HOW DO THE HOMELESS NEWLY DIAGNOSED WITH CANCER RECEIVE SAFE AND COST – EFFECTIVE HEALTHCARE DURING YEAR ONE FOLLOWING DIAGNOSIS?

by

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ABSTRACT

AMY B. EDINGER. How Do the Homeless Newly Diagnosed with Cancer Receive Safe and
Cost-Effective Healthcare During Year One Following Diagnosis?
(Under the direction of DR. STEPHANIE WOODS)

Cancer is one of the most common causes of mortality in homeless adults. When a homeless person is hospitalized, they typically return to the streets, making recovery difficult. Conducting a needs assessment survey of homeless patients who are newly diagnosed with cancer was the first step towards evaluating how they can receive safe and cost-effective healthcare. Collection of information was from three perspectives: the patient, the oncology provider, and costs. Nine qualitative interviews with homeless individuals focused on concerns and barriers to care. Ten qualitative interviews with Medical Oncologists as well as a 20-question using Survey Monkey was sent to all providers and focused on current treatment of their homeless patients. Lastly, a retrospective cost analysis examined costs of inpatient and outpatient care during chemotherapy. Two themes emerged from the patient interviews: "Barriers to care" and "Someone to help". During oncology interviews, three themes were identified: "I worry about everything", "Making decisions", and "Care after chemotherapy". Half of the 19 providers who responded to the survey questions indicated that they would revise treatment plans because of homelessness. All providers stated they would utilize a Housing First option if available for their homeless patients. The retrospective cost analysis of 53 homeless patients with cancer over a 5-year period showed cost savings from inpatient vs outpatient treatment totaled $9.0 million dollars. Drawing up a proposal to share with stakeholders is needed to develop a plan to help this population which may include a Housing First/respite home as a solution.

DEDICATION

To my amazing husband Zach, you have supported and encouraged me every step of the way during this journey, starting with applying to nursing school. Thank you for your unconditional love. You are my soul mate and my rock, and I am a much better person because of you. I am so blessed that God brought you to me on February 29, 1992. I love you with my heart and soul always and forever!!

To my 3 wonderful children Isabel, Jack and Colin, take it from me, you can do anything you want in life, you just have to try and persevere. I am so lucky that you are all mine. I love you guys more!

To my parents Ron and Pat and my mother-n-law Marlene for their encouragement and being proud of the work I have accomplished. You mean so much to me and I love you all! I just wish that Marlene was here now to read this as she couldn't wait for the final product.

To my first homeless patient, Amy Eller, who succumbed to her cancer after 18 months. Amy spent 3 ½ months in the hospital waiting for a safe place to discharge. She received multiple cycles of chemotherapy and radiation therapy while hospitalized. Amy was the person that started me on my quest to discover the many why's and how's. Amy was a beautiful person, and I will never forget her.

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DISCLOSURES

The DNP Project Director is affiliated with Atrium Health-Carolinas Medical Center and Levine Cancer Institute as a Nurse Practitioner. The author reports no conflicts of interest.

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LIST OF ABREVIATIONS

HUD: US Department of Housing and Urban Development

DNP: Doctorate of Nurse Practitioner

HF: Housing First

EBP: Evidence–based practice

LCI: Levine Cancer Institute

SSI: Social Security Income

CDSR: Cochrane Database of Systematic Reviews

C-Diff: Clostridium Difficile

MRSA: Methicillin-resistant Staphylococcus aureus

NC: North Carolina

UNC: University of North Carolina

YNHH: Yale-New Haven Hospital

ED: Emergency Department

ECOG: Eastern Cooperative Oncology Group

IRB: Institute Review Board

GED: General Education Development

GI: Gastrointestinal

GU: Genitourinary

COVID: Coronavirus Disease 2019

TB: Tuberculosis

EPOCH+R: Etoposide, Prednisone, Vincristine, Cyclophosphamide, Doxorubicin + Rituxan

ID: Identification

CMC: Carolinas Medical Center

TRACH: Tracheostomy

ICU: Intensive Care Unit

PEG: Percutaneous Endoscopic Gastrostomy

Chapter 1: Introduction and Background

Cancer is among the most common causes of morbidity and mortality in homeless adults (Asgary, 2018; Badgett et al., 2015). Lifestyle and behaviors of homeless individuals increases their cancer risk which includes alcohol, tobacco and drug abuse, high-risk sexual behaviors, and chronic infections (Holowatyj et al.2019; Lamb & Talbott, 1986). A high level of mental illness in the homeless population coupled with a lack of education proves to be a significant barrier to use of health-care services for cancer prevention and detection (Holowatyj et al., 2019; Hwang, 2001). Many homeless are uninsured, and although they may be eligible for Medicaid, the application process may be challenging due to not having necessary documentation and no address (Biedrzycki, 2018). When a homeless person is hospitalized, he or she does not have the ability to go home afterwards to recuperate. They usually return to the streets, making follow-up and recovery difficult and oftentimes landing them back into the hospital (Hicks, 2018).

A point-in-time survey performed in Charlotte, North Carolina on January 30, 2019 concluded that 2,106 people experienced a night of homelessness (Mecklenburg County, 2019). Of that population, 406 people remain chronically homeless (Mecklenburg County, 2019). The US Department of Housing and Urban Development (HUD) recognizes four categories of homelessness: literally homeless; imminent risk of homelessness; homeless under other Federal statutes; and fleeing or attempting to flee domestic violence (HUD, 2017). Scholars argue that homelessness has multiple dimensions and is experienced as more than simply a lack of housing or lack of a home but involves the lack of physiological, emotional, territorial, ontological and spiritual dimensions (Batterham, 2019). Homelessness may include those that live in shelters, motels, and transiently with friends or family.

The highest risk of homelessness occurs in men aged 45–54 years (Asgary, 2018; Fargo et al., 2012). As the majority of homeless individuals were born between 1940s and 1960s, this puts them at an age where the majority of these adults would need age-appropriate cancer screening (Asgary, 2018; Culhane et al., 2013). As these individuals lack access to primary care providers, due to no income and health insurance, they are not likely to obtain their age-appropriate cancer screenings which increases their overall risk of developing a cancer.

Homelessness is an absolute risk factor for Emergency Department (ED) utilization. Compared to the non-homeless, the homeless are more likely to visit the ED secondary to lack of health insurance, unintentional and traumatic injuries from assault, psychiatric illness, substance abuse, food insecurity, and disproportionate burden of disease (Amato et al., 2018; Kushel et al., 2002).

With a new diagnosis of cancer, the homeless often initially present to a healthcare provider with more advanced symptoms such as an inability to swallow foods or liquids, bleeding from the mouth or anus or severe pain, which often requires an increased level of care and admission to an inpatient facility. These patients often stay longer than the non-homeless patient due to disposition issues, whereas the non-homeless patient will be discharged after the acute hospital stay. The homeless patient will generally remain as an inpatient for at least 12 weeks as they await Medicaid approval with a safe discharge plan.

Locally, the homeless patient with cancer, receiving treatment (chemotherapy and/or radiation), typically will not be discharged to a shelter or the streets because of the anticipated complications from their treatment and lack of transportation for future appointments and obtaining medications. The disposition choices for a homeless patient receiving treatment are to family, if able, a skilled nursing facility (requires Medicaid for admission), a respite facility, i.e., Samaritan House, or Housing First Program, i.e., Moore Place. As the respite program and Housing First Program do not require Medicaid for admission, the homeless patient can be accepted when a bed becomes available. A skilled nursing facility will not accept a homeless patient until Medicaid services are established, which at the implementation location is around 90 days. Tozzi (2019), in an experimental study of utilizing United Health's money to pay for housing, stated that, as a society, we've effectively decided that people shouldn't die on the street, but it's acceptable for them to live there. Tozzi continued that this is where America has drawn the line: We'll pay for a hospital bed but not for a home, even when the home would be cheaper.

Samaritan House is a not-for-profit respite and recuperative care place located in Charlotte, North Carolina and serves people who are homeless and in need of short-term placement following a hospital or emergency room stay. All patients go through a referral system used by social workers and authorized medical personnel at area hospitals. During their stay, patients are provided home cooked meals, transportation to and from all medical appointments, and prescription pick-up. They are also provided resource information that may help them with employment and housing as well as transitioning into other social service programs available to them (Samaritan House, 2018). Samaritan House has limited bed availability as it only serves 12 patients at a time. While Samaritan House does not require Medicaid for admission, having this insurance coverage does assist the homeless patient in obtaining their medications and receiving further systemic and radiation treatments as an outpatient.

Housing First (HF) was originally defined as an evidence–based practice (EBP) housing program for people with a mental illness who are experiencing homelessness (Aubry, Nelson, & Tsemberis, 2015). Housing First is based on a rehabilitation model that emphasizes community integration and psychiatric recovery which has been tested in Canada, the United States, and Europe (Padgett, Henwood, & Tsemberis, 2016). Housing First programs are similar to Samaritan House in that they integrate community-based treatment such as home health services and physical and occupational therapy. Support services are also integrated within both programs and include transportation to and from appointments, prescription pick up, income assistance programs in obtaining Social Security Income (SSI), disability, food stamps, and additional housing resources, including potential permanent residences.

Differences between the two programs are the use of volunteers and sources of funding. Samaritan House utilizes volunteers to organize and manage all services provided. These services are carried out by volunteer and church groups that visit on a weekly basis and who also provide fellowship to the residents (Samaritan House, 2018). Housing First programs utilize federal funding programs as local foundation funding and private donations to pay for staff such as social workers and registered nurses. Samaritan House is 100% not-for-profit and does not receive local, state, or federal funding.

1.1 Problem Statement

Through informal discussions Levine Cancer Institute (LCI) providers identified that they sometimes are unable to provide standard chemotherapy to homeless individuals based on their “social situation,” with some reporting that the risk is too high for increased infections while in an immunocompromised state for those without stable housing. These providers also noted that if they know a disposition option such as Samaritan House is available to send patients with a cancer diagnosis after discharge, they are more willing to initiate standard chemotherapy in the inpatient and outpatient facility.

The homeless population who are newly diagnosed with cancer and need chemotherapy and/or radiation typically lack a support system while undergoing their treatments and experiencing the anticipated side effects. Being uninsured, skilled nursing facilities will not accept the homeless patient during their treatment regimen due to lack of reimbursement. Unless the homeless patient can find a reliable family member to stay with, or a bed is available at a place like Samaritan House, these patients may remain hospitalized for months while they receive their first rounds of chemotherapy and/or radiation and await Medicaid approval. If the homeless patient is discharged to Moore Place which is Charlotte's first Housing First program, patients need to be able to care 100% for themselves and have no identified medical needs i.e., feeding tube. For the ones that do have identified medical needs, where can they go?

1.2 Purpose of Project

This quality improvement project conducts a needs assessment survey of homeless patients who are newly diagnosed with cancer as a first step towards evaluating how the homeless patient can receive safe and effective healthcare and housing during the first year following diagnosis.

1.3 Clinical Question (PICOT)

How do the homeless (P) newly diagnosed with cancer (I) receive safe and cost–effective healthcare (O) during year one following diagnosis (T)?

1.4 Project Aims

This is a quality improvement project, which involves conducting a needs assessment survey with homeless patients who are newly diagnosed with cancer as well as with providers caring for these patients. This needs assessment survey will serve as a first step towards evaluating how the homeless newly diagnosed with cancer can receive safe and effective healthcare with housing during year one following diagnosis. Possible housing solutions will be explored for these patients. There are three aims: patient interviews, provider data, and cost analysis.

Aim 1: Patient Interview: Evaluate the needs of homeless patients newly diagnosed with cancer.

This aim will be evaluated via open-ended interviews with the homeless population through the Patient questionnaire (Appendix A). The Patient Questionnaire asks questions regarding concerns and barriers about accessing cancer treatment and living circumstances when treatment begins, and housing options as treatment continues. The interview also includes questions about a Housing First/respite home option during treatment, services they would like included, and feelings of safety in a Housing First/respite home while undergoing treatment for cancer.

Aim 2: Provider Data: Evaluate provider care practices of the homeless patient newly diagnosed with cancer.

This aim will be evaluated two ways: via an open-ended interview (see Appendix B) with providers at Levine Cancer Institute and a Provider Survey (see Appendix C) delivered by a Survey Monkey format. The open-ended interview and Provider Survey include questions regarding how providers approach the treatment plan for homeless newly diagnosed with cancer, treatment barriers, and consideration of a Housing First/respite home for the homeless as they continue their treatment protocols.

Aim 3: Cost Analysis: Evaluate inpatient costs for hospitalized homeless patients newly diagnosed with cancer and compare with outpatient costs. Assess ED costs incurred as well as chemotherapy costs given inpatient vs outpatient.

This aim will be met through a retrospective review of costs for patients receiving inpatient treatment as well as outpatient treatment over a 5-year time period. Assessing the costs of the hospitalized homeless patients newly diagnosed with cancer will provide a summary of the incurred cost to the hospital which will include ED visits as well as chemotherapy costs. A review of cost savings between inpatient and outpatient care will also be assessed.

Chapter 2: Literature Review

A literature review was conducted, and databases searched included PubMed, Cochrane Database of Systematic Reviews (CDSR), ProQuest Nursing & Allied Health, Science Direct and Google Scholar. The key words used were homeless, cancer, housing first, respite, costs, and cultural care theory. The literature review included research studies and articles published from 2007 through 2020. Exclusion criteria were articles that did not involve homeless individuals or were not written in English.

Upon review, there are limited articles about homeless adults and cancer in general and few discussing cancer screenings such as colonoscopies, mammograms and very few in actual diagnosis or treatment of cancer. When people struggle to live, they lack basic necessities such as safe housing, nutritious food, money to meet basic personal needs, transportation, and access to health care (Hughes & Gudmundsdottir, 2007).

2.1 Patient Review

Limited evidence-based articles about homeless adults diagnosed with cancer or how best to deliver safe and cost-effective healthcare exist. Hauff and Secor-Turner (2014) described the medical needs of homeless patients as increasingly complex. These authors stated issues around needing antibiotics, pain medications, oxygen and the presence of bacteria such as Clostridium Difficile (C-Diff) and Methicillin-resistant Staphylococcus aureus (MRSA), which make it extremely difficult to discharge a homeless patient back to a shelter. Homeless patients may remain hospitalized for several weeks after their acute medical needs have resolved as the staff attempt to arrange satisfactory discharge locations and plans (Doran et al., 2015).

Showering in a homeless shelter or changing one’s socks can become an infection problem for the patients with cancer due to being immunocompromised. Doran et al., (2015) stated that homeless patients may remain hospitalized for days after their acute medical needs have been met as hospital providers attempt to arrange suitable discharge locations and plans.

Larimer et al. (2009), suggested that utilizing permanent housing, would show the truest cost savings of a Housing First home, as the benefits from being housed continued to ensue long after these individuals were housed. Findings support strategies to retain these individuals in housing, including offering on-site medical and mental health services, supportive case managers, and minimal rules and regulations pertaining to their housing. Having a Housing First home was associated with significant improvements in the individual's quality of life. Due to community resources available to the homeless, some were able to find permanent housing, jobs, as well as mental health counseling to improve their well-being.

An Outcomes Evaluation & Service Utilization Study, funded by Mecklenburg County, the UNC Charlotte College of Health and Human services, School of Social Work, and the UNC Charlotte Urban Institute, was completed in November 2020 by UNC Charlotte researchers on how Housing First improves the lives of the chronically homeless (Thomas et al., 2020). Study participants who were housed through Housing First showed substantial improvements across many dimensions. Fewer people were arrested and incarcerated. Housed individuals that were arrested fell 59% and housed individuals incarcerated fell 58%.

Thomas et al. (2020) also noted reduced substance abuse which included alcohol, cocaine and marijuana. The Charlotte Housing First project did not require sobriety or abstinence prior to being housed, yet after housing the percent of participants that used any drug fell 37%. Trauma symptoms decreased 26% after housing. Thomas et al. (2020) discovered housed participants, who had high lifetime rates of traumatic stress, scored 11 points lower on a standardized measure of trauma-related symptoms than did unhoused participants who only scored 1 point lower after baseline.

Thomas et al. (2020) continues that quality-of-life scores improved 30% after housing. Housed participants scored 19 points higher on a standardized quality of life assessment than did unhoused participants who only scored 2 points higher after baseline.

In New Haven, Connecticut, Doran (2015) used a community-based participatory research approach in examining transitioning homeless patients between Columbus House and Yale-New Haven Hospital (YNHH) in 2013. Columbus House is the largest homeless service agency in New Haven and its programs include both a year-round and seasonal emergency shelter for homeless adults, transitional and permanent supportive housing sites in addition to case management, employee assistance, and street outreach. It was noted that transitioning homeless patients from the hospital back to the community was particularly challenging despite providing care for a shared group of homeless clients.

A respite program was developed with a length of stay of 4 weeks and a goal of discharge to permanent housing. The focus of this program was to reduce hospital admission rates and services included case management, visiting nurse services, and transportation to medical appointments. This program took place in the Columbus House shelter and consisted of 12 private rooms, with referrals taken from YNHH. Preliminary data demonstrated that the 30-day inpatient readmission rate for homeless patients placed in respite programs was 21.6% compared to 50.8% among homeless patients prior to initiation of the program (Doran, 2015).

2.2 Provider Review

Hauff and Secor-Turner (2014) discussed how providers validated the need for a medical respite facility in communities. Hospital staff are pushed to discharge patients who are deemed medically stable to keep hospital costs down, but shelters are not equipped to provide medical care for recuperation post hospitalization. Relationships among hospital and shelter staff become strained due to lack of post-acute level care for homeless persons. Hauff and Secor-Turner (2014) stated that providers discussed how homeless patients who are recovering from illness or surgery could be connected with resources and services, while providing an opportunity for education while in a respite program. These patients would also have a place to store and safely administer their medications.

There were few studies that examined oncology provider data when caring for the homeless. Several researchers looked at social disparities and noted the increased impact that social disparities had on symptom burden and symptom distress when compared with other population groups. Salas et al. (2019) examined the perspective of palliative care providers caring for those with advanced cancer and the relationship between social disparities and symptom burden. These authors reported that palliative care providers face challenges when treating patients with social disparities. The results of this study align with other studies that suggest a relationship between social disparities and symptom burden exist (Salas et al., 2019) with higher levels of symptom burden and distress being reported in low-income cancer groups (Martinez et al., 2014; Rannestad et al., 2012).

2.3 Cost Review

Review of the literature found limited studies that analyzed the cost of the inpatient homeless patient and only one article focused on the cost with cancer. Suh et al. (2016) analyzed treatment costs of South Korea homeless adults on initial hospitalization with lung cancer and concluded that median treatment cost constituted 47.3% of the 2013 per capita income and inpatient treatment accounted for 90% of the total hospitalization costs which is significantly high for this country.

In researching safe housing solutions for the homeless, numerous studies were found on Housing First programs which are evidence-based practice programs that have been shown to support people with all types of chronic conditions and reduce emergency department visits, re-admissions, and overall length of stay. Studies in a literature review by Ly and Latimer (2015) showed that Housing First programs significantly increased the time that people are stably housed and can be a very cost-effective intervention for the chronically homeless populations as health and quality of life have been known to improve. Ly and Latimer (2015) also found that ED costs decreased with Housing First programs, while impacts on hospitalization costs were more obscure.

Thomas and colleagues (2020), in the Moore Place study which was Charlotte’s first Housing First program, found extensive reductions in emergency and inpatient hospital billing for a sample of some of the first individuals housed in this project. On average, emergency department billing fell an average of $29,070 per person in the year after individuals were housed. Additionally, there were additional reductions in inpatient hospitalizations and jail stays.

In one article based in the United States, Tozzi (2019) reported the results of UnitedHealth moving one of their own homeless Medicaid members with multiple comorbidities into an apartment home. In the 12 months prior to moving in, this patient went to the emergency room numerous times, was hospitalized, and on average accrued $12,945 in hospital costs per month. Once getting a roof over his head and health coaching, this patient’s average monthly medical expenses dropped more than 80%, to $2,073 per month. Although this homeless patient did not have cancer, if the same structure is applied to the cancer population, then this project may potentially demonstrate the same safe housing benefit and cost-effective analysis. Larimer et al. (2009) stated that the solutions of housing for the homeless individuals reduces hospital visits, admissions, and duration of hospital stays resulting in the public system spending being reduced by nearly as much as is spent on housing.

In the Outcomes Evaluation & Service Utilization Study in Charlotte reported earlier, Thomas et al. (2020), demonstrated the benefits of reducing hospitalization costs for the chronically homeless when comparing those that were housed in the project to the unhoused participants. Housed study participants who had been previously hospitalized (*n* = 54, 32.7%) spent 730 nights in the hospital in the year prior to housing. In the year following housing, housed participants were hospitalized a total of 477 nights, a 35% decrease. Thomas et al., (2020) noted that unhoused participants hospitalizations also decreased 34%.

2.4 Theoretical/Conceptual Framework

Leininger's Theory of Cultural Care Diversity and Universality was developed in the 1950's and described care as a powerful means to help clients recover from illnesses or unfavorable human life conditions (Leininger, 1978). Leininger (1988) firmly believes that care is the central, dominant, and unifying feature of nursing. A qualitative approach was imperative to identify, describe, and account for unknown aspects of cultural care. Her theory is the broadest and most holistic guide to study human beings with their lifeways, cultural values and beliefs, material and nonmaterial forms and living contexts. Applying transcultural theory to the homeless, the complexities of culture can be illuminated and expanded upon (Law & John, 2012).

Using a qualitative approach while interviewing the homeless population helped to provide an understanding of their lifeways, stresses and behaviors, all of which are important to increasing the knowledge of how best to effectively care for homeless newly diagnosed with cancer.

Leininger (1988) developed the Sunrise Model which encompasses the holistic conceptual components of her theory which influences the care, health status of individuals, families, groups, and sociocultural institutions. This model addresses how all of this interface with one another. As the model is used, one can focus on specific areas (i.e., kinship & social factors, religious factors, economic factors) in relation to the different components of the theory. Each component can be examined in detail by a qualitative approach to discover meanings and patterned expressions of care. Care concepts, such as stress alleviation, trust, involvement with touch, stimulation, comfort, engrossment, tenderness, and empathy may be similar or different (Leininger, 1988). All of these concepts give professionals a way to understand and care for individuals, families, and their cultures.

In utilizing Leininger's theory, cultural skill is imperative when assessing clients and includes the ability of a person to develop a comprehensive, holistic and physical assessment (John & Law, 2011). The key transcultural caring skill includes the awareness that one cannot fully know and understand another's culture. Acknowledgement that the patient is the expert is key and once this is accepted, one should feel more comfortable asking the patient what their main concerns are, and how their care can be modified to fit their lifestyle (Law & John, 2012).

Chapter 3: Methods

The Project Director is a Nurse Practitioner who works for Levine Cancer Institute on the Inpatient Solid Tumor Oncology Team at Atrium Health-Main. With seven years of Oncologic experience within the system, the project director has cared for homeless patients with cancer and worked with many of the Solid Tumor Oncologists as they rotate through on the inpatient team in the hospital.

3.1 Setting

The settings for this project were Atrium Health-Carolinas Medical Center, Levine Cancer Institute outpatient clinic, and Samaritan House. Atrium Health-Carolinas Medical Center is an 874-bed acute care facility located in Charlotte, NC. Typically, patients stay in the Oncology units but may also be in the intensive care units or other available units if space is needed. Under the umbrella of Atrium Health is Levine Cancer Institute (LCI) which treats over 11,000 patients with oncological and/or hematological diagnoses each year. LCI spans 25+ locations to ensure that everyone has access close to home (Atrium Health 2019). LCI-Morehead, the main clinic in Charlotte is attached to Atrium Health Carolinas Medical Center

Samaritan House is a not-for-profit recuperative care facility for the homeless population who are in need of short-term care following a hospital or emergency room stay. Staff at Samaritan House are willing to allow patients to stay who require a feeding tube and tracheostomy care as long as the patient can manage the cleaning and maintenance of these items themselves. The House is not considered a shelter and all patients enter through a referral system used by social workers and authorized medical personnel at area hospitals. During their stay, patients are provided home cooked meals, transportation to and from medical appointments, and prescription medication pick-up. Patients are also provided resource information that may help them with employment, long term housing and transitioning into other social service programs available to them. The Samaritan House allows room for 12 guests at a time. This setting was used to provide a cost analysis of patient bed costs per day at Samaritan House vs Atrium Health-Carolinas Medical Center.

3.2 Sample

Approximately nine homeless patients diagnosed with cancer at Atrium Health, LCI or living at Samaritan House were recruited for the qualitative interviews. Patients were recruited via face to face or via phone. One patient was unable to complete the interview due to significant medical complications experienced during his hospitalization, therefore eight patient interviews were analyzed. The age of the sample ranged from 45 to 65 years of age. There were no stipulations on sex and race. Patient 9 was exempt from the study due to inability to speak secondary to requiring a tracheostomy to breathe. As an incentive, a $25 Walmart gift card was offered to each patient at the end of the survey completion.

LCI Solid Tumor Providers currently employed within Levine Cancer Institute and caring for patients newly diagnosed with cancer were recruited via email for the direct provider interviews and survey. Ten oncology providers who had cared for homeless patients participated in the qualitative face to face interview and 19 out of 52 solid tumor medical oncology providers responded for the online survey. The providers sampled were based over 25 locations across the Charlotte area. As an incentive, a $50 gift card was offered to five randomly selected providers at the end of the survey completion.

3.3 Measurement Tools

3.3.1 Data from Patient

Data was collected in a variety of ways. Homeless patients newly diagnosed with cancer were interviewed by the Project Director using a set of open-ended questions. Questions focused on concerns and barriers about accessing cancer treatment, living circumstances once treatment begins, and feelings toward an alternate plan for safe housing vs remaining in the hospital while receiving regimes of chemotherapy or other treatments. Specific questions about what services homeless patients would like to see in place at a safe house while undergoing chemotherapy were also asked, for example, availability of a Social Worker, Nursing staff, and transportation (see Appendix A for patient interview questions).

3.3.2 Data from Provider

Data was obtained in two different ways. Face to face interviews with oncology providers who have cared for homeless patients were conducted by the Project Director using open-ended questions related to the care provided to homeless patients newly diagnosed with cancer. Interviews were recorded and transcribed. Questions focused on concerns and barriers about initiating standard systemic treatment, treatment barriers, living circumstances once treatment protocols begin, and thoughts about an alternate plan for safe housing such as a Housing First/respite program while receiving treatment regimens (see Appendix B for oncology provider interview questions). Data was also collected by the Project Director from providers through an online survey using the Survey Monkey Format. This was sent to 52 Solid Tumor providers within Levine Cancer Institute.

An internal survey conducted by the one of the clinicians three years ago collected information from 43 respondent providers within Levine Cancer Institute about the care they provided to their homeless patients. These providers included Surgeons, Hematologists, Radiation Oncologists as well as Solid Tumor providers. The current survey consisted of 20 questions with yes/no, multiple choice, and open-ended questions. The focus of the questions was on care/treatment regimens the providers give homeless patients, concerns, perceived and actual barriers providers have experienced, and perspectives on housing options versus hospital stay if a respite home/Housing First home were to be made available for use within Atrium Health System (see Appendix C for provider survey). A paper consent form was given to all patients and providers to sign prior to direct face to face interviews (see Appendix D for Patient Informed Consent Form and Appendix for E for Provider Informed Consent Form).

3.3.3 Retrospective Inpatient Costs

Inpatient costs were assessed by the Project Director in a five-year retrospective review of hospitalized homeless patients receiving treatment at Atrium Health and homeless patients having an option to live safely elsewhere (i.e., Samaritan House) while receiving outpatient treatment at an LCI location. Analysis included the cost of chemotherapy (costs inpatient vs outpatient for same course). Daily costs as well as total admission costs were assessed per patient. The Quality Improvement Outcomes Specialist assisted with obtaining costs within Atrium Health-Carolinas Medical Center and Levine Cancer Institute. All patient data was de-identified. These tools have been developed for this project with assistance from the Clinical Expert.

3.3.4 Patient Demographics

Age, gender, race/ethnicity, education level, living arrangements, performance status (as measured by the Eastern Cooperative Oncology Group (ECOG)), and cancer type (i.e., lung, breast, head and neck, gastrointestinal) were included in the dataset. ECOG measures the patient's performance status prior to onset of illness and during illness. The performance status score indicates to the provider the level of a patient's daily living abilities in terms of the ability to care for themselves, daily activity and physical ability (ECOG-ACRIN Research Group, 2020). Providers use this number to determine whether a patient can undergo a clinical trial due to rules and whether to keep pursuing systemic treatment (see Appendix F Patient Demographic Survey).

3.3.5 Provider Demographics

Race, gender, specialty, years worked as an Oncologist, and area worked were included in the data set (see Appendix G Provider Demographic Survey).

3.4 Method of Data Collection/Analysis

This needs assessment project collected data from the perspective of the three aims: patient interviews, provider survey and interview data, and cost analysis.

Aim 1: Patient Interviews. All interviews were conducted by the Project Director. Data was transcribed by the Project Director resulting in 22 single-spaced pages of data. Data was analyzed using a qualitative thematic analysis approach following Braun & Clarke's (2006) six phases of thematic analysis. The first step was familiarization of the data. The second step was Coding, followed by searching for themes, then reviewing themes. The final two steps included defining and naming the themes and writing up the process. The Project Director was one coder; data was also independently coded by an outside coder. During discussions, both coders confirmed themes.

Aim 2: Provider Data. All interviews were conducted by the Project Director. Data was transcribed by the Project Director resulting in 10 single-spaced pages of data. Data was analyzed using a qualitative thematic analysis approach following Braun & Clarke's (2006) six phases of thematic analysis as described in AIM 1. The Project Director was one coder; data was also independently coded by an outside coder. During discussions, both coders confirmed themes. Data was also collected by the Project Director from the Provider Survey responses and evaluated using means, response frequencies, and other descriptive statistics.

Aim 3: Cost Analysis. The first set of costs were evaluated by the Project Director using descriptive statistics to analyze the total costs per inpatient day and total number of days hospitalized which may include chemotherapy and/or radiation treatments. These costs were all inclusive. Costs were assessed by the Project Director retrospectively from homeless patients with cancer over the previous five years. The second set of costs compared costs per day receiving inpatient chemotherapy vs outpatient chemotherapy while residing at a safe place such as Samaritan House.

3.5 Timeline for Data Collection

The DNP Project received Institute Review Board (IRB) approval from Atrium Health on March 27, 2020, and UNCC IRB approval on March 31, 2020. On Oct 1st, 2020 the DNP Project Director sent an email communication to all LCI Solid Tumor Providers to access Survey Monkey and elicit their participation. The potential participants had a two-week timeframe to respond before the DNP Project Director sent a follow up email reminding and requesting participants to complete all components of the program by Oct. 31, 2020. The open-ended patient interviews were conducted with any hospitalized homeless patient diagnosed with cancer, in follow up at the LCI clinic and at Samaritan House, which occurred from May 2020 through December 15, 2020. The open-ended provider interviews were conducted with conveniently sampled Medical Oncologists of LCI during fall 2020. During the same time frame, the Quality Improvement Outcomes Specialist reviewed retrospective data on costs per hospitalization, per homeless patient that have been treated in house with chemotherapy and/or radiation therapy over the last 5 years. Data collection was completed by December 15, 2020.

Chapter 4: Project Findings and Results

4.1 Patient Demographics

Demographic data was collected in paper format at the beginning of the face-to-face interview process with homeless patients. Patient demographics included eight items to obtain information about participant age, education level, race/ethnicity, gender, current living situation, prior employment wages before becoming homeless, current performance status and cancer type (see Table 1).

The sample included nine individuals with a mean age of 55 years (*sd* = 9.7). The demographic results indicate that the majority (89%) of participants were aged 46-65 years. In regard to race/ethnicity, 56% were African American while 44% were Caucasian. Males comprised 89% of the sample while 11% were female. In regard to education level, 44% obtained at least a Graduate Educational Development (GED) diploma, the majority of respondents obtaining their GED while in prison; 33% had some high school education and 22% had an associate degree. Almost 89% of the participants made under $30,000 a year prior to becoming homeless with one participant reporting an annual income of $31,000.

One third (33%) of the participants lived in a shelter/hotel at the time of their interviews, all of which had been arranged through the Urban Ministry in Charlotte, NC. The Urban Ministry Center is an interfaith organization dedicated to providing services to the homeless including shelter, meals, transportation, showers, identification (ID) assistance, etc. One third (33%) of individuals were living on the streets upon interview, 22% were living at Samaritan House, and 11% were living with friends/family. On the measure of performance status (PS), which is a numerical score used to quantify a cancer patient's general well-being and activities of daily living on a scale of 0-4 (0 = *fully active* to 4 = *unable to care for self*; see Table 2) and ability to tolerate treatment. Eighty-nine percent of the participants were considered a 0/1, meaning that all of them would qualify for systemic treatment with chemotherapy or immunotherapy as they would have little to no physical restriction in their daily lives. One participant was considered to have a PS of 4 (see table 2) which meant that he did not qualify for systemic treatment. He was too weak and too ill at the time for consideration and it was suggested that he receive rehabilitation to make him stronger. Thirty-three percent (3) of the individuals had been diagnosed with lung cancer, 33% (3) had pancreatic or stomach cancer, 22% (2) had colon/rectal cancer, and 11% had been diagnosed with a head and neck cancer.

Table 1

Patient Demographics (N=9)

Demographics	*n*	%
Gender		
Female	1	11
Male	8	89
Age		
18-30 years	0	0
31-45 years	1	11
46-65 years	8	89
66-80 years	0	0
Race/Ethnicity		
African American	5	55.6
Caucasian	4	44.4
Hispanic	0	0
Other	0	0
Highest educational level		
Some high school	3	33.3
GED	4	44.4
Associate degree	2	22.2
Bachelor’s degree	0	0
Living situation		
Shelter/Hotel	3	33.3
Samaritan House	2	22.2
On the streets	3	33.3
Friends/family	1	11.1

Table 1 (continued)

Demographics	*n*	%
Prior employment wages		
$0-$30,000 / year	8	89
$31,000-$60,000 / year	1	11
$61,000-$90,000 / year	0	0
Performance status		
0/1	8	89
2	0	0
3	0	0
4	1	11
Cancer type		
Colon/rectal	2	22.2
Pancreatic/stomach	3	33.3
Head/neck	1	11.1
Lung	3	33.3

Note. Patient 9 was not able to complete the entire interview due to ongoing medical complications.

Table 2

Performance Status

Activity Ability	Grade
Fully active, no restrictions	0
Strenuous physical activity restricted; fully ambulatory and able to carry out light work	1
Capable of all self-care but unable to carry out any work activities; only up and about >50% of waking hours	2
Capable of only limited self-care; confined to bed/chair >50% of waking hours	3
Completely disabled; cannot carry out any self-care	4

4.2 Thematic Analysis from Homeless Patient Interviews

A qualitative design was used to acquire the homeless patient perspective on barriers to care that they had experienced when first diagnosed with cancer. A semi-structured interview consisting of seven open-ended questions with follow up questions (see Table 3) was carried out with nine patient participants asking what they considered to be their concerns about accessing cancer treatment and how to best assist them in receiving safe and cost-effective care.

Table 3

Patient Interview Questions

Question Content
Where did you go first for support when you heard about your diagnosis?
What are your concerns about accessing cancer treatment following your diagnosis?
What are your barriers to accessing cancer treatment following your diagnosis?
Where would you stay when treatment begins?
Who's going to be around to care for you during your treatment (chemotherapy, radiation) when you are experiencing nausea and vomiting, fatigue, etc. – helping you get meals, transportation, getting your Rx's, etc.?
If the hospital had a safe place, such as a room in a house or apartment building with access to staff, would you be willing to stay there during the course of treatment? What would make you feel safe at such a house?
What do you like or dislike about the Samaritan House if you have stayed there? What works or doesn't work as far as their process?

Interviews for the patient were audiotaped and transcribed verbatim and later verified for accuracy. Related words or phrases were organized into meaningful clusters noting two primary themes that emerged from the data. The two themes, essentially using exact words or phrases from the patients, were "Barriers to Care" and "Someone to Help". Subthemes were then captured under each main theme (see Table 4).

4.3 Patient Themes and Subthemes

4.3.1 Patient Theme 1: Barriers to Care

Barriers to Care encompasses events before having a diagnosis of cancer and would likely continue throughout their lifetime. Having a new diagnosis of cancer only exacerbated the same problems the patients have been enduring every single day. Every patient described similar issues with having little to no income, no job, no reliable transportation, and for some, no stable home environment. Their living situation had been complicated by substance abuse and mental health issues. During analysis of the patient interviews three subthemes were identified within the theme Barriers to Care. These three subthemes were "Difficulty with Transportation", "Finding a Place to Live", and "Utilizing the Emergency Department for their Healthcare Needs".

***4.3.1.1* Patient Subtheme: Difficulty with Transportation.** Patient respondents expressed events such as having difficulty obtaining bus passes, having to walk wherever they need to go, not having money to pay for bus or cab fare and generally rely on free transportation vouchers from the hospital, Urban Ministry, or the outpatient clinic. One particular patient had their own vehicle, but it was stolen prior to the move to Charlotte. While the patients acknowledged that transportation has been a constant problem for years, they have not had the means to fix this issue.

The patients noted that difficulty with transportation created challenges attending appointments, getting medications, and going to the Social Security office to obtain benefits. Seven of the 9 participants noted that they experienced difficulty with transportation. The following data descriptor speaks to the significance of the subtheme Difficulty with Transportation:

> It’s hard to get resources to go take a shower. You gotta walk, you gotta have a bus pass, you don’t have money for bus passes. You look and see if you can get into the men’s shelter to get a bed (Patient 1).
>
> “The only thing Urban Ministry did was when I needed a bus pass, they would give me money for the bus pass, I would catch the bus and make my appointments there and back” (Patient 6).

4.3.1.2 **Patient Subtheme: Finding a Place to Live.** Several patients noted the difficulties of finding a place to live and each reported their current or past living situation includes tents, shelters, governmental housing, motels, and Samaritan House. Some note the instability as they can only stay in a place for so long and they have to move again for various reasons which may include maximum number of days allowed in one facility. Without a roof over their head, patients find themselves out in the open and the target of threatening behaviors from others, with no place to put their own personal belongings. By not having a stable home environment, this also makes accessing transportation even more difficult as they may have to move further away from bus stops. The following data descriptor speaks to the significance of Finding a Place to Live:

> After I had an appointment there in August, I couldn’t find a place to live so I stayed in an Air B&B and I just kept looking everywhere I could, but I couldn’t find a place and then I ended up coming to the hospital as I had no place to go (Patient 3).
>
> “Urban Ministry put me up at a Motel 6 since May of this year, my lease runs out in December before Christmas and they’re going to try and find me some other place to live” (Patient 6).
>
> I was told by a man at the bus stop, you could live in a rehab place to get you off the streets. Told me where to go, Salvation Army on Central and Beasley. The lady said: come back here and take a urine test for me. I did. When I went back, went through the procedure, she said you don’t have no beer, no weed, no drugs in ya, I can’t help you. I’m sorry sir. No bed for you here. I wish you luck. I left. That was that. (Patient 3).

4.3.1.3 Patient Subtheme: Utilizing the Emergency Department. All of the patient respondents noted they present to the emergency department when they have healthcare needs. For individuals experiencing chronic homelessness, the duration of homelessness reduces the chance of having a family physician and thus engaging in primary and preventative care (Khandor et al., 2011). The following data descriptor speaks to the significance of utilizing the emergency department for healthcare needs:

> I was seeing a doctor and she ordered a colonoscopy to be done and I had got sick at work and passed out. I went to the ED and when I was admitted, they told me that I had Stage 3 Colon Cancer (Patient 8).
>
> I couldn't remember how to get my socks back on. Asked security to help me, I didn't know what was wrong, said I'm confused. The ambulance took me to the hospital, they said you got pneumonia (Patient 3).

Because of the many health challenges faced by individuals who are homeless, and particularly individuals experiencing chronic homelessness, they can be more reliant on the health care system than the general population (Amato, Nobay, Amato, Abar, & Adler, 2019).

> "As I was sitting at the bus stop, thinking of the bad weather, this was a good time to check out that knot on my neck and get out of the weather" (Patient 3).
>
> "I was taking a bath because of the pain, and I slipped and fell and bumped my head on my commode and I went to the ED and found out I had prostate cancer" (Patient 6).

4.3.2 Patient Theme 2: Someone to Help

Someone to help demonstrates that every patient had some sort of emotional support, a family member, friend, or professional that they could talk to. Every now and then, they would feel comfortable asking a family member for a few dollars, but none of them ever felt comfortable enough asking for a place to stay or for any sort of physical support. Some patients felt comfortable enough to rely on staff or residents in the facility that they were staying. Many would speak about prayer and relying on the Lord for guidance. During the review of the patient interviews, three subthemes were identified within the theme "Someone to Help". These three subthemes were "Family and Friends", "Be There for You", and "The Lord Above".

***4.3.2.1* Patient Subtheme: Family and Friends.** The first subtheme family and friends demonstrate that everyone has someone they consider family around them i.e., cousins, brothers, sisters, ex-spouses, friends, sons and daughters. Although the patient can call them and even visit, they do not want to bother them with problems or ask for help. Patients report that these family and friends typically have their own lives with their own problems and state they do not want to burden them. The following data descriptors speak to the subtheme of Family and Friends:

> My cousin has been my lifeline since I’ve been here in Charlotte and he was the reason why I moved to Charlotte, but unfortunately, he tried to make a career change so he’s going through it right now along with his family. And I have a wife of 27 years, we’ve been separated now for 20 years, but we are still best friends, but I can feel it coming from her, me going through this and she’s like oh God I can’t deal with this (Patient 3).

> I have a daughter and son and they know my situation, we try and keep in touch, but I feel like them knowing my situation that they could call me more often you know, should show your face, let me know the true concern. When I got out of jail earlier this year, my daughter had my express card with my government money on it including the stimulus money we got, and she spent all my money knowing the situation I was in and we fell out about that (Patient 7).

***4.3.2.2* Patient Subtheme: Be There for You.** The subtheme “Be There For You” demonstrates how the patients feel comfortable relying on the staff and residents at the facilities they frequently live in. They feel like they look out for them and would help them if they get sick. To these patients, they found support in many different places. One feels like the “boss man” placed him in a motel room because he knew what kind of situation he was in with the new diagnosis of cancer. That meant a lot to this particular patient. The following data descriptor speaks to the significance of “Be There For You”:

> I went to the hospital the first time and then when I came from the hospital, they put me up at the hotel so it's them that did that. It was the director, his recommendation that I went to the hotel. Personally, I feel like as long as they feel like you're trying to go on a positive run and trying to move forward, they gonna be there for you. I've seen incidents at the shelter which guys would get up and do something if they had knowledge of

> particular incident like seizures or something. I say you got 20 to 30% of the guys there that would help the actual residents there (Patient 1).
>
> “I talk to Richard (psuedonym) at Samaritan House. I have another lady here; she sits with me and talks to me when I have a bad day” (Patient 8).
>
> I love Samaritan House. They let us sit around and watch TV, play games and laugh, people have their own opinions, to me that’s family. When someone is discharged and ready to move on, it’s like losing a family member (Patient 5).

4.3.2.3 **Patient Subtheme: The Lord Above.** The subtheme “The Lord Above” speaks to how some of the patients believed in God and relied on God. One of them found Christ again after he had been shot by a gang and spoke about the bible studies he had in the park and the weekly gatherings at his church where he had support from fellow worshipers. The following data descriptor speaks to the significance of “The Lord Above”:

> I found out I had this terminal cancer, and when you have no family, we have nobody but the Lord where do you go now for support? The Lord above. The Lord brought me back for a purpose, he put me here for a purpose whether be trying to get my family back together with His doing, it’s coming and it's wonderful to save my brothers and sisters (Patient 5).
>
> “But by the grace of God, you know I'm gonna keep my faith, He brought me this far” (Patient 1).
>
> “My life was already messed up and then I found out I had prostate cancer back in July, and that I had 3 years to live, and I put it in God’s hands” (Patient 6).

Table 4

Summary of Themes and Subthemes from the Patient Perspective

Patient Themes and Subthemes	Antecedents	Outcomes
Barriers to Care[a]		
Difficulty with Transportation[b]	No bus money No income No car	Difficulty making appointments Difficulty getting meds Difficulty making it to SS office to apply for benefits
Finding a Place to Live[b]	No income No job Can only stay in a place for limited time If you do drugs = no bed	Lives in a shelter Couch hopping Lives in a tent Lives in a motel
Utilizing the Emergency Department[b]	No health insurance No primary care physician or access to this Trying to meet basic needs at time i.e., shelter, food	Multiple trips to the ED for any type of ailment which may result in admission or discharge back to the street
Someone to Help[a]		
Family and Friends[b]	Family i.e., cousins, children, ex-spouse nearby, visit some, Speak on phone Friends want them near by in the same city to visit	No support for when ill from side effects Family may offer a few dollars for medications Not allowed to stay with anyone State no one offers a place to stay and they don't want to impede
Be There for You[b]	Sought out and made friends with staff and shelter/tent residents Feels like they will help support them	Feels like staff/residents are their family Will rely on them if they get ill or need to talk Established trust and safety
The Lord Above[b]	Many believe in God Have Faith Have gone through life	Pray Rely on their own Faith to get through

[a] Theme

[b] Subtheme

4.4 Lifeways of the Homeless

One unintended consequence of the interviews with the homeless newly diagnosed with cancer was that they sometimes veered from speaking about barriers of care to descriptions of some of the things occurring while homeless, or as Leininger would say, their lifeway. That qualitative data is described separately from the thematic analysis specific to “Barriers to Care” and “Someone to Help”. The description in the following paragraphs capture a brief instance in the lifeway of the homeless. Leininger (2002) defined lifeways as safe, congruent, and creative ways of blending holistic, generic, and professional care knowledge and practices so that the client experiences beneficial outcomes for well-being or amelioration of a human condition.

Every patient described what they have been through and are continuing to go through. Patients noted the difficulties with substance abuse and how some continue to experience this today. One patient described being shot by a gang “just because I was homeless” and two were beaten by others because of items they had and were stolen from them. A few patients had recently been incarcerated for various reasons. This is consistent with the literature that shows lifetime rates of arrest for individuals experiencing homelessness range between 63% and 90%, with actual convictions over the course of the lifetime ranging between 28% and 80% and incarcerations ranging between 48% and 67% (Roy et al., 2014). Some in this sample described physical, and sexual abuse, even from their family when they were younger. The following data descriptor describes a Lifeway of the Homeless:

> Family looking down on me, pretty rough sexual abuse as well, pretty much just about all my life even into my adult years, he would get me drunk and he would you know, it’s sad to even be molested by your dad (Patient 4).

A few of the patients described the polysubstance abuse they experienced in the past and how some still currently use. The following data descriptors speak to the significance of the substance abuse issues these patients still struggle with and one person who was unwilling to go for an inpatient stay at a drug rehabilitation:

> When I got discharged from the North Carolina Department of Correction, it took me about 3 years to get classified as disabled. My problem was I got started on cocaine and had a habit and I'm still struggling with it now; I've been clean 3 weeks now since I've been in here (Patient 6).
>
> I met a girl from Tennessee that I got mixed up with, she got me started on crack and drinking. I can't stop using crack. I lost my house because I spent all of my money on crack and didn't pay my bills. A lot of housing places want you to be clean to go there. I'm not willing to go to a drug rehab either to get clean (Patient 2).
>
> Well, I've been through all the drugs, and drinking, that was a big problem in my life. Thank God I haven't had a drink in over two years, I made a big move myself, with no help, I did it on my own (Patient 4).

The homeless continue to have difficulty obtaining and securing services that are imperative to them. Applying for Medicaid, Medicare, and Disability are roadblocks for these patients as they typically do not have a computer, internet access, a mailing address and difficulty with transportation to the social security office. Applications are usually started while a patient is hospitalized. Prior to this, the homeless do not know where to go to obtain this sort of help. The following data descriptors speaks to the difficulties the homeless face applying for services:

> My Medicaid was all done in WV and my car was stolen 2 years ago, so I want to get that transferred down here in order to get the medication when I'm out. I got to have it moved here and activated here 'cause it was done in West Virginia and this is a different state. When asked, "who's going to be able to help you with that", the response received was "I really don't know who it would be, probably from the hospital". When they cut this off, I have to stay over here, I'm gonna have to follow up and get some kind of medication, some treatment working on it right now, so that does weigh heavily on you (Patient 4).
>
> I would ride the bus to the social security office to apply for my disability and even walked for 30-40 minutes to get there only to see a sign on the door that said they were closed because of COVID and not sure when they would reopen their doors. This was back in April [2020] (Patient 7).
>
> I'm actually trying to do the Medicaid Medicare thing because I'm 62, so I'm eligible. I'm trying to do that, but I don't know how… so that would come into second play right there,

> it's just having people knowledgeable around me. How do I do this, how do I do that, now mind you, I've always been one to try to be independent if my life depended on it, you know, but hello, that's changing (Patient 1).

One extreme case noted during this study is Patient 9 who had to withdraw due to difficulty communicating secondary to a tracheostomy placement and subsequent complications of a compromised airway. Patient 9 was originally admitted through the ED with a new diagnosis of squamous cell carcinoma of the neck. He appeared frail and had significant weight loss due to difficulty eating and also had generalized weakness early on in his admission. Patient 9 was homeless, with no income, and no health insurance. The hospital social workers started the process of applying for Medicaid soon after Patient 9's admission.

Care providers decided that Patient 9 was too weak to receive inpatient chemotherapy and recommended that he go to rehab at discharge to gain strength. Early on in his admission, Patient 9 had a feeding tube, placed to improve his nutritional status. Rehab was unable to accept him because he was self-pay and did not have a pending Medicaid number. As time went on awaiting a safe discharge disposition, Patient 9 developed many health complications that would lead him to the ICU for a higher-level care.

During the extended admit, it was determined that he was now too weak to sustain the three hours needed daily at rehab and instead required a skilled nursing facility. To be admitted to the skilled nursing facility required Patient 9 to have a pending Medicaid number, which was still being processed. Weeks turned into months and Patient 9 was unable to get treatment for his cancer which continued to grow. Patient 9 passed away 104 days after admission still awaiting a Medicaid number to be safely discharged.

Leininger's cultural care theory is a guide to study human beings' lifeways, cultural values and beliefs, symbols, material and nonmaterial forms, and living contexts which encompasses the wholistic being (Leininger, 1988). Leininger's theory helps to identify the major concerns of the homeless people, while being able to provide culturally competent care, while improving health care to the homeless in diverse settings (Law & John, 2012). While interviewing the homeless patients with a new diagnosis of cancer, it became strongly evident that the majority of them spoke of their difficult lifeways. Their willingness to share provides a profound understanding of the individuals health needs and being able to provide more culturally appropriate care. Planning and interventions such as psychological/psychiatry and social work services can be identified and implemented for these patients with more ease.

In summary, patients expressed many concerns they had about homelessness and now having a new diagnosis of cancer. Difficulty with maintaining a place to stay, transportation, not having money to afford medications were the same concerns prior to having a new diagnosis, but these same concerns were only exacerbated by the person's current conditions. Many of the sample participants veered off topic and freely spoke about their lifeways during the face-to-face interviews indicating their troubled past.

4.5 Provider Demographics

Semi-structured interviews were conducted with ten oncology providers to obtain their perspectives on caring for homeless diagnosed with cancer. Provider demographic information was comprised of five items: provider specialty, years as an oncologist, area worked in, race/ethnicity, and gender (see Table 5). The demographic results indicate 30% of the Oncologists took care of all tumor types in the outside periphery of the primary Levine Cancer Institute (LCI) clinic in Charlotte, NC. Of the respondents, 20% were primary breast oncologists, 20% were primary gastrointestinal (GI) oncologists, 20% were primary thoracic oncologists and 10% were genitourinary (GU) oncologists. All of the providers had greater than

10 years of experience as a medical oncologist. Further results show that 60% had greater than 20 years of experience while 40% had 18-19 years of experience. The majority (80%) of the providers worked in an urban setting while 20% worked in a rural setting. Seventy percent of the providers were Caucasian while 20% were considered Other (written in as Iranian and Pakistani) and 10% as Asian. Seventy percent of the providers were male and 30% were female.

Table 5

Provider Demographics (N = 10)

Demographics	*n*	%
Gender		
Female	3	30
Male	7	70
Years as an Oncologist		
0-2 years	0	0
3-5 years	0	0
6-10 years	0	0
> 10 years	4	40
> 20 years	6	60
Race/Ethnicity		
African American	0	0
Caucasian	7	70
Hispanic	0	0
Asian	1	10
Other[a]	2	20
Area of Specialty		
Breast	2	20
Gastrointestinal (GI)	2	20
Thoracic	2	20
Genitourinal (GU)	1	10
Other[b]	3	30
Area You Work		
Rural	2	20
Urban	8	80

[a] Other = Iranian=1 (10%) and Pakistani=1 (10%).

[b] Other = melanoma and all tumor types.

4.6 Thematic Analysis from Oncology Provider Interviews

Semi-structured interviews were performed with ten selected LCI providers asking six pertinent questions sets (see Table 6). Interviews for the provider were audiotaped and transcribed verbatim by the author and later verified for accuracy. Transcripts were read and reread, and interviews were compared and contrasted within and across interviews. Two providers asked to not be audiotaped, therefore the interview was transcribed by hand. Related words or phrases were organized into meaningful clusters with three primary themes emerging from the data. The three themes, essentially using exact words or phrases from the providers, captured key concepts and were: "I Worry About Everything", "Decision Making", and "Care after Chemotherapy" (Table 7).

Table 6

Provider Interview Questions

Question Content
If you had to estimate, how many homeless with newly diagnosed cancer do you treat in a year? How do you know they are homeless? Are you treating/caring for any at the moment?
What kind of questions do you ask your homeless patient about who will be helping them/caring for them and were they are going to live following their chemotherapy treatments? Do their answers change your decisions about their course of treatment?
What unique worries or concerns do you have when treating the homeless who are receiving their first rounds of chemotherapy?
When you find out a person is homeless, and you know the first course of chemotherapy will be new and difficult, as it would for anyone, what kinds of things do you consider when making your treatment choice?
Has there ever been a situation where you modified or altered your plan of treatment because a person was homeless and had nowhere to go after a chemotherapy treatment? Can you please describe it?
Homeless patients receiving their first round of chemotherapy often stay in the hospital, or if a bed is open, they may stay at Samaritan House. If another option, such as a Housing First option, was available, would you send patients there during their first or second round of chemotherapy? What kinds of things or services would you like to see in such an option?

Table 7

Summary of Themes and Subthemes from the Provider Perspective

Provider Themes and Subthemes	Antecedents	Outcomes
I Worry About Everything[a]		
Chemotherapy is a High-risk Entity[b]	Knowledge of side effects Understands risk factors Approach patient with understanding	Understand repercussions of administering chemo Can have numerous complications after initiation i.e., myelosuppression, N/V/D
Compliance with Medications[b]	Medications being lost or stolen depending where living How to store medications; how to deliver medications	Inability to finish a complete course of chemotherapy; results in cancer growing, may end up being noncurative
Making Decisions[a]		
Modifying Treatment[b]	IV vs oral chemotherapy Surgical vs chemotherapy Treat for cure	Decreased effects of chemo, doesn't work as well, cancer continues to grow If unable to treat - hospice involvement Space out regimen vs close together
Risk to the Patient[b]	Chemotherapy treatment Living situation: no roof over head Poor transportation Needing more support	Unable to pay for meds, no transportation to pick up meds Unable to control pain controlled, N/V/D Unable to continue due to side effects Implement better recommendations
Care after Chemotherapy[a]		
Shelter[b]	Safe housing Family/Friends around to help	Unable to treat patients who live on the street, possibly a tent depending on what type of treatment, hospice may be recommended, will not be able to get hospice to see them on street/tent/car
Communication[b]	Want to see patient with some support prior to chemo to help with medications, transportation, keeping an eye on them if they worsen. Typically, no family or friends to help them when sick Provide social networks If alternative housing – providers recommend this	All alone, no one to help when symptoms worsen Treatment unlikely due to toxicity If alternative housing, or social support, more likely to treat with standard therapy If no support, patients cannot get treated
Transportation Issues[b]	Patients have been known to have no cars, no bus money, no money in general to get back and forth to appts	Unable to make it to office follow ups, chemo infusions, radiation appts, cancer continues to grow

[a] Theme

[b] Subtheme

4.7 Provider Themes and Subthemes

4.7.1 Provider Theme 1: I Worry About Everything

The theme “I worry about everything” encompassed gauging how a patient would react to the chemotherapy treatment to monitoring for complications, such as fever, and getting patients back into the clinic as quickly as possible for supportive care/assistance.

4.7.1.1 Provider Subtheme: Chemotherapy is a High-Risk Entity. All the providers expressed concern about the toxicity of chemotherapy and the side effects and complications that could occur. In addition to the typical and expected side effects of chemotherapy such as fever, nausea, vomiting, and diarrhea, infections are a major side effect because of myelosuppression and neutropenia.

The following data descriptors speaks to the significance of chemotherapy as a high-risk entity and support the theme:

> “I worry about toxicity with some of these medications, I would worry more about myelosuppression, neutropenia, thrombocytopenia, TB occurring more in this population” (Provider 1).
>
> “A lot of times they just show up to the Emergency Department. I worry about diarrhea and if they have electrolyte abnormalities which can kill them. I worry about them having fevers and not having a thermometer at home” (Provider 10).
>
> “They may have increased issues with diarrhea nausea and vomiting and therefore have a greater risk of dehydration if they don't have the same access to fluids, much less food” (Provider 4).

4.7.1.2 Provider Subtheme: Compliance with Medications. Additionally, seven providers also identified worries surrounding medications being lost or stolen, how medications would be stored, medication compliance and care of/use of a port for delivery of chemotherapy or use of this device for drugs other than those meant for treatment. A provider also noted that patients with infusion pumps living at a shelter was problematic and that there was often not an alternative treatment option (Provider 6).

4.7.2 Provider Theme 2: Making Decisions

The second theme was "Making decisions" about the course of treatment in the care of the homeless with cancer. All providers noted that they preferred to have a good stable plan prior to the initiation of any type of cancer treatment. Provider 5 noted that "I wouldn't want to treat somebody with chemotherapy if I knew they were leaving the infusion and going to sleep in the car." The providers all agreed that they would work to find an alternative means of supporting the patient in the short term.

4.7.2.1 Provider Subtheme: Modifying Treatment. All of the oncology providers talked about modifying the type of treatment in certain situations, such as giving an injection versus oral medications to ensure patients received their treatment (Provider 10) or providing a surgical option versus a chemotherapy option (Provider 8), if available. Provider 9 stated, "If they are curative, I will treat for cure, and will not change the treatment regimen. If they are palliative, I may alter the treatment based on how they are tolerating it."

4.7.2.2 Provider Subtheme: Risk to the Patient. All providers also spoke about the risks to the patient, both from the chemotherapy treatment and their living situation, and how these considerations influenced their decision making. The following data descriptors support the theme of making decisions:

> We felt that their risk was too high because she could end up literally in the gutter someplace and no one would know she was living on the streets. Also, if someone did have a roof over their head and they did not feel safe living there, we would maybe alter treatment depending on that (Provider 6).
>
> I have had to alter treatments rarely, most recently I had to alter a treatment schedule for a small cell lung cancer patient to fit the best transportation times and had to alter supportive medications for another homeless patient because her transportation would not take her from my office (Provider 7).
>
> In fact, frankly knowing that they are homeless helps us because it lets us know how much more support they need so I can't think of an instance where it has altered my recommendations or my efforts to implement those recommendations (Provider 5).

During the data collection, on the inpatient service one day, a provider who was part of the surgery service and not interviewed for this project was consulted on a homeless patient's (Patient 10) hospitalization. Patient 10 received a new diagnosis of metastatic pancreatic cancer. Knowing that he had poor social support it was determined by a provider in the hospital setting that the plan of care had to change.

> "I have discussed the possibility of chemotherapy although I think with the patients current living situation as well as lack of social support and administering outpatient chemotherapy would be incredibly difficult. Would consider consulting palliative care and possibly hospice" (Anonymous provider).

Providers do not feel as if they have alternatives to treat patients in situations such as this, nor did this patient have a voice in deciding their own care, since as it was determined by the providers treating them during the hospitalization that he would not be a good chemotherapy candidate based on his current living situation and lack of social support.

4.7.3 Provider Theme 3: Care After Chemotherapy

The last theme was "Care after chemotherapy" in which providers worried about side effects that come with giving any treatment. Providers wanted reassurance that their patient would remain safe, that they would be able to call the office if they had questions or symptoms, or that they had someone to help in case of an emergency. Concerns were also given about follow up care, repeat lab work and being reliable getting to and from appointments. There are three subthemes to this theme: Shelter, communication, and transportation.

4.7.3.1 Provider Subtheme: Shelter. Foremost among the concerns by eight of the providers was shelter or safe housing and the availability of family support or someone reliable to call if needed:

> "Where exactly they are staying at, if it's with friends or family on a couch versus a car versus the streets" (Provider 10).

> I assume that patients that I have seen that are homeless, and who have family that they are not close to, and there's no-one willing to take them in, so it's not something typically I ask them because it's almost assumed that there really isn't anyone that can help them at all (Provider 1).

4.7.3.2 Provider Subtheme: Communication. An important subtheme was communication, identified by eight of the providers, which included the ability of the homeless patient to talk with the physician/physician's office and for the physician's office to be able to reliably contact the patient as needed. Issues hindering communication included availability of cell phones, ability to recharge the phone, minutes, and dead zones. The following data descriptors support this subtheme:

> If not feeling well who would take care of them, how will the clinic get in touch with them if intervention is required for abnormal labs etc., how will they go back and forth from their appointments, who will monitor their medications (Provider 8).

> "Almost everyone has a cell phone now but sometimes bills are not paid, or they are in building with dead zones where they are not receiving their calls, or they run out of minutes on their phone" (Provider 1).

4.7.3.3 Provider Subtheme: Transportation Issues. A final subtheme identified was transportation for care after chemotherapy, specifically the ability of the patient to reliability get back and forth to follow-up appointments. Eight of the providers identified transportation as an issue following chemotherapy. Providers consistently asked their patients if they had family members or friends who lived locally that they could rely on for transportation. Several providers noted that if transportation was problematic. Vouchers could be provided or the number for the American Cancer Society Road to Recovery could be supplied, both of which indicated that providers knew of some solutions to a transportation problem.

In summary, providers expressed numerous concerns when caring for a homeless patient newly diagnosed with cancer. While some providers may have revised their treatment plan, others have not and have found alternative ways to ensure that their patients receive standard treatment for their cancer. Some providers are more aware and have access to services for homeless patients than others. During the face-to-face interviews, some providers stated that they took the Hippocratic Oath and follow it every day and that oath, in their judgement, means they must consider the benefits to patients and never bring them any harm.

4.8 Provider Survey

To obtain a broader provider perspective regarding care decisions for homeless with cancer, fifty-two email invitations were sent to Levine Cancer Institute (LCI) Solid Tumor Providers inviting them to complete the twenty-question online survey utilizing the Survey Monkey platform. These survey results were reviewed and analyzed to incorporate provider feedback when caring for the homeless patient newly diagnosed with cancer (see Table 8.1 and 8.2). Nineteen providers completed the survey (*response rate* =20%). Many providers that did not complete the survey stated they had never cared for a homeless patient.

Results from the online survey showed that 52% of the providers did not ask their patients about their housing status. Almost half (44.4%) changed the onset of their initial standard treatment protocol because their patient was homeless. Half of the providers (52.9%) altered the patient treatment plan at some point because the patient was homeless. All providers agreed that if they had a Housing First option to send their homeless patient while undergoing treatment for cancer, they would utilize this facility. When asked what the providers would like to see as essentials for a Housing First type option, 61% identified transportation, safe narcotic storage, and access to food.

Table 8.1

Provider Survey of Yes-No Questions

Survey Item	Yes		No	
	n	%	n	%
Do you routinely ask patients about their housing status?	9	47.37	10	52.63
Did you change the onset of the standard of treatment protocol because your patient was homeless?	8	44.44	10	55.56
Did you alter your treatment protocol at any point because your patient was homeless?	9	52.94	8	47.06
If you had a Housing First option available to you for treatment and care, would you feel comfortable sending your patient there during treatment?	17	100	0	0
Do you think your homeless patient suffered a shorter survival due to homelessness? If so, explain.	7	38.89[a]	6 5	33.33[b] 27.78[c]
Do you think your patient experienced greater side effects from one or more of the following therapies due to being homeless?	8 1	100[d] 12.5[e]	0	0
Do you think your patient experienced more of the following symptoms due to homeless? Nausea, Pain, Infection?	5 7 3	62.5[f] 87.5[g] 37.5[h]	0	0
Was your patient hospitalized to keep him/her in a safe housing environment?	3	17.65[i]	14	82.35

[a b c] Greater limitation with Medicaid transportation rules inability to make all appointments esp. if more than one in a week. Noncompliance, unclear as discharged from jail because they knew he wasn't doing well. Less support. Less likely to call with issues. Less informed re: healthcare etc.

[d] Chemotherapy

[e] Surgery, less resources to identify and call about side effects

[f] Pain

[g] Nausea

[h] Infection, due to lost medications, inability to get medications

[i] Overall better when in a controlled environment

Table 8.2

Provider Survey of Patient-specific Descriptors via Survey Monkey

Survey Item	n	%
If he/she was hospitalized due to those reasons, did he/she experience more of the following?		
Pain	2	100
Nausea	0	0
Infection	0	0
In the past 12 months, how many patients have you cared for with acute/chronic homelessness?		
0-1 patients	8	44.4
2 patients	2	11.1
3 patients	1	5.5
4-6 patients	1	5.5
5 patients	2	11.1
6 patients	2	11.1
10-15 patients	1	5.5
Not certain	1	5.5
If you encounter a homeless patient who is newly diagnosed with cancer, which resources would you use to try to help him/her?		
Social worker	14	73.68
Samaritan House	7	36.84
Urban Ministry Center	3	15.79
Local faith-based organizations	3	15.79
RN case manager	9	47.37
All the above	9	47.37
In your experience where did the acute or chronic homeless patient stay once treatment started?		
Shelter	10	52.63
Short-term housing	7	36.84
Hospital	2	10.53
Friends/family	15	78.95
Street	2	10.53
I don’t know	3	15.79
Other	1	5.26
Which of these would you consider to be essential for a Housing First home for treatment and care of the newly diagnosed cancer patient who is homeless?		
Transportation to infusion	5	27.78
Transportation to appointments	1	5.56
Safe narcotic storage	1	5.56
Other[a]	11	61
Which kind of provider are you?		
Medical oncologist	18	100

[a] Onsite 24hour/7day nursing, transportation to all places, safe narcotic storage, access to food, availability of social worker, access to non-chemo and non-narcotic medication

When providers were asked about needs other than housing, such as obstacles patients experienced, sixty-one percent identified patients lack of money, difficulty affording medications, medications not getting picked up from a pharmacy, and not being able to afford food. Transportation issues, multiple locations to travel for medications or other healthcare, keeping track of appointments, and difficulty with phone access were described by 90% of the providers. Patients also have a history of substance abuse problems as well as difficulties in their personal life/relationships which were a concern to the providers. Finally, providers reported concerns about the lack of reliable help with decision-making for the homeless patient which in turn affected the provider's decision-making.

When asked about treatment decisions for their patient based on lack of adequate housing, 44.44% responded that they had changed the onset of the standard of treatment protocol due to homelessness and 52.94% of respondents reported that they had altered their treatment protocol at some point during treatment due to homelessness. A specific example was reported that the provider would change to an oral form of chemotherapy rather than an intravenous form of therapy especially if their patient was unreliable in their regular follow up appointments and/or their communication to the office about anticipated side effects. Other providers reported that they often avoid oral medications due to compliance issues and lack of patient follow up to the office when scheduled. Several providers stated that chose the intravenous route for medication administration and see the patients in the clinic more frequently for follow-up rather than prescribing the patient oral chemotherapy. Providers stated that the type of patient cancer treatment oral or intravenous chemotherapy, must be evaluated in terms of the individual and their lifestyle.

Providers were also asked if they had any other ideas of how to treat and care for the newly diagnosed cancer patient who is homeless. Eight (42%) answered suggesting a partnership with Uber®, the ride-hailing transportation company, as some other outpatient clinics have this arrangement, but it's not currently available at all of the Levine Cancer Institute Clinics. Having a partnership with Uber® would provide quick and reliable transportation to and from the outpatient clinic. Uber® would also be able to transport a patient to the pharmacy to obtain medications for the anticipated side effects from the treatment regimen. A few (17%) providers reported health literacy and mental health issues were key problems with their homeless cancer patients remaining compliant with treatment and follow up appointments. However, the providers were unsure how to address and resolve those specific problems.

One provider surveyed responded that not all social workers or clinical case management workers were aware of available options and resources for the homeless patients. This provider conveyed that they would like to see a nurse or social worker in their outpatient clinic be the contact person for the patients who are homeless.

If a homeless patient is hospitalized due to their cancer, providers were asked if they had difficulty discharging the patient. Eleven (58%) responded they did have difficulty discharging the patient in this situation. All eleven of the responding providers indicated that there were numerous obstacles when attempting to find a safe place for a patient to live as often there is no place for the patient to go. When the providers were asked who helped plan for discharge, all responded they utilized case management. In addition to these responses, Provider 4 wrote on the survey, "Our wonderful Advanced Practice Providers (APPs) that work in the hospital".

Providers were surveyed concerning their role involving hospice services with their homeless patients and asked if they had difficulty involving hospice when appropriate. Fifteen (79%)

responded that they did face difficulties when attempting to involve hospice services with their homeless patients. Lack of a physical address for the hospice services to meet the patient is a significant obstacle because workers do not go to shelters or the streets to provide hospice care for patients. A Hospice House would only be an option if the homeless patient was symptomatic with uncontrolled pain, difficulty breathing, or uncontrolled vomiting.

A provider reported an example of a homeless patient newly diagnosed with cancer that lived in a recreational vehicle and hospice was not able to visit due to the absence of a physical address. Another example reported by a provider was that a homeless patient was lost to follow up (did not attend follow up appointments) and eventually presented to an emergency department and was admitted into the hospital for hospice care. All of these findings are consistent with the providers' face-to-face interviews. Providers across the LCI system in both platforms of interviews and surveys describe challenges that they face when caring for a homeless patient newly diagnosed with cancer, worry about patient's safety, stable housing, consistent communication, lack of consistent transportation for appointments impact provider treatment plans.

4.9 Comparative Costs Inpatient vs Outpatient

Costs for chemotherapy and care are significant issues for anyone diagnosed with cancer, but especially a homeless patient. An initial cost analysis was performed to look at the costs for one chemotherapy regimen as well as daily hospital bed rates (see Table 9). The chemotherapy regimen EPOCH+R given as an inpatient cost an average of $43,194.44 per cycle and is typically given over 5 days. The daily inpatient bed rate at Atrium Health is $2,260. The EPOCH+R regimen plus daily bed rate yields a total net cost of $54,494.44 which is billed to the patient if the treatment regimen is administered to an individual in the hospital (without complications).

If a homeless patient were to stay at Samaritan House while receiving the EPOCH+R treatment their daily bed rate is $73.43. The EPOCH+R treatment administered in the outpatient setting costs an average $19,596.04 per cycle. This regimen plus the daily bed rate for 5 days at Samaritan House yields a total net cost of $19,963.19 per cycle which is billed to the patient. The total net cost savings to move this one regimen of chemotherapy from an inpatient setting at Atrium Health to an outpatient setting at Samaritan House, for example, would save $34,531.25 per person, per treatment regimen.

Table 9

Cost Analysis for One Example of Chemotherapy Drug

Treatment Regimen	Cost
Chemotherapy Inpatient: EPOCH+R	
Per cycle (5-day regimen)	$43,194.44
Daily for inpatient bed in the hospital	$2,260.00
Per 5-day cycle	$11,300.00
Total net cost	$54,494.44
Chemotherapy Outpatient: EPOCH + R	
Per cycle (5-day regimen)	$19,596.04
Daily for outpatient bed at Samaritan House	$73.43
Per 5-day cycle	$367.15
Total net cost	$19,963.19
Total net costs savings to move this example regimen from inpatient to outpatient setting	$34,531.25

A wider cost analysis was performed within Atrium Health Carolinas Medical Center and Levine Cancer Institute comparing total inpatient costs to outpatient costs over the last five years for homeless patients that were newly diagnosed with cancer. Fifty-three patients newly diagnosed with cancer were encountered at Atrium Health Carolinas Medical Center and Levine

Cancer Institute during the reviewed time period from 2015 to 2019. These patients were chosen due to fit of criteria of being homeless and having a new diagnosis of cancer. The data was mined through billing details utilizing a quality improvement outcomes specialist and the electronic medical record. Inpatient and outpatient costs of these 53 patients were analyzed. Total inpatient costs were all-encompassing which included medications, bed per day, chemotherapy, radiology, and anything else pertinent to that particular patient during their hospital stay. Total outpatient costs were all encompassing to include chemotherapy, intravenous fluids, medications, provider visit etc. during their visit. Specific patient numbers who were cared for were broken down by each year with calculated total costs per year. The total net cost for inpatient and outpatient treatment in five years for all 53 patients who were homeless with cancer and had been cared for by Atrium Health Carolinas Medical Center and Levine Cancer Institute was $12,721,045.40 (see Table 10).

Table 10

Cost Analysis for Inpatient/Outpatient Total Cost per Year

Year	N	Cost per year
2015	7	$646,019.00
2016	16	$4,354,694.28
2017	8	$2,117,604.88
2018	14	$4,776,653.20
2019	8	$826,074.00
Total	53	$12,721,045.40

Within the 53 patients noted, 11 were further selected, 2 to 3 from each of the 5-year period, based on significant and nonsignificant cost differences between inpatient, outpatient, and emergency department (ED) settings for the purpose of extrapolating the 5-year average cost savings, per patient, when providing care in an outpatient instead of inpatient setting.

To find the difference in cost savings providing care to the homeless patient in the hospital (inpatient) versus in the outpatient clinic, the ED costs were added to the inpatient costs as these patients were always admitted into the hospital. The outpatient costs were then subtracted from the inpatient costs and the differences noted always resulted in net positivity for inpatient costs. For example, Patient 2 had costs of $368,591.56 inpatient with $21,203.56 in ED costs and $16,815.08 outpatient which resulted in a $372,980.04 cost difference. Patient 11 had costs of $109,170.92 inpatient with $5404.00 in ED costs and $87,792.80 outpatient which resulted in a $26,782.12 cost difference.

The significant cost difference for Patient 2 between the inpatient and outpatient costs could be related to how long Patient 2 stayed in the hospital, with daily bed rates, medications, antibiotics given, possible chemotherapy given inpatient, possible surgery performed inpatient, possible intensive care unit costs, radiographic imaging, possible procedures, possible intubation etc. This cost is all encompassing while in the outpatient setting, the costs incurred could be related to intravenous fluids given, chemotherapy administered, lab draws, provider visits etc. (see Table 11).

Table 11

Differences Between Inpatient and Outpatient Costs per Patient

Patient	ED visit	Inpatient cost	Outpatient cost	Total cost	Cost savings
1	$8,966.48	$284,157.44	$112,873.44	$405,997.36	$180,250.48
2	$21,203.56	$368,591.56	$16,815.08	$406,610.20	$372,980.04
3	$17,677.00	$267,524.00	$13,553.76	$298,754.76	$271,647.24
4	$775.76	$251,463.12	$4,464.28	$256,703.16	$247,774.60
5	$790.12	$28,684.00	$6,605.44	$36,079.56	$22,868.68
6	$4,476.60	$449,401.12	$127,646.16	$581,523.88	$326,231.56
7	$4,553.84	$119,286.72	$52,809.80	$176,650.36	$71,030.76
8	$908.92	$143,891.60	$13,280.84	$158,081.36	$131,519.68
9	$799.08	$172,415.96	$130,646.36	$303,861.40	$42,568.68
10	$0.00	$209,458.64	$20,872.64	$230,331.28	$188,586.00
11	$5404.00	$109,170.92	$87,792.80	$202,367.72	$26,782.12
Totals	$65,555.36			$3,056,961.04	$1,882,239.84

When calculating the cost differences between inpatient and outpatient visits with the 11 selected homeless patients in Table 11, the total cost savings over a 5-year period equals $1,882,239.84. This total divided by the 11 selected patients averages $171,112.71 per person. The total $171,112.71 can then be multiplied by the 53 patients in this study which equals a 5-year cost savings of $9,068,973.63. With these figures it can be estimated that if all 53 homeless patients would see an outpatient provider to obtain their cancer workup and initialization of treatment as an outpatient, as does a non-homeless patient, the total costs savings would be greater than $9 million dollars in a 5-year time frame.

The homeless are known to visit an emergency department for medical care and return to the emergency department within a month of their initial visit, compared to those living in stable accommodations (Amato et al., 2018). The cost of ED utilization and subsequent hospitalization for the homeless have been reported up to 3.8 times that of an average Medicaid recipient which is a huge economic burden (Amato et al., 2018; Bharel et al., 2013). As homeless patients in

Mecklenburg County tend to utilize the Emergency Department (ED) for their healthcare needs, a retrospective review was performed from 2015 to 2019 at Atrium Health Carolinas Medical Center Emergency Department with the same 11 patients as above which demonstrated that $65,555.36 (see Table 11) was incurred through the ED alone. Dividing this number by 11, is $5,959.58 per person per ED visit. If this number was then multiplied by the 53 homeless patients with cancer as noted above in this study, costs incurred over a 5-year period would be $315,857.64 in the ED alone. This number includes basic assessments with the healthcare team, point of care blood tests, intravenous fluids and radiologic imaging which would include Computed Tomography (CT) scans, Ultrasounds (US), Magnetic Resonance Imaging (MRI) etc. While this number may seem low, only homeless patients with a cancer diagnosis were captured at one ED site. A few patients were found to be seen at multiple Atrium Health ED sites during the 5-year time period.

Comparatively, the Moore Place Housing Study which was completed in 2015 in Charlotte, NC, 73 participants were involved in Charlotte's first Housing First study, which also looked at the cost analysis involving the homeless and their ED visits. This study itemized bills of each of the participants over a two-year period prior to being housed and a two-year period after being housed. What they discovered was that among participating tenants the total amount billed for ER-related utilization was $3.6 million two years prior to their move into Moore Place. The two years after the tenants moved into Moore Place, their total bill fell 68% to $1.1 million, a $2.4 million reduction (Thomas et al., 2015). In reviewing the Housing First Charlotte-Mecklenburg Research & Evaluation Project, Thomas et al. (2020) reported that the average emergency room visit cost $4,428.00 in the two large hospital systems in Charlotte. Utilizing primary care and preventative services has been shown to reduce the use of emergency services (Enard & Ganelin, 2013).

4.10 Discussion of Results

The findings from this needs assessment project highlight the difficulties and barriers that the homeless patient newly diagnosed with cancer experiences. The patient participants described barriers to accessing care, securing reliable transportation, struggles with drug addiction, presently and/or in the past, and the stability and safety of their current living situation. Many also reported that although family was near, they were unable to rely on or ask for help as “they have their own issues.” Patient participants reported that they consider the people in the shelters as their family and can “rely” on them for help, even if it is just for listening.

The homeless newly diagnosed with cancer often had difficulty obtaining Medicaid or Disability services because they were not connected with entities such as Urban Ministry and Levine Cancer Institute. These two facilities have consistent access to case managers that are able to assist patients with the needed application process. Without these services many homeless had no health insurance or income.

A few patient participants already received these benefits prior to a cancer diagnoses and were previously connected with Urban Ministry in Charlotte, which is Charlotte’s first Housing First program, and were also receiving Medicaid with a monthly stipend to help pay for housing and other basic needs. These patients were able to secure a motel room with the help of Urban Ministry. Even though a secure living situation was found, the homeless were still not guaranteed long-term stability as one patient reported he still had to worry about being relocated to another place as his lease would run out in the next 30 days. Social Workers in these locations were also able to arrange transportation within the public bus system, Uber®, and cabs to be able to transport patients back and forth to clinic and infusion appointments as well as to the pharmacy to pick up medications.

Patients also discussed safety in their current living environment with some reporting being beaten by others and often enduring broken bones and head trauma or being shot. Some discuss unsanitary living conditions, not being able to wash their clothes, take showers or use the restroom as there are no facilities to utilize. Several patients felt unsafe living on the street, in a tent and at times in the shelters. Those that were able to secure a motel room under the guidance of Urban Ministry felt the safest.

Many of the patient participants gave no thought on how the new diagnosis of cancer would impact the way they currently live. Many of them felt like the people around them in Samaritan House such as the case managers and the other residents that lived in the shelter with them, would provide the support they would need throughout their future treatment. They often consider these individuals as family.

While interviewing providers face-to-face almost all of them discussed how they worry about everything when caring for the homeless. Providers worried about the toxicity of the chemotherapy agents, the ability to contact a patient, and the patient having a stable living environment while undergoing chemotherapy. Half of the providers reported needing to revise a patient's treatment regimen depending on where the patient lived due to the worry of compliance with oral chemotherapy medications. Many of them also mentioned transportation being an issue for their patients and how they may alter regimens because transportation would not take a patient to the pharmacy to pick up medications even after a clinic visit due to transportation voucher policies only allowing one-way trips. Some providers worried about the patient's psychological issues especially when dealing with current substance abuse problems as well.

Providers felt they were able to link patients to additional resources that they need to improve their overall situation:

> Not that the cancer is a blessing by any means but as I said for a lot of people it brings them to attention. Many can now get the help they need that they wouldn't have been able to get such as psychiatry. Many patients had psychosocial issues, undiagnosed disorders which perpetuated the issue at hand. Many of them had substance abuse issues which caused them to spend what money they had on drugs rather than rent which led to losing their home initially (Provider 5).

This project also highlights the cost savings that Atrium Health Carolinas Medical Center could see if the homeless had a consistent and safe place to stay instead of being hospitalized while undergoing treatment. If one chemotherapy regimen was moved from the inpatient setting to an outpatient setting this would save $34,531.25 for each cycle regimen which is given over 5 days. In assessing ED costs from 2015-2019, it was noted that 53 homeless patients with a diagnosis of cancer incurred charges in Atrium Health's Emergency Department facilities at a cost of $315,857.64 in visits alone. These patients who were newly diagnosed with cancer had all of their visits captured, and total charges were assessed, showing cost comparing inpatient vs outpatient treatment equaling $12 million dollars. When sub-divided, for $171,112.71 per person, per year, it could be possible that a housing option could be created and sustained as Atrium Health averages 10.6 homeless patients with cancer a year. This would provide safe and cost-effective healthcare for this vulnerable population.

Chapter 5: SIGNIFICANCE AND IMPLICATIONS

5.1 Interpretation of Results

Discovering how the homeless newly diagnosed with cancer live and what their overall concerns are show us the vulnerability and challenges that they endure on a daily basis. These patients do not appear to have a deep understanding of what it means now that they have a cancer diagnosis and what significant barriers they could face if they truly get sick from side effects due to their chemotherapy. Listening to the patient interviews revealed that they appear to have a hard time looking past their current obstacles to critically think about what certain things they will need to be able to fight this cancer nor do they know where to go for help or what to ask for.

After knowing they have a new cancer diagnosis, patients did not look at their current situation as believing that they will be offered treatment since they know they do not have money or health insurance and cannot pay for these services on their own. Once these patients were educated by the Project Director and knew of their options and that a Social Worker would be assigned to them to help them find a place to stay and offer help to obtain Medicaid in the least, these patients were very interested in receiving chemotherapy or any type of therapy that was offered for their cancer.

In reviewing providers responses, it was made known that when they care for a homeless patient, they worry about everything that encompasses this individual. They acknowledge that this population is challenging for them and they have to work smarter and harder to ensure they are delivering the safest care possible for these individuals. The providers are very empathetic to their patient’s situations and truly do not want to harm them by giving them a treatment that they know will cause significant side effects that the non-homeless patient could endure far better.

This always requires more work by reaching out to families and friends for support or exploring every possible avenue for shelter even if it’s only temporary.

Interpretation of the cost analysis revealed the substantial amount of money that is charged to patients for inpatient stays and chemotherapy administration. In reviewing the inpatient and outpatient costs over the previous five years of 53 homeless patients, it was found that charges incurred to these patients were over $12 million dollars. In reviewing one particular chemotherapy regimen, it was found that if this was given as an outpatient, these charges to the patient were much less and as the homeless patient typically do not have health insurance, the hospital system would not get reimbursed for any inpatient charges. In review of annual savings of moving inpatient treatment to the outpatient clinic to save $1.8 million dollars, it could be possible that a housing option such as a respite home could be created and sustained for this population providing safe and cost-effective healthcare for Atrium Health and LCI. As Charlotte has one respite home for 12 homeless individuals at a time, this home is often full and has a waiting list. Creating an additional home such as this could effectively keep hospital costs down while safely giving standard treatment of care to the homeless patients newly diagnosed with cancer in an outpatient setting. This needs assessment project supported the idea that the homeless patient could receive safe and cost-effective healthcare as patients and providers both agreed that they would be willing to utilize a facility such as this.

In the review of literature, Zerger et al., (2009) supported this project findings in that respite options are cost effective, reduce hospital readmission, and have important social support and service networking benefits for patients. As respite programs address varied and complex health problems, one of the most common diagnoses included cancer. In the 25 respite programs that Zerger et al., (2009) reviewed, at least 20 provided physician or nursing services, all provided case management, 24 provided meals, 23 provided transportation and the majority also provided assistance with dispencing and storing medications, psychiatric services, housing referrals, as well as assistance with job placement.

5.2 Limitations

A limitation noted of this project was that the sample size of the patients was small. All of the homeless patients interviewed were located in the Center City of Mecklenburg County. Patients were sought during a seven-month time period, mostly those that were admitted inpatient and a few in the outpatient setting. The Project Director did not have access to the outpatient clinic charting system and therefore was dependent on providers to notify the Project Director if they were currently caring for a homeless patient. To obtain a larger sample size, solid tumor providers were emailed twice during this time period to inquire about any current homeless patients that were currently being treated in order to obtain patient interviews, and only six providers responded with current patients.

Sample size for the provider online survey was small. The online survey responses consisted of 19 out of 52 providers located at Center City in Charlotte and the surrounding locations in Albemarle, Gastonia, Pineville, and Concord areas. Reasons given by providers for not participating in the online survey included schedule changes due to the ongoing COVID-19 pandemic as well as not ever caring for a homeless patient.

5.3 Future Research and Recommendations

Future recommendations would be to expand the sample to additional inpatient and outpatient sites, including rural areas to obtain larger sample sizes and see if patients and providers in rural vs urban areas reveal additional concerns and note the similarities and differences. Oncology providers have many concerns for treating homeless patients with cancer. The top concern is how to provide safe care while undergoing systemic treatment. Proper housing, transportation, communication and support are essential. A respite/Housing First home option for the homeless patients while undergoing chemotherapy needs to be further researched to decide whether a respite home or a Housing First home would be more beneficial for this population. Either type of housing option would allow providers to offer standard treatment while being able to monitor their patients more closely. The decision may come down to which type of housing would be able to provide more medical care for those that fall through the crack after hospitalizations.

Policy priorities for the homeless newly diagnosed with cancer should be focused on improving the health care system and advancing medical respite care. Treatment and management protocols could be developed through LCI to ensure safe care is being delivered to the patients while undergoing treatment. If a private and public partnership were obtained, policies could be developed to help assist these individuals with much needed social, psychological, and funding needs.

Research is needed to explore why some oncology providers may be unaware of the housing status of their patients. Additional information is needed to discover the possible disconnects between the intake process regarding housing status information, whether housing status information is being collected and by whom, and how are providers and team members made aware of their patient's housing status. It may be that the housing status and other relevant information such as transportation and communication needs should become a formal part of the initial team meeting when discussing the patient's plan of care to ensure that all team members are aware of the housing status of their patients and how best to advocate for them. If housing is not a typical topic at the initial team meeting, it may be that a process needs to be formalized at the institution as to who takes responsibility for making the whole team aware of the patient's housing status and related needs. An awareness of homelessness typically requires some additional care. An educational program could be developed and planned for all providers and team members regarding available community resources for homeless patients to assist with advocacy.

An additional future recommendation would be that a cost analysis of all homeless patients needing medical care should be performed at every hospital located in Mecklenburg County to see how this would affect the City costs as a whole. The cost savings could prompt a respite/Housing First home specifically for all homeless patients requiring any type of continued medical assistance after discharge. This home could serve as a bridge to a final Housing First home built by Urban Ministry. A proposal for this home could be developed for the leadership team within Atrium Health and Levine Cancer Institute. The cost savings shown by inpatient vs outpatient treatment and stay for Atrium Health CMC and LCI alone indicates that for as much money that is currently spent on inpatient treatment, if moved to an outpatient setting, the difference in savings would pay for a home for these patients in less than a year.

In an article by the Charlotte Observer on March 5, 2021 by Lindstrom (2021), as of January 2021, Mecklenburg County data shows more than 3,000 people are experiencing sheltered or unsheltered homelessness during the COVID-19 pandemic. Possible solutions such as harnessing underutilized hotels and constructing them into permanent housing in addition to exploring building tiny houses for these residents are currently under discussion with the County officials. The county commissioners allocated 6.3 million dollars in 2019 to create MeckHOME, which is a rental subsidy program in partnership with Urban Ministry which is Charlotte’s first “Housing first” program (Lindstrom, 2021). This program has already purchased a hotel in southwest Charlotte in 2020 and plans to convert rooms into 88 studio apartments for the chronically homeless (Lindstrom, 2021). If the Mecklenburg County commissioners are looking to establish public-private partnerships, the relationship could be established through Atrium Health and another public private relationship could be dedicated to a respite/Housing First home to those who are homeless with cancer.

5.4 Summary

The prevalence of cancer in the homeless population in the U.S. is rising and understanding what factors shape those experiences is essential in constructing interventions directed at this vulnerable population ensuring safety while undergoing cancer treatment. Homeless individuals with cancer are at a greater risk for not being able to receive the standard treatment for their type of cancer and as a result experience poorer outcome. This needs assessment survey is the first step at providing insights into the difficulties that the homeless and treating providers face with a new diagnosis of cancer.

During the interview process with homeless patients, it was made well known that just because they had a new diagnosis of cancer did not mean that they had any more worries or concerns. The exact same concerns before their diagnosis were the same concerns with the cancer diagnosis. After patients were informed, they would not have to worry about paying for their treatment, and they would get help obtaining Governmental assistance with the help of social workers through the hospital and LCI, patients were then able to think about the treatment plan for their cancer. When asked if Atrium Health had their own respite house or Housing First facility for undergoing cancer treatment, would patients feel safe enough to stay there while undergoing cancer treatment, all of the patient respondents reported “yes.” When asked what should be included in a Housing First option, patients noted the need for social services to assist with applying for Social Security, Disability, or Medicaid. The patients also reported that they would appreciate separate bedrooms and bathrooms or a maximum of two individuals to a room/bathroom. Patients would like relaxed rules so they can come and go as they please. Some even mentioned being able to go on fun trips, like going to the movies once a month, so patients could get out and enjoy themselves.

Every patient and provider surveyed and interviewed agreed that a Housing First option would be welcomed and utilized so that standard treatment could be offered to the homeless newly diagnosed with cancer. Housing is known as a key social determinant of health and the networking between homelessness and health behaviors. Providers are able to use their position of influence to advocate for affordable housing as well as building more affordable housing units appointed toward homeless patients with chronic illness (Pendyal, A. et.al 2019).

Half of the providers from the online Provider Survey Monkey, reported they either do not ask patients about their housing status, or if they discover that their patient is homeless, they will alter treatment knowing the challenges that face them both. While contemplating how to treat his patient who was now unable to care for themselves, Provider 2 stated, "I did have a homeless patient come in about 2 years ago who was living independently but could not return due to her illness/cancer so we kept her in the hospital getting chemotherapy for several weeks until we could get a skilled nursing facility (SNF) set up for her" (Provider 2). This situation shows that providers do not feel they have any alternative solutions in treating their patients and they rely on long hospital admissions just to find their patient a place to live while they can safely administer chemotherapy.

As all providers from the interviews and survey stated they would use a Housing First option to send their homeless patient while under treatment for their cancer, the availability of such an option means that these providers would not need to revise the standard treatment. Feedback was elicited about the home environment to ensure safety and the ability to comply with treatments and appointments. Providers spoke of the necessity of social workers, psychologists, transportation, nutritional support and tools for the homeless to succeed in their journey to make this a transition point into finding something more permanent.

Findings from this study are consistent with other literature on cost savings and Housing First options. Many examples have been shown to improve care for the homeless newly diagnosed with cancer. A combination between a Housing First home or respite home could provide meals, transportation, social and psychological support. Utilizing the resources of these two homes could help provide the gap that has been found to serve the homeless patient newly diagnosed with cancer with additional medical needs such as a tracheostomy or a feeding tube.

Cancer treatment for the non-homeless is significantly complicated let alone those without a home. With chemotherapy, comes potentially life-threatening side effects to those that are already vulnerable. The significance of housing may determine eligibility for which type of treatment i.e., more aggressive vs less aggressive, whether hospital admission is warranted for these individuals. To improve care for homeless individuals with cancer, one would need to move forward with a proposal to obtain housing provided by the hospital system and/or county. Engaging Atrium Health’s leadership along with local and state officials to embark upon a larger scale intervention such as creating a respite or Housing First home for this population is strongly needed to help support patients to receive a safe and standard of treatment care that every human being deserves.

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Appendix A

Instrument 1. Patient Questionnaire
(open ended interview)

Title of Project: How Do the Homeless Newly Diagnosed with Cancer Receive Safe and Cost – Effective Healthcare During Year One Following Diagnosis?
DNP Project Director: Amy Edinger, NP
Contact information: aedinger@uncc.edu; 704-280-0346

Questions:

Question 1: Where did you go first for support when you heard about your diagnosis?

Question 2: What are your concerns about accessing cancer treatment following your diagnosis?

Question 3: What are your barriers to accessing cancer treatment following your diagnosis? Where would you stay when treatment begins?

Question 4: Who's going to be around to care for you during your treatment (chemotherapy, radiation) – when you are experiencing nausea and vomiting, fatigue, etc. – helping you get meals, transportation, getting your Rx's, etc.?

Question 5: If the hospital had a safe place, such as a room in a house or apartment building with access to staff, would you be willing to stay there during the course of treatment? What would make you feel safe at such a house?

Question 6: What do you like or dislike about the Samaritan House if you have stayed there? What works or doesn't work as far as their process?

Appendix B

Instrument 2. Provider Questionnaire
(open ended interview)

Title of Project: How Do the Homeless Newly Diagnosed with Cancer Receive Safe and Cost – Effective Healthcare During Year One Following Diagnosis?
DNP Project Director: Amy Edinger, NP
Contact information: aedinger@uncc.edu; 704-280-0346

Questions:

Question 1. If you had to estimate, how many homeless with newly diagnosed cancer do you treat in a year? How do you know they are homeless? Are you treating/caring for any at the moment?

Question 2. When you find out a person is homeless, and you know the first course of chemotherapy will be new and difficult, as it would for anyone, what kinds of things do you consider when making your treatment choice?

Question 3. What unique worries or concerns do you have when treating homeless who are receiving their first rounds of chemotherapy?

Question 4. What kind of questions do you ask your homeless patient about who will be helping them/caring for them and were they are going to live following their chemotherapy treatments? Do their answers change your decisions about their course of treatment?

Question 5. Has there ever been a situation where you modified or altered your plan of treatment because a person was homeless and had nowhere to go after a chemotherapy treatment? Can you please describe it?

Question 6. Homeless patients receiving their first round of chemotherapy often stay as an inpatient in the hospital, or if a bed is open, they may stay at Samaritan House. If another option, such as a Housing First option, was available, would you send patients there during their first or second round of chemotherapy? What kinds of things or services would you like to see in such an option?

Appendix C

Instrument 3. Provider Survey
(Survey Monkey Format)

Title of Project: How Do the Homeless Newly Diagnosed with Cancer Receive Safe and Cost – Effective Healthcare During Year One Following Diagnosis?
DNP Project Director: Amy Edinger, NP
Contact information: aedinger@uncc.edu; 704-280-0346

Questions:

1. Do you routinely ask patients about their housing status? Yes, No

2. In the past 12 months, how many patients have you cared for who suffer from acute or chronic homelessness (homeless prior to diagnosis)?

3. In your experience, where did the acute or chronic homeless patient stay once treatment started?

4. Besides needing housing, what other obstacles to care did your patient experience (ex: transportation, money for food, affording medicines)?

5. Did you make any treatment decisions for the patient based on lack of adequate housing? If so, describe.

6. Did you change the onset of a treatment protocol because your patient was homeless? Yes, No

7. Did you alter your treatment protocol at any point because your patient was homeless? Yes, No

8. Do you think your homeless patient suffered a shorter survival due to homelessness? If so, explain.

9. Do you think your patient experienced greater side effects from one or more of the following therapies due to being homeless? Surgery, radiation, chemo or systemic therapy

10. Do you think your patient experienced more of the following symptoms due to homelessness? Nausea, pain, diarrhea, infection

11. Was your patient hospitalized to keep him/ her in a safe housing environment?
12. If he/she was hospitalized due to those reasons, did he/she experience more of the following? Pain, nausea, infection

13. Did you have difficulty discharging the patient? Who helped you plan for discharge?

14. Did you have difficulty involving Hospice with the patient if it was felt to be appropriate?

15. If you encounter a homeless patient who is newly diagnosed with cancer, which resources would you use to try to help him/her? Social worker Samaritan House Urban Ministry Center Local faith-based organizations RN case manager

16. If you had a “Housing First” option for treatment and care of the newly diagnosed cancer patients who are homeless, would you feel comfortable and confident sending your patient there during their treatment? Yes, No
Why or why not would you choose such an option?

17. Which of the following would you consider to be essential for a “Housing First” home for treatment and care of newly diagnosed cancer patients who are homeless:
o On-site 24/7 Nursing and other staff
o Transportation to the outpatient infusion clinic
o Transportation to radiology
o Transportation to follow-up doctor appointments
o Access to non-chemo and non-narcotic medications (i.e., Myers Park)
o Safe narcotic storage
o Access to food and nearby foodbanks and grocery stores
o Ease for provider contact
o Availability of social worker
o Other

18. Do you have any other ideas of how to best treat and care for the newly diagnosed cancer patients who are homeless?

19. Which kind of provider are you? medical oncologist, hematologist, radiation oncologist, surgeon, pall med, physician, ACP

20. In which zip code is your office located?

Appendix D

Instrument 4. Patient Informed Consent Form

Atrium Health
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title of Project: How Do the Homeless Newly Diagnosed with Cancer Receive Safe and Cost – Effective Healthcare During Year One Following Diagnosis?
DNP Project Director: Amy Edinger, NP
Contact information: aedinger@uncc.edu; 704-280-0346

INFORMED CONSENT FORM

INTRODUCTION:
You are being asked to participate in Doctorate of Nursing Practice (DNP) Scholarly Project by Amy Edinger, a DNP student at the University of North Carolina Charlotte, evaluating how the Homeless newly diagnosed with cancer receive safe and cost-effective healthcare during year one following diagnosis.

HOW THE DNP PROJECT WORKS:
If you agree to participate in the project, you will be asked to complete:

- Open Ended interview with six questions asked ~45 minutes

All above elements will be anonymous and online in an environment whereas you may start, stop, and continue the online education intervention, if needed.

The Project Director will gather the anonymous results and utilize a thematic analysis concentrating on quotes and the patients' thoughts on being able to stay in a "Housing First" home with supportive services offered by Atrium/LCI while they are undergoing cancer therapy.

RISKS:
There are no anticipated risks involved with this project beyond that of viewing online content.

EXCLUSION CRITERIA:
Non-homeless patients newly diagnosed with cancer. Homeless patients not diagnosed with cancer.

BENEFITS:
This Project may or may not increase your knowledge base. The information that is gathered may benefit Levine Cancer Institute, Atrium Health and the homeless population. Taking this information will hopefully provide meaningful opportunities and housing for this patient population that are newly diagnosed with cancer.
ADDITIONAL COST:
No anticipated additional cost to the participant.

COMPENSATION:
No monetary compensation for participants. If participants complete the interview, a Walmart Gift Card worth $25 each will be given.

WITHDRAWAL:
Your participation in this Project is completely voluntary. You should feel under no pressure to be in the Project. You are free to stop being in the Project if you change your mind after entering it.

CONFIDENTIALITY:
The records of this Project will be kept private. In any sort of report that might be published, we will not include any information that will make it possible to identify a participant. Your records for the Project may, however, be reviewed and/or photocopied, by Atrium Health, or by the University of North Carolina Charlotte. To that extent, confidentiality is not absolute.

AUTHORIZATION:
If you wish to take part in this clinical study, you will be asked to sign the consent form. It allows the Project Director to collect and process any relevant personal information collected from you during the Project. These are activities that are routinely carried out during all clinical studies.

You have been told that personal information about you will be reviewed, collected on a computer database, stored in electronic or manual files, audited, and/or otherwise processed by:

- The Project Director, Amy Edinger,
- Regulatory or other government authorities of the United States and other countries,
- Other persons authorized by the Project Director,
- Atrium Health, Levine Cancer institute and Samaritan House employees,
- Other persons or agencies as required by law or allowed by federal regulations.

You have been told that your personal data are being collected and processed to:

- Check your suitability to take part in the Project,
- Support the development of the Project objectives

You have been told whenever your personal information is processed; it will be kept confidential and secure, to the best of our ability. It will be used only for the purpose for which it was collected.
This Authorization does not have an expiration date. You have been told that according to the guidelines for good clinical practice, the Project Director will keep your personal information for at least 6 years. If you do not withdrawal this Authorization in writing, it will remain in effect indefinitely. If you wish to revoke authorization to use your personal information, you will notify the Project Director, Amy Edinger, aedinger@uncc.edu, 704-280-0346, in writing. In addition, you may contact Dr. Stephanie Woods, the Project Chair at the University of North Carolina Charlotte, 9201 University City Blvd, Charlotte, NC, 28223 at swoods16@uncc.edu. Some of the data obtained from your record prior to your revocation may still be used if considered necessary for the Project.

FINANCIAL INTEREST OF PROJECT DIRECTOR:
There are no financial interests of the Project Director to disclose.

QUESTIONS:
The Project Director of the study at Carolinas HealthCare System and the University of North Carolina Charlotte is Amy Edinger, NP. You may ask her any questions you have now. If you have questions later, you may contact Amy Edinger, NP at aedinger@uncc.edu or amy.edinger@atriumhealth.org or 704-280-0346.

The Institutional Board is a group of people who review the research to protect your rights. If you have questions about the conduct of this Project or about your rights as a Project subject, you may call the chairperson of the Institutional Review Board of Carolinas HealthCare System for information regarding participants' rights in a Project. You can obtain the name and number of this person by calling 704-355-3158.

CONSENT:
I have read the above information. I have asked any questions I had, and those questions have been answered. I agree to be in the DNP Project and authorize the use of my personal information. Amy Edinger, NP will give me a copy of this form.

Patient Print Name	Date	Time
Patient Signature	Date	Time
Signature of Person Obtaining Consent	Date	Time
Project Director Signature	Date	Time

Appendix E

Instrument 5. Provider Informed Consent Form

Atrium Health
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title of Project: How Do the Homeless Newly Diagnosed with Cancer Receive Safe and Cost – Effective Healthcare During Year One Following Diagnosis?
DNP Project Director: Amy Edinger, NP
Contact information: aedinger@uncc.edu; 704-280-0346

INFORMED CONSENT FORM

INTRODUCTION:
You are being asked to participate in Doctorate of Nursing Practice (DNP) Scholarly Project by Amy Edinger, a DNP student at the University of North Carolina Charlotte, evaluating how the Homeless newly diagnosed with cancer receive safe and cost-effective healthcare during year one following diagnosis.

HOW THE DNP PROJECT WORKS:
If you agree to participate in the project, you will be asked to complete:

- A 31-question survey regarding the homeless patients' you care for with a new diagnosis of cancer ~15 minutes

All above elements will be anonymous and online in an environment whereas you may start, stop, and continue the online education intervention, if needed.

The Project Director will gather the anonymous results and utilize a thematic analysis concentrating on provider feedback on altering treatment due to homelessness, what specific difficulties the providers had in caring for these individuals, and do they believe being able to utilize a Housing First home with supportive services for their patients through Atrium/LCI would increase using standard treatments on this population.

RISKS:
There are no anticipated risks involved with this project beyond that of viewing online content.

EXCLUSION CRITERIA:
Non-homeless patients newly diagnosed with cancer. Homeless patients not diagnosed with cancer.

BENEFITS:
This Project may or may not increase your knowledge base. The information that is gathered may benefit Levine Cancer Institute, Atrium Health and the homeless population. Taking this

information will hopefully provide meaningful opportunities and housing for this patient population that are newly diagnosed with cancer.

ADDITIONAL COST:
No anticipated additional cost to the participant.

COMPENSATION:
No monetary compensation for participants.

WITHDRAWAL:
Your participation in this Project is completely voluntary. You should feel under no pressure to be in the Project. You are free to stop being in the Project if you change your mind after entering it.

CONFIDENTIALITY:
The records of this Project will be kept private. In any sort of report that might be published, we will not include any information that will make it possible to identify a participant. Your records for the Project may, however, be reviewed and/or photocopied, by Atrium Health, or by the University of North Carolina Charlotte. To that extent, confidentiality is not absolute.

AUTHORIZATION:
If you wish to take part in this clinical study, you will be asked to sign the consent form. It allows the Project Director to collect and process any relevant personal information collected from you during the Project. These are activities that are routinely carried out during all clinical studies.

You have been told that personal information about you will be reviewed, collected on a computer database, stored in electronic or manual files, audited, and/or otherwise processed by:

- The Project Director, Amy Edinger,
- Regulatory or other government authorities of the United States and other countries,
- Other persons authorized by the Project Director,
- Atrium Health, Levine Cancer institute and Samaritan House employees,
- Other persons or agencies as required by law or allowed by federal regulations.

You have been told that your personal data are being collected and processed to:

- Check your suitability to take part in the Project,
- Support the development of the Project objectives

You have been told whenever your personal information is processed; it will be kept confidential and secure, to the best of our ability. It will be used only for the purpose for which was collected.

This Authorization does not have an expiration date. You have been told that according to the guidelines for good clinical practice, the Project Director will keep your personal information for at least 6 years. If you do not withdrawal this Authorization in writing, it will remain in effect indefinitely. If you wish to revoke authorization to use your personal information, you will notify the Project Director, Amy Edinger, aedinger@uncc.edu, 704-280-0346, in writing. In addition, you may contact Dr. Stephanie Woods, the Project Chair at the University of North Carolina Charlotte, 9201 University City Blvd, Charlotte, NC, 28223 at swoods16@uncc.edu. Some of the data obtained from your record prior to your revocation may still be used if considered necessary for the Project.

FINANCIAL INTEREST OF PROJECT DIRECTOR:
There are no financial interests of the Project Director to disclose.

QUESTIONS:
The Project Director of the study at Carolinas HealthCare System and the University of North Carolina Charlotte is Amy Edinger, NP. You may ask her any questions you have now. If you have questions later, you may contact Amy Edinger, NP at aedinger@uncc.edu or amy.edinger@atriumhealth.org or 704-280-0346.

The Institutional Board is a group of people who review the research to protect your rights. If you have questions about the conduct of this Project or about your rights as a Project subject, you may call the chairperson of the Institutional Review Board of Carolinas HealthCare System for information regarding participants' rights in a Project. You can obtain the name and number of this person by calling 704-355-3158.

CONSENT:
I have read the above information. I have asked any questions I had, and those questions have been answered. I agree to be in the DNP Project and authorize the use of my personal information. Amy Edinger, NP will give me a copy of this form.

________________________ Patient Print Name	____________ Date	____________ Time
________________________ Patient Signature	____________ Date	____________ Time
________________________ Signature of Person Obtaining Consent	____________ Date	____________ Time
________________________ Project Director Signature	____________ Date	____________ Time

Appendix F

Instrument 6. Patient Demographic Survey
(To be given to patient to fill out)

Title of Project: How Do the Homeless Newly Diagnosed with Cancer Receive Safe and Cost – Effective Healthcare During Year One Following Diagnosis?
DNP Project Director: Amy Edinger, NP
Contact information: aedinger@uncc.edu; 704-280-0346

Questions:

Question 1: Participant’s Age:

a. 18-30
b. 31-45
c. 46-65
d. 66-80
e. >80

Question 2: Highest level of education completed:

a. High School Diploma
b. Associates Degree
c. Bachelor’s Degree
d. Master’s Degree
e. Doctorate Degree

Question 3: Race/Ethnicity:

a. Caucasian
b. African American
c. Asian
d. American Indian
e. Hispanic

Question 4: Gender

a. Male
b. Female

Question 5: Current Living Situation

a. Shelter
b. Samaritan House
c. On the streets
d. Intermittently with family/friends

Question 6. Prior Employment Wages

- a. $0- $30,000
- b. $31,000 - $60,000
- c. $61,000 - $90,000
- d. $91,000-$110,000

Question 7: Performance Status

- a. Fully active, no restrictions (0)
- b. Strenuous physical activity restricted; fully ambulatory and able to carry out light work (1)
- c. Capable of all self-care but unable to carry out any work activities; only up and about >50% of waking hours (2)
- d. Capable of only limited self-care; confined to bed/chair >50% of waking hours (3)
- e. Completely disabled; cannot carry out any self-care (4)

Appendix G

Instrument 7. Provider Demographic Survey
(To be given to provider to fill out)

Title of Project: How Do the Homeless Newly Diagnosed with Cancer Receive Safe and Cost – Effective Healthcare During Year One Following Diagnosis?
DNP Project Director: Amy Edinger, NP
Contact information: aedinger@uncc.edu; 704-280-0346

Questions:

Question 1: What is your specialty:

f. Breast
g. GI
h. Thoracic
i. GU
j. Other ___________

Question 2: How many years have you been an Oncologist:

f. 0-2 yrs.
g. 3-5 yrs.
h. 5-10 yrs.
i. >10 yrs.

Question 3: Which area do you work: rural vs urban

e. Rural
f. Urban

Question 4: Race/Ethnicity:

f. Caucasian
g. African American
h. Asian
i. American Indian
j. Hispanic

Question 5: Gender

c. Male
d. Female

Appendix H

Instrument 8. Needed Resources and Marketing

Communications		Cost Analysis	Cost
Email	All Communication from DP Project Director	Participant work Email	$0
Interviews	All performed by DNP Project Director		$0
Hardware		**Cost Analysis**	**Cost**
Desktop or Laptop	Post-year 2000 processor with a minimum of 512 megabytes of memory to be able to access, view, interact with subject matter	If participant does not have a personal computer access is available for free at their workplace.	$0
Internet Connection		**Cost Analysis**	**Cost**
Internet Connection	DSL, Fiber, High Speed, Satellite, Broadband utilized to share information, submit forms, access literature, access tech support	If participant does not have connection access is available for free at their workplace.	$0
Software		**Cost Analysis**	**Cost**
Operating System	Recommend system updated to Windows XP, 2000 or greater for PC and System 8.1 for Mac users	If participant does not have personal access it is available for free at their workplace.	$0
Structure for Storing Data		**Cost Analysis**	**Cost**
Personal USB or Cloud account	A secure way to store information and data as needed (i.e., long-in information, demographics to be determined)	Not required for this project	$0
Data Collection and Retrieval		**Cost Analysis**	**Cost**
Survey Tool	Open-ended interview questions; Survey Monkey	Free Access	$0
Cost Analysis	Obtained by data outcomes specialist	Free Access	$0
Statistical Analysis	Working with UNCC Statistician	School provided funds	$150
Transcription	Transcription services of interviews will be performed via Dragon software	Free Access	$0
Marketing		**Cost Analysis**	**Cost**
Email	Email reminders from DNP Project Director	Free Access	$0
Gift Cards	Gift Cards to homeless patients that undergo interview	$25	$225
Gift Cards	Gift Cards to providers for completing the Survey Monkey	$50	$250
		Total Cost	$625

Appendix I

Instrument 9. SWOT Analysis

Strengths	**Weaknesses**
Patients are under the care umbrella of LCI and Atrium Health.	Unpaid time to complete online intervention for providers
Established Online Survey Monkey for providers	Lack of tested online interventions and tools
Patient interviews are open ended	Homeless population sample may be somewhat difficult to obtain in a short amount of time
Provider sample population readily accessible and DNP Project Director is employed at LCI for 6 years and has good communication with providers	Need approval from both Atrium and LCI after proposal for Samaritan type home
Opportunities	**Threats**
Very little literature / Information	To stay within project and establish enough interviews with homeless patients newly diagnosed with cancer
Apply newly learned information into a proposal on Atrium building a post hospital home for the homeless	Not enough providers completing survey monkey
Increase knowledge of total costs for keeping homeless patients' inpatient at Atrium Health while searching for a safe place to discharge	Willingness of homeless patients to be interviewed

Appendix J

Instrument 10: Patient Themes and Subthemes

Patient Themes	Subthemes	Antecedents	Outcomes
Barriers to Care	Difficulty with transportation	No bus money No income No car	Difficulty making appts Difficulty getting meds
	Finding a place to live	No income No job Can only stay in a place for limited time Depending on facility if you do drugs or don't do drugs = no bed	Lives in a shelter/motel Couch hopping Lives in a tent Unable to find a place if no income
	Utilizing the ED	No health insurance, no primary care provider, trying to meet basic needs, acute or chronic illness	Multiple trips for any type of ailment which may result in admission or discharge back to streets.
Someone to help	Family/Friends	Estranged family lives in other states Children don't have relationships with parent Friends want them near in the same city	No support for when is ill from side effects Family may offer a few dollars for meds Not allowed to stay with anyone, no one offers
	Be there for you	If living in facilities, have staff, residents around	Feel like can rely on these people for support; established trust
	The Lord Above	Lost family support, have been through drug addictions, physical and sexual abuse, lost jobs, kicked out of homes to live on streets	Provide peace and comfort that the Lord has always guided them and got them as far as they have come Rely on Faith

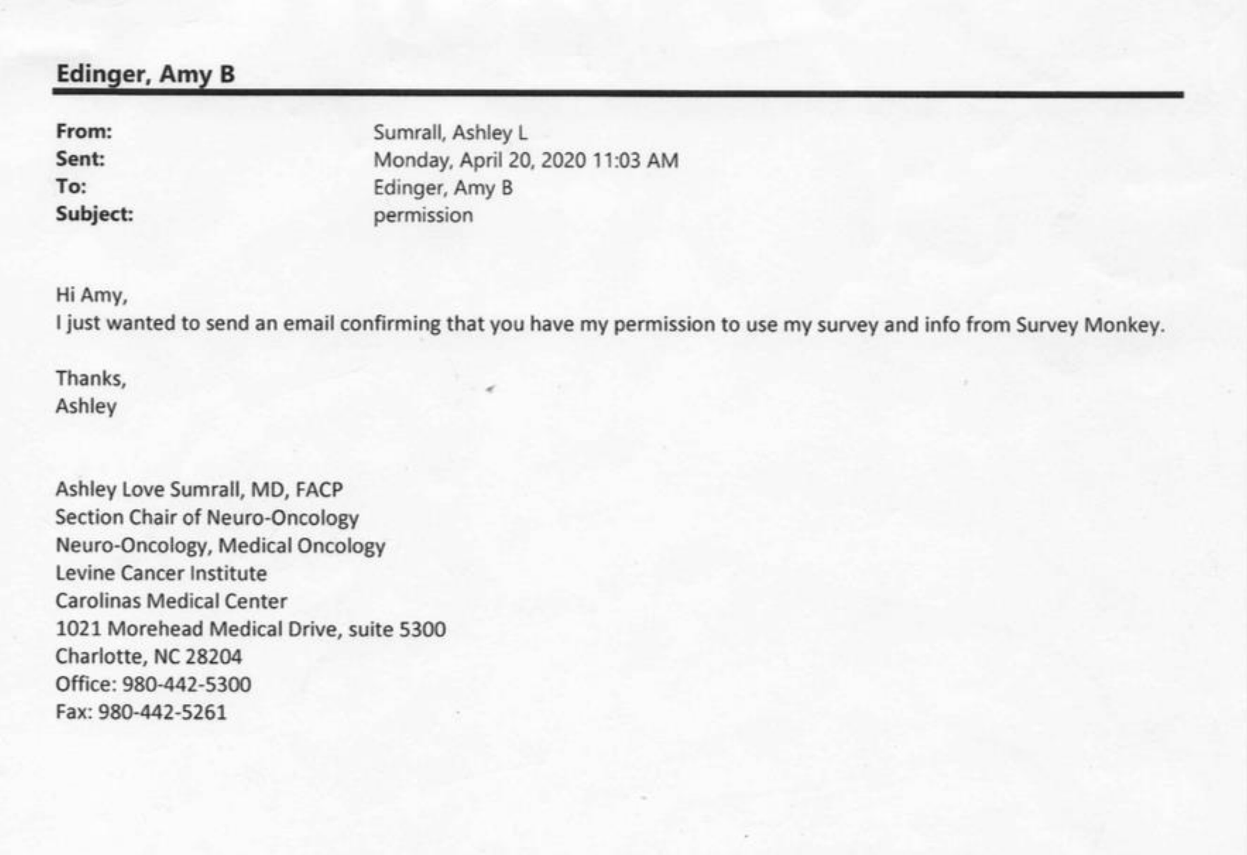
Appendix K

Instrument 11: Provider Themes and Subthemes

Provider Themes	Subthemes	Antecedents	Outcomes
I worry about everything	Chemotherapy is a high-risk entity	Knowledge of side effects of chemo	Understand repercussions of administering chemo
	Compliance with medications	Knowledge of no form of communication, patients w/no phones	Recognize difficulty scheduling appts, reminder phone calls
Making Decisions	Modifying treatment	Performance status, roof over head, support IV vs oral chemotherapy Treat for cure	Decreased effects of chemo, doesn't work as well, cancer continues to grow, hospice involvement
	Risk to the patient	Chemotherapy treatment Living situation: no roof over head Poor transportation Needing more support	Unable to pay for meds, no transportation to pick up meds, unable to control pain/N/V/D, Unable to continue therapy due to side effects
Care after Chemotherapy	Shelter	Typically, no family or friends around to help them when they are sick Safe housing	Unable to treat when live on street. All alone, no one to help when symptoms worsen
	Communication	Need to know they have access to phone to call clinic if symptoms or questions	If no support, cannot get treated. worsening symptoms, risk of death
	Transportation Issues	Known to have no cars, no bus money, no money in general to get back and forth to appts	Unable to make clinic appts, chemo infusions, radiation appts, cancer continues to grow

Appendix L

Permission to Use Portions of Dr. Ashley Sumrall's Previous Survey Monkey Questions



Edinger, Amy B

From:	Sumrall, Ashley L
Sent:	Monday, April 20, 2020 11:03 AM
To:	Edinger, Amy B
Subject:	permission

Hi Amy,
I just wanted to send an email confirming that you have my permission to use my survey and info from Survey Monkey.

Thanks,
Ashley

Ashley Love Sumrall, MD, FACP
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