

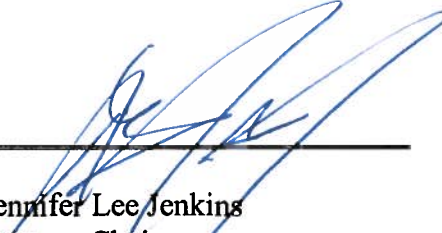


APPROVAL SHEET

Title of Thesis: Challenges of managing diabetes while homeless

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## ABSTRACT

Title of Document: CHALLENGES OF MANAGING DIABETES  
WHILE HOMELESS  
Hanna Jardel, Master of Science, 2017

Directed By: Department Chair Dr. J Lee Jenkins, Department  
of Emergency Health Services

**Objective:** This study investigated structural challenges that homeless individuals in Baltimore face in managing diabetes and how social services interact with these challenges. **Background:** Homelessness is associated with poor health, and diabetes is of increasing concern. Poor health contributes to heavy use of emergency departments, placing enormous financial burden on the healthcare system. **Methods:** Qualitative data were collected with 15 interviews from individuals gathered from Healthcare for the Homeless Baltimore. **Findings:** Findings emphasized instability in diet and medication storage as well as competing needs that divert precious resources. Difficulties are exacerbated by the low density of grocery stores and a primary healthcare system limited in effective scope. **Conclusion:** In order to manage their diabetes, participants showed perseverance, employing strategies to overcome challenges. Social services are able to reduce the effects of some difficulties, especially in medication access and healthcare access, but also have opportunities to more effectively address challenges. Findings suggest that the structure of social services would be more effective as a cohesive, cooperative network to aid clients manage complex conditions in challenging circumstances.

CHALLENGES OF MANAGING DIABETES WHILE HOMELESS

By

Hanna Jardel

Thesis submitted to the Faculty of the Graduate School of the  
University of Maryland, Baltimore County, in partial fulfillment  
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## Chapter 1: Introduction and Research Questions

### *Diabetes in Baltimore*

Diabetes is a major problem in the United States (US), with 22 million people (9.6% of the total population) actually living with the disease and over 86 million who were pre-diabetic in 2014 (Centers for Disease Control [CDC], 2015a; CDC, 2014a; Colby & Ortman, 2014). Based on a 2010 diabetes estimated frequency of 26.8 million people, by 2030 there may be as many as 36 million people with diabetes in the US, or a 34% increase in prevalence and a much greater public health challenge (Shaw, Sicree, & Zimmet, 2010). The prevalence of diabetes in 2017 was greatest among older populations (about 25%), among non-Hispanic blacks (about 16%) and among those with low incomes (about 13%) (Stamez, Wei, Kim, Narayan, & Saydah, 2017).

Not an innocuous disease, direct medical cost (not accounting for disability, work loss, or early death) associated with diabetes in 2010 was estimated to be US\$116 billion (CDC, 2011). Additionally, diabetes is associated with a 50% increased risk of death at any given time for adults in the US (CDC, 2014b). In 2014, the mortality rate due to diabetes in the US was 20.9 deaths per 100,000 residents, causing 76,488 deaths (2.9% of the total deaths in the US for 2014), and making diabetes the seventh highest cause of death for the nation (Kochanek, Murphy, Xu, & Tejada-Vera, 2016). Baltimore, Maryland has a population of 622,793 people, or 10% of the total population of Maryland, but accounts for 15% of deaths due to diabetes

for the state (Department of Health and Mental Hygiene [DHMH], 2014). The mortality rate due to diabetes in Baltimore is clearly higher than that of the whole state, at 32.1 deaths per 100,000 residents, and the mortality figures are also increasing more quickly than those of Maryland, increasing the diabetes mortality gap by 21% in just 2 years (DHMH, 2014; DHMH, 2012). The problem of diabetes may particularly affect homeless individuals, as an increased number of material insecurities is associated with poor diabetes control even among a pool of the general population, and homelessness is primarily characterized by housing insecurity or inadequacy (Berkowitz *et al.*, 2015; USDHUD, 2015).

### *Homelessness in Baltimore*

Homeless individuals include those with no place to sleep, in shelters or transitional housing, in crowded living areas, staying in structures not fit for human inhabitation, and with insecure housing (USDHUD, 2015). Point in time estimates are the preferred method of tracking populations of homeless individuals because they account for unsheltered homeless individuals, not only individuals in shelters (National Alliance to End Homelessness [NAEH], 2016). In Maryland, there were 8,390 homeless individuals on one 2015 night, which is a 6.8% increase from 2014 (NAEH, 2016). Baltimore City contained 32.7% of that population in 2014, or about 2,569 individuals (Chasse, Kramer, Powell, Shulman, & Zimmerman, 2015).

In Baltimore specifically, homeless individuals suffer as a result of city government initiatives such as recent encampment disbanding, holly bush plantings that disallow encampment setting, and an attempt to lower the emergency shelter

trigger temperature from its current 13°F to 0°F (Anderson, 2015; Reutter, 2015; Shen, 2015). Even without the noted city government actions, homeless individuals in high income countries experience an increased mortality rate compared to the general population of their country, the population of the surrounding metropolitan area, and the lowest income bracket of the area (Baggett, Hwang, O'Connell, Porneala, Stringfellow, & Orav, 2013; Barrow, Herman, Cordova, & Struening, 1999; Hwang, Wilkins, Tjepkema, O'Campo, & Dunn, 2009; Nusselder, Sloekers, Krol, Sloekers, Looman, & van Beeck, 2013).

### *Pathophysiology of diabetes*

Diabetes, according to the CDC, is when one's "blood glucose levels are above normal...[one's] body does not make enough insulin or can not use its own insulin as well as it should" (CDC, 2015b). It is also known as hyperglycemia (ADA, n.d.). Type I Diabetes occurs when the pancreas does not produce a normal amount of insulin, and Type II Diabetes occurs when body's cells are tolerant to insulin and require more insulin to import glucose than the pancreas provides (CDC, 2014b). The vast majority of diagnosed diabetes cases in the US are of Type II Diabetes, which can be treated with oral medication for a time and with insulin as the disease progresses (American Diabetes Association [ADA], 2014a; Fonseca, 2009). Risk factors for development of Type II Diabetes include obesity and poor nutrition (Fonseca, 2009). Disease progression, characterized by complications of vascular dysfunction, can be slowed with proper glycemic control (Wukich, Crim, Frykberg, & Rosario, 2014; Ang, Jaiswal, Martin, & Pop-Busui, 2014). Glucose can attach to a

protein on red blood cells, hemoglobin (Hb), to form glycosylated hemoglobin (HbA1c) and does so more often when there is more glucose in the blood (ADA, 2014b). Because red blood cells have a life of a few months, levels of blood glucose over several months can be gauged with levels of HbA1c, with 7% or less of red blood cells with HbA1c showing good glycemic management (ADA, 2014a).

Management strategies for Type II diabetes include medications and lifestyle changes such as altered diet and physical activity. Medical costs for medication and diabetes-associated treatment of complications are twice as high for those with diabetes than for those without diabetes (CDC, 2014b). Multi-morbidity, defined as two or more chronic conditions in the same patient, is most prevalent in adults with the lowest incomes, thus placing a huge burden on a population incapable of shouldering it (Stamez *et al.*, 2017). Among all adults in the US, the risk of death at any given time is 50% higher among those with diabetes, and as with all health conditions this risk increases the longer diabetes goes untreated (CDC, 2014b). Early diagnosis, and thus proper education/treatment, depends on access to healthcare, and early management with primary healthcare is needed to reduce the risk of complications.

### *Homeless and unhealthy*

Studies have shown that many homeless individuals experience less healthy and truncated lives. Lebrun-Harris *et al.* (2013) found that homeless patients had a greater burden of substance use, chronic medical and mental health problems, and Baggett *et al* (2013) found that the mean age at death for a cohort of homeless

individuals in Boston was 51 years of age. Their lives are also plagued by unique challenges to chronic disease management as discussed in the literature review (Gelberg, Andersen, & Leake, 2000; Hwang & Bugeja, 2000; Hwang *et al.*, 2009; Morrison, 2009; Wilk, Mora, Chaney, & Shaw, 2002; Zlotnick & Zerger, 2009). Not only are their lives less healthy, but their perceptions of health are poor with about 36% of homeless individuals reporting poor or fair health compared to 10% of the general US population (Baggett *et al.*, 2013; Gelberg *et al.*, 2000). While high transmission rates of infectious disease among the homeless are well documented, chronic conditions such as metabolic disorders (i.e. diabetes) are of increasing concern as discussed in the literature review.

Homeless individuals experience unique difficulties managing diabetes and the consequences of poor condition management even in countries with strong healthcare infrastructures. A country that is similar to the US in this respect is Canada; in Canada homeless individuals have faced many diabetes management challenges such as little control over poor quality shelter food, inability to store medications, inability to correctly time insulin doses due to shelter policy, and shelter policies forbidding needles in the facility (Hwang, 2000). A similar qualitative study from the midwest US shows similar challenges in diabetes management for homeless individuals, specifically a disorganized life, food availability, access to care, difficulty in accessing medication, stress, competing needs, and substance abuse (Elder & Tubb, 2014).

In an effort to bring healthcare to those who otherwise have difficulties accessing it, Health Care for the Homeless (HCH) Baltimore offers healthcare geared

specifically towards the homeless population and strives to ever improve its services based on client input. This includes steps to reduce the challenges to managing diabetes. Despite major client-informed strides in efficiency at HCH, the city of Baltimore still disproportionately suffers from diabetes related mortality (DHMH, 2014).

### Research Questions

In a city that holds 2,569 individuals experiencing homelessness and where 200 residents died in 2014 of diabetes, the challenges facing homeless diabetics are important to explore (Chasse, Kramer, Powell, Shulman, & Zimmerman, 2015; DHMH, 2014). In order to understand the daily lives of individuals experiencing homelessness and diabetes, it is critical to examine this structure through an intersectional lens. This theory focuses on how structures of society are intertwined and how these structures affect an individual's daily life differently according to an individual's different identities (Collins & Bilge, 2016). In this particular case, the identities of being homeless and being diabetic are examined; the pressures of homelessness and the pressures of having diabetes combine to form a whole effect greater than just the pressures of homelessness and the pressures of diabetes combined. In other words, the structural pressures on homeless diabetics are synergistic in nature and are more complex than pressures from either identity individually. This study focused on the personal experiences of the structural context, or circumstances created by Baltimore City institutions, surrounding diabetes

management for homeless individuals to answer these questions.

Research Question 1: What are the structural variables affecting diabetes management for homeless individuals?

Research Question 2: How do social services in the area facilitate or hinder homeless individuals' management efforts?



## Chapter 2: Literature Review

Not all homeless individuals are easily identified. There is a diverse array of presentations, and the many definitions of homelessness reflect this. For the purposes of this paper, homeless individuals include those who sleep on the streets called rough-sleepers, those in shelters, and those in crowded living areas or otherwise insecure housing situations (USDHUD, 2015). A 17% increase in the visibly homeless population, which is likely to be a low estimate of the overall homeless population, between 2014 and 2015 in Maryland means that rising numbers of homeless individuals are exposed to shortened life expectancy and poor health (USDHUD, 2015; USDHUD, 2014).

### *Morbidity and healthcare utilization among homeless*

Homelessness is associated with increased risk for many negative outcomes including infectious diseases and high rates of acute medical service (emergency department (ED) and hospital admission) utilization, partially because homeless individuals are not integrated into a primary healthcare system and many have no regular source of treatment or preventative care (D'Amore, Hung, Chiang, & Goldfrank, 2001; Gelberg *et al.*, 2000; Zlotnick & Zerger, 2009). Poor access to and utilization of primary healthcare creates a vicious cycle whereby poor health status and medical crises are created and lead the individual to local EDs for medical treatment. In a 2003 study from the HCH User Survey, 73% of individuals reported at least one unmet healthcare need, representing a low estimate due to survey

demographics but one that still is several times the percentage of those with unmet needs in the general US population (Baggett, O'Connell, Singer, & Rigotti, 2010; Medical Expenditure Panel Survey, 2006). This finding was corroborated by another nationally representative study that found homeless patients in federally supported health centers to have twice the odds of having unmet health services needs and twice the odds of visiting an emergency department in the previous year than housed patients in the same facility (Lebrun-Harris *et al.*, 2013). Not surprisingly, self-reported poor health status is higher among the homeless population than the general population (Gelberg *et al.*, 2000; Zlotnick & Zerger, 2009). About 40% of homeless individuals in San Francisco had visited an ED in the past year and about 8% visited it over 3 times, with poor health status a contributing factor (Kushel, Perry, Bangsberg, Clark, & Moss, 2002). Of those who visited the ED, 18% used it as their only source of healthcare (Kushel *et al.*, 2002). In Massachusetts, 33% of 6494 homeless Medicaid members had at least one hospitalization and about 66% had at least 1 ED visit, with heavy users, 12% and 21% of the population respectively, contributing over 70% of the hospital admissions and over 70% of ED visits (Lin *et al.*, 2015).

When homeless individuals do seek medical attention, studies show that in the 1990s it was often in the form of emergency medicine (Crow & Hardill, 1993; Padgett, Struening, Andrews & Pittman, 1995). During that time, homeless individuals in Hawaii were found to be admitted to hospitals five times as frequently as the general population and in New York homeless individuals were staying longer in hospitals than low-income patients (Martell *et al.*, 1992; Salit, Kuhn, Hartz, Vi &

Mosso, 1998). A study of frequent ED users found that homeless individuals compose a disproportionately high percent of frequent users and that they, place a significant financial burden on the healthcare system (Ku *et al.*, 2014). Interestingly, several studies suggest that homeless individuals who frequently use EDs also use other forms of healthcare at a higher rate, suggesting overall high healthcare usage instead of substitution of all healthcare usage with ED visits (Lin, Bharel, Zhang, O'Connell, & Clark, 2015; Mitchell, León, Byrne, Lin, & Bharel, 2017). This burden on the healthcare system is extremely costly, as on average those with diabetes incur medical costs twice as high as those without diabetes, and many homeless individuals have neither health insurance nor personal funds to help mitigate the losses to hospitals (Gelberg *et al.*, 2000; Gelberg, Gallagher, Andersen, & Koegel, 1997; CDC, 2014b; Zlotnick, Zerger, & Wolfe, 2013). An analysis of Medicare claims analysis of HCH Boston patients showed that those with three or more conditions incurred the greatest cost, and that those using the ED frequently had on average twice the non-ED healthcare costs as non-frequent ED users (Mitchell *et al.*, 2017). Unfortunately, little research has been done on healthcare costs of homeless diabetics and in how acute healthcare expenditures for homeless individuals affects the overall public health budget of the US. It has been documented, however, that extremely high medical costs may cause an individual's living situation to become unstable due to bankruptcy, which may eventually lead to homelessness (Himmelstein, Thorne, Warren, & Woolhandler, 2009).

Diabetes is of particular concern for the health of the homeless population for a number of reasons. For instance, a survey of chronically homeless adults in 11 US

cities showed that 57% of them were overweight or obese, a major risk factor for development of diabetes (Tsai & Rosenheck, 2013). Additionally, studies suggest that the homeless population may be aging at a rate beyond that of the general population (Gelberg, Robertson, Arangua, & Leake, 2000; Hahn, Kushel, Bangsberg, Riley, & Moss, 2006; North, Eyrich, Pollio, Spitznagle, 2004; Robertson & Cousineau, 1986). This is concerning because the burden of chronic conditions (including diabetes) lies disproportionately with older populations and those with low incomes (Stamez, 2017). Further supporting this concern is the 3.6 times increased risk for homeless individuals over 50 years old to suffer from a chronic disease, and over two times risk for heroin dependency, than younger homeless individuals, showing increased risk of presenting a complex medical situation (Garibaldi, Conde-Martel, & O'Toole, 2005). Despite these concerns and suggestions otherwise, one 2015 meta-analysis finds no significant difference in diabetes prevalences between the homeless population and the general population (Bernstein, Meurer, Plumb, Jackson, 2015). This particular study also finds that most diabetes prevalence estimates among the homeless are based on self-reports and therefore may not present accurate estimates (Bernstein *et al.*, 2015). Conversely, one study of free clinic users found that diagnoses of diabetes were not significantly greater among homeless individuals than other individuals using the clinic (Notaro, Khan, Kim, Nasaruddin, & Desai, 2012).

### *Mortality among homeless*

Studies have shown mortality rates several times higher among homeless individuals than among those of the surrounding population and reduced life

expectancy (Baggett *et al.*, 2013; Barrow *et al.*, 1999; Hwang & Wilkens, 2001; Nusselder *et al.*, 2013). For instance, Barrow *et al.* (1999) found that New York City shelter residents die at rates 3 times higher than the city population and Morrison (2009) found a 1.4 hazard ratio when comparing the homeless and most deprived non-homeless populations. Increased mortality among homeless individuals is due to increased prevalence of disease but also due specifically to homelessness and the inherent stressors (Morrison, 2009). Conditions including visual impairment, skin/foot/leg problems, asthma, stroke, mental health disturbances, hypertension, tuberculosis, Hepatitis C, and diabetes are more prevalent in homeless populations than the general population (Gelberg *et al.*, 2000; Macnee, Hemphill, & Letran, 1996; Strehlow, Roberston, Zerger, Rongey, & Arangua, 2012; Zlotnick & Zerger, 2009).

### *Barriers between homeless individuals and healthcare*

Diabetes can cause many medical complications in an individual including stroke, infections that lead limb amputation, blindness, and renal failure if not properly managed. Proper management requires regular follow-up visits with a physician as well as compliance with lifestyle changes and medication schedules. Many homeless individuals are not integrated into the primary healthcare system, and thus do not achieve adequate diabetes management. Failure to fully utilize available primary healthcare resources may be due to any number of factors including frustration with or mistrust of healthcare providers, and difficulty managing logistics to work around gatekeeping mechanisms that make accessing healthcare time consuming (Gelberg *et al.*, 2000; Nikasch & Marnocha, 2009, Zlotnick *et al.*, 2013).

### Homeless diabetes management: Medication

Among logistical problems are competing needs, scheduling difficulty, and a lack of transportation (Gelberg, Browner, Lejano, & Arangua, 2004; Gelberg *et al.*, 2000). Even after diagnosis with diabetes, individuals may not be able to follow self-care instructions because of trouble with lifestyle changes or with medication logistics, especially with insulin. Insulin poses particular problems because blood glucose levels must be monitored and medication administered at the proper times. Unfortunately many homeless individuals have no way to test their blood glucose levels to properly time insulin doses (Davachi & Ferrari, 2012). Additionally, traditional insulin must be kept cold, and many homeless individuals do not have access to a refrigerator, let alone one that is safe from thieves. Insulin pens may be unrefrigerated for longer periods of time, but are more expensive (Selam, 2010). A study of homeless individuals in Toronto found that 16% had difficulty storing their medication in a place safe from thieves (Hwang & Bugeja, 2000).

Insulin also typically is administered through subcutaneous injection. Needles should be disposed of in sharps containers, which are not readily accessible to many homeless individuals (Wilk *et al.*, 2002). Also, shelters may not allow needles and syringes into their facilities. In shelters other shelter occupants may steal medications, or the medication may be kept in a locked area away from the individual so that they are unable to properly time their doses before meals or according to blood glucose levels (Hwang & Bugeja, 2000; Wilk *et al.*, 2002). Proper insulin dosing is important because improper or misinformed use of insulin can lead to diabetic ketoacidosis (caused by extremely high blood glucose levels where cells cannot import glucose

and thus digest fat, forming ketones and possibly damaging the body) or a hypoglycemic coma (caused by extremely low blood glucose levels) (World Health Organization, 1992).

### *Homeless diabetes management: Diet*

Blood glucose control through diet management is a lifestyle technique that is part of diabetes management. A lack of control over one's diet in the face of diabetes is a struggle that many individuals, regardless of living situation, experience (Davachi & Ferrari, 2012; Hwang & Bugeja, 2000). In Baltimore especially, nutrient rich food is difficult for about 25% individuals to find because of the proliferation of food deserts, as defined by lack of nearby stores with adequately nutritional food, lack of transportation, and relative poverty (Buczynski, Freishtat, & Buzogany, 2015). The American Diabetes Association (ADA) recommends that a meal for diabetics be composed of 25% protein, 25% starchy foods, and 50% non-starchy vegetables while the US Centers for Disease Control (CDC) recommend reducing intake of saturated fats, sodium, sugars, and overall caloric intake to manage diabetes (CDC, 2015a; ADA, 2015a; ADA 2015b).

Among low-income patients food insecurity, defined as unstable ability to access and buy safe and nutritious food, was significantly associated with poor glycemic control and poor feeling of control over one's health, (Seligman, Jacobs, López, Tschann, & Fernandez, 2012). Food insecurity in the entire pool of patients at four Massachusetts facilities was associated with poor diabetes control, and among those with poorly controlled diabetes in a Washington state study 47.4% were food

insecure, of whom medication in adherence was greater (Berkowitz *et al.*, 2015; Silverman *et al.*, 2015). The situation is magnified for the homeless population, as 81.2% experience food instability, making food insecurity more common than among even impoverished housed individuals (Lee & Greif, 2008). Data from the 2011 National Health Interview Survey shows that of diabetics in food insecure households, over 45% fail to comply with medication recommendations, cutting back (“scrimping”) more than food secure and marginally food secure diabetics (Knight, Probst, Liese, Sercy, & Jones, 2016). As a result of food insecurity, some individuals may turn to less expensive foods that are calorically dense, less satisfying, and not nutritious but high in fats, sugar, and refined grains, or exactly what diabetics are not recommended to eat (Drewnowski & Darmon, 2005).

A diabetes management diet is difficult to achieve when homeless. Even when individuals use food services; some meal services are found to not comply with standards of high fiber, many fruits/vegetables, low fat content set by the US Centers for Disease Control and Prevention (2015a) and American Diabetes Association (2015a, 2015b) (Sprake, Russell, & Barker, 2014; Davis, Holleman, Weller, & Jadhav, 2008). One study showed that even in transitional housing, achieving diet control poses challenges and some individuals even felt that the shelter diet contributes to chronic diseases and their symptoms (Davis *et al.*, 2008). In Toronto, 64% of homeless individuals (n = 50) found shelter food not conducive to diabetes management, with many starches, sugars, and fats to the detriment of fruits and vegetables (Hwang & Bugeja, 2000). In order to compensate for the poor quality of the meals, some chose to throw out food rather than eat it (Hwang & Bugeja, 2000).



A poorly controlled diet can increase the risk of lower extremity infection and a well-controlled diet can slow the progression of diabetes related complications such as neuropathy (Wukich *et al.*, 2014; Ang *et al.*, 2014).

### *Homeless diabetes management: Physical activity*

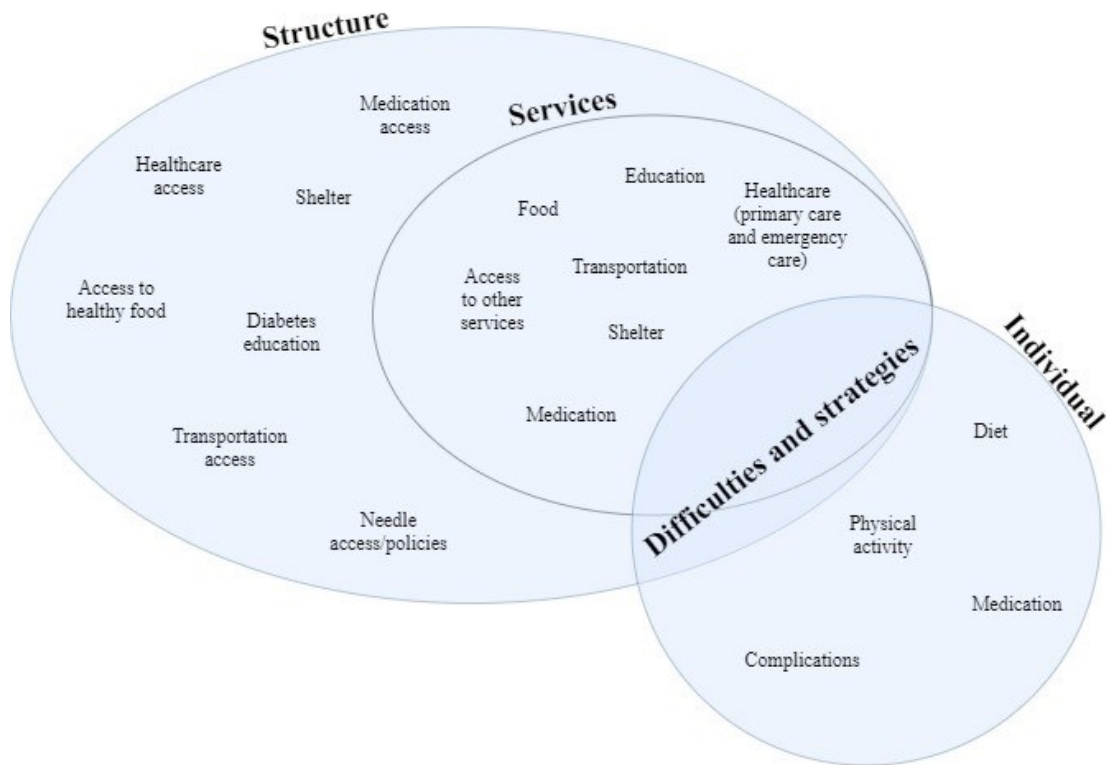
Another lifestyle modification to manage diabetes is an increase in physical activity. There is limited literature on physical activity as an illness management technique among individuals experiencing homelessness. Because homeless individuals are not uncommonly the targets of theft, concerns of theft while they are otherwise occupied may reduce motivation to increase physical activity (Lee & Schreck, 2005). Physical activity helps to reduce insulin insensitivity while also promoting a non-obese physique. In a study of the homeless populations in 11 cities, obese individuals were simultaneously more likely to be encouraged to increase physical activity by a healthcare provider and less likely to actually increase physical activity (Tsai & Rosenheck, 2013). This shows that while obesity is a risk factor for developing Type II Diabetes, it also is associated with a decreased likelihood of participating in this type of diabetes management. Studies suggest that chances of developing symptomatic and asymptomatic osteoarthritis of the knee increase with obesity (Coggon *et al* , 2001; Felson, Anderson, Naimark, Walker, & Meenan, 1988). Osteoarthritis can cause pain and contribute to the perception of incapacity to be physically active, which may also contribute to a failure to manage diabetes through physical activity for obese individuals (Hendry, Williams, Markland, Wilkinson, & Maddison, 2006).

## Diabetes related morbidity and mortality in homeless individuals

As diabetes progresses, it can damage many parts of the body by damaging blood vessels. Complications that arise from diabetes-related vascular dysfunction include blindness secondary to retinopathy, kidney failure, heart disease, stroke, and lower extremity amputation (ADA, 2014a; CDC, 2014b; Winters & Jernigan, 2000). Diabetes, in well-developed nations, is the leading cause of blindness and the progression of retinopathy due to diabetes is compounded by an increased risk of cataracts among the homeless, making homeless individuals particularly susceptible to losses in visual acuity (Congdon, Friedman, & Lietman, 2003; Pitz *et al.*, 2005). In 2010 adults with diabetes accounted for 73,000 lower extremity amputations which pose a large challenge for homeless individuals (Gregg *et al.*, 2014). Lower extremity wounds are difficult for homeless individuals to properly care for, as homeless persons often rely on their feet for transportation and do not always have clean socks or correctly fitting shoes to wear, thus making them more susceptible to complications such as infection (ADA, 2014a; Gregg *et al.*, 2014). Taking care of an amputation site poses its own problems similar to those posed by managing lower extremity wounds and managing diabetes medication. Amputations also limit movement of that individual to essential services, such as social services for job training and permanent housing.

## Chapter 3: Conceptual Model

### Conceptual Model of Structural Factors Affecting Diabetes Management



**Figure 1: Diagram of factors affecting diabetes management for individuals experiencing homelessness**

This conceptual model draws on themes of homelessness and Intersectionality and provides a framework by which to understand this study (see Figure 1). The structure that this study addressed included all factors outside of the individual experiencing homelessness, and it composed the context of their daily lives. The structure is composed of factors including healthcare access, transportation access, medication access, needle access/policies, access to healthy food, diabetes education, and shelter. This structure includes the social service structure of the area which is composed of all services provided by institutions, both private and governmental,

including provisions of education, food, healthcare, medication, transportation, shelter, and access to other services. At the intersection of the individual and the structure is the daily life of an individual experiencing homelessness. This study focused on the daily difficulties and strategies that were part of diabetes management for individuals experiencing homelessness. This conceptual model highlights the intersectionality present in the daily lives of individuals experiencing homelessness and diabetes simultaneously, exposing them to layers of disadvantage.

### *Term definitions*

(see Chart 1)

#### Structural context/characteristics

The structural context of individuals experiencing homelessness and diabetes is composed of all factors outside the individual. As part of this structural context, services provided by public and private institutions create a network that endeavors to aid individuals experiencing homelessness, a social services structure. The overall structural context includes policies that individuals are subject to, the rules by which they must abide, the physical environment they inhabit, and the service structure ( or lack thereof ) in individuals' sphere of travel. Structural characteristics as experienced by an individual include medication access, medication storage, access to healthy food, diabetes education, access to and policies concerning needles, access to transportation, and access to healthcare.

Medication and needle access as well as medication storage directly influence an individual's ability to manage diabetes with medication. Medication storage is directly influenced by shelter type, as many shelter facilities will not allow needles/vials into the facility without stipulations and theft is a factor both inside and outside such shelter facilities.

Medication access, healthcare access, necessity of designated physical activity time, and access to healthy food are all influenced by an individual's ability to transport herself/himself to the appropriate facilities.

Access to healthy food influences diet management, as it concerns the quality of charity foods (e.g. from shelters or soup kitchens) and the proximity of grocery stores with affordable prices. Access to healthy food is influenced by both shelter type and transportation access as some facilities may provide poor quality food and some grocery stores may be large distances away.

Availability of education has the potential to inform how an individual manages her/his diabetes. Diabetes education may be conveyed during healthcare encounters and is thus influenced by access to healthcare. Access to healthcare includes involvement in primary care infrastructure, proximity of care facilities, perceived stigma associated with accessing free healthcare, and emergency medical infrastructure utilization. Access to healthcare, especially at Healthcare for the Homeless, is important because often such facilities are the only ways for an individual without expensive medical equipment to monitor her/his progress in managing her/his diabetes.

Each of the above structural characteristics shapes an individual's range of possible behaviors, thus affecting how well an individual's diabetes could conceivably be managed.

### Services

The concept of "services" referred to services available specifically to individuals experiencing homelessness including provision of shelter, food, clothing, medical services, and education. Many services available to aid individuals experiencing homelessness may influence diabetes management by contributing to the structural context that individuals live in. Just as services available are diverse, so too are the effects they have on diabetes management through many avenues. Services available and the associated practices compose a large part of the structural context that individuals experiencing homelessness live in. These services help individuals experiencing homelessness cope with limited resources. Questions pertaining specifically to Services concerned use of services, problems in taking medications while using services, and critical thinking about challenges posed by services while managing diabetes.

### Healthcare access

Healthcare access specifically referred to involvement in primary healthcare, proximity of a primary care facility, perceived stigma associated with accessing available healthcare, and use of emergency departments. Healthcare access is a very complex question and should be addressed beyond this study's capacity in the future. Questions concerning this factor included use of Healthcare for the Homeless,

emergency department visits in the last year, hospital admission in the last year, and if and how often she/he visits a primary care doctor.

### Transportation access

Transportation access referred to difficulties in translocating, specifically the cost of public transportation and the existence of transportation infrastructure to include bicycle lanes and sidewalks. It also refers to physical difficulties in accessing transportation services and/or in autonomous translocation. Questions concerning this factor included those about getting around the city and if transportation affects the individual's diabetes (or vice versa).

### Medication access

Access to medication referred to ability to obtain a prescription, ability to access a dispensation establishment, and ability to pay for the medication. The question that directly addressed this factor inquires simply about if the individual can obtain her/his medication.

### Medication storage

Medication storage referred to an individual's strategies for storing her/his medication correctly even if it required refrigeration, ability to transport the medication, and ability to guard it from theft. Interview questions that directly addressed this factor include those concerning medication theft and storage.

### Needle access/policies

Access to needles and policies concerning needles included the ability to appropriate clean needles, how the individual stores her/his needles, if the needles are the subject of theft, disposal of used needles, social stigma and repercussions surrounding needle use, and police concern about needle use and possession.

Interview questions that addressed this factor include necessity for using needles, disposal strategies, problems posed by others when she/he takes medication requiring needles, and needle access/storage.

### Access to healthy food

Access to healthy food referred to the access that an individual has to foods deemed healthy and includes the quality of food offered at shelters, soup kitchens, and in donations as well as her/his ability to utilize grocery stores. Interview questions that addressed this factor include food access strategies, the quality of food accessed, and how/if the individual manages her/his diet in light of the food quality and quantity.

### Diabetes education

Diabetes education referred to the level of understanding that an individual has of diabetes, its management, and its consequences. This understanding may have been informed by healthcare provided information, pamphlets about diabetes, or participation in a diabetes support group as offered at Healthcare for the Homeless. Education concerning diabetes may have informed an individual's management and



behavior choices. Interview questions that addressed this factor include formal diabetes education and understandings of diabetes, its management, and complication associated with poor management.

### Shelter

Shelter referred to physical shelter, whether provided by a tent or other impermanent or not appropriate permanent use area, or use of a shelter facility specifically offered to individuals experiencing homelessness. There were no specific questions concerning shelter status, however when shelter services were referenced the interviewer followed-up with questions about difficulties pertaining to diabetes management that resulted from shelter status.

### Individual characteristics/behaviors

The structural context in which an individual lives greatly affects that individual's behaviors. Without access to healthy food, proper diet management is extremely difficult, just as without access to medication, access to needles for administration, or the ability to store it correctly, management with medication is virtually impossible. Complications of diabetes and other underlying conditions can affect an individual's ability to be physically active but a lack of transportation, or inability to access the available transportation, may require that she/he walk to her/his destinations. In this way, services available are able to exert an extreme amount of influence on an individual's ability to properly manage her/his diabetes.

### Medication

Medication referred specifically to use of medication as a diabetes management strategy. It encompassed medication storage and compliance with dosing amounts, times, and routes as well as conceptions concerning the use of medication. Questions pertaining to individual factors of medication included questions about route through which the participant took the medication and if she/he took it at the recommended times.

### Physical activity

Physical activity referred to use of exercise as a behavioral strategy for managing diabetes. It referred to efforts towards or inability to exercise. It also encompassed discussion on the built environment (e.g. parks) that impact physical activity. Questions pertaining to individual factors of physical activity included perceived importance of physical activity to the participant's diabetes management as well as exercise habits.

### Diet

Diet referred to use of diet modification as a behavioral strategy for managing diabetes. It referred to any modification of diet to achieve/maintain glycemic control including eating only small portions of specific foods, eating only specific foods, or eating at specific times. Questions pertaining to individual factors of diet included those about what compromises the participant needed to make when eating as well as

follow-up questions to referenced difficulties the participant encountered when obtaining or eating food.

### Complications

Complications referred to physical conditions that result from poor diabetes management. These complications include manifestations of vascular dysfunction (e.g. retinopathy, kidney failure, heart disease, stroke, and lower extremity amputation (ADA, 2014a; US, 2014; Winters & Jernigan, 2000). Complications may be the first sign of diabetes for those that do not utilize primary care. Questions pertaining to individual complications included follow-up questions as to if the participant had ever experienced any complications they associated with poor diabetes management.

### Perceived diabetes management

Perceived diabetes management referred to an individual's perception of the effectiveness of their diabetes management techniques. Perceived diabetes management may affect future actions an individual chooses to take in relation to diabetes management.

Diabetes management is one's ability to maintain glycemic control which disallows or slows damage to an individual's tissues. Management is achieved via behavioral modifications, diet and physical activity, and by taking medication in the proper dosage at the proper times after storing it properly. Proper management through these techniques demands a balance of time and effort, which limits time available for other pursuits. Improper diabetes management may lead to

complications such as polyneuropathy, retinopathy, prolonged flesh healing processes, and lower extremity infection (ADA, 2014a; US, 2014; Winters & Jernigan, 2000). Major complications may lead to more difficulty while exercising and transporting oneself, which in turn affects other aspects of management. Each of the three management techniques is the responsibility of an individual to balance and maintain, but individual action is subject to constraints. Questions pertaining to received diabetes management include an inquiry as to whether the participant felt their diabetes was well managed and why this was so.

## Conceptual Model Term Definitions

Structural Factors	Definition	Questions Addressing Factor
Diabetes education	Healthcare provider information Pamphlet Diabetes group Understanding-level of diabetes and management/consequences	What can you tell me about what diabetes is? Have you had any education about diabetes? What does diabetes management mean? What might happen if your diabetes is not well managed?
Access to healthy food	Quality of charity (shelter, kitchen, donated) food Grocery stores (locations/prices)	Can you tell me about your diet? What is the food like? Do you try to watch what you eat because of your diabetes?
Needle access/policies	Access Storage/robbery Disposal Social stigma surrounding needles Police concern about needles	If you use insulin, how does using needles affect your life? Do you ever have problems with your medications while using services?
Medication storage	Robbery Refrigeration Transportation	How do you store your medication?
Medication access	Pharmacy access Prescription problems Payment problems	How do you get your medication?
Healthcare access	Primary care involvement Primary care facility proximity Perceived stigma associated with accessing healthcare Emergency care	Do you see a primary care/regular doctor? More or less often than emergency departments? What do they help you with in terms of diabetes management?
Transportation access	Cost of public transportation Transportation infrastructure (bicycle lanes, sidewalks)	What do you do in a typical day? Does transportation affect your diabetes?
Services	Any public service geared specifically towards aiding the homeless/impoverished and its interactions with the above factors	What services are around this area? Do you ever have problems with your medications while using services? What services do you typically use? What advice would you give to someone about using the services to someone who has not been diabetic for long? Why do you come to HCH?

Chart 1: Summary of terms, their definitions, and questions concerning them

## Chapter 4: Methods

### Methods of data collection

This cross-sectional study examined homeless individuals of all genders who have experienced homelessness, as defined by USDHUD (2015) to include broader living situations, and diabetes simultaneously for at least 1 year. Open-ended interviews were used to gather information about these individuals' lives.

Participants were recruited and interviewed in the Healthcare for the Homeless (HCH) Baltimore facility on Fallsway over two weeks. HCH is a federally funded initiative to treat homeless individuals. It strives to remove many barriers to healthcare access by encouraging utilization and engagement with outreach initiatives, client driven change through Consumer Advisory Boards, and medical respite care for those discharged from hospitals but not well enough to manage alone (Zlotnick *et al.*, 2013). HCH also offers case management services which are able to help clients navigate the proper avenues in accessing available social services. Located near two separate service facilities operated by Catholic Charities of Maryland, Our Daily Bread and the Weinberg Housing and Resource Center, HCH Baltimore is uniquely positioned to serve homeless individuals accessing this service facility rich area. Recently, HCH Baltimore has partnered with Bon Secours Hospital in West Baltimore to establish a temporary clinic in anticipation of establishing a more permanent facility that is able to reach individuals on the west side of the city.

To be eligible for participation, a person needed to have several characteristics: be over 18 years of age, speak English as their primary language, have been simultaneously homeless and living with diabetes for at least 1 year, and be currently prescribed medication for diabetes treatment. Potential participants were passively recruited from the second floor lobby area. HCH Baltimore administrators selected this location because it ensured building security by requiring potential participants to have already passed security and because it was close to the interview room. This recruitment method posed several challenges, among them a possible overrepresentation of individuals seeking compensation while sharing limited experience. HCH employees distributed information about the study to their clients who meet participation criteria, but they did not take any active part in recruitment itself. This means that participants were not be filtered through HCH employees, thus contributing to the risk of recruiting individuals with limited experience to share. To mitigate the effects of this recruitment challenge, the recruiter sat at a desk in the waiting area with a sign inviting individuals to come speak with the researcher that did not specify compensation (see Appendix C).

Potential participants needed to demonstrate acceptable alertness and orientation as well as acceptable capacity to hear, understand, and respond to questions asked by the researcher. They were read the consent document (see Appendix D) in a private room on the second floor of HCH Baltimore and were given a copy of their own to follow and keep. The potential participants were given ample time to ask any questions about the project.

Participants needed to correctly answer one question about the consent document asked by the researcher (“When can you decide to stop participating?”). As this study posed minimal risks and those risks were largely derived from breach in confidentiality, participants gave oral consent; they were asked to state that they have been given ample time to ask questions and would still like to participate. This statement was recorded in the same audio file as their interview, which began promptly. This consent process ensured that no identifying information was collected and thus minimized risks of participation.

The semi-structured interviews were estimated to take about 60 minutes, but only a single interview actually reached and exceeded this time. Each participant was asked a base set of questions, but as they answered these questions the interviewer probed them further into their answers, thus not all questions were asked of all participants. Questions explored conceptions of diabetes and its management, management strategies, and challenges experienced in managing diabetes. Throughout the interview participants were encouraged to talk about anything they deemed relevant to the topic, but few actually took the invitation to speak freely without question prompts. This semi-structured interview approach facilitated exploration into the topic. Each participant was compensated with \$20 cash after completion of the interview.

Each interview was recorded, transcribed by a professional transcriber, and verified for errors. Following coding by the researcher with Atlas.ti, major themes were extracted with code based and question based analysis (see “Methods of



Analysis” below). This project was approved by the UMBC Institutional Review Board.

### *Methods of analysis*

Analysis took place after thematic coding. A professional transcriber transcribed the interviews and resultant transcriptions were verified for accuracy by the researcher. The unit of analysis in this study was the structure in which individuals live, not the individuals themselves. This study gathered information from interview participants about how the structure they live in affects their efforts to manage diabetes. This study did not analyze the entirety of each participant’s life in a narrative fashion and did not examine how their identities affected attempts of diabetes management. The researcher then managed and analyzed the data with the assistance of Atlas.ti, a qualitative data management program. Coding was iterative and augmented by analytic memos kept throughout the coding process. Analytic memos tracked coding processes and emergent patterns (Saldaña, 2013). Coding was informed by the literature review and was partially open, or inductive, to allow for exploratory analysis of the structural factors that affected participants’ attempt to manage diabetes (Bernard & Gravlee, 2015; Saldaña, 2013). The codebook consisted of 55 codes that were queried in combinations to reveal patterns and themes (see Appendix E).

## Chapter 5: Findings

This chapter will primarily address the structural difficulties that participants faced in trying to manage their diabetes, followed by social service efforts to eliminate or reduce the effects of these difficulties. It will, as part of the presentation of social services, consider how their efforts did not reach full potential in reducing the previously discussed difficulties. This study was designed to focus on the difficulties that participants faced, and through this exploration strategies for circumventing these difficulties arose as well. Throughout these sections, the analysis will examine the strategies that participants employed to minimize difficulties they face. In the discussion this paper will examine how these strategies highlight participant perseverance in managing their diabetes.

### Demographics

<b>Participant Characteristics</b>	
<b>Female</b>	7
<b>Ethnicity</b>	
<i>African American</i>	10
<i>White</i>	3
<i>Latino</i>	1
<i>African</i>	1
<b>Age (years)</b>	22-74
<b>Months homeless</b>	18-300
<b>Months diabetic</b>	2-264
<b>Type II diabetes</b>	14
<b>Have insurance</b>	13
<b>Health status</b>	
<i>Poor</i>	2
<i>Fair</i>	6
<i>Good</i>	5
<i>Very good</i>	2

**Table 1: Select participant characteristics. Note uncertainty in type of diabetes (four participants) and insurance status (two participants)**

Each of the 15 participants was assigned an arbitrary pseudonym for ease of discussion, but their accounts have retained their integrity except where identifying information was given. Their pseudonyms are Althea, Bernard, Cindy, Diane, Elaine, Fabian, Gertrude, Helen, Ian, Joe, Kaden, Leonard, Michael, Nancy, Oscar. The 15 participants were recruited over a period of several weeks. One participant, Kaden, did not fit the inclusion criteria, having been diabetic for only two months, which was revealed over the course of the interview. The inclusion criterion for at least one year living as a diabetic was designed to ensure relevant experience with the topic of study. Because the unit of analysis for this study was the structure that participants live in, and not the participants themselves, Kaden's data has been retained and analyzed with the rest of the data because he brought valuable experience to the study. His experiences not only corroborate others' but also further develop findings. This suggests that the inclusion criterion for at least a year living as a diabetic was more stringent than necessary.

Of the 15 participants, seven were female, 10 were African American, three participants were white, one was African, and one was Latino. Participant age ranged from 22 to 74 years old (average: 49 years) (*see Table 1*).

Participant experience varied greatly, as a result of their varied total time homeless and diabetic. Participants experienced homelessness for a range of durations, from 18 months to 25 years (with an average of 75 months). They also were diabetic for a range of durations; total time elapsed since diagnosis with diabetes ranged from two months to 22 years (with an average of 92 months). Of the 15 individuals, four were unsure or unclear about their diagnosis but 14 stated they had

Type II diabetes. Elaine is the only participant who clearly stated she has Type I diabetes. Additionally, two participants were unsure or unclear about their insurance status, but 13 individuals stated they had insurance. It was unclear what type of insurance the participants had, as the questions inquired as to whether they had insurance and not what type. Perceptions of health ranged from poor to very good, with the majority stating fair (6) or good (5) health and the remaining four evenly divided among poor and very good health. Of the 15 participants, five were in permanent housing, one was in transitional housing through a drug recovery program, two referenced using shelters, and 5 were sleeping outside. The remaining two, Joe and Ian, did not specify their living situations. For the purposes of this study, the term “unhoused” refers to those not in permanent or transitional housing and encompasses six participants: Bernard, Kaden, Leonard, Nancy, and Michael. The then permanently or transitionally housed participants (Althea, Cindy, Diane, Fabian, Helen, Oscar) were asked for focus on the times that they were homeless for the purposes of the study, and the housing status for their answers is indicated if not reflective of their current status.

### Difficulties

Homelessness is defined as a lack of permanent residence or unstable housing conditions and the risk of experiencing homelessness is significantly greater among those with low incomes (Link *et al.*, 1994). The data collected shows an overall trend of low incomes not only reducing options for diabetes management but also forcing participants to be flexible with their management routines. This flexibility was forced

upon participants in a variety of arenas through a plethora of ways, but most prevalently through processes of instability. This finding does not reflect what was presented in the conceptual model, but as this study is exploratory in nature the conceptual model does not need to constrain this analysis. In response to difficulties, participants used strategies designed to help manage their diabetes that may first seem irrational, but when taken with structural difficulties are reasonable and rational.

Many difficulties that participants faced in trying to manage their diabetes resulted from the housing instability that accompanies homelessness. Effects of instability were both direct, through destabilizing individuals' food and medication routines, and indirect, through creating time and money constraints. Other difficulties arose from societal and city structures with limited effective scope such as the primary healthcare system and food provision. This section will first examine instability, its direct and indirect influences, followed by a discussion of the larger societal structures, healthcare and food provision, that exerted influences on the participants' diabetes management.

### Structural instability

Instability permeated many aspects of the lives of unhoused participants via housing insecurity and low incomes, most notably medication and food routine instability. There is a fine distinction between direct and indirect influences: direct influences immediately prevented or impeded participants' ability to follow healthcare recommendations while indirect influences diverted resources that would allow the participant to follow healthcare recommendations. Thus, as will be

presented below, circumstances such as food instability exerted both direct influence, by influencing the purchase of foods, as well as indirect influence, by forcing participants to take time looking for food, on diabetes management. In other words food instability is both a cause and an effect of structural instability.

### **Direct influences of instability**

#### *Medication instability*

Homelessness and low income status posed serious direct challenges for participants in unexpected aspects. For instance, there were only two references to difficulties in medication access due to expense while there were two primary challenges in medication storage; theft and cool storage issues for those prescribed insulin. The strategies for addressing these challenges made it more difficult for participants to adhere to medication recommendations to varying degrees, another instance of forced flexibility due to limited resources.

Cool storage posed a challenge for the majority of the eight participants who were prescribed and receiving insulin. Insulin manufacturers recommend that opened insulin vials be kept cool, absolutely no hotter than 86 degrees Fahrenheit, and out of direct sunlight in order to stay safe and effective (NovoLog® Storage, n.d.). Ideally, those with insulin store it in a refrigerator, as unopened vials must be kept below 46 degrees Fahrenheit (NovoLog® Storage, n.d.). Most of who that referenced challenges with cool storage of insulin contrasted refrigerator access that housing would give. In light of this, medications often were stored in non-refrigerated ways, which poses risks other than reduced effectiveness and safety: Oscar describes some problems associated with such a storage scheme:

“One time, I dropped my insulin out the hole in my bag- it broke.” – Oscar

By carrying his insulin in his backpack, Oscar shows one modification he was forced to make to manage his diabetes. His strategy went against recommendations to keep his insulin cool and also ran the risk of losing his medication altogether if the integrity of his bag was compromised, but given his circumstances was reasonable. Others stored their insulin in their pockets or, in Leonard’s case, his tent. The exceptions to this were Gertrude, who used an insulin pen, as well as Cindy and Helen who were housed and had access to a refrigerator.

To overcome the challenge of keeping insulin cool without a refrigerator, participants used two innovative strategies. Oscar, having experienced the above discussed difficulty and faced with a lack of refrigerator access, learned from “some old man” how to put his insulin in a filled water bottle to keep it cooler than ambient temperature. Bernard, always wary of thieves and concerned about the heat of summer, would conceal his insulin for the day:

“...I would leave it somewhere dark where – see if it stays dark, it still stays cool....and you see a little small tree where the shade at somewhere, you can stick it right there ‘cause it’s cooler up in the rocks and bricks.” – Bernard

Bernard would try to find a cool spot to leave his insulin and attend his other needs during the day. This particularly innovative solution to medication storage challenges

means that he was not able to take his prescribed mid-day dose, but was able to take his morning and evening dose and store his medication in a somewhat cooler way than a pocket offers. Because insulin is supposed to be stored at temperatures below 86 degrees Fahrenheit and because the human body is quite a bit warmer than that, storing insulin in a pocket may well render the medication ineffective (NovoLog® Storage, n.d.). Oscar had a particularly difficult time storing his medications, challenged by storing even more stable medications.

Most participants were prescribed diabetes management medication in the form of pills. While pills are not recommended to be kept refrigerated, their storage still poses challenges. Participants' pills were often stored in backpacks or pockets for the unhoused participants and in a designated area of the house for the housed participants. Carrying pills in bags poses problems similar to carrying insulin in bags. Oscar, again, brought up important points:

“Carrying it around in your bag and stuff, that’s not a healthy way to carry your medicine around. And then sometimes it rains, so your bag gets wet, your pills get wet.” –Oscar

In this quote it is unclear what Oscar was basing his assessment of “healthy” on, but it is clear that he saw carrying pills in his bag as less than optimal. Carrying medicine in his bag exposed it to the elements, which had the potential to compromise the efficacy, safety, or palatability of the medication, but given his circumstances, again, it was a reasonable strategy. He did not indicate what would be a more “healthy” way to store his medication.



Another potential danger of storing medications in bags lies in the potential for theft. Theft can be seen as the result of a failure to securely store medications. Multiple unhoused participants expressed this concern while none of the housed residents did. Bernard was sleeping outside, having cited the risk of theft in shelters too great:

“Cause you close your ears, someone gonna bust your head and take everything you got.” – Bernard

Bernard was particularly attuned to the risk of physical harm and theft, but he was not the only one: four of all 15 participants, unsolicited, referenced medication theft as a concern. With the shelter instability inherent in homelessness, though, finding a place to safely store medications is a challenge. This particular challenge was met with a strategy that, while not necessarily conducive to medication adherence, keeps medication safe. Three participants who were “sleeping rough” sent their medication to be stored at a family member’s house. Kaden received medication and stored it for later:

“I give it to my wife...[she] put it up for me...because I don’t have no way- I’m homeless so- they steal medicines around here.” – Kaden

Kaden, knowing that medications get stolen, specifically sent his medication to be stored by his wife. Kaden also revealed that he did not in fact take his medication, making this strategy a feasible solution to theft while not promoting his diabetes

management. This strategy shows that Kaden was forced to compromise his diabetes management as a result of theft.

### Food instability

Diet is an important part of diabetes management and overall health. Food instability, defined as unstable ability to access and buy (attain) safe and nutritious food can threaten the careful balance that diabetes management dictates (Seligman *et al.*, 2012). Homelessness and related shelter instability contributed to participant food instability. These factors specifically prevented participants from cooking their own food, storing food, and controlling when they ate.

The issue of cooking food was very apparent in discussion surrounding food instability, and is also very prominent in discussions of why housing is preferable. It characterized the food instability that many of the participants experienced while highlighting larger issues surrounding healthcare recommendations. For instance, Elaine, when asked about how her eating habits differ from an ideal diabetes management diet replied:

“It’s different because you don’t really have a place where you utilize the kitchen, where you’re cooking your own meals.” – Elaine

Here Elaine was saying that her ideal diabetes management diet was not entirely attained, a result of her unhoused situation. Because she is not able to cook her own meals, she was not able to totally control what she ate, and as a secondary factor,

when she ate. This is important because diabetes management requires tight control of what an individual eats in order to reduce increases in blood glucose.

Food storage can help mitigate food instability by allowing an individual to take advantage of a surplus of food when it is available. This surplus came most often from food pantries and in one case a church, as will be discussed below. The unhoused individuals did not reference successful food pantry use, and Elaine also exemplified this by bringing up food storage problems:

“Even though they have food banks and stuff, it’s really hard because you have nowhere to store it.” – Elaine

Thus, even after she found food of acceptable quality in surplus, it was very difficult for her to gain any temporary stability because she was not able to store the surplus. The only participants who talked casually about storing food were Althea, Cindy, Diane, and Helen, who were all housed. Diane was an especially avid food saver, which served to reduce periods when she has no food:

“Because I don’t like to waste food. It’s the initial meal, sandwiches, salad, and soup.” –Diane

Like Diane, other housed participants talked about cooking large meals and eating leftovers at a later time as well as storing food prior to cooking it. This allowed them to enjoy a level of food stability that their unhoused counterparts did not, as they were able to not waste food and thus enjoy it later while also saving the cost of buying more food immediately. The freedom to store food would have allowed for a more

regular and less time-consuming food routine, freeing an individual to address other needs with the saved time. For those without housing, food storage posed a unique challenge that Gertrude was able to meet by relying on a family member. Similar to the strategy of storing medication at a family member's house discussed above, Gertrude stored food at a family member's house:

“Sunday they're giving out some biscuits, cookie, and banana,  
and orange...I will go take it to my storage...where my son is.”

– Gertrude

Gertrude was able to take advantage of the plentiful food opportunity because she was able to store the food with her son. She was thus able to provide herself with dinner for up to a week and avoid the endangering situation of having no food that food instability can lead to without spending her limited funds on pre-prepared food.

Expense was a particularly salient issue when examining food instability; it was directly referenced as a challenge to participants eating what they deemed appropriate food, or eating at all. Fabian, who was housed, suffered difficulties with food expense

“I don't eat too much. I only eat one time in the morning or one  
time in the night. That's it. If you got money, you will eat fine,  
but if you don't have money...” –Fabian

Fabian ate only once per day and still struggled with foodless periods of up to three days approximately six times over the course of a year. He was not alone in this

experience, as both Diane and Helen referenced several days with no food when they were homeless and Bernard, Cindy, Gertrude, Joe, Kaden, Leonard, Michael, Nancy, and Oscar referenced slightly less extended periods of no food, while four of the remaining participants referenced general hunger and insufficient food quantity. Out of 15 participants, all but a single participant, who was housed, suffered from inadequate food quantity and subsequent hunger at some points and with varying frequency. In a life where it is difficult to obtain enough food to satiate oneself, healthcare recommendations ask for selectivity in what diabetic patients eat. It is unclear what participants did eat, either because their answers would change as follow-up questions were presented or because their answers were vague. Vague answers, such as “just healthy” or “whatever I get” may have been due to a poor memory or a general lack of pattern to the foods they eat.

#### **Indirect influences of instability**

The instabilities discussed above led not only to challenges that stood directly between participants and their management techniques, but they also posed challenges more peripheral to management behaviors. These indirect challenges were posed by competing needs. These competing needs can be understood as “either-or” situations where the participant had to choose to either manage their diabetes or address another need. As each individual is faced with different challenges, the intersection of their different challenges formed unique barriers to diabetes management. These needs had the potential to occupy both the time and the money of participants trying to manage their diabetes, but also to completely distract them from diabetes management altogether or motivate a willful disregard of it. The most

prominent competing need was hunger. The distinction between time consumers and money occupiers, or fund diversion, is not always clear, thus they will be addressed together.

### Hunger

Hunger, as described above, was experienced by almost every single participant. Six participants explicitly stated that when they are hungry they eat whatever they can, regardless of quality or quantity. Ian struggled to manage his diabetes especially in the winter when he didn't get enough food:

“If I'm hungry, I'll eat it anyway, even though I'm not supposed to.” – Ian

Ian's hunger was able to take priority over what he understood was appropriate diabetes management through diet. He was not alone in choosing his hunger over diabetes management: Bernard, Gertrude, Nancy, Oscar, and Fabian all agreed that hunger takes precedence. Bernard suggested that perhaps going against general health recommendations, not just diabetes management recommendations, was a possibility:

“Cause sometimes you wake up at nighttime, it's like your stomach is taut to your back. I ain't been that bad to eat out of trashcans. But I never say I might never do it.” – Bernard

Bernard's description of his hunger, a hunger that woke him up at night, puts diabetes management in perspective: when someone is so hungry they consider eating out of trash cans, they may find it difficult to justify being selective about food. In this

particular case, hunger had the potential to take precedence over good hygiene practice.

Hunger has heretofore caused indiscretion in what participants decided to eat. Joe had the opposite problem; his discretion caused his hunger. Interestingly, Joe sometimes didn't get enough to eat, especially in the evenings, because of his management:

“[Not enough to eat] ‘cause my dietary limitations force me.” –

Joe

Joe presented a contrasting case to the argument of hunger as the cause of lapses in diabetes management because his adherence in diet management is what led to his hunger. The implication is that if he wasn't limiting what he ate to manage his diabetes that he would be less hungry. Food instability led to more than hunger, as inadequate food quantity spurred quests for food, which took time and/or money.

#### *Time and money*

Competing needs that posed challenges requiring participants to divert time and monetary resources were very diverse, ranging from school and transportation to heating and substance use. These competing needs did not uncommonly completely distract the participants from their diabetes management.

Food and shelter instability, while discussed above as direct challenges to diabetes management also pose indirect challenges. Bernard, as someone sleeping outside, lived a particularly unstable situation:

“You know, you walking around, trying to figure out where you’re gonna eat, what you’re gonna get...” – Bernard

Bernard needed to take the time to find a source of food, and later discussed finding a place to sleep, “some little hole” for the night and how poorly he normally slept. The time spent looking for a place to sleep and a place to eat was necessary for Bernard to survive.

Both Gertrude and Helen were taking classes. Enrollment in classes posed different challenges for Gertrude and Helen: Helen’s classes, along with her drug recovery program, occupied her time while Gertrude’s school, being geographically removed, consumed time for transportation as well as money for the classes:

“If you pay for more, you can go. But I don’t have money, so I’m paying for one course.” “Two buses. Like yesterday, I waited for one hour thirty minutes” – Gertrude

Gertrude struggled to pay for school, but it was important enough to take priority over other needs that would demand money, such as alleviating her food instability. Her travel to and from school relied upon the Maryland Transit Administration (MTA) bus system. Throughout her interview she emphasized that MTA busses to both took inordinate amounts of time and also stressed her few funds. Indeed, during her interview she stated that she would need to borrow money from her son for that month’s bus pass.



The time it took to travel using MTA services was paired with sometimes prohibitive cost. While Gertrude, Oscar, and Kaden reported inconvenient wait times or transport times, Michael, Helen, Oscar, and Gertrude all reported prohibitive cost of transportation. Cindy was able to use MTA Mobility, a service provided to disabled individuals to promote mobility:

“The thing is that you’ve got to have money to pay transportation...with Mobility I pay...If I ain’t got money to get here, it is a difficulty.” – Cindy

Without money, Cindy could not get to her destination, as she had severe difficulty walking. The money used for transportation could have been used elsewhere, such as to alleviate her food instability, however transportation was important enough that she pays fare to use MTA services. Helen struggled once having boarded MTA buses, unable to transport her groceries due to space constraints. Joe also struggled with buses; because of his limited mobility it was difficult to move through throngs of people. In Baltimore there is a free public transit program called the Charm City Circulator. Its geographic scope is limited, which prevents Oscar from using it, but Nancy has successfully used it to access food resources.

One prominent way that participants skirted the challenges posed by transportation was walking. Walking was rarely referenced as a form of physical activity that participants used to manage their diabetes, but many did walk to their destinations. Walking required no fare, however six participants experienced pain with physical activity and an additional two had trouble walking due to strokes. These

difficulties further hindered travel to other parts of the city. One participant who experienced pain, Michael, had a swollen leg at the time of his interview:

“Diabetes ...makes my life very difficult...so that’s like the swelling of my leg where I can’t really get around.” – Michael

Michael’s swollen leg was impeding his movement, and he was under 30 years old which means that the majority of participants were older than he was. His inability to “get around” contributed to his assessment that he did not arrive at his travel destinations a full 70% of the time. Such a high failure rate may have contributed to his food instability; three times in a week he does not have enough food. The problems of fund diversion and difficult strategic solutions to a challenge are not unique to schooling and transportation.

Ian, as discussed earlier, struggled to have enough food in the winter. This is specifically because of fund diversion to combat the winter weather:

“Well, you gotta keep warm..just trying to stay warm, you’re not even thinking about eating, just staying warm. It’s better than freezing to death.” – Ian

Because Ian needed to keep warm, he consciously made the decision to fund heating instead of food. Without eating, he was hungry and faced the exact problem seen above; eating things regardless of whether he should. Indeed, he reports not even thinking about eating. A distraction such as this from diabetes management was not uncommonly caused by competing needs not limited to heating.

Substance use, either drug or alcohol, was explicitly reported by six participants, and Elaine stated a 32 year duration of interrupted drug use. These six participants all explicitly made the connection between substance use and neglect of diabetes management. Diane exemplified this neglect:

“I was just ignoring it. I know why. ‘Cause I was using at the time.” – Diane

Because she was using drugs during the referenced time she ignored her diabetes, preoccupied with other priorities. Bernard specifically also struggled with managing his health during his time of drug and alcohol use, instead worried about surviving until the next day instead of the long term effects of his failure to manage his health. Interestingly, Helen associated “getting clean and sober” with an exacerbation of her diabetes, specifically because of her subsequent weight gain, as opposed to an opportunity to start managing her diabetes.

### Societal structures

#### **Primary healthcare system**

Only one participant stated that she had a primary healthcare physician at the time she was diagnosed. It is unclear if any of the other participants had primary care physicians when they were diagnosed, but it is apparent that they did not benefit from the advances in diabetes screening that effective primary healthcare would have provided. Of the 10 participants who discussed how they were diagnosed, six of them discovered their condition through an emergency department. Multiple participants

were in the ED for trauma (e.g. car accidents and gunshots), and Oscar's diabetes actually was likely the result of, or at least exacerbated by, a gunshot wound that destroyed his pancreas. Several participants were in the ED for medical conditions that may well have been partially the result of unchecked diabetes such as stroke, ulcers, and fevers. Nancy, the only participant who referenced having a primary healthcare physician when she was diagnosed, was not one of the six who were diagnosed in an ED. Of the remaining four participants who discussed their diagnosis, two were in jail at the time.

### **Food provision**

Participants faced a number of challenges to diabetes management, as seen above, which include expense and transportation challenges. These challenges made it difficult to find effective strategies addressing the challenge of the unhealthy food provisioning structure in Baltimore City as discussed by Buczynski, Freishtat, & Buzogny (2015). Both Oscar and Althea were living in permanent housing, so had kitchens to cook in. Althea needed to get her food from a nearby suburb:

“I gotta go to the stores out-like in Columbia where I go to daycare.” – Althea

Even though Althea had the most secure food situation of all the participants, she needed to travel outside of the city to access the food she bought. This travel took time and monetary compensation, which could have been used for other priorities. Similarly, Oscar knew of no grocery stores that were close to the Healthcare for the

Homeless Baltimore, Fallsway facility, and because he had neuropathy in his feet it was sometimes difficult to walk.

As a strategy to combat the lack of sources for other acceptable food, Diane, Fabian, and Gertrude all bought prepared food. Diane frequented Lexington Market, Fabian ate Subway sandwiches, and Gertrude bought food from establishments close to her school. It is important to note that both Diane and Fabian were also housed and thus had kitchens in which to cook, and also cited expense as a factor in accessing food. In contrast to such stark food access challenges, every participant used social services as a strategy to access food.

### Reactions to difficulties

The difficulties that participants experienced caused different reactions in participants related to diabetes management, but the vast majority of participants were either permanently housed or seeking housing. Housing was conceptualized as stability with relative control and in direct contrast to homelessness and its instabilities. Participants weren't explicitly asked about housing, but the interview data show that participants have different understandings of housing as stability: to help with food security and adherence (Althea, Diane, Elaine, Helen, Oscar, Bernard, Gertrude), time maintenance (Gertrude, Cindy, Helen), medication adherence (Helen, Michael), and creating an exercise plan (Gertrude).

A prominent theme throughout the interviews was the idea of perseverance in terms of diabetes management: "you gotta do what you gotta do." This phrase embodied the attitude that participants had about the difficulties they faced and the

strategies they developed in response to those difficulties, which given the structure they lived in were reasonable. Out of 15 participants, nine stated this specific quote explicitly or implicitly. Some found the strength to persevere through religion, as did Cindy, Diane, and Gertrude. For Gertrude there was a particularly strong relationship between diabetes management and religion:

“I add prayer...telling God to cure the sickness because ...my body is where God lives. The sickness gonna go out so that God will have enough room in my body.” – Gertrude

Gertrude’s relationship with God helped her manage her diabetes by motivating her to keep her body well for God’s inhabitation. She also said that God keeps her from dying when she eats something she is not supposed to. This allowed her a certain level of comfort with her condition, stating that it is not an important part of her life, even while continuing to manage her diabetes well. Faith as a motivation parallels other themes in perceived strengths; participants not infrequently explained intangible, non-behavior, things as their strengths, thus showing their motivation for perseverance. For instance, Joe managed his diabetes because he wants to stay alive and Michael wanted to be strong for his children.

While some family members or friends provided motivation to manage diabetes, others took action to help a participant by teaching them (Bernard, Elaine), storing food/medication (Gertrude, Kaden, Leonard, Michael), or administering medication (Cindy). In other cases, family hindered participants by, in Ian’s case,

causing his homelessness and in Nancy's case distracting her from eating. Specific actions of family members are described throughout this entire Findings section.

### Services

With the motivation to persevere, participants developed multiple strategies to avoid or reduce challenges as described in the Difficulties section and as will be discussed below. The primary strategy was asking for help and using services to access needed resources. Services provide resources and services that combat some of the difficulties discussed above. The interviews revealed that while many services might have a primary function they practice well beyond the scope of that function. This section is thus organized based on resources provided by services as opposed to specific individual services. Resources provided include: education, food services, healthcare services, medication services, transportation aid, shelter, and access to governmental services.

### **Education**

Education about diabetes and diabetes management is important for empowerment and effective diabetes management: it is impossible to effectively manage diabetes without knowledge of how to do so. Services were directly referenced by Althea, Gertrude, Diane, Joe, and Leonard as sources of education through classes or support groups. Services were also reported to be providing education through healthcare practitioners (including doctors, nurses, and nutritionists) by the majority of participants. Only three people, Fabian, Diane, and

Michael, referenced pamphlets or papers as helpful, and Ian explicitly stated that he received them but never read them.

Questions focusing on education level and responses to other questions revealed a trend of basic understandings of what management behaviors were, such as taking medication, diet management, and physical activity. There was little understanding of the underlying mechanisms of diabetes and the specifics of management behaviors. In other words, participants knew what they were supposed to do but not always why. For instance, Fabian was very fastidious about his diabetes management and always listened to what healthcare providers recommended:

“What I do best-whatever they tell me I have to do, I do.” –

Fabian

Fabian did all that was asked of him, but when questioned about what type of diabetes he had he was unsure. He also was unable to name a single long-term consequence of prolonged poor diabetes management. A similarly minimal understanding can be seen with medications as well: only Gertrude and Elaine (out of nine participants prescribed insulin) explicitly stated that they refrained from taking their medication when they didn't have any food. Of all participants, six participants identified starch and six identified fried foods as food items to avoid and identified as target foods fruits/vegetables (eight participants), or just general “healthy foods” (two participants). It is important to note that participants did not take a knowledge test, so there is no definitive data about their knowledge of diabetes or diabetes management.



This means that comparing participants' knowledge about diabetes with that of another group of people is not appropriate for this study.

In terms of the mechanisms of diabetes, the best understanding was seen in experienced diabetes consequences such as neuropathy, stroke, headache, lethargy, frequent urination, and bleary eyes. Participants were able to name their experienced physical complications and took steps to manage them. Nancy often walked for transportation and suffered from low blood sugar sometimes as a result:

“Walking for long distances with no food [bothers me]...’cause I get dizzy and get these major headaches...sometimes...I have to sit down if I get dizzy.” – Nancy

Nancy's food instability and her mode of transportation frequently caused her to experience headaches and dizziness due to hypoglycemia, or low blood sugar; she later stated that her dizziness and headaches occurred between two and four times each week. To handle this, she rested. Both Joe and Oscar took steps to not only handle hypoglycemia, but to prevent it as well by carrying food. This strategy was not always successful for Oscar:

“It's an uncomfortable feeling when your sugar drop and you ain't got no food. I had to beg somebody – walk in a store, begging, 'please can I get a piece of candy.' For my sugar had dropped.” – Oscar

To avoid experiencing his symptoms of hypoglycemia, dry mouth and blurry vision, Oscar tried to carry candy with him. In this particular situation, this strategy of carrying food did not succeed, so he needed to find another strategy, which was asking, or begging, for help. He understood how to avoid low blood sugar, as did many participants. This understanding of blood sugar did not often extend to overall understanding of diabetes; several participants made reference to a level or a level check, but most were unable to identify what the level was measuring or what range it should be in. Some participants struggled to name specific long-term effects of poor diabetes management other than death or hospitalization.

### **Food**

Services aided diabetes management in food access as well as adherence to diabetes diet management. Participants referenced several local soup kitchens, HCH, shelters, food pantries, and a church as food sources. These services provided food to a variety of individuals with different needs, but some specifically took steps to aid those with diabetes. For instance, Joe reported that some shelters, though they provided dinner only earlier in the evenings, had snacks available to diabetics in case they experienced hypoglycemia. Additionally, local soup kitchens changed out regular meals for meals deemed more healthy for diabetics; one even had a vegetarian tray that was touted by the majority of the participants as healthier for diabetics. The food pantry that Cindy went to sometimes gave surplus food to her when she asked:

“If they ask you what type of food you need, be honest and truthful and tell them the stuff you need...they’ll give you extras. It’s a secret that people don’t know.” – Cindy

Cindy went to this food pantry and was able to benefit from their surplus by asking. She also reported that some people sell their food pantry bags for a few dollars on the corner, which she sometimes took advantage of. Her food situation was particularly unstable even though she was housed because she needed to support her teenage son as well. She did receive food stamps (Supplemental Nutrition Assistance Program – SNAP benefits), but these were not able to sustain them both for the entire month, as they were designed to; even the ability to store food and food stamp aid is not able to adequately mitigate the effects of food instability in her life.

Throughout the interviews, mention of food stamp inadequacies abounded. Of the seven participants who stated they used them, five of them were unable to stretch this benefit for the entire month, increasing their risk of hunger at the end of each month. Michael slept outside and received food stamps:

“When I don’t have enough to eat...it can be anywhere from the [middle of the month] to the end of the month...Food stamps run out.” – Michael

Because he slept outside he did not have a kitchen to cook food in or store it, and his food stamps were unable to sustain him through the month, thus increasing his risk of experiencing the blackouts, headaches, and dizziness that happen when he doesn’t

have enough food. He was not alone in suffering hunger towards the end of the month, but many participants also experienced hungry episodes in the evenings. No participant referenced trading food stamps for other things.

Similar to the way food stamp inadequacies failed to prevent hunger throughout the month, service food absence in the evenings contributed to a failure to prevent evening hunger. Participants consistently referenced eating morning meals and noon meals, and participants who were in shelters got dinner unless they were too late and arrived after dinner was over. For those who were not housed and not in shelters are left to fend for themselves in the evening, leading to food inadequacies focused on the evenings. One strategy for dealing with food inadequacies was begging for food or money, which several participants referenced including Nancy, who stated that winter was better for begging because people felt bad for her. Bernard, someone who slept outside, begged as well:

“Hope I find somebody to give me something to eat. I might beg money from someone else in the streets...I can get...from the store...bologna and bread. And that’ll last me the whole night.” – Bernard

By begging for money, Bernard was able to buy food, bologna and bread, to last until morning. That was only possible if he was able to garner a few dollars from people in the street. The implication is that if he was unable to get money, Bernard would have been unable to eat. Bernard was supposed to take his insulin three times a day, but only took it in the morning and at night. He also did not talk about not taking his

insulin when he has no food. A lack of food in the evenings, paired with his medication dosing habits, would have exposed Bernard to risk of medication caused complications.

Some participants saw room for improvement in services that actually provided food instead of vouchers. Food access and adherence specifically posed many challenges to participants, even after accessing services. While the majority of the participants gauged service food generally acceptable without going into the specifics of what the meal included, Oscar had detailed criticisms of the vegetarian tray provided by a local soup kitchen when asked about what the food was:

“Any and everything. A bunch of slop. You got the choice to get a vegetarian tray, but the vegetarian tray had all sugar on it, all starchy foods. Macaroni and peanut butter and jelly and a bunch of fruit that’s too sugary.” – Oscar

Oscar listed specifically what the vegetarian tray includes and made a negative qualitative assessment of its quality. In contrast to non-specific assessments of the vegetarian tray, Oscar’s assessment of the vegetarian tray was based on its composition, a meal that included components that many participants explicitly stated they were not supposed to eat. This shows that while some participants understood what they weren’t supposed to eat, they may not be able to apply that knowledge or may be in a situation that is food unstable enough to warrant a critical assessment of any service help they receive. As this study did not involve interviewing service providers, it is unclear if the quality of service food was the result of few resources

afforded to services or if it was the result of poor education on the part of the food service providers

Sometimes service food was deemed to be not enough, and sometimes it was deemed to be of poor quality. Bernard had a more nuanced view of service food relating to its quantity and quality:

“You know, some places give you enough, but if they give you enough the food ain’t no good. When the food’s good, they give you less, ‘cause you have more people eating. If the food ain’t no good, they have less people going to the place to eat.”

– Bernard

In this quote Bernard stated that he didn’t get enough of the good food and if he got enough of something it is likely not good food. This relationship he reported was due to demand for good food, implying that there is not enough good food available to meet demand. This is pertinent to the discussion of food instability and diabetes management because services struggled to meet the need for good food, a failure that almost necessitated the choice between satiating hunger and managing diabetes.

### **Healthcare**

Healthcare was well provided by services for these participants. Of the 12 participants who had primary care doctors, two of them had primary care doctors not in HCH. The healthcare and mental services at HCH were referenced by most participants, and always in a positive way. For instance, Fabian got “his teeth” and his glasses from HCH. In response to client forgetfulness and subsequent failure to make

appointments, HCH gives a card for appointment reminders to each client, which Gertrude directly referenced as very helpful:

“I will be here before the time they told me unless I forget...the appointment. If I did not bring my card to check...but if I didn't check it, I will forget.” – Gertrude

Gertrude struggled with her memory in multiple aspects of her life; she forgot her medication before she had a pill box and forgot appointments. The card that HCH gave her helps her remember when she has appointments so that she can follow up with any services she uses, including medical services. This is important to diabetes management because regular primary healthcare appointments are important to monitor diabetes management success, identify behaviors that need to be changed, and address any complications that have arisen.

HCH was the most often referenced source of healthcare. There were many positive assessments of HCH, its services, and its people. Participants, when they addressed it, always without exception said it was helpful to them in a variety of ways. There was only a single difficulty associated with HCH: time until appointments. Bernard was well acquainted with the difficulties of missing an appointment:

“Only thing about it, you can get an appointment, don't miss it, 'cause it takes like two months to get another appointment.” – Bernard

Bernard may have missed an appointment in order to know that rescheduling appointments is difficult. Time was brought up not only in the difficulty that rescheduling missed appointments posed, but also in wait times even if a participant had an appointment that they showed up for. Fabian stated that times spent in the waiting room were less than optimal for people that need to do other things, and Michael actually had come in to HCH as a walk-in but was unable to receive care. This is important to diabetes management because regular primary healthcare visits are important for proper management, but if rescheduling a missed appointment is so difficult it may discourage an individual from following up.

While not a social service, insurance was cited as inadequate by multiple participants. Two participants actually did not have any insurance that they knew of, but for those who did have insurance, sometimes it was deemed inadequate. Oscar used insulin in its traditional form, a vial with a syringe, but stated he would like to move towards using a pen for its ease. His insurance didn't cover insulin pens, so he considered changing insurance plans. Similarly, Cindy did have insurance, but it was not as helpful as she needed it to be:

“...but they only pay for...you to check your sugar ...two or three times...and I should take my sugar four times a day...I take it maybe twice...because I am not able to pay the money for the extra strips.” – Cindy

Cindy was able to use her glucometer to check her sugar fewer times than she should because insurance did not cover the number of strips required. Because she struggled



monetarily, she was unable to make up the difference and instead made concessions by not checking her blood glucose as recommended. The fact that she had a glucometer put Cindy at a distinct advantage over the majority of the other participants, as a total of six participants referenced having glucometers. The majority of those who did have glucometers are not in shelters or on the streets; Althea, Cindy, Diane, and Helen. Nancy and Kaden also had glucometers, but Kaden, similar to the way he handled his medication, sent his to be stored at a family member's house. This reduced his chances to use the glucometer, as he had last checked his sugar two months prior to the interview.

The inability to properly manage diabetes can lead to serious complications that many participants, as discussed above, were not aware of. All but two participants had been to a local ED in the past year at least one time and some quite frequently: Joe went twice a month, Kaden went every three weeks, and Nancy had been to the ED six times in the past year. Bernard and Cindy had just been released from the hospital at the time of the interview and Helen stated that HCH staff told her she actually probably should have been in the hospital at the time of the interview. Of those that went to the ED in the past year, five of them explicitly stated that it was for diabetes related conditions. Fabian used the ED when he got swelling in his legs because he was worried about his circulation. Michael also used the ED:

“Getting dizzy. I had to be rushed to the hospital several times.” – Michael

Michael struggled to manage his diabetes, in part because he started refusing any medications and he was food insecure, three times a week not having enough food. His symptoms of poor glycemic control became severe enough that he needed to go to the hospital. While only five participants explicitly needed to use the ED for their diabetes symptoms, because of the general poor understanding of the more long-term diabetes complications, some of the other nine participants who used EDs may well have not known that their condition was due to diabetes. Even if the principal condition leading to ED use was not diabetes, it is probable that diabetes contributed to the condition negatively. While there were two participants who expressed negative perceptions of EDs, not a single participant stated that the ED did not give them the care that they needed. Multiple participants received medications from hospitals, including Ian, who struggled to effectively use the local services.

### **Medication**

There were multiple services noted to provide medication, including local hospitals, HCH, and a local pharmacy. Almost no participants referenced difficulties accessing their medications; even Kaden, who does not take his medication and is given medication, which he then passed off to his wife for storage. Medication success hinges not only on access, but on adherence as well, which posed its own challenges for participants. The competing needs that distracted participants from diabetes management led to challenges that were more direct in nature, such as memory lapses. Memory lapses went beyond forgetting to take medication to forgetting if she/he forgot to take medication. For instance, Gertrude, even after remembering that she was supposed to take medication, forgot if she had taken

medication. In response to patient forgetfulness, the nurses at HCH give plastic pill schedule containers to some clients, including Gertrude, as part of a medication assistance program:

“Otherwise I will think that I [had] taken it in the morning. But when I take by this thing for putting medication [in]...I will bring it out. I check if I have forgotten it” – Gertrude

The pill container helped Gertrude not only store her medications, but helped her keep track of her medication, thus allowing her to check if she had forgotten to take it. Previously she had been unable to keep track of her medication and had not infrequently missed doses. The pill box was filled for her each week by the pharmacy attached to HCH, so she was sure to be taking the correct medication. She attributed her diabetes management to this very pill box.

While storage did not pose many problems for participants in shelters, as the shelters referenced all had designated refrigerators for medication storage, medication adherence with insulin was different. The most probative circumstance was actually created by government entities in the city; both Oscar and Michael had their needles confiscated. Oscar had a particularly difficult time with this on one occasion:

“[The police] swore me up and down it was for drugs...I got locked up...they gave me a paraphernalia charge for my own needles.” – Oscar

Oscar had been sleeping in an abandoned house and the police had come because he was trespassing. When they discovered that he had syringes, and in light of the prevalence of intravenous drug use in Baltimore, they assumed that his needles were for drugs. Despite Oscar's protest otherwise, he was still penalized for having what was deemed drug paraphernalia.

Not all obstacles to insulin adherence were as prohibitive. While not as direct or prohibitive a challenge to insulin adherence as having needles confiscated, one challenge to insulin adherence was the lack of a clean, private area in which to administer the insulin, especially when in shelters. Both Elaine and Gertrude had this trouble:

“Nowhere to take insulin. If you enter the bathroom – say you will take it in the bathroom – toilet will be smelling like...I will run away.” – Gertrude

Gertrude could only go to the bathroom to take her insulin, but the bathroom was so unclean that she found this difficult. Similarly, Oscar referenced one shelter policy that discouraged his insulin adherence; there are no doors on the bathrooms and residents needed to inform shelter staff that they were administering insulin. The staff would then collect the used needle afterward. Oscar found this circumstance discouraging because it was embarrassing and would take his doses later than prescribed.

One other circumstance that was not uncommon dealing with insulin was the question of needle disposal. While no participants cited this as a challenge,

inadequate needle disposal can potentially pose a public health risk. Only Elaine said that she had a sharps container, but to empty it she just put a bag of her used needles in a dumpster. Leonard kept his in a bag and Oscar put his in a water bottle while Michael just had trouble finding ways to dispose of his needles. This general lack of appropriate needle disposal options was not cited as a reason for imperfect insulin adherence, but it is still relevant since even Elaine, who stayed in a shelter, disposes of her needles in a regular trash receptacle, thus creating a hazard for others.

### **Transportation**

Many participants, as discussed above, experienced difficulty with transportation. To help mitigate these challenges, four participants effectively used tokens. The tokens allowed them to move around the city without the worry of finding money for public transit fare. MTA Mobility was used by at least two participants, and was not at all mentioned by two participants, Fabian and Diane, who very obviously would have qualified for MTA Mobility service based on their severe difficulty walking. There was no mention of other transportation options originating from social or public service. Transportation thus was an obstacle for those with no money/tokens and difficulty ambulating.

### **Shelter**

Of the participants who referenced using shelters, their most prominent explicitly stated benefit was food provision. One participant also did reference the access to cool storage for her insulin. The promise of a place to stay, though, by extension would remove some of the demand that finding a place to sleep would place on an individual sleeping outside. It would also protect them and their

medications from being exposed to the elements, such as Oscar, who struggled with medication storage. One major detractor from shelters was the potential for theft: both Oscar and Bernard talked about having belongings stolen while in a shelter.

### **Physical activity**

One point that was not addressed often by participants, and even less often in reference to resources available, was physical activity. All participants were explicitly asked, but there were only six participants who performed physical activity specifically to try to manage their diabetes. Only Elaine reported being able to leave her belongings in the shelter during her physical activity. This would allow her to complete her activities without needing to carry her belongings. It is unclear if others in the shelter were able to do the same and if they found this helpful if so. Despite the notable absence of physical activity with the express purpose of managing diabetes, previously discussed transportation challenges necessitated walking for many participants. Out of all 15 participants, 13 participants did do some type of physical activity, whether for transportation or with the express purpose of managing diabetes.

### **Access to other services**

Because the social and government services helped participants eliminate or at least mitigate the effects of some challenges, it is important to continue to promote access to these services. Ian specifically had used almost no services to help him with his challenges. Even when using a soup kitchen, he did not tell the staff that he was diabetic and thus was unable to even find out if they could further help him manage his diabetes. Access to governmental resources is an important service, as otherwise Cindy would not have been able to get help with her gas utility bill and Althea,

Cindy, Diane, Fabian, and Oscar would not be in permanent independent housing. Also, no participant would have been able to get food stamps or use MTA Mobility. Althea referenced HCH as a place for things other than healthcare:

“..Have a drug program here at HCH...and you got social workers. I can use ...the social workers. ‘Cause it helps get mobility, stuff like that.” – Althea

Althea had used resources available at HCH to do things as diverse as get housing and pursue the ability to use MTA Mobility. It is unclear if she actually did have access to MTA Mobility, as she did not mention using it for transportation. Althea was just one of the many participants who referenced HCH as a place that was helping or had succeeded in getting a participant access to some other service, such as housing and insurance. One problem that did come up was a lack of knowledge about the services available in Baltimore generally. Some participants knew of just the services in the general area of HCH, few knew about services that were further removed, and some did not know of any services outside of HCH. It is unclear how the other, better informed, participants learned about the services that they knew of, but the knowledge was not widespread.

## Chapter 6: Discussion

This study sought to examine the difficulties that homeless individuals in Baltimore face when they try to manage diabetes. It specifically investigated some of the structural variables that affect diabetes management for this population as well as how the social services in the area facilitate or hinder diabetes management efforts. This study found a complex web of challenges, social service efforts, and participant strategies for eliminating or mitigating the effects of these challenges. Difficulties revolved around direct influences on diabetes management, food instability and shelter instability, as well as indirect influences, from competing needs which divert resources from diabetes management efforts. Larger societal and city structures, the primary healthcare system and food provisioning structure respectively, also failed to effectively serve these participants. The majority of participants did have health insurance, but the coverage afforded was not always deemed adequate. In efforts to deal with these difficulties, participants often utilized social services for education food, healthcare, medication, shelter, and access to other services. These services, however, do not always succeed in eliminating difficulties to diabetes management. In addition, service provision had notable gaps, including the absence of services specifically to provide effective transportation, to aid with physical activity, and to provide evening meals. Perseverance in the face of difficulties was a common theme, and was highlighted by strategies of overcoming or avoiding challenges. These strategies were developed in response to difficulties, and represent rational and responsible decisions given the context of instability and other difficulties.



Participants thus employed a variety of strategies in their diabetes management efforts. As there were only 15 participants, there is no possibility for statistical significance in supporting or challenging larger quantitative studies, but this study corroborates the findings of some previous studies and fails to support others, as discussed below.

Because diabetes management recommendations are the same for all diabetics, each person with diabetes may have challenges concerning medication, physical activity, and diet management. Indeed, two studies with non-homeless populations identify medication challenges as the most common precipitating factor in recurrent and first time hypoglycemic emergency visits for diabetics (Yan *et al.*, 2017; Randall *et al.*, 2011). In this study the potential for challenges to diabetes management was exacerbated by homelessness: many challenges found in this study were the result of instability that comes with homelessness and low incomes. These include problems surrounding medication. This study found very few concerns with accessing medications, which contrasts with some previous studies (Elder & Tubb, 2014). This contrast may be the result of recruitment from HCH, a service that works specifically to improve medication access. Even though accessing medication was not a challenge, difficulty storing medications once received did pose issues from exposure to the elements to, more commonly, theft. Difficulty storing medications, specifically in places safe from thieves, was also seen in Toronto with homeless diabetics, again suggesting similarity in experiences of homelessness in cities of high-income countries (Hwang & Bugeja, 2000).

Medication, especially insulin, is supposed to be taken at specific times and exactly as prescribed. Insulin should be part of a well balanced glycemic process, and blood glucose levels indicate where the balance currently lies. Glucometers are necessary for reading blood sugar, knowledge which should then inform diet and medication decisions. This study found a relatively small number of participants with glucometers. This finding directly agrees with a previous study done with homeless individuals (Davachi & Ferrari, 2012). Regardless of this, this study found that participants still attempted to manage their diabetes but perhaps in a less informed manner.

Insulin can come in pens or, traditionally, in vials with syringes. After insulin is injected from either source, the apparatus should be disposed of properly in a sharps container. This study found that needle disposal was not something that participants found challenged their diabetes management, and participants ultimately used regular trash receptacles. Needle disposal was also a problem that Wilk *et al.* (2002) found; while some participants tried to mitigate puncture risks by placing needles in secondary containment (e.g. soda cans), they ultimately still disposed of them in regular trash receptacles. Even though participants did not see this as a challenge, there is a public health risk associated with improperly handled sharps as dirty needles can transmit infectious diseases.

This study found that a large challenge to participants was food instability and food service, including poor access to high quality food. It is well documented that Baltimore City is rife with food deserts, and about 25% of Baltimore's population lives in those food-scarce areas (Buczynski, Freishtat, & Buzogny, 2015). This study

shows that living in a city with food deserts affects homeless diabetics, forcing them to travel long distances to access high quality food. A study of homeless diabetics in the midwest US revealed challenges to accessing food as well (Elder & Tubb, 2014). This suggests that difficulty accessing acceptable quality food may be a widespread problem faced by homeless diabetic individuals. Difficulty accessing high quality foods contributed to the food instability that this study found, and the common occurrence of food instability itself was not unexpected in light of previous studies (Lee & Greif, 2008). This study found that food instability caused participants to eat indiscriminately, an insight that extends a previous study's finding; food insecure individuals are more likely to buy cheaper foods that are worse for diabetes management (Drewnowski & Darmon, 2005). These studies both show that a diabetes management diet does not take priority over food quantities large enough to satiate hunger. This study explicitly makes the connection between food insecurity, hunger, and failure to observe an ideal diabetes management diet. One way of combating food instability was seeking food at local services.

Approximately half of the participants in this study reported poor or fair health, as findings from previous studies suggested may be the case with more homeless individuals reporting fair or poor health than the general population (Baggett *et al.*, 2013; Gelberg *et al.*, 2000). Diabetes management can contribute in large part to overall health status because it affects a variety of bodily processes, as these participants experienced to varying degrees. This study found very few challenges to accessing healthcare and very few participants were not receiving healthcare at the time of the interviews. Wait time and time to reschedule

appointments posed indirect challenges to healthcare access but there was no indication of mistrust of healthcare workers. This study thus does not corroborate a study that found frustration and mistrust in the provider-patient relationship but it does show time management as a factor in diabetes management for homeless individuals (Elder & Tubb, 2014; Gelberg *et al.*, 2000; Hwang & Bugeja, 2000; Nikasch & Marnocha, 2009; Zlotnick *et al.*, 2013). Difficulties in time management point to competing priorities, of which this study found many, including competition for time and money as well as transportation difficulties. Substance use, while not explicitly stated, presumably acted as both a time and monetary resource drain in addition to being a distracting influence.

These challenges to managing diabetes were sometimes able to exert enough influence on a participant's diabetes management that they experienced a crisis. Baltimore has a number of local EDs and participants took advantage of this uniquely high capacity, not once citing inordinate wait times or ineffective care. In this study, multiple people had used the ED for explicitly stated diabetes complications. Several used the ED quite frequently, enough to be high-frequency users. Perceptions of health status may well have influenced participant's individual use of EDs as suggested by Kushel *et al.* (2002). This study found that very few participants did not have primary care doctors at HCH, challenging the notion that homeless individuals often use just EDs and supporting a theory of heavy usage of the healthcare system as a whole, focused on HCH and EDs (D'Amore *et al.*, 2001; Gelberg *et al.* 2000, Lin *et al.*, 2015; Mitchell *et al.*, 2017; Zlotnick & Zerger, 2009). Such heavy usage of the overall healthcare system has the potential to put an enormous financial burden on the

healthcare system even if the individual has health insurance. This suggests that improving the health of homeless individuals, of which adequate diabetes management is a part, has the potential to save the healthcare system massive sums of money. A study of homeless frequent ED users in a single city, over half of whom had Medicaid, revealed that over one year frequent users incurred almost \$5 million in costs but the hospital only recovered about \$800 thousand (Ku *et al.*, 2014). This trend of frequent ED use has the potential to cost the healthcare system massive sums of money in light of Medicaid's failure to fully fund ED visits. It also, along with all encompassing lack of control and instability, makes this population very vulnerable in the case of a large scale emergency or disaster, when EDs would be required to handle a large influx of patients. Large influxes of patients have the potential to strain or overwhelm ED resources, from healthcare professionals to medical supplies, thus making it difficult to serve each and every patient adequately.

Frequent use of EDs, while suggesting heavy overall use of healthcare apparatus in this study, does not necessarily speak to a failure of the primary healthcare system, as the vast majority of participants had a primary care physician and said that they followed up when asked. Given the multitude of difficulties found in this study, it is not unreasonable to suspect that participants' lack of control and instability played a large part in their ED use. This demonstrates an overarching theme in homeless healthcare: healthcare recommendations rendered unattainable or unfeasible to pursue by homeless diabetics' circumstances. Another overarching theme, perseverance, leads to strategies designed to overcome challenges to diabetes

management and shows that participants still strove to attain adequate diabetes management.

The findings of this study show potential for a variety of interventions. To ensure efficacy in this population, all interventions should take into account the limited options available for clients and help them problem solve around resource instability. Additionally, it should be part of a cohesive service provision network and not a standalone endeavor, promoting coordinated efforts and preventing duplicated effort. This would also allow for individuals experiencing need to be funneled to the appropriate service to fulfill that need. Finally, all interventions should be well advertised among the population of potential clients so that individuals have a better understanding of where to address which needs. The gaps in service provision show where policies and interventions, following the above guidelines, should be investigated.

### *Intervention Recommendations*

This study found that individuals experiencing homelessness and diabetes may not benefit from advances in diabetes screening that effective primary healthcare would have provided. A unique feature of Health Care for the Homeless facilities is its outreach and mobile health clinics, allowing practitioners to reach individual who may not be able or inclined to access services otherwise (Zlotnick *et al.*, 2013). An expansion of this practice to include specific diabetes screening days may be beneficial, bringing the benefits of diabetes screening to those who may not be well integrated into the primary healthcare system. With this screening should come

education on diabetes and its management, along with an emphasis on the need to come to the permanent facility for further healthcare. Similarly, a clinic, perhaps as part of Healthcare for the Homeless, that specifically serves diabetics, not just diabetes as a condition, would be beneficial as diabetes affects the entire body and presents complex medical problems.

Once an individual knows they have diabetes and decides they would like to manage it, this study found that a number of challenges may stand before her/him. Among these challenges is medication storage, which could be solved with medication lockers set up in an air conditioned building that an individual can stock and access. The medication need not be refrigerated, as air conditioning should be able to keep insulin below the required 86 degrees Fahrenheit (NovoLog® Storage, n.d.). Because of the competing needs that this study found, this building should be accessible at most hours of the day, not just during business hours. A more ambitious project to solve medication storage, among other, challenges would be a modification of supervised injection facilities, one of which has been piloted among injection drug users in Canada since 2003 (Rubin, 2016). In these facilities, clients use their own illicit drugs in a clean place with clean needles, and watched by healthcare practitioners who also provide basic healthcare such as vaccinations and wound care (Rubin, 2016). An adaption of this idea would allow for individuals experiencing homelessness and diabetes to store medication in the facility, access clean needles, dispose of used needles, take advantage of basic medical care, attend diabetes specific classes, and have their diabetes management monitored. Ideally, this facility would be in or close to a food services facility, allowing for more precise timing of medication

doses in response to meals and blood glucose levels. In the absence of such a facility, food services and shelters having a designated person to take blood glucose levels and inform clients about best management practices may help individuals dose themselves appropriately.

This study showed that transportation posed both monetary and temporal barriers to individuals experiencing homelessness and diabetes. Instituting a shuttle to go between service facilities and to other popular destinations would aid in reducing these barriers somewhat. This may also be realized, perhaps to a lesser extent, by an expansion of the Charm City Circulator routes to include areas of where service providers are located. Transportation solutions may also reduce the pressure on those who have pain upon walking. This study also found that no services were stated to help achieve physical activity recommendations. To fill this gap, shelters should consider having a designated activity room or physical activity classes. These classes should cater to a wide range of physical abilities, as some clients may have multiple physical challenges not limited to pain upon walking. Policies also can offer viable solutions to some challenges that this study found.

### *Policy recommendations*

One policy topic that has the potential to have a massive positive effect on challenges that face individuals experiencing homelessness and diabetes is that of food quality. The city or state could require that any publically funded food provider also provide meals specifically for those with diabetes. These meals would need to be monitored for composition and quality to ensure that the policy is well enforced. To



reduce the effect that resource shortages play in food provision, a national law should be passed that reduces grocery store waste by requiring food be donated instead of thrown away. A precedent for this bold policy can be seen in France; starting early February 2016 grocery stores over 4305 square feet are required to sign a donation contract with a charity or face a monetary penalty (Chrisafis, 2016). The implementation of a similar law throughout the US would prevent grocery stores from moving out of just the state of Maryland to avoid the obligations and would also benefit charities throughout the nation.

Considering that the rate of death in Baltimore due to diabetes is so much higher than that of the US as a whole, the city should create a task force to assess the management levels and difficulties of the entire population, as the challenges found in this study may not be isolated only to individuals experiencing homelessness. Also, a task force instituted and supported by the city would be able to make policy and intervention recommendations which may help reduce challenges for the general population, which have the potential to also positively affect individuals experiencing homelessness and diabetes. In addition to institution of these new services and the introduction of new policies, current services can modify their practices to make diabetes management for this population more attainable.

### *Service provision modifications*

In order to make adequate diabetes management more attainable, there are a number of modifications that services can explore. Because housing was referenced as having so much influence over diabetes management, improvements in permanent

housing access should be a goal for the government and needs based services alike. Food provision should not only strictly follow diabetes management guidelines but also be expanded to include dinner, whether a hot or bagged meal. This would reduce the episodes of hunger that occur in the evenings. Additionally, food stamps were referenced to be woefully inadequate and unable to provide sustenance throughout the entire month; services can work with legislators to increase the minimum food stamp allotment. According to the US department of Agriculture, a household with one member will be allotted \$194 each month at maximum, with the expectation that beneficiaries will spend 30% of their monthly income on food (US Department of Agriculture, 2016). Using just the allotment, for 30 days in a month and 3 meals a day, each meal is allotted \$2.15. If a person does have a monthly income to contribute, it might be possible for \$2.15 a meal to be adequate, but it would be more difficult for someone without a monthly income to manage for a month. An increase in food stamp allotment may not be able to compensate for the lack of grocery stores in the city, but it would allow for the potential of a more stable food situation at the end of each month.

Services could also provide more glucometers while expanding their diabetes education programs, empowering clients with the ability to use the glucometers and the power of understanding what their blood glucose levels mean. This would allow clients to, given the opportunity, alter their behaviors to more effectively manage their blood glucose levels. In order to facilitate transportation, services can give out more bus tokens, as some participants still referenced cost as a challenge to using public transit. Facilitating transportation would allow clients to more effectively

handle their affairs, thus reducing the number of competing needs, and also make it easier to be present for a follow up appointment easier. In the interest of public health, services could provide used sharps receptacles to keep them from entering the stream of general refuse.

### Future research

There is much research concerning the health of homeless diabetics that still must be done, and the *Social determinants of health framework* provides guidance as the direction for future efforts. The social determinants of health, created by the World Health Organization (2010), provide a framework to conceptualize how a society impacts the health of those who live in it and thus creates a gradient of health equity. This framework addresses multiple levels of society and an individual's position in that society, from governance to individual characteristics. The cultural and political context of a society leads to socioeconomic position, which affects intermediary determinants of health, including material circumstances. The intermediary determinants of health lead to the health equity gradient. In this framework the health system is somewhat peripheral, as opposed to traditional understandings of health resulting directly from the healthcare system. As a result, this framework suggests that change to any of its major components (political context, socioeconomic position, intermediary determinants) has the potential to more greatly change the health of individuals and the gradient of health equity than does change to the health system. It also suggests that shifts in the global community can

affect an individual's health by changing the political and cultural context of the society.

This study focused specifically on the intermediary determinants of health, as influenced by societal structures, and its interface with the health system in order to better understand what impacts the health of homeless diabetics in Baltimore (it is important to note that this study defines "structures" as any part of the environment that an individual inhabits, whereas the WHO includes political context and socioeconomic factors as structural determinants). Future research should focus on the other levels of this framework and their interfaces with each other. This includes investigating how global economic shifts influence the health of homeless diabetics. More specifically, because this study did not address actual success in diabetes management, investigation of the relationship between challenges faced and success in diabetes management is needed. As this study focused on the structural challenges of diabetes management, further study is needed to assess how the intersection of different personal identities contributes to challenges in diabetes management. Further investigation is also needed to assess the cost that poorly managed diabetes in the homeless population exerts on the healthcare system. An extension of such a study could investigate how diversion of public funds to address poorly managed diabetes among homeless individuals affects other public health budgets. A study of similar topic but with, a larger sample size to assess the prevalence of these challenges is needed as well. The findings from the suggested studies will be key to driving policy change, or changing the political context, that will potentially reduce the health difficulties facing homeless diabetics.

### Reliability and validity

Because no identifying information about participants was collected, this analysis has not been presented to and discussed with participants to ensure credibility. The codebook was examined by an independent party experienced in qualitative research in order to ensure its breadth and appropriateness. The codebook was comprehensive and systematically applied to all interviews. The data did have sources providing similar information about the same themes, meaning data triangulation contributes to the credibility of this study.

### Limitations

This study has several limitations related to its small sample size and research design. The small sample size did not allow for data saturation, which would have greatly improved this study's credibility. Because each of the participants was self-identified in all aspects, including being diagnosed with diabetes, there was potential that some individuals, who in addition to Kaden, did not meet the inclusion criteria. Participants were asked to recall past health related events, and just as with any qualitative study involving sometimes far past events, there were lapses in participants' memory, both apparent and hidden. One study did find, however, that homeless individuals are not unreliable historians of their own healthcare use (Hwang, Chambers, & Katic, 2016). Recruitment took place from the second floor lobby of HCH Baltimore, in an area where individuals waited for medical attention. Due to the recruitment technique and location, those utilizing HCH Baltimore for medical, mental health, or social work services were overrepresented, thus the results

of this study are generalizable only to that population. Also due to recruitment, there likely is a smaller representation of healthcare access difficulties than in the general homeless population of Baltimore City. This study excluded undiagnosed diabetics, thus lack of diagnosis as a barrier to management may not have been as prominent in the data as it otherwise would have been. It also excluded non-English speaking individuals, and thus failed to examine difficulties posed by a language barrier to proper diabetes management. However, this study was exploratory and is not designed to be generalizable to the entire population of homeless diabetics in Baltimore. This study serves to inform larger, more generalizable studies. This study could have benefitted from more time and funds, allowing it to be more comprehensive in design and to include more participants.

## Chapter 7: Conclusion

The results of this study show that individuals experiencing homelessness and diabetes are subject to the synergistic pressures of both diabetes and homelessness, a prime example of how intersectionality produces pressures that bear down on the daily lives of individual people. The challenges that people who are homeless and have diabetes face directly and indirectly hinder their management efforts, which may lead to poor control over the condition. This poor control has large scale implications for public health, as even with primary care involvement participants utilized the ED in sometimes very high frequencies. Heavy ED use places an enormous financial burden on the healthcare system.

In order to make diabetes management more attainable by this population, social service provision structures should form a more cohesive network through coordination between service providers. Coordination between service providers would reduce or eliminate some of the challenges that participants face by identifying client needs and addressing them. This requires more coordination than a case-worker is able to provide; the structure of the service provision network will need to be a more coherent unit. Policies on the local and national levels can support this service provision network by addressing food instability among this specific population as well as giving more public attention to diabetes for the general population. In addition, because housing was understood to mitigate the effects of or eliminate a majority of the challenges experienced by reducing food and shelter instability, low cost housing solutions should be implemented.

## Appendix A

### Sample Questions

#### 1. Demographics

1. Age
2. Gender
3. Months homeless (this specific time and total)
4. Insurance status

#### 2. General

1. How are you feeling health-wise today?
  1. How would you rate your overall health (excellent, very good, good, fair, poor)?
2. What type of diabetes do you have?
  1. When were you diagnosed?
    1. Was it before, during, or after you experienced homelessness?
3. Do you have family or friends that help you with your diabetes management?
  1. How?

#### 3. Diabetes

1. What can you tell me about what diabetes is?
  1. What do you call it?
  2. Can you tell me about what it means for your life?
2. Have you had any education (classes, pamphlets, healthcare provider) about diabetes?

#### 4. Management

1. What does diabetes management mean?
2. How large a part of your life is managing your diabetes (e.g. on a scale of 1 to 10, very important, etc.)?
  1. How do you manage your diabetes?
3. Do you think your diabetes well managed?
  1. Why do you think that?

#### 5. Medication

1. Is medication a part of your diabetes management?
2. What type of medication do you have for your diabetes?
3. How do you get that medication(s)?
4. How do you store your medication(s)?
5. How do you take your medications (e.g. pill, needle)?
  1. Do you take it at the times you are supposed to?
  2. If you use insulin, how does using needles affect your life?
6. Have you used services (e.g. shelters, kitchens, medical facilities, etc.) while diabetic?
  1. Do you ever have problems with your medications while using services?



1. What are they?
2. Some places have rules about using insulin. Have you experienced this?
  1. How did it impact your diabetes management?

## 6. Food

1. Can you tell me about your diet?
2. What do you do for food in the...
  1. morning?
  2. noon?
  3. evening?
  4. non-meal times (late at night)?
3. What is the food like (what is it, is it good, what is the quality, etc.)?
4. Do you try to watch what you eat because of your diabetes?
  1. Think about your ideal diabetes management diet. How does the diet you have now differ?
  2. What kinds of compromises do you need to make?
  3. How do you watch your diet (quantity, quality etc.)?
5. How would you characterize your diet (not enough food, enough, poor quality, fair quality, etc.)?
6. Do you ever not have enough to eat? When (times of day, days of week, months, seasons)?
  1. How does your diabetes management change when that happens?

## 7. Physical activity

1. Is exercise important for your diabetes management?
2. How do you decide if you are going to exercise?
  1. What do you do when you do decide to exercise?

## 8. Transportation

1. What do you do in a typical day?
  1. How do you get to where you need to go?
  2. Is it easy to get where you need to go?
2. Does transportation affect your diabetes management?
  1. How?

## 9. Consequences

1. What might happen if your diabetes isn't well managed for a day?
  1. Has any of that ever happened to you?
2. What might happen if your diabetes isn't well managed for a long period of time (months to years)?
  1. Has any of that ever happened to you?
3. Do you see a primary care/regular doctor (either at HCH or elsewhere)?
  1. If yes, what do they help you with in terms of diabetes management?
  2. Do you see her/him more or less often than emergency departments?

## 10. Services

1. What services (shelters, soup kitchens, etc.) are around this area?
  1. Which do you typically use?

1. Have you experienced any problems relating to diabetes management with the services that you have used?
2. How do they help you manage your diabetes?
3. How do they make it harder to manage your diabetes?
4. How do you get around any problems from services?
2. Why do you not use the services that you don't use?
2. What advice would you give someone about using services who hasn't been in the area or hasn't been diabetic for long?
3. Why do you come to Healthcare for the Homeless?

**11. Overall**

1. What is the biggest problem you face in managing your diabetes?
2. What is your biggest strength in managing your diabetes?
3. What do you wish you could change to make managing your diabetes easier?

# Appendix B

## Graduate Student Association Participant Compensation Tracking

RECEIPT FOR FUNDS DISBURSED TO STUDY PARTICIPANT (**Confidentiality Assured**)

Date of Disbursement: \_\_\_\_\_

I certify that I have completed an interview for case # \_\_\_\_\_ and that \$ \_\_\_\_\_ has been disbursed to that person for their efforts.

\_\_\_\_\_  
Name of Interviewer (please print)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Interviewer Signature

\_\_\_\_\_  
Date

Appendix C

**Recruitment Sign**

**Have you been homeless and diabetic for at least 1 year? Do you have diabetes medication (insulin or pills)?**

**Do you want to talk to me about how you try to manage diabetes?**

**Come say “Hello!”**

## Appendix D

### Consent Script

Whom to Contact about this study:

Principal Investigator: Hanna Jardel

Department: Emergency Health Services

Telephone number: 410-455-3223

*Challenges of managing diabetes while experiencing homelessness*

#### **I. INTRODUCTION/PURPOSE:**

I am being asked to participate in a research study. The purpose of this study is to find what challenges there are to managing diabetes while experiencing homeless. I am being asked to volunteer because I identify as having been homeless and diabetic for one year (cumulative time) and am prescribed a medicine for diabetes. My involvement in this study will begin when I agree to participate and will continue until the end of the interview. About 15 persons will be invited to participate.

#### **II. PROCEDURES:**

As a participant in this study, I will be asked to have a conversation with the researcher about diabetes. The conversation will take place here and now and will be audio recorded. My participation in this study will last for one hour. No personally identifying information will be collected.

#### **III. RISKS AND BENEFITS:**

I have been informed that participation in this study may involve risks associated with a breach in confidentiality (e.g. others finding out what you say in the interview). I have also been informed that my participation in this research will not benefit me personally, but that this study may help others in managing their diabetes.

#### **IV. CONFIDENTIALITY:**

Any information learned and collected from this study in which I might be identified will remain confidential and will be disclosed ONLY if I give permission. The investigator (s) will attempt to keep my personal information confidential. To help protect my confidentiality the researcher will not record my name at all and will de-identify anything you say during the interview after transcription. My files will only be labeled with an arbitrary code. Files will be password protected and kept in a password protected computer. Any hard copies of files will be destroyed after the study.

Only the investigator and members of the research team will have access to these records. If information learned from this study is published, I will not be identified by name because my name will not have been collected. By giving oral consent I allow the research study investigator to make my records available to the University of Maryland Baltimore County (UMBC) Institutional Review Board (IRB) and regulatory agencies as required to do so by law.

Consenting to participate in this research also indicates my agreement that all information collected from me individually may be used by current and future researchers in such a fashion that my personal identity will be protected. Such use will include sharing anonymous information with other researchers for checking the accuracy of study findings and for future approved research that has the potential for improving human knowledge.

I give  permission to record my voice.

I do not  give permission to record use my voice.

#### V. COMPENSATION/COSTS:

My participation in this study will involve no cost to me. I will be paid \$20 in cash after the interview.

#### VI. CONTACTS AND QUESTIONS:

The principal investigator(s), Hanna Jardel has offered to and has answered any and all questions regarding my participation in this research study. If I have any further questions, I can contact Hanna Jardel at (410-455-3223, [jahan1@umbc.edu](mailto:jahan1@umbc.edu)).

If I have any questions about my rights as a participant in this research study, contact the Office of Research Protections and Compliance at (410) 455-2737 or [compliance@umbc.edu](mailto:compliance@umbc.edu).

#### VII. VOLUNTARY PARTICIPATION

I have been informed that my participation in this research study is voluntary and that I am free to withdraw or discontinue participation at any time. I have been informed that data collected for this study will be retained by the investigator and analyzed even if I choose to withdraw from the research. If I do choose to withdraw, the investigator and I have discussed my withdrawal and the investigator may use my information up to the time I decide to withdraw.

*I will be given a copy of this consent form to keep.*

**VIII. ORAL CONSENT**

The above-named investigator has answered my questions and I agree to be a research participant in this study.

## Appendix E

### Code families and constituent codes

Code Family: Care

Codes (4): [Emergency care] [HCH] [Insurance] [Primary healthcare]

Quotation(s): 202

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Code Family: Education

Codes (9): [Class/support group] [Experienced complications]

[Family/friends/SO] [Food knowledge as challenge] [Origin of diabetes] [Other source of education] [Primary healthcare] [Understanding of diabetes mechanism]

[Understanding of not-experienced complications]

Quotation(s): 375

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Code Family: Food

Codes (13): [Competing needs] [Expense] [Food knowledge as challenge] [Food quality] [Food quality - acceptable] [Food quality - bad] [Food quantity] [Food quantity - bad] [Food quantity - good] [Food source] [Food storage] [Food strategy] [Hunger]

Quotation(s): 309

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Code Family: Location/housing

Codes (6): [Aspire to housing] [Food source] [HCH] [Homeless residence location] [Housing as stability/control] [Service]

Quotation(s): 323

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Code Family: Medication

Codes (8): [Adapt] [Competing needs] [Cool storage place] [Glucometer]

[Medication access] [Medication adherence] [Medication storage] [Needle problems]

Quotation(s): 243

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Code Family: Misc



Codes (11): [Adapt] [Competing needs] [Expense] [Family/friends/SO] [Pain]  
[Physical activity] [Should but don't] [Substance abuse] [Theft] [Transportation]  
[Uncertainty]  
Quotation(s): 357

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Code Family: Qualitative Assessment  
Codes (9): [Difficulty] [Help] [Negative perception] [Neutral] [No difficulty] [No  
success] [Not much help] [Success] [Uncertainty]  
Quotation(s): 390

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Code Family: Sequelae of disease  
Codes (5): [Diagnosis reason] [Experienced complications] [Pain] [Understanding  
of diabetes mechanism] [Understanding of not-experienced complications]  
Quotation(s): 231

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Code Family: Single-minded perseverance/Motivation  
Codes (5): [Adapt] [Difficulty] [Do what you gotta] [Should but don't] [What  
would change (life)]  
Quotation(s): 228

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Code Family: Weakness/Strength  
Codes (4): [Difficulty] [Intangible strength] [Knowledge as strength] [Tangible  
weakness]  
Quotation(s): 15

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