# THE EXPERIENCE OF ILLNESS IN THE DAILY LIVES OF PERSONS LIVING WITH BEING CHRONICALLY HOMELESS

by

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#### ABSTRACT

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Individuals from all segments of society are affected by homelessness – the old and young, men and women, single individuals and families. The majority of individuals will experience homelessness only on a short-termed basis. However, about 10-20% will experience homelessness for years. Although, the chronically homeless represent only a fraction of the total homeless population, they utilize the majority of resources available. Current literature has focused primarily on other groups within the homeless community, leaving little to be known about the chronic homeless. Without a better understanding of this unique group, interventions can only be based upon assumptions.

The purpose of this descriptive phenomenological study was to better understand the experience of illness in the context of being chronically homeless. Twenty chronically homeless individuals shared their experiences of being ill while living on the streets. These individuals participated in private, audio-taped interviews in order to explore their daily struggles while being sick. The individuals identified barriers as they attempted to access health care and recover from an illness. Themes that were identified from this study were: (a) trying to survive, (b) access to care, (c) being stigmatized, and (d) trying

iv

to be healthy. Each of these themes were further discussed in detail and compared to other published literature. This information can be helpful, not only for policy makers, but for other health care workers as then plan for future interventions to provide appropriate care directed at the chronically homeless.

### TABLE OF CONTENTS

ACKNOWLEDGEMENT	iii
ABSTRACT	iv
LIST OF TABLES	X
Chapter	Page
1. INTRODUCTION AND SIGNIFICANCE OF THE PROBLEM	1
1.1 Introduction to the Problem	1
1.2 Background and Significance	2
1.3 Philosophical/Theoretical Perspective	6
1.4 Study Questions	9
1.5 Assumptions	9
1.6 Chapter Summary	10
2. REVIEW OF RELEVANT LITERATURE	11
2.1 Introduction	11
2.2 Homelessness as a Societal Issue	12
2.2.1 Definition	12
2.2.2 Risk Factors	14
2.2.3 Prevalence	15
2.2.4 Cost Associated with Homelessness	17
2.3 Homelessness as a Health Issue	19
2.3.1 Health Conditions	19
2.3.2 Access of Health Care	24
2.3.3 Barriers to Health Care	25

2.4 Homelessness as a Lived Experience	26
2.5 Chapter Summary	30
3. METHODS AND PROCEDURES	32
3.1 Introduction	32
3.2 Research Design	32
3.3 Setting	33
3.4 Participant Selection	34
3.5 Recruitment Procedure	35
3.6. Data Collection Method	35
3.7 Human Subjections Protection	37
3.8 Data Analysis	39
3.9 Chapter Summary	41
4. FINDINGS	42
4.1 Introduction	42
4.2 Demographic Data	42
4.3 Qualitative Findings	46
4.3.1 Theme 1: Trying to Survive	47
4.3.3.1 Sub-theme 1: Earning a living in difficult times	48
4.3.3.2 Sub-theme 2: Finding housing I can afford	49
4.3.3.3 Sub-theme 3: Lack of support from family and others	51
4.3.2 Theme 2: Access to Health care	52
4.3.2.1 Sub-theme 1: No way to pay for healthcare	52
4.3.2.2 Sub-theme 2: Inconvenient hours and days of clinics.	53

4.3.2.3 Sub-theme 3: Transportation	54
4.3.3 Theme 3: Being Stigmatized	54
4.3.3.1 Sub-theme 1: Perceptions of the public	55
4.3.3.2 Sub-theme 2: Perceptions of health care workers	56
4.3.4 Theme 4: Staying Healthy	57
4.3.4.1 Sub-theme 1: Lack of preventative care	58
4.3.4.2 Sub-theme 2: Obstacles to eating healthy	58
4.4 Chapter Summary	59
5. DISCUSSION OF RESEARCH FINDINGS	61
5.1 Introduction	61
5.2 Interpretation of Results	61
5.2.1 Demographic Data	62
5.2.2 Theme 1: Trying to Survive	64
5.2.2.1 Sub-theme 1: Earning a living in difficult times	64
5.2.2.2 Sub-theme 2: Finding housing I can afford	66
5.2.2.3 Sub-theme 3: Lack of support from family and others	68
5.2.3 Theme 2: Access to Health care	69
5.2.3.1 Sub-theme 1: No way to pay for healthcare	70
5.2.3.2 Sub-theme 2: Inconvenient hours and days of clinics	70
5.2.3.3 Sub-theme 3: Transportation	71
5.2.4 Theme 3: Being Stigmatized	71
5.2.4.1 Sub-theme 1: Perceptions of the public	72
5.2.4.2 Sub-theme 2: Perceptions of health care workers	72

5.2.4 Theme 4: Staying Healthy	73
5.2.5.1 Sub-theme 1: Lack of preventative care	73
5.2.5.2 Sub-theme 2: Obstacles to eating healthy	74
5.3 Chapter Summary	75
5.4 Limitations of the Study	77
5.5 Recommendations for Future Research	78
5.6 Implications for Nursing	79
5.7 Conclusion	80
REFERENCES	81
APPENDIX	
A. RECRUITMENT	98
B. INFORMED CONSENT	99
C. COUNSELING SERVICES	102
D. DEMOGRAPHIC QUESTIONS	105
E INTERVIEW GUIDE	107

## LIST OF TABLES

# Table

2.1 States with higher proportions of homeless people	16
2.2 Health Problems of individuals who are homeless	23
4.1 Gender and Race of a Sample of Chronically Homeless Participants	43
4.2 Education Level and Martial Status of Participants	43
4.3 Age and Years Spent Homeless of Study Participants	44
4.4 Mental Health Problems and Substance Abuse Reported	45
4.5 Health Related Issues of Participants	45

#### **CHAPTER I**

#### 1.1 Introduction

Thirty years ago, very few people ever experienced homelessness in the United States. Tonight, over one-half million men, women and children will either sleep in a shelter or on the street in the United States (U.S. Department of Housing and Urban Development [HUD], 2016). These numbers continue to fluctuate despite the 2 billion dollars a year infrastructure designed to address the problems associated with homelessness. This leads one to wonder, "What are the fundamental components that prevent individuals from escaping homelessness?" Nurses and advanced practice nurses have been or will be expected to provide care to those experiencing homelessness and can play an important role in targeting interventions specific to the unique needs of the homeless.

Since the early 1980's, considerable research has focused on the causes of homelessness, not only in the United States but also in the United Kingdom (Jahiel, 1992; Ropers, 1988; Rossi, 1994; Toro & Warren, 1999; Wagner & Gilman, 2012; Wasserman & Clair, 2014). These studies have raised important discussions about why certain individuals were at risk for becoming homeless. Several debates about the population estimates and growth have also stemmed from this research. Although these social and policy issues are important, nurses are concerned about the health of the persons involved. Little research has focused on the daily lives and struggles of homeless individuals and the effects of these challenges on the physical and psychological health among the homeless.

Without having a better understanding of this unique culture, interventions can

only be based upon assumptions about how to resolve homelessness. In order to resolve homelessness in the United States, many metropolitan areas have taken an approach called "housing first", which moves the homeless person into housing immediately (Byrne et al., 2015; Lariner et al., 2009; Montgomery, 2013; National Alliance to End Homelessness [NAEH], 2006). Not to minimize the importance of having shelter, but healthcare professionals must first understand how other factors operate during the time of being homeless. Homeless people have a range of problems that include substance abuse, mental health, and chronic health problems; therefore, they live their lives in ways that respond to their vulnerability (Anderson & Christian, 2003). Understanding how homeless individuals live their lives will not prevent others from becoming homeless; however, researchers will be able to conceptualize a better plan of action, and design appropriate health services tailored to the specific needs of this vulnerable population.

#### 1.2 Background and Significance

Homelessness first began to gain attention in the early 1980s. Between 1982 and 1983, the United States experienced a recession that dramatically increased unemployment, which led many Americans into poverty (Nowalk, Tucker, Addis & Zelman, 1998). Many people interpreted the increase in homelessness to be a short-term problem, but even with the economic growth in the late 1980s, homelessness did not disappear or even slow in growth (Nowalk et al., 1998).

Individuals from all segments of society are affected – the old and young, men and women, single persons and families, whites and minorities (HUD, 2016; Tarrant County Homeless Coalition [TCHC], 2016). In the 1990's, researchers identified a subpopulation, the chronically homeless. Approximately 80% were found to exit from

homelessness within about two weeks (Culhane, Chang-Moo & Wachter, 1996; Gaetz et al., 2014). They often had more personal, social, and economic resources than other homeless individuals. About 10% were homeless for up to two months; this was a result of time waiting for housing availability and affordability. Around 10%, however, were homeless for over a year (Culhane et al., 1996; Gaetz et al., 2014). This subgroup that tends to be the most visible began to be referred to in the literature as the chronically homeless (Culhane & Kuhn, 1997). More recently, government agencies have documented that the chronically homeless represent only a fraction of the homeless population, but they use the majority of the public resources available (Texas Interagency Council for the Homeless [TICH], 2011)

At least 2.3 million people, and possibly as many as 3.5 million, experience homelessness at some point during an average year (HUD, 2016). HUD's most recent point in time count found that on a single night in January 2016, there were 549,928 homeless people in the United States (HUD, 2016). HUD estimated that five states accounted for nearly half of the United States' total number of homeless individuals, which were California, New York, Florida, Texas, and Washington (HUD, 2016). Luckily, most individuals only experience homelessness for a short term and exit with little assistance. However, for about 100,000 people, homelessness becomes a way of life (HUD, 2012; HUD, 2016; NAEH, 2016).

Poor health is closely associated with homelessness. The rates of both chronic and acute health problems are high among the homeless population (Morrison, 2009; Strehlau et al., 2012). Homeless individuals experience barriers to the most basic needs such as shelter, food, clothing and access to health care (Zlotnick, Zerger & Wolfe,

2013). Conditions associated with homelessness have a profound effect on one's ability to maintain good health, to access treatment when one's health is compromised, and to recover even after treatment is received. For individuals experiencing homelessness, having access to a healthy diet is difficult due to lack of access to prepare food or funds to buy food (Canavan et al., 2012). Even the ability to stay clean and avoid infections is difficult without access to appropriate facilities. Sleeping in dirty, accommodations infested with rodents and insects, or out on the streets in the weather presents obvious risk to health and well-being.

The chronically homeless have to overcome many barriers in order to receive appropriate health care. Previous research found that the chronically homeless were more likely to be admitted to the hospital and to have increased length of hospitalization (Ku, Scott & Pitts, 2010; Cheung & Hwang, 2004; Hwang, Aubry & Hock, 2011; Martell, Seitz & Harada, 1998). Even though the homeless have similar health care problems as the general public, they have fewer encounters with ambulatory care for their health problems as compared to the non-homeless individuals (Fischer et al., 1986; Ku et al., 2010). As a result, the homeless tend to have chronic illnesses, which are poorly controlled. At the end of the day, health care among the homeless competes with more immediate needs such as obtaining adequate food and shelter (Gelberg, 1997; Zlotnick et al., 2013).

Homelessness itself is associated with increased mortality. In a classic study done in New York City, Kuhn found that the age – adjusted mortality rates for homeless men and women were approximately four times greater than those found in the general population (Kuhn & Culhane, 1998). Individuals experiencing homelessness have been

estimated to have three to five times higher rates of mortality than the general public (Cheung & Hwang, 2004; Hwang, Weaver, Aubry & Hock, 2011). Morrison (2009) found that homelessness itself was associated with an all-cause mortality hazard ratio of 1.6. Given the high rates of disease, morbidity and mortality, providing appropriate care is critical for improving the health of the homeless population.

Few qualitative studies of the lived experience among the homeless have been published. The majority of qualitative studies with the homeless focus on residents in a particular shelter (Banyard, 1995; Fogel, 1997), those with specific medical diagnosis under treatment (Cheung, 2002), or participants in specific programs directed toward the treatment of a disease (Dunford, 2006). Some studies of the lived experiences of being homeless have involved primarily children or women with children (Baumann, 1994; Deforge et al., 2001; Farkas & Yorker, 1993).

A better understanding of the characteristics and service needs of the chronically homeless is essential in order to identify future prevention or intervention strategies. Health care providers, nurses, and policymakers should not assume that care can be delivered the same way to the homeless as to the general public. Unique barriers may exist among the homeless, which have to be considered in order to maximize their health. Resolving homelessness, especially for persons who experience it on a long-term basis, is much more complex than just providing a place to live. Without adequate health, escaping the cycle of homelessness may be impossible.

Consequently, there was a need to study the experience of illness as it relates to being homeless. This phenomenological study addressed this gap in knowledge. This study described, through the stories of homeless persons, what it is like to live with an

illness while experiencing homelessness. It also examined the numerous barriers homeless individuals face in accessing both preventative and routine medical, mental health and substance treatment services.

#### 1.3 Philosophical/Theoretical Perspective

The purpose of the study was to understand the experience of illness in the context of being chronically homeless. This study did not use a specific theoretical framework or model of illness to examine the illness experience of the chronically homelessness. Rather than approach the illness experience with a theoretical framework, the experience was inductively determined from the data using a phenomenological approach.

This study was guided by descriptive phenomenology. This qualitative methodology uses unstructured, in depth interviews to collect data. According to Gerhardt (1990), understanding the illness experience can best be achieved by "providing authentic data, namely, collecting and displaying evidence on the experiential side of how illness and its treatment affect a person" (p. 1149).

The Oxford English Dictionary (2016) describes phenomenology as: (a) The science of phenomena as distinct from being, (b) That division of any science which describes and classifies its phenomena. So, in it's root meaning, phenomenology is the study of phenomena literally as opposed to reality. Phenomenology is the study of structures of consciousness as experienced from the first–person point of view. Phenomenology research describes experiences or phenomena as they are lived or in phenomenological terms, to capture the "lived experience" of the participants.

Phenomenology began as a movement in philosophy in the nineteenth century by

Franz Brentano. Brentano introduced the concept of phenomenology in a lecture in 1889 in which he used the term phenomenology as a synonym for descriptive psychology (Moran & Mooney, 2002). According to Brentano, every mental phenomenon, or act of consciousness, is directed toward some object, and only mental phenomena are so directed (Brentano, 1995).

Although Brentano introduced the concept of phenomenology, Edmund Husserl is more commonly known as the founder of phenomenology (Moran & Mooney, 2002). Phenomenology, as known today was launched by Husserl in his logical investigations. In Husserl's' (1963) work, two different types of theory came together: a psychological theory and a logical theory.

For Husserl (1963), phenomenology integrates "a kind of psychology with a kind of logic". It develops a descriptive or analytic psychology in that it describes and analyzes types of subjective mental activity or experience, in short, acts of consciousness. However it also develops a kind of logic in that it describes and analyzes objective contents of consciousness. These components of content are sharable by different acts of consciousness, and in that sense, they are objective, ideal meanings (Husserl, 1963).

Husserl (1989) developed his ideas about phenomena in an effort to resolve the conflict in thought between the human sciences and the basic sciences. Phenomena are the world of experience. These phenomena cannot be explained by only examining the causal relations. Phenomena only occur when someone experiences the phenomenon. Thus, the experience must be described, not studied using statistics.

Phenomenology as a methodology is typically divided into either descriptive or hermeneutic. Husserl claims descriptive phenomenology "describes what is given to us

in immediate experience without being obstructed by pre-conceptions and theoretical notions". Husserl's phenomenological method purports to offer pure description. Giorgi and Giorgi (2003) state that the method of Husserl is "descriptive in the sense that the end result of the analytical process is a description of the structure of the experience provided by the participants" (p. 245). Hermeneutic phenomenology is "a descriptive methodology because it is attentive to how things appear and it is an interpretive methodology because it claims that there are not such things as uninterrupted phenomena" (van Manen, 1990, p. 180). As van Manen states, there is no uninterpreted phenomenon or no purely descriptive account of an experience. The notion of phenomena as already interpreted can be further understood as how the facts of lived expedience are already meaningfully hermeneutically experienced (van Manen, 1990). Therefore, hermeneutic phenomenology provides both descriptions of the life world as lived and descriptions of the meaning of the life world as expressed in a symbolic form (van Manen, 1990).

The purpose of this descriptive phenomenological study was to understand the experience of illness in the context of being chronically homeless. This approach provided an insider's perspective. A qualitative method, like phenomenology, focuses:

...directly and explicitly on the subjective experiences of living with and in spite of illness. It focuses specifically on the perspective of people with illness and attempts to examine the illness experience in a more inductive manner. (Conrad, 1990, p. 1260).

The understanding of the illness experience focused on the individuals with illness rather than on the sick people as patients.

The purpose of this study explored the experience of illness in the context of

being chronically homeless through descriptive phenomenology. Phenomenology allows the researcher to approach the experience by going to it directly by, approaching those individuals who have experience with the phenomenon under investigation. Most of the daily management of an illness takes place at home and is performed by the individual themselves (Royer, 1995). Therefore, it was important to explore an individual's experiences of illness as an element of their everyday life.

#### 1.4 Study Question

The research question for this study was: "What is the experience of living with an illness while being chronically homeless?" The specific aims of this study were:

 To uncover the essential aspects of the illness experiences of chronically homeless individuals including: a) living with illness in everyday life; b) utilization of shelters; c) working with health care providers and nurses; and d) accessing the health care system.

#### 1.5 Assumptions

For this descriptive phenomenological study, one assumption was that individuals who experience chronic homelessness were able to describe their experiences with illness. These participants were able to describe their experiences with the health care system. They shared experiences common to other individuals who experience homelessness. The participants had some strategies for survival that may be unique to the social, political and cultures context in which they live. Finally, an assumption was made that they responded honestly to the researcher's questions and provided accurate insight into the experience of illness.

#### 1.6 Summary

Fortunately, most individuals only experience homelessness for a short time, exit with little assistance, and do not experience homelessness again. However, for some individuals, chronically homeless becomes a way of life. Even though the chronically homeless represent a small percentage of the total homeless, they utilize a disproportionate amount of resources available to the homeless. Despite this extremely high use of resources, the chronically homeless have poor psychological and physiological outcomes.

Researchers, health care professionals, social service providers, states and local leaders have been able to agree upon one aspect of the homeless. No matter what subgroup, the numbers of homeless individuals are steadily growing. While further research may eventually identify strategies to end homelessness, the health care provider must be informed to provide appropriate health care now. The first step begins with having a better understanding of the experiences of homeless individuals and the meanings they ascribe their illness experiences may lead to changes in current practices. Without this information, it is impossible to construct a program that provides appropriate care while addressing the root causes of homelessness.

#### **CHAPTER II**

#### 2.1 Introduction

The multitude of challenges faced by individuals experiencing chronic homelessness leads to worsening health conditions and an overall increase in premature mortality. The increased cost associated with the chronically homeless has not resulted in a decrease in this subgroup among the homeless. Studies have found that the chronic homeless cost the public between \$30,000 and \$50,000 per person per year due to their inappropriate use of emergency rooms, hospitals, jails and other crisis services (Culhane, 2002; Linkins, Brya & Chandler, 2012; United States Interagency Council on Homelessness [USICH], 2014). Because of the cost in lost human lives and the waste of public dollars, understanding the experience of illness in the context of being chronically homeless is a moral and fiscal imperative. Only with this understanding can appropriate future programs be developed.

To prepare for this qualitative research study, a thorough review of both research and lay literature was conducted. Searches conducted within nursing, sociological, and psychological databases resulted in a limited number of relevant articles for the study. Quantitative and qualitative articles were included from a variety of disciples including nursing, medicine, sociology, psychology and public health. The majority of qualitative studies with the homeless were outdated. These studies focused on residents in a particular shelter (Banyard, 1995; Fogel, 1997), those with specific medical diagnosis under treatment (Cheung, 2002) or participants in specific programs directed toward the treatment of a disease (Banford, 2006). The studies of the lived experiences of being homeless have mainly involved either children or women with children. However, most

of what has been written about the homeless has been primarily quantitative in nature, obtained from surveys and questionnaires. This review of literature reflects the limited sources available including the very few publications in the past five years. The lack of current research provides evidence of the need for future research.

The literature review is organized into three sections. The first section describes homelessness in terms of societal issues. This includes definitions, risk factors, prevalence's and cost to society. The second section describes homelessness in terms of health issues. The final section reviews all qualitative articles that were found on both short term and chronically homeless. The literature review provides a foundation to understand the lived experience of the homeless as well as again supporting the need for further research.

#### 2.2 Homelessness as a Societal Issue

#### 2.2.1 Definition

The definition of homelessness has been a cause for debate. There has been great debate over developing an acceptable definition for the homeless. Most definitions pertain to the population, not to the problem. Using the common-sense approach, one would find in the Oxford English Dictionary (2016), homeless is defined as "having no home or permanent shelter". The ambiguity of what exactly is meant by the terms "home" and "permanent" renders the definition of limited use. According to this definition, a shelter built by a homeless individual could easily have areas for sleeping, cooking and bathroom facilities, thus qualifying the structure as a home within the dictionary's definition.

Historically, some researchers have attempted to develop a conceptual definition

of homelessness. For example, Rossi (1989) states "homelessness, at its core, means not having customary and regular access to a conventional dwelling; it mainly applies to those who do not rent or own a residence" (p. 28). Baxter and Harper (1981) define homeless as "those whose primary nighttime residence is either in the publicly or privately operated shelters or in the street" (p. 36).

The United States federal government promotes a broader view of homelessness.

The U.S. Department of Housing and Urban Development (HUD) defined a homeless person as:

...someone who was (a) sleeping in an emergency shelter; (b) sleeping in places not meant for human habitation, such as cars, parks, sidewalks or abandoned or condemned buildings; (c) spending 30 consecutive days or less in a hospital or other institution, yet ordinarily sleeping in the already mentioned types of places; (d) living in transitional/supportive housing but having come from streets or emergency shelters; (e) being evicted within a week from a private dwelling unit and having no subsequent residence identified and lacking the resources and support networks needed to obtain access to housing; or (f) pending discharge from an institution and having no subsequent residence identified and lacking the resources and support networks needed to obtain access to housing (HUD, 2016, p. 2).

The federal government's definition of chronic homelessness, which is used in policies and programs adopted by HUD, Health and Human Services (HHS) and the Veterans' Affairs (VA), "is an unaccompanied homeless individual with a disabling condition who has either (a) been continuously homeless for a year or more or (b) has had

a least 4 episodes of homelessness in the past three years" (HUD, 2016). Many states and programs have expanded this definition to also include families. For example, the Homeless Emergency Assistance and Rapid Transition to Housing (HEARTH) Act of 2009 expanded the definition of chronic homelessness to include families, although they represent only a small fraction of the chronically homeless population (Culhane & Byrne, 2010). The definition of disabling conditions also varies among groups. Some agencies include severe and persistent mental illness, severe and persistent alcohol and drug abuse problems, and HIV/AIDS in their list of disabling conditions (TICH, 2011).

#### 2.2.2 Risk Factors

Few long-term studies of the course of homelessness have been conducted. However, the data that are available indicate those who are homeless for long periods of time are older in age, persistently unemployed, have poor family support, and poor coping skills (HUD, 2011; HUD, 2012). Canton et al. (2005) reported that the most important predictors of chronic homelessness were older age and arrest history.

The limited research available indicated that individuals who often experienced chronic homelessness had psychological, physical or social problems. The persons who became chronic homeless has not changed much in the past decade (Fagan, 2016).

Disabilities resulting from behavioral health, substance abuse or health related comorbidies were reported with high rates among the chronically homeless (HUD, 2011; HUD, 2016).

Lifetime mental health problems have been reported in over 60 percent of chronically homeless (Greenberg & Rosenheck, 2010; Levitt et al., 2009). According to HUD's 2016 Annual Homelessness Assessment Report, 1 in 5 people experiencing

homelessness had a severe mental illness. Edens et al. (2011) found that chronic homeless individuals (n=1,430) receiving housing assistance reported 4 times the national rate of depression, 18 times the national rate of schizophrenia and even higher rates of bipolar disorder. However, one has to remember that many people in society experience mental health and substance abuse problems and never experience homelessness. Because researchers have not explored when the substance abuse and mental health issues of their subjects began, it is not known whether these factors precipitated or contributed to the person being homeless or whether they were coping mechanisms of the chronically homeless.

#### 2.2.3 Prevalence

The prevalence of chronic homelessness varies depending on the definition used, the duration of time observed, and the method of data analysis. Most methods include either point-in-time counts, literally counting all people on a given day or during a given week, or period prevalence counts, counting the number over a given time period. Some people will find housing and escape homelessness while new people will lose housing and become homeless. For these reasons, point-in-time counts are often criticized as misrepresenting the magnitude and nature of homelessness due to this "snapshot" picture. Other issues affect national estimates of homeless Americans. Many people are not counted because they are not in places where the researchers will collect data. A national study found the most common places people who were homeless stayed were vehicles (59.2%) and makeshift housing (24.6%) (Link et al., 1995). Factors such as these suggest many attempts to estimate the prevalence of homelessness in America may have significantly under estimated the number of homeless persons.

In January 2016, a point-in-time count estimated approximately 549,928 people experienced homelessness on any given night in the U.S. (HUD, 2016). Of this count, 68% (n=373,571) were living in shelters while 32% (n=176,357) were unsheltered. Individuals who were homeless accounted for 65% (n=357,453) while 35% was composed of families (n=192,475). Overall the chronically homeless accounted for 15.8% (n=99,894) of the count (HUD, 2016).

An adult living in the USA has a 1 in 201 chance of becoming homeless (HUD, 2011). Members of minority groups have a higher risk of becoming homeless than being diagnosed with cancer. Veterans have a substantially higher risk of becoming homeless than the rest of the population (HUD, 2016).

According to HUD (2016), California accounted for more than 1 in 5 homeless people in the United States or 22%. Five states accounted for nearly half of the nation's total homeless population: California (22%), New York (16.0%), Florida (6%), Texas (4%) and Washington (4%). From this count, there were 27 states with less than 1 percent of the nation's homeless population. Together, these states accounted for only 11.4% of all homeless people in the United States (HUD, 2016).

Table 2.1 States with higher proportions of homeless persons

State	% of Nation's Population	% of People Under Poverty Level	% of Nation's Homeless Population
California	12.15%	13.2%	22%
New York	6.11%	14.5%	16%
Florida	6.38%	11.1%	6%
Texas	8.62%	16.2%	4%
Washington	2.26%	14.1%	4%

(HUD, 2016; U.S. Census Bureau, 2016)

On a single night in January 2016, a statewide count in Texas found 23,678

individuals were experiencing homelessness (HUD, 2016). These individuals were living in shelters, cars, under bridges and other places not intended for human habitation (TICH, 2015). Approximately 9 individuals out of every 10,000 persons in Texas are homeless. (HUD, 2016). The study also found that 6.3% of the state's homeless population or 3,778 individuals were chronically homeless (HUD, 2016).

The Tarrant County PIT count of 2016 reported that at any point in time approximately 1,985 individuals are homeless (Tarrant County Homeless Coalition [TCHC], 2016). This number represented a 3.7% increase from the 2015 PIT count. The annualized number determined that over the next year 6,706 individuals will experience homelessness in Tarrant County (TCHC, 2016). Of the homeless in Tarrant County nearly 1 out of 3 are children, 1 in 5 are women with children, and over 1 in 6 are veterans.

Overall, about 20% of sheltered homeless adults would qualify as chronically homeless, according to the federal definition (HUD, 2016). The literature on the phenomenon of homelessness is dated. Kuhn and Culhane (1998) studied shelter utilization patterns in New York and Philadelphia. They determined approximately 10% of individuals staying in the shelter were chronically homeless. Another 10% where episodically chronically homeless, moving in and out of shelters, hospitals, jails and treatment centers. Burt (2001) also found similar results from cluster analysis from the NSHAPC study, determining that about 27% of the homeless population had an average duration of homelessness in excess of four years.

#### 2.2.4 Cost Associated with Homelessness

The availability of adequate access for homeless individuals is unknown. What is

known is that homeless individuals experience poor access to health care. This contributes to uncontrolled chronic medical conditions and a delay in accessing care for acute problems. The homeless are forced to rely on emergency departments for access to care which results in higher rates of hospitalizations, often for preventable conditions. This inappropriate utilization of care only results in extraordinarily high cost.

Culhane et al. (2002) found that, before placement into supportive houses, 4,679 homeless individuals used about \$40,451 per year per person in community services.

More than 85% of this cost was associated with health care and mental health services, primarily care delivered in hospital settings. This was the largest study to compile such data; however, smaller studies have found similar results.

In Portland, Oregon, a study of 35 chronically homeless adults found that an average of \$42,075 was spent per year per person for health care (Moore, 2006). More than 80% was spent for inpatient hospitalizations for medical care and emergency room visits (Moore, 2006). A study of Denver's Housing First Collaborative Program found that cost of health care services per individual resulted in a cost of \$17,381 per year. Inpatient or emergency room care was associated with 90% of this cost (Perlman & Parversky, 2006).

In Boston, 119 persons who experienced chronic homelessness had more than 18,000 emergency room visits over a five-year period, with an average cost of \$1,000 per visit (United States Interagency Council on Homelessness, 2007). Researchers in Asheville, North Caroline reported that, over a period of three years, 37 homeless men and women cost the city and county more than \$800,000 each year. This included 280 episodes of emergency medical services (EMS) for \$120,000 and \$450,000 in

hospitalization costs (Chaplan, 2007).

Other researchers have shown that homeless individuals who have an addiction to alcohol over-utilize health care resources, police interventions, and detoxification services. In San Diego's Serial Inebriate Program (SIP), charges for ambulance and hospital care over a four-year period totaled \$17.7 million, more than \$8,000 per year per client with alcoholism (Dunford et al., 2006). An older study conducted among the homeless who were frequent users of detoxification services had similar findings. Cox et al. (1998) found that medical charges for 298 homeless individuals averaged more than \$2.5 million per year during the three year study. In today's economy the cost is equivalent to \$8,000 per person.

The cost of homelessness in Tarrant County was conservatively estimated as \$30,918,884 in 2007 (Cardarelli, Carlson, Jackson & Ward, 2008). Approximately \$5,595,771 in local tax dollars was spent reactively on the health care cost of the homeless (Cardarelli et al., 2008). In 2007 alone, the 10 most expensive homeless patients at John Peter Smith Hospital, the county supported hospital, cost taxpayers more than \$508,034 or \$48,736 per person (Cardarelli et al., 2008; Mayor's Advisory Commission on Homelessness, 2008).

#### 2.3 Homelessness as a Health Issue

#### 2.3.1 Health Conditions

Poor health is closely associated with homelessness (Fazel et al., 2008; Levitt et al., 2009; National Health Care for the Homeless Council [NHCHC], 2011). The conditions associated with homelessness have a profound effect on an individual's ability to maintain good health, obtain adequate access to care, and recover even after the

treatment is delivered. Consuming an adequate diet is difficult with lack of access to cooking facilities and no funds to buy food. The impact of nutritional deficits on homeless people alone can be life threatening (Ontario Association of Food Banks [OAFB], 2014). Staying clean in order to avoid skin infections can be difficult without access to appropriate bathing facilities. Sleeping in dirty, overcrowded shelters or out on the streets, exposed to the elements, presents obvious risk to health and wellbeing (Jackson & McSwane, 1992).

The rates of both chronic and acute health conditions are extremely high among the homeless population (Morrison, 2009; Strehlau et al., 2012; NHCHC, 2011). Health conditions of the homeless either exist prior to, or in some cases contributed to becoming homeless, or for others resulted from being homeless. Whether preexisting or occurring as a result, the health problems commonly found among the homeless are generally exacerbated by homelessness. For example, boils, ulcers and pneumonia are frequent, often the direct result of the living conditions associated with homelessness. Homeless individuals are also at greater risk of trauma from muggings, beatings, and rape (National Coalition for the Homeless, 1999; Hawng, Gososis & Dunn, 2011; Woolley, 2015).

The most common acute illness in the homeless population are upper respiratory infections, trauma, and skin problems (Lindsey, 1989; NHCHC, 2011; Woolley, 2015). Upper respiratory infections are often endemic among the homeless (McMurry-Avila, 2001; Woolley, 2015). Skin infections from scabies and lice are also often found among the homeless (Gelberg, 2000; Woolley, 2015). Homeless children are particularly vulnerable. Research has shown that homeless children have twice as many ear infections, 4 times as many respiratory infections, and a 4 times greater likelihood of

asthma as compared to children who are not homeless (National Center on Family Homelessness, 2008).

Lacerations and wounds are the most common traumas followed by sprains, bruises and fractures. Homeless individuals are at a greater risk than the general population from muggings, beatings and rape (National Coalition for the Homeless, 1999; Hwang et al., 2011). Wright (1990) found that homeless persons are 2 to 6 times more likely to be injured than individuals who are not homeless. These acute illnesses account for approximately two thirds of health conditions in which homeless persons present for care (McMurray-Avila, 2001).

The most common chronic disorders in the homeless population reported in the literature are hypertension, dental, gastrointestinal disorders, and neurological problems (Wright, 1990; NHCHC, 2011; Woolley, 2015). Gelberg (2000) found that of homeless adults diagnosed with hypertension, fewer than half of who were currently taking medication. Mason, Jenson and Boland (1992) reported that the most frequently identified chronic health issue was joint problems followed by cardiovascular diseases. Among the homeless, chronic physical conditions account for approximately 1 and 3 of the medical conditions in which the homeless individual's presents for care (McMurray-Avila, 2001).

Homeless individuals are at a higher risk for infectious diseases such as hepatitis, tuberculosis and HIV (Cheung et al., 2002; Robertson, et al. 2004; Stratigos & Katsambas, 2003; Woolley, 2015). Some infectious diseases may have been contracted while homeless due to crowded shelters, rape, or exchanging sex for survival needs (McMurray-Avila, 2001). The literature has shown the prevalence of tuberculosis to be

between 9% and 79% with the prevalence of active tuberculosis to be between 1.6% and 6.8% (Raoult et al., 2001). A San Francisco study found that HIV seroprevalence was greater among homeless individuals than in the city overall (Robertson et al., 2004). A New York City study of the health of sheltered homeless individuals reported that the death rate from HIV/AIDS was 9 times higher among sheltered single women than the general populations (Kerker et al., 2005). Among the homeless population, approximately 20% have some communicable disease (McMurray-Avila, 2001).

An estimated 20% to 25% of the homeless report having experienced some form of mental illness (Koegle et al., 1996; Reinking et al., 2001; HUD 2016; Woolley, 2015). Burt (2001) found that 43% of homeless people in the United States have some form of mental illness. Research among the homeless has found an unusually high incidence of mental illness, however some researchers find some of these findings questionable (Snow et al., 1996). Some conditions, such as depression, may be a result from or exacerbated by homelessness (McMurray-Avila, 2001). Some of these behaviors may be an adaptive response to the rigors of life among the homeless (Snow et al., 1996).

Smoking is more common among homeless populations and prevalence may be as high as 80% (Heffron et al., 1997; Holohan, 2000; National Coalition for the Homeless [NCH], 2009). Homeless people tend to practice few risk-reduction behaviors, and often engage in high-risk behaviors. This leads to high rates of alcoholism and drug dependencies among the homeless (Hwang, 2011).

The two most common reported illegal drugs were heroin and cocaine (Fountain, 2002; Lempens & Barendregt, 2003; Hwang, 2011; National Institute of Health [NIH], 2013; NAEH, 2016). Some studies have reported that up to 80% of homeless individuals

report chronic alcohol or drug problems (Canton et al., 2007; NCH, 2009). Foutain (2002) found that 39% of those who had been homeless for one year or less had used heroin in the last month, compared to 49% of individuals who had been homeless for over 10 years had used heroin in the last month.

Homelessness itself is associated with increased mortality as might be expected due to the health issues identified in the review (Table 2.2). In a classic study done in New York City, Kuhn found that the age adjusted mortality rates for homeless men and women were approximately 4 times greater than those found in the general population (Kuhn & Culhane, 1998). Individuals experiencing homelessness have been estimated to have 3 to 5 times higher rates of mortality than the general public (Cheung & Hwang, 2004; Hwang, Weaver, Aubry & Hock, 2011). Morrison (2009) found that homelessness itself was associated with an all-cause mortality hazard ratio of 1.6. Given the high rates of disease, morbidity and mortality, providing appropriate care is critical for improving the health of the homeless population.

Table 2.2 Health problems of individuals who are homeless as documented in the literature

Category	Prevalence among the homeless	Preexisting, resulting or exacerbated by homelessness	Commonly seen conditions
Acute Illness	Approximately 2/3 of health conditions	Often direct result of homelessness	Respiratory infections, laceration, dental infection, pneumonia
Communicable Disease	Around 20% have some communicable disease	Some infections like HIV may lead to homelessness. Others often contracted during homelessness	Lice, Scabies, STD's, Hepatitis, HIV

Mental Health	20 to 40 % many have some form of mental illness	Often occur prior and may be cause of homelessness. Other forms may result after homelessness such as depression/anxiety	Depression, schizophrenia, bipolar disorder, anxiety
Substance Abuse	Reports up to 80% of alcohol and drug abuse	Homeless tend to engage in high risk behaviors	Cocaine and heroin tend to be most common abused illegal drug

#### 2.3.2 Access of Health Care

As previously discussed, homeless individuals often use the emergency department for their health care needs. Homeless participants have reported that hospital emergency rooms are the most common site in which they seek health care due their lack of access to other types of health services (Adams et al., 2007; Berne et al., 1990; Caton, Wilkins & Anderson, 2007). Homeless people are forced not to seek health care until symptoms seriously affect their lifestyle or daily living activities. They then turn to the hospital emergency rooms where the focus is crisis oriented, and health promotion and disease prevention are lacking. In an older study, Berne et al. (1990), found that homeless children use emergency rooms at a rate of 2 to 3 times the rate of the general pediatric population in the United States. Other studies have found that the homeless used the emergency room 3 times more than the general population (Stark, 1992). In San Diego, Folsom et al. (2005) found that homeless patients with mental illness were 10 times more likely to use crisis residential treatment and 4 times more likely to use psychiatric emergency units than housed individuals (n=10,340).

The over utilization of health services reflected poorer access to appropriate and timely health care (Lim, Anderson, Leake, Cunningham & Gelberg, 2002; Verlinde et al., 2010). Therefore, the homeless often miss out on health promotion initiatives. Research has shown some progress with the younger homeless population in regards to direct services but little success was made with incorporating health promotion into health services. The lack of research indicates that the chronically homeless have been largely ignored. The barriers to health promotion that were identified several years ago, included little coordination or collaboration between health promotion agencies, few initiatives aimed specifically at homelessness and housings, homeless people feeling alienated from health promotion materials that often require high levels of literacy, and low self-esteem and low expectations preventing engagement with health promotion activities (Power & Health Education Authority, 1999).

#### 2.3.3 Barriers to Health Care

A number of small and larger studies were found that examined the barriers homeless individuals face (Caton et al., 2007). Some of these barriers included lack of available services, lack of transportation, cost of care, lack of knowledge, and waiting times for appointments (Canavan et al., 2012). Other homeless individuals identified a lack of trust in providers and coordinators as barriers (Canavan et al., 2012).

Available services are difficult for homeless persons to access. Emphasis on short term hospital care, health promotion, and disease prevention assumes one has the ability to pay for services and control over their environment. As a result, health care services received by homeless individuals were often crisis oriented (Canavan et al., 2012).

A Texas state wide survey conducted January 29, 2009 (n=10636), roughly a third

of the homeless population had insurance (THN, 2009). Only 34% of the respondents reported having coverage, but the survey included all individuals experiencing homelessness. The rate of insurance coverage of those experiencing chronic homelessness may be even lower. By comparison, 64% of individuals living under the federal poverty level during the same time reported having health insurance (Henry J. Kaiser Family Foundation, 2009).

Even when able to pay for care, a visit can be very difficult for a homeless individual. Waiting weeks to a year for an appointment prevents homeless individuals from accessing both preventative and routine medical care (Canavan et al., 2012). Homeless individuals often lack identification and sometimes are intimidated by forms and questions about health histories. Many facilities label these patients as "noncompliant", "dirty", or undesirable clients. These negative attitudes are often detected by the homeless individuals, and as a result they may avoid the process altogether (Canavan et al., 2012).

#### 2.4 Homelessness as a Lived Experience

The cost of crisis-related healthcare for the homeless is unacceptable and points to the need to better understand homelessness from perspective of the affected person.

Previous qualitative studies about the lived experience among the homeless are limited and were published over 10 years ago. As noted earlier, qualitative studies have been conducted in a single setting or treatment program or limited to women, children or persons with a specific medical condition.

Homeless children expressed many meanings and feelings about the lived experiences of being homeless. From a number of studies published between 1991 and

2003, themes emerged such as hope, safety, loss, and feelings of sadness. Others expressed feelings of being uncomfortable and experiencing a stigma about their living situation (Baumann, 1994; DeForge et al., 2001; Farkas & Yorker, 1993; Heusel, 1995). The children often discussed their embarrassment and shame of being homeless. There was an understanding among the children residing in the same shelter not to discuss their lives with others at school (Farkas & Yorker, 1993). The children expressed a strong fear of being ridiculed if their peers learned that they lived in a shelter (DeForge et al., 2001).

Many negative feelings of living in a shelter were identified among the children. They described living in a shelter as hard (Farkas & Yorker, 1993). The children described rules such as curfews which made life feel restrictive. The children perceived the feelings of being restricted as frustrating and difficult for them understand (DeForge, 2001). Another aspect of living in a shelter reported by the children was the lack of privacy associated with being homeless.

Children in all of the studies described violence as a day-to-day occurrence. Some had become accustomed to a life where violence was assumed. Heusel (1990) found that the children in her study feared gang fights and worried about harm coming to them or their family when they walked the streets.

The interviews did identify positive aspects of being homeless among the children. In addition to a place to eat and sleep, the shelter provided an opportunity to develop friendships (Baumann, 1994; Farkas & Yorker, 1993; Heusel, 1995). The friendships were described as fun and influenced their sense of responsibility for looking out for one another (Baumann, 1994). Another positive aspect discussed by the children was the relative safety provided by living in a shelter. These children may view this

experience as preferable to previous arrangements, especially if they experienced violence (DeForge, 2001).

The other samples of qualitative studies were mothers with children. From the review of the four studies about mothers caring for children, five themes emerged from the interviews. These themes included safety, loss, depression, stress, and survival strategies (Banyard, 1995; Fogel, 1997; Johnson, 1999; Menke & Wagner, 1997).

Fear for the personal safety of themselves and of their children due to their living situation was a persistent theme among the studies. The mothers often perceived the shelters to be a dangerous place. Others felt that they could not trust the other homeless individuals in the shelter. Homeless shelters were often located in neighborhoods with higher incidence of shooting, muggings, illegal drugs and vandalism (Menke & Wagner, 1997). Mothers in multiple studies expressed fears for their safety and their children while they were on the streets (Banyard, 1995; Fogel, 1997; Menke & Wagner 1997).

Upon entering the homeless shelter, many women expressed a feeling of loss. The main issue was losing their home. Because they lived in shared spaces, loss of privacy meant that feelings such as love, anger, and frustration had to be expressed around other residents and shelter staff (Banyard, 1995; Fogel, 1997; Johnson, 1999; Menke & Wagner, 1997). Others described the loss of freedom, which represented a loss of their previous lifestyle (Johnson, 1999). Rules of the shelters had to be followed, regardless of the context, leaving them with the feeling they had no other choice. Although mothers felt there were too many rules and regulations to follow, most agreed that the rules were needed to maintain order (Fogel, 1997). Others expressed feelings of loss related to losing the respect of family and friends. One mother's family labeled her as an unfit

mother due to the fact she had become homeless (Menke & Wagner, 1997).

In addition to their experiences, women in multiple studies reported feeling depressed and devastated about being homeless. They described having to contend daily with feelings of sadness, fatigue and frustration and depression (Banyard, 1995). Other mothers spoke of crying frequently. Some expressed that they had suicidal thoughts since becoming homeless, but did not act because of their children (Johnson, 1999).

Mothers often described varied survival strategies to help them cope with being homeless such as crying, smoking, walking, and trying to seek help (Banyard, 1995; Fogel, 1997; Johnson, 1999; Menke & Wagner). Many turned to religious practices and spirituality to cope with the stressors of being homeless. Prayer seemed to help relieve their burden of frustration. Prayer provided a source of comfort, feelings of not being alone and a feeling of being care for (Banyard, 1995; Menke & Wagner, 1997). Others looked to social support from other individuals. This included family, friends, shelter staff, and other shelter residents. In one study, shelter staff provided individualized counseling, parenting classes, and support group meetings (Fogel, 1997).

Many of the mothers had feelings of stress. This often left them with feelings of uncertainty, stress, helplessness and hopelessness (Banyard, 1995). Several mothers perceived themselves as not having any control over their future. Stressors were such problems as trying to find food for their children and worrying that something might happen to their children, such as an illness (Menke & Wagner, 1997). Others voiced stressors such as lacking transportation and living with so many people they did not know (Banyard, 1995).

The singular theme shared by the two studies conducted with men was feeling

rejected. These feelings were attributed to lack of support from families and friends, other homeless men, and other people in the community (Boydell et al., 2000). Some homeless men described others in the shelter as insensitive and untrustworthy. Others experienced rejection from people such as library staff and the police. They often felt this was due to their physical appearance. Lafuente and Lane (1995) discovered that seven of the participants claimed they had been jailed because of the police reacted to them negatively.

Lack of identity was described on two levels. The lack of a permanent address caused a lack of established identity (Lafuente & Lane, 1995). This loss of established identity also reduced the access to entitlement and right. Others described this loss on a more personal level - many had pride in their former identity which was now lost to them (Boydell et al., 2000).

Fear was expressed during some of the interviews. Some homeless individuals were concerned about catching a disease (Boydell et al., 2000). Others described a constant fear of not knowing when and where you were going to be mugged (Lafeunte & Lane, 1995).

Homeless men often described the theme of isolation. Feelings of being detached, alone, and dependent of others characterized their experiences of social isolation. Several individuals referred to themselves now as becoming introverted. Life on the street has taken away their desire to communicate with others and they keep their feelings and thoughts to themselves (Boydell et al., 2000; Lafeunte & Lane, 1995).

### 2.5 Summary

The experiences of obtaining access to health care from the perspective of the

homeless are largely unknown. What is known is homeless persons do experience higher rates of acute and chronic illness than the general population (Morrison, 2009; Strehlau et al., 2012). They experience poor access to health care that leads to a higher reliance on emergency departments for health care, which is often disease focused and lacks preventative interventions. This type of medical care only results in higher rates of hospitalization and poorer outcomes, which all come at very expensive price.

The review of literature has primarily focused on the lived experiences of being homeless among children and mothers. These individuals usually experience homelessness either episodically or only during a brief time. This experience is due in part that women and children frequently qualify for public assistance programs. Men are more likely to not be eligible for most safety net programs, so they may experience homelessness on longer basis.

The studies do provide valuable information about the lived experiences during the earlier stages of being homeless. However, the themes that emerged may be typical of anyone who had recently entered into homelessness. A new focus needs to include the lived experience of the chronic homeless. This unique subgroup among the homeless would provide a valuable understanding of the homeless culture. Fortunately, many who experience homelessness enter into and exit within a very brief time. For a small group, homeless becomes a way of life possibly due to choice or the lack of skills needed to exit homelessness. Without better understanding of health needs and culture of persons who are chronically homeless, effective, culturally acceptable interventions cannot be developed.

#### CHAPTER III

### 3.1 Introduction

This chapter consists of the research process that was used in this study. The purpose of the study was to describe the experience of illness in the context of being chronically homeless. The study focused on chronically homeless adult individuals. Chronic homelessness is an understudied phenomenon. Understanding the perspective of persons who experience chronic homelessness was an important next step to develop the evidence in this area

# 3.2 Research Design

Phenomenology was the qualitative methodology used to guide this study. Phenomenology offers a descriptive, reflexive, interpretive and engaging mode of inquiries in order to derive the essence of an experience (Van Manen, 1990). It is the method of choice when seeking to understand or make sense of a phenomenon. Also, phenomenology is not just a research method, but also a philosophy (Morse & Field, 1995).

Phenomenology is used as a qualitative research method to explore the lived experience of the research participants. Researchers explore the feelings and beliefs of these individuals involved in this unique relationship (Bassett, 2004). An attempt is made to understand another person's subjective experiences and feelings by studying his or her expressions. This field of expression may include speech, expression, gestures, and intonations (Bassett, 2004).

Insight into the phenomenon is gained though conducting intense dialogues with people about the meaning of the experience (Bassett, 2004). This method of inquiry

usually does not include predetermined research questions (Morse & Richards, 2002). The researcher typically follows the cues of the participant and the conversation proceeds thoughtfully. The purpose of this interview is to find out what is essential in order for the phenomenon to exist (Bassett, 2004). During the data collection process the research attempts to grasp an essence by reflecting on concrete experience, trying to imagine it from all aspects (Morse & Richards, 2002).

The descriptive phenomenological psychological method was used in this phenomenological study. This method is a five-step system of research, based on Husserlian phenomenology as its philosophical foundation (Giorgi, 1985). Giorgi (2009) modified Husserl's method in order for it to be useful in psychology because Husserl himself was a philosopher not a psychologist. Guided by Giorgi's method, researchers can implement studies with scientific rigor without being reductionistic. This method developed by Giorgi provides the scientific rigor while not being reductionist in its description of the persons it studies.

# 3.3 Setting

The research participants were recruited from a metropolitan city in North Central Texas of over 740,000 citizens (U.S. Census Bureau, 2010). On any given night over 2,000 individuals will be homeless, and more than 5,000 individuals will experience homelessness in this city each year (TCHC, 2013). Two nonprofit organizations primarily provide transitional housing for the homeless. There are other nonprofit and public programs that attempt to provide other types of resources such as health care, mental health services and assistance to overcome substance abuse to the homeless (TCHC, 2013).

## 3.4 Participant Selection

Data for this phenomenological study were gathered from adults who have experienced chronic homelessness. The sampling guideline proposed by Cooper and Schindler (2008) was used for the study: "keep sampling as long as your breath and depth of knowledge of the issues under study are expanding and stop when there is no new knowledge or insights "(p. 169). At this saturation point, the data became redundant, and without any newer emergent themes. According to Creswell (1998), a researcher might need to interview up to ten people to reach this "saturation" point.

The number of participants, or sample size, for this qualitative study, was given extensive consideration. With no strict requirements for the number of research participants, the exact number was based on saturation. The saturation point for this study was reached with a sample of 20 participants.

Only chronically homeless individuals were recruited for this study. The definition of chronic homelessness, adopted by HUD was applied as being, an individual who had either (a) been continuously homeless for a year or more or (b) had a least 4 episodes of homelessness in the past three years.

Criteria for inclusion in the sample were: (a) an individual who had experienced chronic homelessness as defined by HUD; (b) were at least 18 years of age; (c) were able to engage in a discussion using the English language; (d) had the cognitive ability to give informed consent; and (e) had experienced a health-related illness while being chronically homeless. Exclusion criteria were anyone who was acutely ill, inebriated, or under the influence of psycho-active drugs.

### 3.5 Recruitment Procedure

Obtaining research participants from this socially devalued population was challenging. For this reason, a purposive sample was used to obtain the participants (Burns, Grove & Gray, 2012). The principal investigator relied on his own judgment when he selected individuals to participate in the study. The principal investigator identified persons who met the study criteria and determined during the first meeting whether the person was appropriate for inclusion. The principal investigator believed a representative sample could be obtained by using sound judgement. These individuals provided the greatest insight and essential information about the lived experiences of being homeless. This sampling method allowed homeless individuals to be recruited who had the expertise to provide the experiences needed to address the purpose of the study (Burns, Grove & Gray, 2012).

Once a week, the principal investigator visited locations frequented by homeless individuals, such as city parks and public libraries. Any potential research participants were approached. The principal investigator explained the benefits of participating in the study that included the opportunity to "tell their lived experiences" as well as the \$10 Visa gift card for compensation of their time (Appendix A).

#### 3.6 Data Collection Method

There were three phases to the research study. The first phase was informing the participant about the purpose of the study and obtaining signed consent (Appendix B). The procedure of the study and the participant involvement were explained to the participant. The participant was informed that there would be no direct benefits for involvement in the research project, but the findings might inform future services how to help the chronically homeless.

Upon completion of the informed consent and agreement to participate, the participants were given a questionnaire. If the person was unable to read, the questionnaire was read by the principal investigator and completed with the investigator documenting the person's responses. Demographic information such as age, sex, level of education and years of being homeless was collected and used to describe the sample (Appendix D). Additional health care related questions were included to assess the general health status, types of health care services utilized and the efforts of preventative health care services.

The final phase of the study included the interview of the lived experience of illness while being chronically homeless. This description was the first-person account of the experience as it was lived and understood by the participant. Since no other person can co-experience the subjective-psychological perspective of any lived experience, the best and only record was within the memory of that individual. Therefore, a separate inperson interview was recorded with each of the participants about his or her experience.

The principal investigator conducted the interview with each participant. The interviews were held in a private room at a site convenient and comfortable for the participant and included the public libraries, local hospitals, and shelters. This allowed the participant assurance of privacy without interruption. The time of each individual interview depended on the engagement of the participant. There was no set length of time for each interview but none lasted longer than 60 minutes.

The interview consisted of unstructured, interactive interview process. This type of interview allowed the participant the opportunity to tell his or her story without the interruption of the principal investigator. Guidance was used during the interview to help

maintain conversation rather than interrupting the participant's flow of thought. Probes or questions were developed during the interview in order to learn about all aspects or to clarify responses during the interview (Appendix E). These probes were not purposefully "leading" in the sense of trying to "pull out" of the participant particular information.

Rather, the interviewing technique was intended to re-explore an aspect of the phenomena that was presented but not fully and expressly described by the participant.

# 3.7 Human Subjects Protection

The study was conducted in such a manner in order to protect the participant's human rights. All participants were at least 18 years of age. Individuals were excluded from the study that appeared to be incompetent and incapable of giving informed consent, or who were not alert and oriented to person, place, date and time.

The study began with obtaining informed consent (Appendix B). The participant was informed that this activity is a study, the purpose of the study, and an explanation of the study procedures. The principal investigator provided an explanation of the purposes of the research and the expected duration of the participant's involvement. There were no anticipated risk or discomforts associated with the interview. However, the principal investigator observed the participants for any signs of distress during the interview. If any concerns or problems had been noted, the interview would have been stopped. Any issues which could not have been resolved by the principal investigator would have been referred to appropriate individuals for counseling (Appendix C). The principal investigator would have stayed with the participant until a counselor was with the participant or the crisis was resolved.

There were no direct benefits to the participant in the research project. The

participants were informed that they could refuse or stop participation in the study at any time. The participants were assured confidentiality, with the understanding that some of the data would be published and/or presented at meetings without their name being associated with the information. Participants were then allowed time to ask questions about the study. Individuals that participated were given a copy of the informed consent, if they wanted one. The informed consent included a statement of their rights as participants and the names and phone numbers of contact individuals, in case, they had any questions about the study. Each individual was also given a list of services available to the homeless population within the county.

The interview was held in a private room at a site convenient and comfortable for the participant. The most common locations for this study's interviews was the public library. An interview code was assigned to the demographic data sheet, tapes and any notes taken during the interview to protect confidentiality. The principal investigator transcribed each interview. During this process, all personal identifiers were removed. The clean transcripts were used for the analysis. The demographic data were entered into a statistical analysis program and saved to a flash drive. The researcher maintained a master file in which all of the materials were organized.

The tapes, transcripts, demographic data, notes, and flash drive were stored in a locked cabinet. This cabinet was at the home of the principal investigator, accessible only to the investigator during the study. All transcripts were coded and kept separate from the informed consent forms. At the completion of this phenomenological study, the data will be retained at the University of Texas at Arlington, College of Nursing and Health Innovations and remain accessible for a period of three years.

## 3.8 Data Analysis

The data obtained from the demographic questionnaire included such information as age, gender, race educational level, and years of being homeless. Frequencies of the descriptive variables were calculated for gender, race and educational level. Measures of central tendency were determined by calculating the mean for continuous variables such as age and years of homelessness.

The phenomenological analysis was a process of reading, reflection and writing that enabled the principal investigator to transform the lived experience into a textual expression (Van Manen, 1990). The researchers gained insights into the phenomena by analyzing the data using the data analysis method developed by Giorgi (1970).

According to Giorgi (1970), individual elements of the phenomenon were identified: however; their importance was not established by the frequency of their occurrence but by the intuitive judgment of the researcher. Giorgi (1997) presented five basic steps: (a) collection verbal data, (b) reading of this data, (c) breaking data into smaller sections of text, (d) organization and expression of data from a disciplinary perspective, and (e) synthesis and summary of the data for purposes of communication to the scholarly community. These steps were followed to analyze the textual data.

The first step of the phenomenological method was for the principal investigator to assume the psychological attitude (Giorgi, 1997). The principal investigator began by analyzing the data by listening to an audio-tape and reading the related interview straight though to allow a sense of the whole. This immersion in the data allowed the researcher to reflect on the data in its entirety. Next, the principal investigator reread the same transcript again in a purposeful manner. Each sentence was examined for descriptive

expressions that might be identified as the core components of the phenomena of being ill and chronically homeless. These descriptive expressions were marked for continued analysis. These statements were rephrased until they could be described in a few sentences. The end result of this process was a series of meaning units or themes (Burns & Grove, 2008). The themes were then recorded.

The second step required the principal investigator to read the entire "naïve description" in order to get a sense of the whole experience (Giorgi, 2009). The "naïve description" was recorded from the participants in a way that he or she would experience things in their everyday experience. This was done without a critical reflection on the experience but from the commonsense perspective.

In the next stage the principal investigator examined the previously determined themes for redundancies, clarification, or elaboration by related themes to each other (Giorgi, 2009). This step allowed the demarcation of "meaning units" so that the data could be analyzed in manageable portions (Giorgi, 2009). These themes constituted the essence of the phenomena. Although some themes were common to all of the participants, others were not. The principal investigator reflected on the themes and extrapolated the essence of the experience for each participant. The use of quotes from the interviews as illustration provided a realistic and accurate portrayal of the lived experiences of being homeless. The time required for this portion of the study was 12 months.

Within the fourth step, the "meaning units" were transformed into psychologically sensitive descriptive expressions. Each transformation described what the "meaning unit" was as a psychological expression without any interpretation. It only described how

it was experienced and understood from the participant's point of view. It did not attempt to explain "why" it was experienced in the way it was by the participant.

The final step was the synthesis of the general psychological structure from the psychological constituents, or individual research participants, of the experience.

Constituents differed from the concept of elements because they were context dependent (Giorgi, 1985). Constituents were independent of each other but were a necessary part of the whole structure. The purpose of this procedure was grounded in the phenomenological concept of parts and wholes. This concept expressed the ideal that the "whole" of something were irreducible to its parts. The value of the whole was greater than the sum of its parts.

# 3.9 Summary

This study used a descriptive phenomenological approach in order to describe the lived experiences of illness while being chronically homeless. The interviews were audio recorded and transcribed in order for the researcher to become immersed in the data. The analyzed data was then coded and analyzed for emerging themes using Giorgio' method of phenomenological inquiry.

### **CHAPTER 4**

### 4.1 Introduction

The purpose of this study was to explore the experience of illness in the context of being chronically homeless. A descriptive phenomenology approach was used to explore the experience of the phenomenon under investigation. Conducting a qualitative study allowed the principle investigator to explore an individual's experiences of illness as an element of their everyday life.

The interviews were conducted by the principal investigator until no new information was obtained. The point of data saturation occurred after interviewing 20 chronically homeless individuals. Each interview lasted between 30 and 60 minutes. Each interview was audio taped and transcribed by the principal investigator. Each interview was reviewed and themes that emerged from the data were organized. The participants' tapes, transcripts, and questionnaires were labeled using a letter "A" followed by a number up to 20 (A1 through A20). The data was then transcribed using the participants' own words.

### 4.2 Demographic Data

The participants were primarily recruited on the streets outside of the nearby homeless clinic. Interviews were conducted with 20 English speaking participants. The participants in the study were all adults who were chronically homeless. All participants met the required inclusion criteria and provided verbal consent to be included in this research study.

Demographic information available from all 20 participants, are summarized in the tables below. Most persons were male (70%). The largest proportion of the sample was White followed by African American and Hispanic (see Table 4.1).

Table 4.1 Gender and Race of a Sample of Chronically Homeless Participants

Characteristic	Number (n)	Percentage
Gender		
Male	14	70%
Female	6	30%
Race		
White	12	60%
African American	5	25%
Hispanic	3	15%

Seventeen of the participants were single, divorced, widowed, or separated. Only three had a significant other, whether spouse or someone with whom they lived (Table 4.2). The majority had completed high school education or attended college. The remainder had less formal education than 12 years.

Table 4.2 Education Level and Marital Status of Participants

Characteristics	Number (n)	Percentage
Education Level		
Grade School	1	5%
Some High School	5	25%
Completed High School	9	45%
Some College	4	20%
Completed College	1	5%
Marital Status		
Single	6	30%
Divorced	7	35%
Widowed	1	5%
Married	1	5%

Living with Partner	5	25%
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Participants in this research study ranged in age from 35 to 70 years with a mean age of 49.75 years (see Table 4.3). All of the individuals that participated in this study have experienced homelessness on a continual basis. Time of homelessness ranged from 2 years to 36 years with an average of 8.7 years.

Table 4.3 Age and Years Spent Homeless of Study Participants

Characteristic	Number (n)	Percentage
Age		
(M = 49.75  years)		
20-29	0	0%
30-39	3	15%
40-49	7	35%
50-59	9	45%
60-69	0	0%
70-79	1	5%
Years Homeless		
(M = 8.6  years)		
0-5	10	50%
6-10	4	20%
11-15	1	5%
16-20	1	5%
21-25	3	15%
26-30	0	0%
31-35	0	0%
36-40	1	5%

As for health care coverage, 15 (75%) had some type of insurance. This coverage was either provided through the county hospital, their homeless program, or through some other funding source such as Medicare. All of the participants, 20 (100%), were aware of the county hospital and the services available.

Mental health problems and addictions often compound an individual's ability to access care. Of the participants in this study, only one (5%) had ever been hospitalized for mental health issues. However, ten (50%) admitted to having a mental health problem. Individuals who admitted to alcohol use accounted for seven of the participants (35%) while eight (40%) admitted to illegal drug use (see Table 4.4).

**Table 4.4 Mental Health Problems and Substance Abuse Reported by the Participants** 

Mental Health and Abuse	Number (n)	Percentage
Mental Health Problems		
No	10	50%
Yes	10	50%
Mental-Health Related Admissions to the Hospital		
No	19	95%
Yes	1	5%
Reported Alcohol Abuse		
No	13	65%
Yes	7	35%
Reported Drug Abuse		
No	8	40%
Yes	12	60%

Of the 20 participants, 14 (70%) reported having some underlying health-related issues. The remaining six (30%) were unaware of any medical problems. The two most common diagnoses were hypertension and hepatitis. Diabetes was a known problem for about 20% of the sample. Interesting, two participants identified autoimmune disorders with one have lupus and the other rheumatoid arthritis.

**Table 4.5 Health Related Issues of Participants** 

Health Related Issues	Number (n)	Percentage
Hypertension	8	40%
Diabetes Mellitus	4	20%

Hepatitis Infection	8	40%
Dental Problems	1	5%
Renal Disease	1	5%
Thyroid Disease	1	5%
Pulmonary Disease	1	5%
Immune Disease	2	10%

# **4.3 Qualitative Findings**

The data analysis process developed by Giorgi (1970) was utilized to review the audio-taped interviews. The principal investigator first began to analyze the data by listening to the audio-tapes. Next, each of the audio-taped interviews was transcribed verbatim. The immersion in the data allowed the principal investigator to reflect on the data in its entirety.

As the principal investigator reread the transcripts again, themes were identified as they emerged by examining each individual's interview. These themes were placed in Table 4.6. The themes were identified in order to describe what was the real meaning verbalized by the research participants.

Table 4.6 Themes Identified from Analysis of Interviews with 20 Chronically Homeless People

Themes	Sub-Themes
Trying to Survive	
	Earning a living in difficult times
	Finding housing I can afford
	Lack of support from family and others
Access to Healthcare	
	No way to pay for healthcare
	Inconvenient hours and says of available
	healthcare
	Transportation
Being Stigmatized	
	Perceptions of the public
	Perceptions of health care workers
Staying Healthy	
	Lack of preventative care

Obstacles to eating healthy

# 4.3.1 Theme 1: Trying to survive

# 4.3.3.1 Sub-theme 1: Earning a living.

Many of the participants recognized that the current economy was the sole reason they were in their current predicament. "If I had any money or at least a good paying job I would not be in the situation I am now. Having money is everything" (A17). What was most needed, in their opinion were higher paying jobs. "I make around \$400 per month and nobody is going to let me pay \$400 with bills paid for a place to stay" (A15). Without money, you are just "basically trying to survive" (A13).

However, most had come to realize that they would have to wait much longer than hoped for a job that paid enough to exit homelessness. "I work every day. Sometimes I work from six to six. But when you are making minimal wage – it does not add up to much. So, I'll just keep trying. I'll keep lugging away until a better job comes around" (A17). Even with technical training or education others found it difficult to find a job. Another participant verbalized that he has "skills but you take what you can get. Instead of like banging your head, you find different ways to go about embracing it" (A11).

Many mentioned that the lack of education, skills, and knowledge were keeping them from being a marketable employee, especially with fewer jobs available. "It wasn't until recently that everyone and their grandmother wanted you to have a high school diploma just to work in a warehouse or to wash dishes" (A17). This participant also recalled that, "they want to pick your brain. I'll give you an example. It was a custodial

job. They wanted me to do 50 math equations – for cleaning toilets. What do I need to do 50 math equations to clean damn toilets?"

Others made comments about their age. "When people see me they're not giving me any work. I'll be 59 soon and it's like they want to hire young people" (A17).

Another complained that temp services do not want to send out older people (A18). "You are the last person they'll send out. They'll send 20-year old's or 30-year old's out because they can do more hard work" (A17). The jobs available to the homeless were primarily daily labor jobs that are very physically demanding. One participant commented that he was "not able to do that kind of work because I have a jacked up back" (A1).

Several participants recognized, however, that the current economic situation was "not going to improve" so their possibility of exiting homelessness was slim. The research participants agreed that homelessness was tied to the economy. Without a stronger economy, participants felt homelessness would "continue regardless of how others help the homeless."

One participant complained that "Trump wants to decrease the minimum wage – I am never getting out of here" (A18). Another stated that he "went from making \$13 something to \$8 when the Mexicans came in and that eventually all jobs went away" (A1).

"Back in the old days you could walk in and ask for a job. Several times I would just walk into a restaurant and say "you need a dishwasher". They would say "well I'll try you". You don't get anything like that. Now a days you ain't doing that. The jobs are already taken" (A17).

When you are homeless you are "on the bottom of the pile man. They don't care if its flipping burgers or what man. It's like everything out there works against you" (A10).

# 4.3.3.2 Sub-theme 2: Finding housing I can afford.

For many participants, having access to housing was a barrier to maintaining health, especially when ill. The participants had no toilets, showers, washers or ways to store and prepare food. Many slept under bridges where they were exposed to the weather, while others took their chances at the shelters.

Participants acknowledged that not having permanent housing was "very stressful". One participant indicated he was often very drained and fatigued (A16). He explained that "I'm afraid to fall asleep and someone is gonna kill me when I'm asleep or something".

"You got to worry, there's danger at every hand. You know, either somebody wants to jump you and take the crap that you do have or somebody wants to jump you just for fun. And you think about those cases years ago, in New York where they were setting homeless guys on fire while they were asleep for fun...never have a sense of security" (A13).

Most of the participants choose not to stay in shelters. One man described the shelters by saying:

"There are a lot of bad things going down at the shelter. I don't drink or do drugs. I don't do that stuff. They know I'm not going to do anything with them so I'm already the outsider there. Not to mention the bed bugs and everything else that goes with that place. It's like they let the inmates run the jail -- it's – unbelievable" (A17).

The participants described the shelters as "being too cooped up" (A2, A6, A10, A18) and "always a lot of fighting and arguments – you just want to get away from all that" (A15) One participant provided the insight that the homeless shelters as being full of "young people in their twenties and thirties that are doing a lot of crack cocaine" (A18).

Some found it difficult to stay in the shelter "because of all the rules" (A18, A6, A8). "When you have to be in the shelter by 6:00 P.M. See if I'm on the north side. I don't get back on this side of town till after 6:30 P.M. or 7:00 P.M. You have no choice but to stay somewhere else" (A12). It appears with the high use of drugs in the shelters as reported by the participants, many homeless individuals that reside in the shelters are "not thinking right or acting right" (A6, A8). "For a place to stay it is really not worth it. I could do better outside" (A17, A18, A15).

Others use the homeless shelter especially "when they are ill". One participant commented, "you just learn to avoid certain situations while at the shelter" (A13). You learn to stay "out of all of the drama" (A12). Since shelters typically only allow an individual to stay for a "few days" they are typically used "as a place to get rest and take a shower" (A11).

The struggles and frustrations for permanent housing were apparent, with frustration with the system spanning years (A16). "I applied for housing like four years ago. I'm supposed to go back there in a week to find out where I'm on the list". "Getting help with housing is kinda slow. I know it is a money issue" (A4). Another participant learned "they couldn't help me, I was making too much money, I even had the church try to help me" (A9).

"It is a long process. I have applied for help and returned in 30, 60, 90 days in 30, 60, 90 days they told me they forgot about me. I feel they forget about you hoping I would forget and not come back. That is the way I feel" (A20).

Other participants talked about the lack of reliable and accurate information about resources available to them. The often felt "put-off" from public agencies when they asked for housing assistance (A15, A8).

# 4.3.3.3 Sub-theme 3: Lack of support from family and others.

The lack of family and friends' support was found as a common theme among the chronically homeless. This experience may be a significant risk factor that differentiates individuals that experience homelessness on a short-term basis versus others that are homeless for longer periods of time.

Some no longer had any support systems. Many had lost both parents and had no one to ask for help (A13). Research participants that had living parents were not always financially able to help. "I called this morning to see if I could get any money. My mother said she could not do it now – she had wrecked her car and needed the money for the repairs" (A10).

Others had siblings that were often of no help. "I called my brother to ask for help the other day. He said, "man I've got four kids to take care of, click. He hung up the phone" (A16). Other participants had their own children but found them unable to help. "They call me, daddy need money, daddy need money. I only hear from them when they want something. All I can tell them is that I am homeless and I don't have any money" (A12).

Others have had some support systems but utilized them only when they were desperate. "I have friend that lives in Illinois. He sends me money when he can" (A4). "I have two sisters that I could go live with. We have had some difficulties in the past. But they just don't understand. I would rather just keep living out here" (A7).

#### 4.3.2 Theme 2: Access to health care

The research participants shared experiences of the difficulties of obtaining primary care when one is homeless. Seventy-five percent of the participants had some sort of income or source of funding to pay for health care; however, other barriers were identified. They acknowledged that without a home, it was hard to get good health care.

# 4.3.2.1 Sub-theme 1: No way to pay for healthcare.

For this research study, most of the participants had some type of funding to pay for healthcare. Some of the participants had federally funded programs like Medicare. Others had state funded programs such as Medicaid, while others were able to find insurance through the Affordable Healthcare Act programs. For all other homeless people, the county hospital provided a program in which they had open access to resources through the county hospital at no cost to the participant.

They described a situation in which insurance representatives were working with some of the faith-based programs to provide homeless individuals with health care insurance.

"I was at the church, the place that feeds me on Thursdays. A couple of brothers wearing normal clothes were trying to hook up a lot of people and when they said you can get dental, I said okay, cool. Now I have Well Care Insurance" (A13).

Others have acknowledged that social workers have been helping them with finding funding sources for their health care.

"I have been working with the SOS team they call them. They come out and see the homeless people and stuff. I got a counselor with one of them who was able to up my Medicaid" (A10).

The participants that have not yet obtained any funding source were aware of the county program, but had not taken the time to apply.

## 4.3.2.2 Sub-theme 2: Inconvenient hours and days of available healthcare.

The hours of operation were often brought up as barrier to obtaining health care. Many clinics that provided primary care were available to the homeless, but open only 8:00 A.M. to 5 P.M. The clinics were also typically only open Monday through Friday. This was a problem not only with private clinics but also the clinic operated by the county hospital system.

Even with "insurance it is difficult to get regular care". "I work 12 hours a day, sometimes not getting home to after six thirty or seven (A11). Where am I to go if I'm sick? My only option is the emergency room" (A11). Others verbalized that without the charity clinics they would not have access to routine care. "You get what you pay for but at least they're available to us" (A16).

With the changes in primary care, however, research participants found it difficult to access care when they had no flexibility in their daily schedule. One participant described how he always had to utilize the emergency room for care. "Those guys set up a primary care doctor, but you have to wait three months. Within the three months you're waiting your only option is to go to the emergency room" (A4).

# 4.3.2.3 Sub-theme 3: Transportation.

Transportation, or in other words, the lack of transportation was often brought up in the interviews. Although the area in which the study was conducted had public transportation, participants lacked money to ride or often felt not welcomed.

The unavailability of transportation was directly related to obtaining preventative health care was directly related to transportation.

"I have insurance through the county, but the clinic was a long way from where I was staying. With no bus service, I just couldn't get there. So, it's really hard to get there" (A13).

Homeless individuals that reside in locations without reasonable access to public transportation often depended on others. It was not that they did not attempt to obtain preventative health care, but one participant said, "when I can get a ride I go to the clinic" (A19). Luckily, for the participants who resided near the homeless clinics, public transportation was available. However, "if you're sick you can't wait on the bus, the ambulance is your only way" (A10).

# 4.3.3 Theme 3: Being stigmatized

Participants felt that once they were identified as being homeless they were treated differently by people in society. "The way you look makes a big difference when you are asking for something" (A13). Thus, some participants explained that they try not to "look" homeless when seeking assistance or care in order to be treated better.

"I don't stay away from the homeless, I just like, in order to not be labeled as homeless you gotta do stuff that, like where you won't be labeled as homeless.

So, when you leave the shelter, you not with homeless people no more, you're with people that have houses, so you have to dress and act like them" (A11).

Others feel they are being treated differently because people just do not understand their situation

"Okay, well she's homeless, so she must be on drugs. You know, drugs brought her there. Or "ooh", like I have some kind of disease or something and it is sad to live this way" (A4).

## 4.3.3.1 Sub-theme 1: Perceptions of the public.

Perceptions of the public were a negative experience for the participants.

"You can tell the way you are going to be treated by the car they drive or the clothes they wear. A lot of preppy people or people who's got money are treat you the worst. It is the middle class on down, they are the people that will help you. That's because most of them struggle a lot themselves and understand" (A4).

The study participants did not acknowledge any racial difference in how they were treated among the public. "They're pretty much the same – I can't say there is more Black or White or Mexicans that would help you more than the other people" (A4). However, it is noted that "religious people will come and talk to you, more than a person who is not religious" (A4, A8).

Police officers tended to be portrayed as either supportive of homeless persons or negative towards the homeless.

"I think Arlington is doing a systematic kind of thing, trying to get rid of all the homeless. Every time a cop comes up on you and sees that you're homeless, even if you're not doing anything, they try to convince you to either go to another city and stay in one of the shelters there. They just keep giving you a hard time until you give up and leave" (A13).

Others have acknowledged that the police can also be very helpful and understanding.

"Officer White as one the of the nicest cops I ever met in my life. He comes by and check on me every day. Well, not every day but like a couple times per week" (A13).

# 4.3.3.2 Sub-theme 2: Perceptions of health care workers.

The consensus among the research participants was that the "majority of doctors and nurses treat the homeless with respect". One participant stated "it is in their name – health" "care" ". There were many examples, however, of negative treatment by health care workers towards the research participants. These examples occurred predominately when care was sought at a private health care facility.

"When you are at a [large hospital], they treat you poorly because you are homeless" (A15). "Over at [another large hospital] there a lot rude people. They really don't give a crap about homeless people" (A4). Some reported that, "since they do not want to see you, they just put you in a room for a long time hoping you will leave". Others felt they were "ran through the system as fast as they could."

One female participant described a time when she was at a local private hospital. "I was given a prescription. The social worker told me if you do not have insurance or anything like that, either you go without that or either have somebody to pay for it".

She felt if the social worker did care, they would have "networked and found a way to get the prescription filled" (A5). Participants felt that some heath care workers acted like it was a "waste of their time," helping them with their unique social issues.

Others found the health care provided through the county hospital to be much better. "Everyone over here treat me like a human being" (A5). Also, there appeared to be more positive interactions with the hospital staff. "I've talked to them and they're like, "aah. It really made me feel like they cared" (A8).

Others talked about the services provided. "These guys are awesome. They gave me enough stuff to take care of my wound and gave me food" (A8). "Oh yeah, it's a lot better because I can afford all of medication because they're free" (A14).

Many explanations were given about the behaviors that were projected towards the homeless participants. Some healthcare facilities "only care about their bank accounts – it's what they care about – it's a money thing" (A13). "To me they just, like, long as that pill get in my pocket, they got paid, so it's just like I'm a meal ticket for them" (A12). Others felt that since they are pushed to seek care in the emergency rooms, there was a "red flag" that goes up. "Well, she's been here too many times to be really sick" (A4).

The research participants overall acknowledged the personality of health-care providers were the determining factor in how they treated the homeless. "If a person wants to take that time with you, they have that type of personality, they will treat you with respect" (A5). They understood it was something they "could not change" and hopefully they treated all patients that way and "not just the homeless."

### 4.3.4 Theme 4: Staying healthy

The participants described they could remember having a healthcare visit for the sole purpose of health promotion, but others could not. The lack of preventive care and health promotion made staying healthy difficult.

# 4.3.4.1 Sub-theme 1: Lack of preventative care.

Many participants voiced an understanding that having routine preventive checkups was the key to living a health life. Having routine care allowed them to live the quality of life that they wanted to live (A16).

"Out on the streets you have to stay healthy, you do what you need to kept from being sick, that includes having checkups" (A11). "It's just you out here and you have to take care of yourself, making sure you are healthy is part of it" (A5). Participants who had hypertension and diabetes understood that getting regular checkups prevented further disability. "I did not take my diabetes seriously at first but then they had to cut off part of my foot. You betcha I do not miss any appointments now" (A13).

# 4.3.4.2 Sub-theme 2: Obstacles to eating healthy.

Participants voiced the understanding that eating a healthy meal was essential for good health. However, they felt that eating healthy was a very difficult challenge while facing homelessness. "It is just basic survival, you have little money in your pocket, you know, you get what you can get to eat" (A13).

"I try my best not to get sick, stay healthy so I eat a lot of fruits and vegetables" (A11). He went on about how healthy food was not often served to the homeless. He had to spend what extra money he had to purchase the healthy foods.

"Eating healthy is not cheap" (A8). Often food that is available or what they can afford is very unhealthy. "I don't have five dollars, but if I had five dollars, I'd go get a

hamburger. I know it is not good for me but I have to eat" (A13). Participants that ate at the homeless clinics often described the food as "deep fried, greasy and they are full of salt".

Some participants did have access to food stamps. However, they found that their allowance was not enough to purchase healthy foods. Stretching the amount of money provided was the only way to survive on the streets. "When I'm all out of money, I have spent my food stamps, I don't want to panhandle, but my only option is to go out and ask for food" (A3).

Others felt the frustration when working with their health care providers about eating healthy. "It seems like they are not listening to what I'm saying" (A4).

"I understand what you're saying, but you have to take consideration. You tell me to "eat lean". Ok. Where do I go to eat lean? You have to understand, I'm homeless" (A12).

## 4.4 Summary

The purpose of this descriptive phenomenological study was to explore the experiences of living with an illness while being chronically homeless. A total of 20 chronically homeless individuals were interviewed. Each interview was transcribed and analyzed. Emerging themes were coded using Giorgio's method of phenomenological inquiry.

The interviews revealed several common themes. The four themes that emerged from the interview analysis were: (a) trying to survive, (b) access to health care, (c) being stigmatized, and (d) staying healthy.

The phenomenon obtained may contribute to the understanding of the chronically homeless while providing care to them. The knowledge found in the literature and throughout this study may be used to help develop better programs to help the chronically homeless. This chapter's findings will be interpreted and discussed more in depth in Chapter 5.

#### **CHAPTER 5**

### 5.1 Introduction

This descriptive phenomenological study explored the experiences of living with an illness while being chronically homeless. Emerging themes were coded using Giorgio's method of phenomenological inquiry. This five-step method of research, based on Husserlian phenomenology as its philosophical foundation, was used to interpret the individual translations (Giorgi, 1985).

The research participants in this study were all adult who were chronically homeless. Fortunately, most individuals only experience homelessness for a short time, exit with little assistance, and do not experience homelessness again (Gaetz, 2014). However, for some individuals, chronically homeless becomes a way of life. Even though the chronically homeless represents a small percentage of the total homeless population, they utilize a disproportionate amount of resources available to the homeless (USICH, 2010; HUD, 2016).

Twenty research participants were interviewed using a semi-structured interview tool. The interviews were conducted at a location that was comfortable to the participants, audio-recorded, and transcribed by the principal investigator. The research participants provided a rich understanding of the experiences of illness in the context of being chronically homeless.

### **5.2 Interpretation**

The research findings are described in detailed below. The demographic results were compared to what was available in the recent literature. The qualitative data from this study were arranged into themes and interpreted in the passages below.

## 5.2.1 Demographic Data

The demographics of this study have been compared to current national statistics point-in-time (PIT) studies. Unfortunately, many studies and reports do not give specific data about the chronically homeless. Often national, state and local population reports include all homeless individuals when demographic data were reported. Regardless, demographic data of chronically homeless are presented and compared to findings available in the literature.

The chronically homeless account for 10% to 20% of the total homeless population at any one point in time. In the 2016 PIT counts, HUD reported that the chronically homeless population accounted for 23% of the total homeless population in the United States. In 2016, Tarrant County Homeless Coalition (TCHC) reported that the chronically homeless comprised only 22% of the total homeless population in the county (TCHC, 2016).

The research participants in this study were over the age of 35 years with the oldest 70 years of age. The mean age was 49.75 years. The most current national PIT studies reported that 69% of the homeless population was over the age of 24 (HUD, 2016). The PIT counts for Tarrant County found that 68% of the total homeless population was over the age of 24 (TCHC, 2016). Several published articles between 2004 and 2006 reported that the average age of the chronically homeless was around 50 years (Caton, Wilkins & Anderson, 2007). The sample in this study was comprised of persons who reflected the age of the homeless population in the county where it was conducted.

Of the 20 research participants in this study, 70% were male. National estimates have reported that 60% of people experiencing homelessness were men (HUD, 2016). As for Tarrant County, men accounted for around 77% of the total homeless population (TCHC, 2016). Caton et al. (2007) reported that 75% to 80% of the individuals experiencing chronic homelessness are men. This study's findings were consistent with the gender reported in the county and in the literature.

The participants in this study were primarily White, with the next largest racial group being African American. The smaller group was Hispanic. HUD (2016) reported that in the United States, the homeless population was composed of 48% Caucasian, 39% African American and 22% were Hispanic. However, Tarrant County reported that 57.5% were Caucasian, 27.3% Hispanic and the remaining 15.2% were African American (TCHC, 2014). The racial composition of the sample in this study reflected the local homeless population.

Few of the participants in this study were in a relationship, with the majority being divorced, single, separated or widowed. Canton et al. (2007) found that 48% of homeless individuals were single, 24% had divorced, and 15% were separated. Dallas County in 2012 reported that of their surveyed homeless population, 59% were single, 23% divorced, 9% were separated, 6% were married and 3% were widowed. The martial status of this population was consistent with local and national statistics.

Most of the participants in the study had completed high school with some of those completers continuing their education in college. Canton et al. (2007) found that among the homeless persons in his study, almost half had not finished high school.

According to the U.S. Census Bureau (2010), among the general population in the United

States, over 85% adults has completed high school and 27% has received at a bachelor's degree. Thus, the chronically homeless individuals in this study had more years of formal education than chronically homeless persons in Canton et al.'s study but fewer than the U.S. general population.

Only 18.5% in the general population has mental illness (National Alliance of Mental Illness, 2017). Half of the participants in this study reported having mental health problems. In the published literature that was reviewed, the incidence of mental health issues varied widely among homeless samples. What was evident was that the incidence of mental health among the homeless was disproportionally higher than the general population. In a national publication, the authors noted that the rates of mental illness were up to 60% in the chronically homeless. (U.S. Interagency Council on Homelessness, 2017).

In this sample, current alcohol abuse or past history of alcohol abuse was greater than 65% with, current or previous drug abuse being reported by a slightly smaller group (60%). Studies have reported rates of substance abuse to be as high as 80% (U.S. Interagency Council on Homelessness, 2017). However, none of the studies indicated whether substance abuse was the pathway to homelessness or was a consequence of being homeless.

#### 5.2.2 Theme 1: Trying to survive

#### 5.2.2.1 Sub-theme: Earning a living in difficult times.

The economy and rates of homelessness were well interconnected. Climbing out of homelessness seemed virtually impossible for those who were not working in a paid

position. For those with limited skills or experience, opportunities for jobs that paid a living wage were very limited.

Employment and homelessness have been documented as being connected throughout history. For example, after the Stock Market collapse in October 1929, homelessness rose as people lost their jobs and were unable to pay mortgages or taxes. Eviction from rented housing also increased the reportedly thousands found shelter wherever they could. No documentation has been found, however, of how many people were homeless following the market collapse (Gregory, 2009). When the United States entered World War I, an estimated 17 million unemployed Americans returned back to work in 1939 (Burton, 2010).

The majority of the research participants complained that their sole reason for experiencing chronic homeless was related to the inability to find a "decent job". Frustrations with wages was also found among the research participants along with concerns that the current president's policies would further lower the minimum wage.

More than four decades ago, a worker earning minimum wage was paid enough to raise of family of three above the poverty line (Solar, 1995). Even with minimal wage today of \$7.25, a family of three will remain about \$3,000 below the poverty line (U.S. Department of Health & Human Services, 2010). Economic growth in the past two decades has benefited those who were wealthier and has not benefited the chronically homeless population. The participants were concerned that their homelessness was permanent.

With the current job market in the United States, it has been difficult even for well-educated individuals to find a decent paying job. Several participants in this study

mentioned that their lack of education did not make them a marketable employee. With a saturated job market, employers can be more selective and most are requiring at least a high school diploma. With 30-50% of the homeless population not having completed high school, they are disadvantaged when seeking higher paying jobs.

The research participants also verbalized other barriers that made finding employment difficult, such as disabilities, previous criminal behavior, and age. Many of the jobs available to the homeless were day labor jobs that required physical stamina and strength to lift heavy objects. As one participant complained, "I cannot do that kind of work because I have a jacked up back".

Age discrimination related to employment was brought up by several participants. The individuals in this study had an average age of around 50, an age at which other Americans have reported experiencing age discrimination. The assumption is that younger employees can "go faster", adjust to the changing technological requirements easier, and have less missed days due to illness, but the assumption has not been supported by evidence (Parramore, 2013)

#### 5.2.2.2 Sub-theme 2: Finding housing I can afford.

Lack of affordable housing has often been cited as one of the major reasons that health care disparities continue among the homeless (HUD, 2016). With a lack of stable housing, the chronically homeless persons were also unable to provide basic needs to maintain wellness. When one was faced with illness, without housing, the shelter was the only place for them to recover. Anderson et al. (2009) found significant differences in health outcomes between the homeless and someone who had housing. With decreasing

wages due to the economy, barriers to finding a job, affordable housing has become increasingly less attainable by persons who are chronically homeless.

The sociopolitical environment has reduced the supply of affordable housing units in the United States. The number of affordable housing units in 1970 was 300,000, but was reduced by 50% when the federal budget was cut in the 1980's (Petronhiolos, 2014). By 1985, 8.9 million poor renters, competed for the 5.6 million available housing units, a shortage of over 3 million. By 2009, the shortage grew to being 5.9 million units of low income rental space. As the homeless population continued to grow, available housing continued to shrink (Petronhiolos, 2014).

The participants in the study expressed their reality poignantly. "I only make \$400 and something each month. Nobody is going to let me pay \$400 a month with bills paid for someone today" (A15). In comparison, in 2010, the median gross rent in Texas was \$870 per month, compared with \$1,243 in California, \$1,117 in New York and \$998 in Florida (U.S. Census Bureau, 2010) When a homeless individual finds affordable housing, initial expenses for the first month's rent, a security deposit, and initiation fees for utilities quickly exceed the income of a person living without a home. A full-time employee who is able to rent average-cost housing is making an estimated \$14.69 (Newman, 2017). Without some housing assistance, housing becomes unaffordable and more people have no option but to live in the streets.

Many of the research participants verbalized the frustrations with housing assistance. Participants noted bureaucratic obstacles including delays from application to receiving assistance and being denied because of making more money than the qualifying level. Self-respect and pride, however, prevented some homeless participants from

applying for any type of assistance to avoid stigma and losing face. Applying for assistance labeled them as homeless and low social status. The frustration experienced while seeking affordable housing works against the purpose of programs such as housing assistance. In order for homelessness to end, simpler, efficient, and respectful processes for seeking and receiving assistance are needed.

Although shelters were available to use, the majority of the research participants avoided them due to the prevalence of substance abuse, fighting, and other forms of violence. Shelters tended to lack cleanliness, and were populated by a disproportionate number of persons with mental illness. As a result, more than one participant indicated the emotional cost of staying in a shelter was greater than the benefits of food and protection from the weather.

The participants verbalized that not having toilets, showers, laundry facilities or ways to store and prepare food were all barriers to maintaining health. The lack of permanent housing was described as "very stressful" by many of the participants. Living on the streets was evaluated as being very stressful and interfering with adequate sleep and rest. One noted being afraid to fall asleep for fear of being robbed and attacked.

# 5.2.2.3 Sub-theme 3: Lack of support from family and others.

As noted in the literature review, the majority of individuals that experience homeless do so only on a short-term basis. These individuals possess some type of a support system that allows them to exit homelessness quickly. However, for the chronically homeless, the lack of some support systems seems to be a causative factor.

Participants described limited social support due to the death of family members and avoidance of family and friends so as to not burden, inconvenience, or shame them.

Asking for support was viewed by one as a sign of weakness.

It has been argued that the chronically homeless are socially isolated, with limited social support and that this lack of social resources contributes to their poor health (LaGory, Ritchey & Fitzpatrick, 1991; Solarz & Bogat, 1990; Hwang, et al., 2009). Social support has been hypothesized to affect one's health in different ways (Hwang et al., 2009). For example, having someone to talk with can buffer the effects of a stressful event that could negatively affect one mental or physical well-being.

Social support was found to provide an individual with access to positive influences that encouraged healthy behaviors (Berkman & Glass, 2000). Other studies have found that social support had protective effects on one's physical health, such as prevention of cardiovascular disease (Berkman & Glass, 2000), depression, and anxiety (Kawachi & Berkman, 2001). Low social support may be a negative health consequence. From this research study, the chronically homeless were found to have high support demands not met by family and friends, contributing to their marginalization.

#### 5.2.3 Theme 2: Access to health care.

Many homeless individuals who are ill and need treatment do not receive the care they need. Despite having insurance, health is lacking due to not knowing where to go for preventative care and barriers such as no accessible transportation and inconvenient clinic hours. As a result, the hospital emergency room is their primary source of health. People who experience homelessness are 3 to 4 times more likely to die than the general

population (O'Connell, 2005). The average life expectancy of the homeless individual has been reported to be 62 years (U.S. Interagency Council on Homelessness, 2010).

# 5.2.3.1 Sub-theme 1: No way to pay for healthcare.

Financial barriers to care, which can be the reality of the health care system, are especially problematic for chronically homeless people. The National Health Care for the Homeless Council (2008) estimated that 70% of homeless individuals do not have insurance. Counter to that finding, the participants in the study, for the most part, had some type of health insurance. Among those who did not, the lack of insurance limited their options for care. Being uninsured while homeless is associated with lower use of ambulatory care, more frequent hospitalization, and an almost three-fold increase in self-reported inability to obtain needed care (NHC, 2008).

Having insurance did not guarantee improved health, because the participants reported most of their day was spent meeting basic survival needs. Consistent with Maslow's hierarchy of needs (Maslow, 1954), survival needs decreased the priority placed on preventive care and resulted in use of emergency medical care.

# 5.2.3.2 Sub-theme 2: Inconvenient hours and days of available healthcare.

Many of the research participants verbalized the frustrations of clinic hours of operation. One such frustration was the conflict between appointment times and the times when they could obtain a free meal or lining up to ensure getting a place to sleep at the shelter. For the few who were working, clinic appointments were missed due to employment.

Clinics that provide health care to the persons who are homeless could provide better assistance to the recipients of their care by creating more accommodating hours.

The literature provides many excuses for the lack of access experienced by the homeless. Some blame decreased funding of clinics that provide care to the homeless by the government for the reduction in their clinical hours (Thomas, 2014), although others relate it to shortages of health care providers in many communities occupied by high concentrations of low-income individuals causing them to be short staffed (Thomas, 2014). Regardless of the cause, having flexibility in a clinic schedule is very important for a homeless individual to attempt to gain preventative care.

#### **5.2.3.3** Sub-theme 3: Transportation.

Transportation was especially important for a few participants who resided in areas where public transportation did not exist. Transportation to health care facilities was rarely available, and the clinics were located many miles away.

When money was available, a few participants paid friends to transport them to clinics with no guarantee of a return trip. Fortunately, most of the research participants resided near public transportation, making it a non-issue. The low cost of a ride on the city bus made it a feasible source of transportation. However, for those that cannot, assistance was frequently provided by the clinic's social workers so the patient could purchase a bus pass.

# **5.2.4** Theme **3**: Being stigmatized

Participants described being labeled and stigmatized, not only by the public but also health care workers. Some participants were subjected to various forms of discrimination on a daily basis. In contrast, others had stories of individuals who were caring and compassionate towards people who were homeless. Regardless, these

interactions only added to the daily stress that a chronically homeless individual experiences on a daily basis.

# 5.2.4.1 Sub-theme 1: Perceptions of the public.

Related to this subtheme, Lott (2002) reported that non-poor individuals tended to interact with the poor using a "demeaning and devaluing" approach. Consistent with Lott, one of the participants had experienced discriminatory treatment from persons with money. Negative treatment of a person with fewer resources, including stereotypes or prejudices, constitutes classism. According to Lott (2002), social class distinctions have significant consequences for everyone, especially the distinction of being poor.

Participants described more positive interactions with persons who understood their struggles and religious individuals. The fact that participants described interactions with persons who professed strong religious beliefs was not unexpected. Two clinics designed to meet the needs of homeless persons were supported by faith based organizations. In a similar way, several of the services provided for persons who were chronically homeless, such as soup kitchens were supported by faith based individuals or organizations.

# 5.2.4.2 Sub-theme 2: Perceptions of health care workers.

The consensus among the research participants was that these negative interactions primarily occur at either private clinics or hospitals. Not every individual in these organizations who interacted with the homeless persons seeking care felt negatively towards homeless persons. However, in this research group, the majority of negative expression came from these private organizations as compared to other facilities.

These negative interactions can produce powerful psychological barriers.

Feelings of embarrassment, fear of being judged by health care workers, and selfconsciousness about their appearance and hygiene may keep a chronically homeless
individual from seeking care. As a result of these factors, their illness is only prolonged.

However, it is not to say that all health care workers or systems negatively stigmatize the homeless. The research participants often felt that organizations that provided care to the poor were much more understanding and compassionate.

#### **5.2.4** Theme 4: Staying healthy

Poor health can be both a cause and a result of chronic homelessness (American Psychological Association [APA], 2010). Homeless people are three to six times more likely to become ill than persons with housing (NHCHC, 2008). Lack of good nutrition, good personal hygiene, and basic first aid only added to the complex health needs of the chronically homeless individuals (NCH, 2009).

# 5.2.5.1 Sub-theme 1: Lack of preventative care.

The finding in this research study that homeless individuals were engaged in preventative care contrasted with the literature and commonly held beliefs of healthcare providers. The majority of the participants had had a health care visit with the focus on preventative care within at least the past two years. Health was reported as being important, including routine screenings. In a supportive finding, Ferenchick (2002) noted that 16% of individuals who experienced homelessness on a chronic basis had medical visits that were for health maintenance.

Contrary to commonly-held beliefs, persons who were chronically homeless were seeking health-promoting and disease detection activities. In this study, many of the

chronically homeless individuals were interested in maintaining and improving their health. Without good health, the possibility of exiting chronic homelessness is slim.

#### 5.2.5.2 Sub-theme 2: Obstacles to eating healthy.

The participants noted the food in the shelters was frequently unhealthy. This is consistent with reports in the literature. Foods provided to homeless individuals through the shelters and soup kitchens were often high in fat and salt, low in fiber, and inadequate in most nutrients (Davis, Weller, Jadhav & Holleman, 2008; Johnson & McCool, 2003; OAFB, 2014). Canned fruits in heavy syrup were frequently offered with fresh fruit offered rarely. The programs often relied heavily on donations and may not have been able to afford healthier menus for the shelters. In addition to the cost of purchasing healthy foods, the service organizations may not have had cooking facilities, which makes it nearly impossible to provide a varied diet. With limited budgets and unlimited clients, these organizations that provide food to the homeless find it difficult offer a balanced diet.

Due to costs and few human resources, the shelters and soup kitchens usually provided one meal a day, which resulted in participants going hungry. When they lacked access to a free meal, the participants described searching dumpsters or other free food sites as well as begging for money to use at fast-food restaurants.

Because the chronically homeless are usually the poorest of the poor, their nutritional and vitamin intake is far below recommendations (Lee & Greif, 2014; Lyles et al., 2013; OAFB, 2014). Even when food stamps were provided to the participants, they found the purchasing power very limited and would not buy healthier foods in order to buy more food. Participants voiced the understanding that eating a healthy meal was

essential, with increased need during times of sickness. The positive effects of vegetables in health maintenance are well documented (Steinmetz, 2006; Lyles et al., 2013; OAFB, 2014). For example, lack of Vitamin C impairs wound healing (Lyles et al., 2013). Persons with hypertension who are homeless are at high risk to negative effects from diets high in salt, fat, and cholesterol (United States Conference of Mayors, 2010; Lyles, 2013; OAFB, 2014).

#### **5.3 Summary**

The focus of the study was the lived experience of being chronically homeless and ill. Four themes emerged from interviews with 20 participants who met the inclusion criterion of being chronically homeless. These themes included: (a) trying to survive, (b) accessibility of health care, (c) being stigmatized, and (b) trying to stay healthy. These are similar issues as reported in the literature by the general population, however, it appears that the chronically homeless may have different experiences.

Trying to survive as a theme emerged from participants' concerns about barriers to exiting homelessness. The barriers included the lack of money that persisted despite working full time jobs, frequently in a temporary, daily job making minimum wage.

Obtaining higher paying jobs was unattainable because they had inadequate education and training. The inability to obtain a better paying job was directly associated with their inability to exit homelessness.

Housing is an issue that affects both short-term and chronic homeless. Homeless shelters did not meet the needs of the participants because they were inflexible, filled with disease and illness, and often inhabited by individuals with either substance abuse

problems or uncontrolled mental illnesses. They verbalized that finding a place to stay outside of the shelter was the safer housing.

The chronically homeless participants appeared to have very little, if any, social support, which seemed to be one of the reasons they remained homeless. Individuals with social support frequently entered and exited homelessness in a short time. Individuals who remained homeless over time lacked the contacts, the relationships, or the ability to ask for and receive assistance and find a more permanent place to live.

The majority of the individuals in the study had some type of funding to pay for health care. The longer an individual has been homeless, the more they learn about resources available to them. However, despite having funding, the participants encountered other barriers such as the availability of clinics open on days and at times they could obtain care to meet their health needs.

Consistent with the literature, the participants in this study had been labeled and stigmatized. Their perceptions were that healthcare providers employed by hospitals and clinics that provided care to the indigent were often more understanding and compassionate in the care that was delivered.

In contrast to most literature, the participants were interested in and had received at least some preventive care. They recognized good health as being essential to exiting homelessness. For the most part, the participants were meeting their basic needs and were able to invest time and energy to attain higher levels of health. Despite their interest in attaining health, however, persons who remain homeless long-term may experience the same struggles when they were ill as persons who are homeless for a shorter time.

Through their experiences, the chronically homeless have developed survival skills and ways to stay healthy and seek care when ill.

# **5.4 Limitations of this Study**

This descriptive phenomenological study explored the illness experiences of 20 chronically homeless adult men and women in a large metropolitan city in North Texas. One limitation of this study was its setting being a specific urban community and the participants were only English Speakers. Individuals who are chronically homeless in other regions of the country may have different experiences with the variations in resources across communities. Individuals who do not speak English may experience health care and homelessness differently, creating a different lived experience. Some individuals experience chronic homelessness before reaching 18 years of age but were not interviewed for this study. The principal investigator excluded from the study persons who experienced mental illness and substance abuse in addition to being chronically homeless.

Community resources may have shaped the lived experiences of the participants. Even those without insurance had an option to access health care through the county hospital. And there were other resources such as volunteer health clinics available to them. In addition to healthcare options, the participants had access to other resources such as homeless shelters, soup kitchens, and other volunteer organizations. For people that reside in cities or rural areas that do not offer such programs, being chronically homeless and ill would likely be experienced differently.

The purposive sample was recruited by the principal investigator at parks, vacant lots and along the street in a relatively small area of this metropolitan city. This type of

sampling is vulnerable to selection bias and influences beyond the control of the researcher. Thus, one could argue that the experiences identified by these individuals do not represent the chronically homeless population of the area.

The focus in this one area meant the description of chronic homelessness was contextually situated. Because of providing health care to many of the same persons, the principal investigator had previous interactions with some participants, which may have helped them feel more comfortable in sharing richer experiences or may have limited their communication with him in unknown ways.

The weather during the summer and fall months when the study was conducted made other options for shelter available to the participants. Also, during this time of year, the prevalence of illness decreases and many have affected the participants' recall of being ill. The experience of being chronically homeless may vary across seasons.

## 5.5 Recommendations for Future Research

Without having a better understanding of the chronically homeless, interventions can only be based upon assumptions. Understanding the experiences of persons who are chronically homeless will not prevent others from becoming homeless. However, researchers using these findings may be able to conceptualize a plan of action and design appropriate health care services tailored to the specific needs of this vulnerable population.

More research is needed to better understand the dynamics and trends that are reflected in the experience of chronically homelessness. A closer examination of this experience could help identify risk and protective factors associated with being

chronically homeless. This information may have the potential to help break the cycle of homelessness

Within the last decade, researchers have increased efforts in order to better understand how to provide care to persons who are chronically homeless. Programs, such as supportive housing and innovative clinics, have outpaced research. Further research is needed in order to evaluate the experiences of the persons these resources serve and provide scientific evidence as to the resources' effectiveness. The practice-based evidence that will develop from these efforts may help the next generation decrease the number of persons who become chronically homeless.

## **5.6 Implications for Nursing**

The chronically homeless are often stigmatized and treated differently than the general population when they attempted to receive care. The experience of being stigmatized for being homeless was described by the study's participants and corroborated the findings of published studies. Delays in seeking care may be due to previous negative treatment and accentuate the persons' fear and anxiety in healthcare settings.

Nurses in multiple settings need to become better educated about the chronically homeless. Formal education does not always eliminate false assumptions about their care recipients. Awareness and deeper understanding of the daily struggles and experiences of persons who are chronically homeless may make plans of care more realistic.

Homeless individuals are often in need of help. Unfortunately, many are too embarrassed to ask. However, making time to understand the barriers of the chronically homeless can be the difference in their patient's outcome.

#### 5.7 Conclusion

Persons who experience chronic homelessness often suffer from acute and chronic health problems. The context and characteristics associated with being chronically homeless can have profound effects on the individual's ability to maintain adequate health. The barriers that arise from being chronically homeless not only affect the ability to obtain access to care but also the ability to recover once treatment has been received. Unfortunately, when combined, these factors dramatically increase the mortality rate among the chronically homeless.

The purpose of this descriptive qualitative study was to explore the experiences of living with an illness while being chronically homeless. The themes that were revealed in the interviews were described in the words and experiences of the research participants.

These experiences were then explored and compared to available findings in the current literature.

The findings of the study may improve the understanding of the vulnerabilities of persons who are chronically homeless. With a better understanding of the chronically homeless, programs can be developed with increased likelihood of effectiveness.

Concentrated, consistent efforts may eventually result in the end of homelessness once and for all.

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## Appendix A

#### Recruitment

Opportunity to Participate in a Research Study

Hello, my name is William Henderson. I am a doctoral student at the University of Texas at Arlington, College of Nursing. I am doing a research study as part of my degree. The focus of my research is with the chronically homeless.

I want to understand the experiences of living with an illness while being chronically homeless. I want to better understand how the chronically homeless manage their health care needs. The best ways that I do this is the listen to those experiences and find the meanings within these stories.

Benefits, if you chose to participate, include the opportunity to tell your story. For your time you will receive a \$10 gift card that you can use anywhere. The conversation is expected to last no more than 60 minutes. The meeting will occur in a safe and private location such as the public library or shelter. Bus fare will be provided if needed. The conversation will be recorded so that it can be studied later. Everything will be confidential. Your name will never be disclosed.

You will need to sign consent before you tell your experiences. You can ask questions at that time or any time during the conversation. You can also decide to stop the conversation at any time and you will still get paid for your time.

To be eligible for the study you must:

- 1. Be chronically homeless
- 2. Be at least 18 years old
- 3. Ability to give consent
- 4. Willing to share your stores

If you are interested, have other questions, or unsure if you fit all the requirements to be part of this study, please call me on my cell phone. I would be happy to talk with you. Thank you for your time.

Sincerely,

William Henderson, MSN, NP

#### Appendix B



#### INFORMED CONSENT

PRINCIPAL INVESTIGATOR: William B. Henderson, MSN, NP

TITLE OF PROJECT: The experience of illness in the daily lives of persons living with being chronically homeless

You are being asked to participate in a research study by William Henderson at the University of Texas at Arlington College of Nursing.

This Informed Consent will explain about being a research subject in an experiment. It is important that you read this material carefully and then decide if you wish to be a volunteer.

<u>PURPOSE</u>: The purpose of this research study is to describe the experiences of being ill while dealing with the challenges of being chronically homeless. It is hoped that this study will help nurses and other health care providers understand the unique challenges that the chronically homeless experience while attempting to seek health care.

<u>DURATION</u>: Each interview is expected to last a minimum of 30 minutes to a maximum of 2 hours. The time required will be dependent on how long you need to describe your experiences of being ill while being chronically homeless.

PROCEDURES: If you chose to participate, the principle investigator and you will meet at the date and time chosen. The principle investigator and you will meet in a private location that is in a safe location which has been determined appropriate by you such as at the local public library. The procedures, which will involve you as a research subject, include you to complete a short survey which will include such information as your age, race, years you have been homeless, and medical conditions. The principal investigator will then interview you. Each interview will be recorded so it can be reviewed later. The principal investigator will ask you to describe your experiences of being ill while dealing with the challenges of being chronically homeless.

<u>POSSIBLE RISKS/DISCOMFORTS</u>: The possible risks and/or discomforts of your involvement from this research study including feelings of distress. You do not have to answer any questions you do not want. You can stop the interview at any time if you feel upset. The interview will be set at time and place which is best for you. Bus tokens can be given to you if needed. You will also be given a list of names and phone numbers that you can use if needed to discuss any problems that might arise.

PRINCIPAL INVESTIGATOR: William Henderson, MSN, NP

TITLE OF PROJECT: The experience of illness in the daily lives of persons living with being chronically homeless

Another risk that could come from this research study is the release of any private information. Your privacy will be protected to the extent that is allowed by law. The interview will take place in a private placed that you and the private investigator Agree upon. Only the principal investigator, his advisor will have access to the recordings. These recordings, written copies and any other papers will be locked in a filing cabinet in the principal investigator's office. The consent forms will be locked in a separate box. The recordings and any papers will be shredded three years after the research is complete. If the results are published, no names, initials or any identifying facts will be released.

The principal investigator will try to prevent problems that could arise because of the research study. You should let the principle investigator know at once if there is any problems.

<u>POSSIBLE BENEFITS</u>: There will be no direct benefits of being in this study. However you will have the ability to give your experiences which can be helpful for nurses and other health care providers who provide care to the homeless.

You are not required by any person or agency to be in this study. If you wish to participate, you will receive a gift card of \$10 which can be used anywhere. You may stop your interview at any time; you may still keep the gift card. Also, you will receive a list of services available to the homeless population within Tarrant County.

<u>ALTERNATIVE PROCEDURES / TREATMENTS</u>: There will be no alternative procedures if you elect not to participate in this research study.

<u>CONFIDENTIALITY</u>: Every attempt will be made to see that your study results are kept confidential. A copy of the records from this study will be stored in (name the specific location where records will be kept) for at least three (3) years after the end of this research. The results of this study may be published and/or presented at meetings without naming you as a subject. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA IRB, the FDA (if applicable), and personnel particular to this research (individual or department) have access to the study records. Your (e.g., student, medical) records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as noted above.

<u>CONTACT FOR QUESTIONS:</u> If you have any questions, problems or research-related medical problems at any time, you may call William Henderson at 817/504-3588, or Dr. Jennifer Gray at 817/272-2776. You may call the Chairman of the Institutional Review Board at 817/272-1235 for any questions you may have about your rights as a research subject.

PRINCIPAL INVESTIGATOR: William Henderson, MSN, NP

TITLE OF PROJECT:	The experience of illness in the daily lives of persons
living with being chronic	ally homeless

<u>VOLUNTARY PARTICIPATION:</u> Participation in this research experiment is voluntary. You may refuse to participate or quit at any time. If you quit or refuse to participate, the benefits to which you are otherwise entitled will not be affected. You will be told immediately if any of the results of the study should reasonably be expected to make you change your mind about staying in the study.

By signing below, you confirm that you have read or had this document read to you. You will be given a signed copy of this informed consent document. You have been and will continue to be given the chance to ask questions and to discuss your participation with the investigator.

You freely and voluntarily choose to be in this research project.	
PRINCIPAL INVESTIGATOR:	
	DATE
SIGNATURE OF VOLUNTEER	DATE

#### Appendix C

## Counseling Services Available in Tarrant County

Agape Christian Counseling 817-283-1420 Accepts most insurance, Medicaid and sliding scale (\$40+/session). Provides individual and couple counseling. Located at 1901 Central Dr., Ste 205, Bedford, TX.

Baptist Marriage & Family Counseling 817-921-8790 Provides counseling referrals to low income individuals. Located at 4540 Frazier, Ft Worth Ballenger, James LCSW 817-975-8015 Specializes in anger management, anxiety, chemical dependency, mood disorders and psychotic disorders. Provides couples counseling, individual and family counseling. \$50 to \$60 per session, does offer a sliding scale fee as well. Located at 4200 S Freeway - Suite 2325, Fort Worth, TX 76115

Barron House Counseling Center 817-335-3222 ext. 105 Sliding scale available. Provides affordable mental health services to Tarrant County specializing with the GLBT community.

Burleson Church of Christ Counseling 817-295-2233 Sliding scale/ability to pay. Provides individual, marital & family counseling. Located at 820 SW Wilshire Blvd.,

Burleson, TX. Catholic Charities 817-534-0814 Sliding scale fee. Provides individual, child, marriage, family & bilingual counseling. Located at 249 Thornhill Dr. Fort Worth, TX 76115

Center for Creative Living 817-534-2818 Sliding scale up to \$25, Medicaid and private ins. Provides counseling for all age groups, classes and testing. Located at 2401 Oakland Blvd, Fort Worth, TX 76116.

Fort Worth Family Christian Resources 817-281-0101 Sliding scale \$60-\$165 session. Provides faith based counseling to individuals, families and couples. Located at 5750 Rufe Snow, North Richland Hills, TX.

Family Counseling 817-877-3707 Accepts most insurance & Medicaid. Provides all forms of counseling including depression, stress, anxiety, grief & self-esteem.

Glick House 817-531-4859 Sliding scale only. Provides family, couple and individual counseling. Located at 3001 Ave D, Ft Worth, TX.

Lena Pope Home 817-255-2652 Accepts most insurance, CHIP and sliding scale. Provides individual, family, marriage, children and groups. 3+ week waiting list.

Miller, Dennis, PhD, LCSW 817-338-9553 Accepts Medicare, Medicaid, private insurance and has limited sliding scale availability. Travels to the home of the client in Tarrant Co. area. Limited travel to areas outside of Tarrant Co. - call for details.

Opportunities Counseling Center 817-360-2983 Accepts most insurances, medicaid and cash pay (\$40-\$100). No Sliding scale. Provides indiv., couple and group counseling. Located at 601 University Dr., Ste 105, Ft Worth, TX. Currently 6mo waiting list.

The Parenting Center 817-332-6348 Provides parenting classes, self-esteem building programs, family counseling and individual counseling. Sliding scale offered and most insurance providers accepted. Offers services in Spanish as well. Located at 2928 West Fifth Street, Fort Worth, TX 76107

Pastoral Care and Training Center of TCU 817-257-7573 Sliding fee scale. Provides counseling for individuals, couples and families. Located at 2828 W. Lowdon St., Fort Worth,

TX Safe Haven of Tarrant County 817-535-6462 Provides help for battered women and their children including counseling, shelter, legal assistance and a 24-hour hotline (877-701-7233). Located at 6815 Manhattan Blvd., Fort Worth, TX.

Semillas Counseling 817-731-7107 Accepts insurance, CHIP, Medicaid and sliding scale. Provides counseling to individuals, couples, families, children 5+ and groups. Located at 1015 Pennsylvania Ave, Street 3, Ft Worth. Provides services in Spanish as well.

Southcliff Baptist Church 817-924-2241 No insurance or sliding scale. Set fees of \$20 & \$30 per session. Provides individual, couple and children counseling. 4+ week waiting period.

Travis Avenue Baptist Church 817-924-4266 Set fee of \$18 per session, no insurance or sliding scale. Provides individual and family counseling. Located at 3401 Travis Ave., Ft Worth, TX 76110.

Women's Center of Tarrant County 817-927-4040 Sliding scale. Women & men. Rape crisis services. Services for victims of violent crime with counseling and education. Also offers welfare-to-work program. Located at 1723 Hemphill St., Ft Worth, TX.

Women's Helpline: 817-927-4000.

Rape and Crisis Hotline: 817-927-2737.

Anger Management Family Matters (through Lena Pope) 817-255-2686 Sliding scale (\$20-\$60 per 2 hour session). Provides a 7 week anger management/prevention program for adults and mature adolescents. Located at 401 W. Sanford, Ste 1600, Arlington.

Metropolitan Center for Counseling 817-535-6300. Provides anger management counseling in groups and individually. Private pay, Medicaid, Private Insurance, reduced fees considered. Located at 2516 Oakland Blvd, Suite 5, Ft Worth, TX.

Fort Worth Brief Therapy 817-923-1444. Accepts some insurance and groups set at \$20/session. Provides anger management counseling in 12 week group sessions and individually. Located at 3113 S. University, Street 201, Fort Worth, TX.

Fort Worth Center for Therapeutic Change 817-446-9770 \$25/session set fee. Provides an 8 week anger management group program. Two Locations: 6320 Brentwood Stair, Ft Worth, TX and 605 E. Border, Arlington, TX.

# Appendix D

Demographic Questionnaire	ID Number
	question. Do not write your name on this sheet. in "X" on the line in front of the answer that best
Please indicate your current age in Age in years.	n the blank below:
<ul><li>Indicate your gender:</li><li>(1) Male (2) Female</li></ul>	
3. What race and ethnic descriptions	do you most closely associate with
YES NO (1) Caucasian (2) African Am (3) Hispanic (4) Asian (5) Other	nerican
4. What is your current marital status  (1) Single  (2) Divorced  (3) Widowed  (4) Married  (5) Separated  (6) Living with someone	s?
5. What is your highest level of educe (1) Grade School (2) Some High School (3) Completed High School (4) Some College or Technic (5) Completed College or T (6) Graduate School	ical School

7.	When was your	last physical health exam?
	Years	Months

6. How long have you been homeless?

Years \_\_\_\_ Months

8.	Do you have health insurance? Yes No
9.	Are you aware of medical benefits though the county hospital? Yes No
10.	Are you aware of any medical conditions?  (1) High Blood Pressure  (2) Diabetes  (3) Hepatitis  (4) Dental Problems  (5) Other (please list below)
11.	Have you ever been treated for any mental health problems?
	Yes No
12.	Have you ever been hospitalized for any mental health problems?
	Yes No
13.	Do you drink alcohol?
	Yes How many times per week
	No
14.	Do you use any drugs?
	Yes How many times per week
	No

## Appendix E

#### Interview Guide

Interview Guide for Research Study: What is the experience of living with an illness while being chronically homeless?

- 1. Please tell me about yourself? How long have you been homeless? What did you do before becoming homeless? What caused you to become homeless?
- 2. When was the last you had a physical? Do you have any medical problems in which you are not seeing a medical provider for at this time?
- 3. Tell me about a time when you were sick? Did you go to a clinic? Did you go to a hospital for care?
- 4. What was experience like when you sought care? What did you do? How did staff/provider treat you? How did you feel? What stands out in your mind?
- 5. When you take medication and you describe that experience? How do you obtain the medication? Where do you keep the medication?
- 6. What sort of thing do you do to keep yourself healthy? Are you aware of free clinics to provide care to you?
- 7. Any other thing you would like to add? How might a clinic/organization/provider improve care provided?