**Review Article**

**Lived Experience of Homeless Individuals with Type 2 Diabetes Mellitus**

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**How to cite this article:** Hamilton DJ, et al. (2023) Lived Experience of Homeless Individuals with Type 2 Diabetes Mellitus. Int J Nurs & Healt Car Scie 03(01): 2023-179.

**Submission Date:** 03 January, 2023; **Accepted Date:** 11 January, 2023; **Published Online:** 16 January, 2022

**Abstract**

Type 2 Diabetes Mellitus (T2DM) is a chronic disease. Chronic Disease Self- Management (CDSM), Diabetes Self-Management Education (DSME), and other Chronic Disease Self-Management Programs (CDSMPs) help to decrease complications from chronic diseases and improve the quality of life among those experiencing these diseases in the general population. The incidence of chronic disease is high among the homeless population; furthermore, they experience an increase in morbidity and mortality rates from these diseases. The literature related to homeless individuals with diabetes and the management of their diabetes in the homeless environment is limited. The aim of this study was to explore the lived experience and interpret the experiences reported by persons with diabetes who live in a homeless environment. The study provided the evidence to increase the understanding of how people with diabetes can self- manage their disease in a homeless environment. This study was a qualitative study using the principles of interpretive hermeneutic phenomenology.

**Keywords:** Diabetes self-management education; Diabetes self-management support; Homelessness; Type 2 diabetes mellitus

**Abbreviations**

CHO : Carbohydrates

CDSM : Chronic Disease Self- Management

CDSMPs : Chronic Disease Self-Management Programs

DSME : Diabetes Self-Management Education

DSMES : Diabetes Self-Management Education and Support

HIV : Human Immunodeficiency Virus

T2DM : Type 2 Diabetes Mellitus

**Introduction**

Type 2 Diabetes Mellitus (T2DM) is a growing problem in the United States and throughout the world. Research studies have shown that diabetes self- management strategies, such as blood glucose monitoring, blood pressure control, weight control, and eating a proper diet, will assist in controlling symptoms related to diabetes and preventing complications from diabetes- including complications such as kidney disease, heart disease, blindness, loss of limbs, and strokes [1-3]. Most of these studies were conducted in the general population and not among the homeless population [1,2].

According to the literature, the incidence and prevalence rates of chronic diseases including T2DM is higher in the homeless population compared to the general population [4-7]. Homeless individuals with T2DM may not have the resources to properly manage their diabetes to control their symptoms and prevent or delay complications from diabetes. This phenomenological study described the lived experience of homeless individuals with diabetes and obtained an increased understanding how homeless individuals manage their disease in the homeless environment.

**Purpose of the Study**

Research studies conducted in the general population have demonstrated that diabetes self-management strategies used by individuals with diabetes help to decrease long-term complications of the disease, such as blindness, kidney disease, stroke, and peripheral vascular disease [1,2,8-10]. Diabetes self-management in individuals with diabetes living in a homeless environment has not been clearly examined in the literature.

There is a gap in the literature regarding the self-management skills and abilities of homeless individuals with diabetes related to their diet control, weight reduction, glucose monitoring, medication management, and follow-up appointments with health care providers to ensure proper management of their disease. Research studies have provided the evidence that diabetes self-management behaviors and support help to improve management of the disease and decrease the complications that may occur from diabetes. The best approach for helping patients with diabetes in the general population is self-management. Although a considerable amount of information regarding the self-management of diabetes is available for the general population, it is not clearly understood how homeless individuals with diabetes can self-manage their disease. The American Diabetes Association Diabetes Care [2] does address the homeless population as a vulnerable group and provides some recommendations for the management of diabetes among the homeless. However, it is not completely known how homeless individuals with diabetes manage their disease.

**Review of the Literature**

**Incidence of Chronic Disease**

There are discrepancies related to the definition of chronic diseases and how the information is reported to different local, state and federal agencies, CDC in partnership with the Council of State and Territorial Epidemiologists, and the National Association of Chronic Disease Directors developed chronic disease indicators. These indicators allow a more accurate reporting of chronic diseases to track the rate of incidence in the U.S. [11].

The incidence of chronic disease is increasing in the general population due to aging in the U.S. population; individuals living longer with chronic diseases which leads to an increase in disabilities from such conditions as arthritis and heart disease [12-16]. Around half of the adults in the U.S. have at least one chronic disease and 26% of the population has two or more chronic diseases [17,18]. The homeless population in comparison to the general population have an increased incidence of chronic disease with increased rates in morbidity and mortality [4,19-24].

**Prevalence of Chronic Disease**

Chronic diseases in the U.S. affect 117 million people, and one out of four adults in the U.S. have two or more chronic diseases [11,12,25,26]. Seven of the top ten causes of death in the U.S. are from chronic diseases [11]. Chronic diseases with the highest rate of leading to death are heart disease and cancer [11,16-18].

The exact prevalence rates for chronic diseases for the homeless population is difficult to obtain due to the reporting and tracking of the homeless population, however the prevalence rates are higher for the homeless than the general population [27-29]. Homeless individuals tend to be a medically vulnerable population with a high burden of disease and decreased ability to access health care which prevents for early identification of health problems that are treatable [5,30-32].

**Diabetes Mellitus Type 2**

T2DM is a heterogeneous disease that is characterized by chronically increased plasma glucose levels in the body [33]. T2DM occurs when the pancreas can no longer meet the demands of the body for insulin requirements or the beta cells in the pancreas are totally worn out or burned out. Additionally, insulin resistance may occur with T2DM when the person continues to produce insulin, but the insulin is ineffective in breaking down glucose and making the glucose ready for the cells to use for energy [2,34-36].

Three tests may be used to diagnose T2DM; fasting plasma glucose, 2-hour glucose tolerance test after a 75-gram glucose load is consumed, and A1c [1,2]. There is no preference of one diagnostic test over another, all are equally effective [1,2]. There is evidence to support the correlation of increase in age, increase in body mass index, and prediabetes as risk factors for the development of T2DM [1,2]. When diabetes is diagnosed in an individual person, a team approach in the management of the diabetes is needed to help decrease complications. This team generally includes primary health care providers, along with a dietician, podiatrist, ophthalmologist, case manager or registered nurse, a social worker if needed, and a certified diabetes educator [1,2,8]. Every person with diabetes should have an individualized plan of care based on national standards as the guide [1,2,8].

There are several research studies that support the concepts of self- management of chronic disease such as arthritis, heart failure, coronary artery disease, chronic kidney disease and diabetes to improve patient outcomes and help to decrease the cost of health care in patients with chronic diseases [17,37-45]. There are several studies in which different approaches for management of T2DM in people were studied in the general population and minority groups to exam the impact on blood pressure control, diet control, heart disease or cardiovascular events, and A1c levels [46-57].

Research studies support that diabetes self-management strategies which includes eating a proper diet, maintaining a blood glucose levels close to normal with an A1c level less than or equal to seven, adequate blood pressure control, weight control, and adequate medical care improves the overall quality of life of individuals with diabetes [1,2,9]. There are limited studies that exam diabetes self-management in the homeless population.

**Homelessness**

Homelessness, a growing public health concern in the U.S. is defined as a situation in which a person does not have a fixed, adequate, nighttime residence or a situation in which a person is living in a location supervised through a private or public shelter that is providing temporary housing [58]. However, there are also other ways people are homeless. For example, people who live on the “streets” or on a family member or friend’s couch are also homeless. Additionally, there are homeless individuals who are described as the “Chronically Homeless”, such as U.S. veterans who may have mental illness or substance-abuse problems [59]. Some people who are “chronically homeless” may choose to remain homeless, and they may prefer to live under bridges and in tents on the streets [60].

The homeless population continues to be a concern in the U.S. despite governmental and private initiatives to end homelessness [60]. The homeless population continues to be vulnerable and at increased risk for the development of chronic health issues, as compared to the general population. The homeless population is 3 to 6 times more likely to become ill as compared to the general population experiencing mental illness, substance abuse, Human Immunodeficiency Virus (HIV), and chronic diseases, such as T2DM [6]. Chronic diseases in the homeless population carry an increase in morbidity and mortality rates related to their homelessness, lack of health insurance, and/or lack of access to health care [5]. The homeless population has a higher rate of hospitalization than the general population, and they are 3 to 4 times more likely to die at a younger age than the general population [6].

**Methods**

The purpose of this research was to interpret the lived experience of individuals with Type 2 diabetes mellitus (T2DM) living in a homeless environment to obtain a deeper understanding of how they self-manage their disease. A Heideggerian interpretive phenomenology approach guided the study [61]. The study received IRB approval and participants were recruited.

Participants were interviewed in a private area at a parish in Northeast Ohio to understand their perspectives on having diabetes and being homeless. The interviews were analyzed using the seven-step method of critical hermeneutic analysis according to the modified procedure outlined by Diekelmann, et al. [62].

Flyers were distributed to homeless adults two days a week at the parish prior to breakfast and evening meals while they were in line outside the parish. Additionally, the primary researcher approached potential individuals during mealtime to discuss the study and determine if individuals met inclusion criteria since all who came to the parish for meals were not homeless.

Purposive sampling was used to recruit 32 homeless individuals from a parish located in Northeast Ohio. The parish provides a variety of services to the community including meals. Most of the meals were high in Carbohydrates (CHOs) and limited in fruits and vegetables. Individuals were given a brown paper bag filled with bread to take with them as they left the parish. Some individuals would secretly pack up some of the food provided during mealtime to take with them for later. Individuals were not allowed to remove food from the parish, but they were allowed second and third servings of food from what was left over.

The primary researcher used a snowball sampling technique, which allowed homeless individuals who had already been interviewed to discuss and recommend the study to other homeless individuals. Thirty-two individuals who met the inclusion criteria of being diagnosed with T2DM and being homeless participated in the study. The data from three participants were lost due to technical problems with the digital recorder and one participant’s interview was stopped by the primary researcher due to the individual’s cognitive inability to respond to the research questions. The analysis of the data included responses from twenty-eight participants.

**Results**

The overarching theme of “Being homeless and having diabetes is difficult” addressed the research question: What is the lived experience of homeless individuals with type 2 diabetes? Data supporting the subthemes of “It stresses me out “and It’s hard to take care of myself” answered these research questions: What is the meaning of self-management in persons with diabetes living in a homeless environment? and, How does persons with diabetes manage their disease in a homeless environment? Sources of non-medical resources described most often by participants were shelter, transportation, and food.

All the participants provided exemplars that answered the research questions. Lack of medical resources such as regular appointments with medical providers for health care, lack of glucometers for testing blood glucose levels, obtaining test strips, and storing medications were barriers to diabetes self-management. These resources are required for proper self-management of diabetes.

**Demographic Data**

The demographic characteristics of the participants are displayed in (Table 1). Of the twenty-eight participants, eighteen were male and ten were female. Their ages ranged from twenty-one to sixty-three years with an average of forty-eight years. The time from being diagnosed with T2DM ranged from one month to twenty years. Participants described being homeless for two weeks to twenty + years. Eight participants (28%) were homeless more than two years and two (7%) were homeless intermittently for more than twenty years.

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| --- | --- |
| Gender Females 10 Males 18 | |
| Age Average age = 48 years Range age = 21-63 years | |
| Diagnosis of T2DM prior to becoming homeless | n = 23 Females = 9 Males = 14 |
| Diagnosis of T2DM after becoming homeless | n = 5 Female = 1 Males = 4 |
| Length of time after T2DM diagnosis (all participants) | 1 month to 20 years (range) Average 5.28 years |
| Length of time being homeless (all participants) | 2 weeks to 20+ years (range) Average 2.73 years |
| Identified PCP Yes n = 23 (Female 8, Male 15) No n = 5 (Female 1, Male 4) Visits: Range: once a month to twice a year Average: Every 3 to 6 months | |
| Frequency of visits with PCP (as reported by participants) | |
| Once a month | 2 |
| Every 6 weeks | 1 |
| Every 3 months | 6 |
| Every 3 to 4 months | 1 |
| Every 4 months | 1 |
| Every 6 months/twice a year | 6 |
| Once a year | 5 |
| Outlier (Miscellaneous/no report) | 6 |

**Table 1:** Demographic Data N = 28.

Twenty-three participants (82%) reported receiving medical care from a primary care provider (PCP), and five participants (18%) did not identify a PCP. One male participant reported receiving medical care in the Emergency Department (ED), and another male participant reported receiving medical care at a community clinic.

Participants reported frequency of visits with their PCP. Eight participants (29%) reported visiting a PCP every three to four months. Six participants (21%) reported visiting a PCP every six months or twice a year. Five participants (18%) reported visiting a PCP once a year. One participant reported visiting a PCP every six weeks. Two participants (7%) reported visiting a PCP every month. Six participants (21%) reported no visits with a PCP.

Twenty-three participants (82%) were diagnosed with T2DM prior to being homeless, and five participants (17%) were diagnosed with T2DM after being homeless. The participants that were diagnosed with T2DM prior to being homeless demonstrated greater understanding of T2DM and enhanced knowledge related to self- management of diabetes. The participants who were diagnosed with T2DM after being homeless were less knowledgeable about T2DM and were unsure how to self-manage their disease.

**Limitations**

There were several limitations to this study. First, conducting a pilot study or a feasibility study would have been helpful to assess the interview questions. The initial semi-structured interview questions did not allow participants to provide rich descriptions of their lived experience being homeless with T2DM. Many participants needed to be redirected to the interview questions related to diabetes self-management. The participants wanted to talk about how people did not care about them and how they were misjudged by people. Interviews were short in duration requiring an increased number of participants for data saturation.

Second, using individual interviews may have limited the participants’ responses to describe their lived experiences. Focus group interviews may have allowed the participants to expand their stories based on other participants responses in the group [63,64]. According to Krueger and Casey [65], focus group interviews are useful for participants to explore and gather information about their lived experiences and share their experiences with others in the group. Focus groups may have allowed the participants in this study to feel more comfortable sharing their stories about being homeless with diabetes. In addition, the combination of using individual interviews with focus groups may enhanced the richness of the data [66].

Third, the study was conducted at one location in Northeast Ohio. This limits the ability to generalize the findings to other homeless populations. Homeless individuals from different locations may differ in their description of their lived experience of being homeless with T2DM. And finally, race and ethnicity were not obtained in the demographic data. This information would have been helpful to further describe the sample but would not yield any additional information related to homeless individuals and their lived experience of managing diabetes.

homeless individuals. Health care providers of many types, registered nurses, dieticians, social workers, case managers and certified diabetes educators will have an increased understanding of the needs of homeless individuals with diabetes. Research has shown that individuals with diabetes in the general population need on-going support to help with diabetes self-management behaviors.

**Discussion**

The findings of this study can guide future development of Diabetes Self-Management Programs (DSMPs) and Diabetes Self-Management Education and Support (DSMES) that are tailored to the needs of homeless individuals. Health care providers of many types, registered nurses, dieticians, social workers, case managers and certified diabetes educators will have an increased understanding of the needs of homeless individuals with diabetes. Research has shown that individuals with diabetes in the general population need on-going support to help with diabetes self-management behaviors.

There were several barriers preventing homeless individuals from maintaining adequate diabetes self-management behaviors. Findings from this study provide evidence for health care providers and health care teams to establish Diabetes Self-Management Programs (DSMPs) and Diabetes Self-Management Education and Support (DSMES) in the homeless community to provide continuous support and resources for homeless individuals with their diabetes self-care. This study provides an early foundation for further studies exploring the phenomenon of homeless individuals with diabetes and other chronic diseases.

**Acknowledgements**

The author wants to acknowledge Dr. Pamela Stephenson, PhD, RN from Kent State University College of Nursing, Kent, Ohio with assistance of identifying the research themes.

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