr. Cohen. Do you have any questions or concerns about it?]

OR

[Since you have been to the Tuesday evening clinic and Urgent Care, you are an ideal patient for this study. If you don't mind, I would like to tell you more about this study and its benefits to you.]

Wait for response, and answer questions accordingly.

- 2) *Participation in this study involves coming in for an hour-long interview with me to talk about your experiences with using primary care and urgent care to take care of your medical problems. Your feedback will be used to help improve the health care we give to patients like you. Your participation is completely optional. If you choose to participate, we will provide you with \$40 for volunteering your time. Your decision to participate or not participate will not affect the medical care that you receive at MGH Chelsea. Are you interested?*

If yes, continue to #4 below.

If no: I understand. Thank you for your time.

- 3) *Great. I would also like you to know that all of your responses will be kept confidential, and they will not be added to your medical record. Are you still interested?*

If yes, proceed to schedule the appointment, and then continue to #4.

If no: I understand. Thank you for your time.

4) *Your appointment with me is scheduled for [appointment date] at [appointment time] at MGH Chelsea Adult Medicine. I will give you a call a few days before to remind you of this appointment. Thank you for volunteering your time. I look forward to speaking with you in-person! Good-bye.*

Appendix III: Semi-Structured Interview Guide

Chronic Illness Management

To begin the interview, I would like to learn about your medical problems, and what you do to keep yourself healthy.

1. Pretend that I do not know anything about medicine, and you are teaching me about it. How do you take care of your ongoing medical problems (if limited in time, choose top 2 ambulatory-sensitive problems)?
 - a. After doctors make a diagnosis, they usually give patients specific instructions to take care of the problem. Describe all of the things you should do to prevent the problems from getting worse (e.g. medication use, physical therapy, diet/exercise, coming to appointments).
 - i. In your daily life?
 - ii. At the clinic?
 - b. Describe all of the symptoms or health conditions you might experience if you do not follow the doctor's instructions.
 - c. What are you supposed to do if your symptoms get worse (e.g. call the doctor, take certain medications)?
 - d. What are you supposed to do if your symptoms improve? Can you stop your usual therapy? Can you do your usual therapy less often (phrasing of "therapy" is tailored to the patient's account)?
2. Have you been able to follow the doctor's instructions (e.g. medication use, physical therapy, diet/exercise, coming to appointments, getting labs done, calling the doctor if indicated)? Explain what you do.
 - a. If yes: It is not an easy task to follow the doctor's exact instructions. What helps you stick to your treatment (reflect on any and all factors, including medical, familial, community, religious, relationships, personal knowledge, information sources)?
 - b. If no: Some patients do not follow the doctor's instructions because they have trouble remembering to do it, do not want to do the therapy, or perhaps have another reason. Tell me your story. What can we do to help you stick to your treatment? Are there other outside resources that would be helpful?

Primary Care (Access to and Role in Chronic Illness Management)

Next, I would like to learn about your experience with primary care in the United States.

1. Do you have a primary care doctor? If so, how long have you had a primary care doctor (since you moved here)?
 - a. How long were you without a primary care doctor while in the United States? Why did you not see a doctor for that long?
2. How did you care for your medical problems without the help of a primary care doctor in the past?
3. Did you have trouble getting a primary care doctor? If so, tell me more about your obstacles (e.g. affording health care, getting health insurance).
4. In what ways has your primary care doctor helped you care for your medical problem(s)?
 - a. Is there anything that your primary care doctor does that *doesn't* help you take care of your medical problem? How can your primary care doctor do a better job?
 - b. Are there any resources that would be more helpful than your primary care doctor in taking care of your medical problem?

Decision to use urgent care

Now I would like you to reflect on your visits to Chelsea Urgent Care over the past year.

1. Tell me the story about why you visited urgent care on _____ (date)?
 - a. What problems were you having?
 - b. What do you think caused these problems?
 - c. How did you try to take care of the problem on your own?
 - d. How long did you delay seeking any medical help?
 - e. Did you seek health care from another place before going to Chelsea Urgent Care (e.g. doctor, pharmacy, mobile clinic, etc)? Tell me about what happened.
 - f. What made you decide to go to urgent care at that moment?
 - g. Why did you decide to go to urgent care rather than another health care facility?

- i. Was the cost of care a reason to go to urgent care? Convenience? Lack of a regular doctor? Lack of health insurance? Explain.
 - ii. Tell me about the care you expected to receive at Chelsea Urgent Care.
 - iii. How does that differ from care that you might have received from other health facilities?
- h. What do you think would have happened if you delayed seeking medical help any longer?

Perception of care received at Chelsea Urgent Care

1. Tell me about the care you received. What physical exams, laboratory tests, or imaging studies did they perform? [Don't ask; look this up in LMR]
2. According to the doctor, what was the cause of the symptoms? What was the prescribed treatment? [Don't ask; look this up in LMR]
3. What specific concerns did you want addressed at Chelsea Urgent Care?
 - i. Was there anything that was not addressed? How could have the medical team done a better job at providing you care?
4. Did anyone at Chelsea Urgent Care ask you about your access to primary care? What was the conversation about?
 - i. Tell me about your referral to MGH Chelsea for primary care.
5. Tell me about what happened to your urgent medical problem after you were discharged from Chelsea Urgent Care. Were you able to follow the doctor's instructions? Was the problem resolved?
 - i. If yes, comment on what made it possible to do so.
 - ii. If not, what were you able to achieve? Why wasn't treatment completed as prescribed?
6. Do you think that this urgent care visit could have been prevented? If so, why? What could have been done to prevent your urgent care visit?

Brief Closing Questionnaire

I would like to end this interview by asking a few simple questions about your social history and health-seeking patterns.

1. Have you ever smoked?
 - a. If so, when did you start?
 - b. Do you still smoke?
 - c. If yes, how much do you smoke?
2. How many drinks of alcohol do you consume per week?
3. When you get sick, where do you normally go to get help? Rank according to 1st, 2nd, and 3rd choice.
 - a. Primary care provider
 - b. Dentist
 - c. Pharmacy
 - d. Urgent care
 - e. Hospital emergency room
 - f. Other
4. Housing status
 - a. Own home
 - b. Rent home
 - c. Living in someone's home
 - d. Homeless
5. Number of hospitalizations in past 12 months
 - a. Dates of visits
 - b. Reasons for visits
 - i. Injury
 - ii. Unexplained symptoms/acute illness
 - iii. Illness related to currently-diagnosed illness