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**Perception of Illness and Its Association with Willingness to Adhere to Treatment in  
Chronic Hepatitis C Patients with New Diagnosis of Nonalcoholic Fatty Liver Disease**

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## Abstract

Chronic liver disease is becoming the most common cause of mortality, morbidity, and utilization of healthcare services globally. Both nonalcoholic fatty liver disease (NAFLD) and chronic hepatitis C (CHC) are frequent causes of chronic liver disease. Recently, there have been significant findings on the relationship between NAFLD and CHC; patients with CHC have a higher incidence of NAFLD. The introduction of direct-acting antivirals has cured more CHC patients than ever before. Unfortunately, the current interventions for NAFLD requiring behavioral change remain ineffective. Patient's ability to follow advice depends largely on their health beliefs; therefore, understanding their illness perception is an integral part of planning effective interventions. In a cross-sectional study enrolling 81 CHC patients with NAFLD, the Brief Illness Perception Questionnaire explored their illness perception and willingness to adhere to treatment. The data showed that only 23.5% of patients fully understood their NAFLD diagnosis. Most participants did not experience symptoms (61.7%) and did not think their illness affected their lives (56.8 %). Although 39.5% of patients perceived NAFLD as a long-term condition, only 14.8% believed they have extreme personal control, and only 48.1% believed there is some form of treatment for their illness. Regarding emotional representation, only 12.3% were emotionally affected, and only 27.2% were extremely concerned. Causal factors were believed to be related to dietary habits, obesity, and lack of physical activity. Despite the low illness perceptions, 91.4% were willing to adhere to treatment.

*Keywords:* nonalcoholic fatty liver disease, hepatitis C, illness perception, Brief Illness Perception Questionnaire, lifestyle modification

## **Perception of Illness and Its Association with Treatment Willingness Among Hepatitis C Patients with Newly Diagnosed Nonalcoholic Fatty Liver Disease**

The purpose of this Doctor of Nursing Practice (DNP) clinical inquiry (CI) project was designed to explore the perception of illness and its association with willingness to adhere to treatment among CHC patients newly diagnosed with NAFLD. The paper seeks to explore and address gaps in the care management of these patients with the overall goal to improve health outcomes. Patients referred for Hepatitis C treatment at a North Central Arkansas Gastroenterology Clinic were noted to have incidental findings of NAFLD after routine ultrasonographic elastography. In chronic Hepatitis C viral (HCV) infection, NAFLD has been reported with a mean prevalence of about 55% (Adinolfi et al., 2016). Since the introduction of new direct-acting antivirals to treat CHC infection, cure rates have steadily and incrementally increased, reaching greater than 90% even in patients who were previously difficult to treat (Piecha et al., 2020). For NAFLD, there are no approved pharmacologic therapies; lifestyle modifications focusing on dietary changes and exercise targeted towards weight loss remain the only effective therapy. Poor compliance to lifestyle modifications poses a significant challenge to healthcare providers and limits the effectiveness of these therapies creating substantial healthcare burden, costs, and poor patient outcomes (Bailey et al., 2021). Effective and sustainable lifestyle modification programs are needed; however, building and implementing such programs may be complex without an adequate understanding of patients' perceptions of their disease and treatment (Zelber-Sagi, 2017). The Brief Illness Perception Questionnaire (BIPQ) was used to assess the cognitive and emotional representations of illness among CHC patients with a new diagnosis of NAFLD.

### **Background and Significance**

In spite of the threat that NAFLD causes to human health, the global health response to NAFLD is weak and fragmented (Alemany-Pages et al., 2020). Awareness amongst healthcare providers is low, and adherence to clinical guidelines regarding diagnosis, monitoring, and management is poor; furthermore, awareness amongst the general population is lacking, and adherence to therapeutic interventions is poor.

NAFLD and HCV infection are common causes of chronic liver disease in Western countries (Cheung, 2008). In HCV infection, significant hepatic steatosis or superimposed nonalcoholic steatohepatitis (NASH) is associated with disease severity and poor response to antiviral therapy (Cheung, 2008). Nearly 55% of patients with CHC will have concomitant hepatic steatosis (Adinolfi, 2016; Patel & Harrison, 2021). Clinical practice guidelines for diagnosing and managing NAFLD recommend that patients with CHC who have abnormal imaging consistent with hepatic steatosis should be evaluated and treated for NAFLD (Chalasani et al., 2018). The American Association for the Study of Liver Disease (AASLD) suggests that lifestyle modifications are recommended for all NAFLD patients due to cardio-metabolic benefits. Treatment with drugs should be limited to those with progressive liver disease such as steatohepatitis and fibrosis (Younossi, 2017).

Younossi et al. (2016) poignantly depict the daunting and enormous prevalence of NAFLD and its associated clinical and economic burden in the US. The astronomical healthcare costs will increase as NAFLD prevalence increases, and stakeholders are called to action to address this. The cost associated with NAFLD will soon outweigh the cost of liver diseases of viral origin as more CHC patients are treated with curative antiviral regimens (Mazzotti et al., 2018; Chalasani, 2018).

The role of illness perception has received little attention in the treatment of NAFLD. Personal motivation and willingness to change behavior can play a major role in the success of NAFLD treatment (Arora et al., 2018). Patients' perceptions and beliefs about their illness are not static; instead, they can be favorably modified by targeted interventions that increase low levels of perceptions. (Dhaliwal, 2020). A few studies have assessed the effectiveness of interventions to change illness perceptions. Personal control over illness and beliefs about its cause is the perceptions most amenable to changes (Basu, 2016). Asking patients how they view their condition allows healthcare providers to identify and correct inaccurate beliefs they may have and optimize medical management. Therefore, the cognitive, social, cultural normative, and contextual factors that affect patients' beliefs, attitudes, and motivation should be addressed to improve adherence behaviors (DiMatteo et al., 2012).

### *Prevalence*

NAFLD has become a significant public health concern globally, and its unrelenting increase in prevalence has led to a substantial rise in healthcare and economic burdens. According to a meta-analysis of the epidemiology of NAFLD, it is estimated that the overall global prevalence of NAFLD diagnosed by imaging is around 25.24%. The highest prevalence is reported in the Middle East at 31.79%, and South America at 30.48%, whereas the lowest prevalence rate is reported from Africa at 13.48% (Chalasani et al., 2018). The prevalence of NAFLD in the United States is estimated to be 24% and will increase to 100.9 million in 2030 from 83.1 million in 2015. The annual direct healthcare cost is estimated to be \$103 billion, with over \$7 billion attributed to NASH alone (Dokmak et al., 2020). A remodeling study by Estes et al. (2018) estimated that the prevalence of NAFLD and NASH in the US would rise by 21% and 63%, respectively, with a correlated increase of 178% in liver-related mortalities to an estimated



78,300 deaths by 2030. For this reason, there is a critical need to identify and treat potentially modifiable risk factors to reduce the morbidity and mortality associated with this serious disease.

A recent systemic review and meta-analysis by Rich et al. (2018) reported that NAFLD prevalence was highest in Hispanics, intermediate in whites, and lowest in blacks. Among patients with NAFLD, the risk for progression to NASH was higher in Hispanics, with relative risk, 1.09; 95% confidence interval, 0.98–1.21; and lower in blacks, with relative risk, 0.72; 95% confidence interval, 0.60–0.87, than whites. Most data suggest that the ethnic difference reported for NAFLD may be explained by the genetic variation related to the patatin-like phospholipase domain-containing protein 3 (PNPLA-3) gene (Chalasani, 2018). The prevalence of NAFLD among the American-Indian and Alaskan native population seems to be lower, 0.6%-2.2%, although these rates need to be confirmed (Chalasani et al., 2018). Arshad (2020) reports that the exact contributions of genetic and environmental factors to these differences in prevalence rates have not been determined.

In chronic HCV infection, NAFLD has a prevalence ranging from 40% to 86%, with a mean prevalence of 55%, depending on the HCV genotype and local prevalence of metabolic syndrome (Adinolfi et al., 2016). The most recent estimate of HCV prevalence in the United States was generated from an analysis of 2013 to 2016 National Health and Nutrition Examination Survey (NHANES) data. According to Spach (2021), an estimated 4.1 million persons living in the United States were HCV antibody-positive, and 2.4 million were HCV RNA positive. Compared with earlier NHANES studies, the number of persons with a positive HCV antibody has remained relatively stable, whereas the number of HCV-RNA positive persons has decreased significantly from the estimated 3.2 million HCV RNA-positive persons between 1999 to 2002. The declining HCV RNA-positive prevalence likely has resulted from a

significant number of persons obtaining a cure for chronic HCV infection with direct-acting antiviral therapy (Spach, 2021).

The global prevalence of non-obese NAFLD among the NAFLD population is over 40%, and the prevalence of non-obese NAFLD in the non-obese population is almost 20%. This suggests that BMI alone should not be the sole criterion to determine NAFLD testing (Ye et al., 2020).

There is no data on NAFLD prevalence in North Central Arkansas or South Central Missouri, where this clinic offers a broad range of gastrointestinal specialties.

### ***Recommendations for NAFLD Screening and Diagnosis***

There are no guidelines for screening for NAFLD. The American Association for the Study of Liver Disease (AASLD) practice guidance stated that routine screening for NAFLD in high-risk groups attending primary care, diabetes, and obesity clinics is not advised because of uncertainties surrounding diagnostic tests and treatment options, along with the lack of knowledge related to long-term benefits and cost-effectiveness of screening (Chalasani et al., 2018).

The AASLD practice guidelines suggests that with a high index of suspicion for NAFLD and NASH in patients with type 2 diabetes, clinical decision aids such as NAFLD fibrosis score, fibrosis-4 index, or vibration controlled transient elastography can be used to identify those at low or high risk for advanced fibrosis (Chalasani, 2018). The National Institute for Health and Care Excellence (2016) recommends that early detection of NAFLD may be helpful to identify those with potentially silent progressive fatty liver disease.

Although most cases remain non-progressive, some patient can progress to NASH, cirrhosis, liver cancer, and ultimately death. (Tanaka et al., 2019). The lack of identification and

untimely management of NAFLD delays the diagnosis of NASH and advanced fibrosis and often leads to complications causing irreversible liver damage (Dokmak et al., 2020). In the past, liver cirrhosis was considered an irreversible phenomenon. Still, many experimental data and clinical studies have provided evidence of liver fibrosis regression and reversal of cirrhosis if treatment with antifibrotic therapy is initiated (Young, 2017).

### ***Diagnostics for NAFLD.***

Hepatic steatosis is defined as the histologic or radiologic presence of excess fat in more than 5% of hepatocytes without secondary causes. These secondary causes include alcohol excess, drugs, viral hepatitis, endocrine abnormalities, and glycogen storage disorders. (Wenhao, 2020). Liver biochemistries can be normal in patients with NAFLD and may not be sensitive to serve as screening tests. Hepatic steatosis is usually determined by ultrasound which may be performed for various reasons such as investigating abnormal liver biochemistry or unrelated liver diseases like CHC. Liver biopsy remains the gold standard for characterizing liver histological alterations in patients with NAFLD; however, it is expensive and invasive and requires expertise for interpretation. Magnetic resonance imaging is an excellent noninvasive modality for quantifying hepatosteatosis. The use of transient elastography (TE) or Fibroscan to obtain continuous attenuation parameters is a promising tool for quantifying hepatic fat in an ambulatory setting. However, when the liver has a great deal of fat, these ultrasound-based tests may not be very reliable for diagnosing more advanced liver diseases, such as NASH and liver fibrosis (Juo & Livingston, 2019). The sensitivity of detecting fatty liver disease using FibroScan is 73%, and the specificity is 69% (Kamali et al., 2019).

### ***Populations of NAFLD***

Obesity, described as an excessive mass index (BMI), is the most common and well-documented risk factor for NAFLD. The entire spectrum of obesity, ranging from overweight to obese and severely obese, is associated with NAFLD (Chalasani, 2018). Divella et al. (2019) reported that the prevalence of NAFLD is close to 50-90% in obese subjects and correlates with the obesity rate. Hepatic steatosis is found in 65% of subjects with grade I-II obesity with BMI=30-39.9 kg/m<sup>2</sup> and 85% in patients with grade III obesity with BMI=40-59 kg/m<sup>2</sup>. The prevalence of NAFLD in morbidly obese patients who undergo bariatric surgery has been reported to be as high as 95% (Iqbal, 2019). Although there is a strong association between NAFLD and excess body weight, NAFLD can also present in patients with a normal BMI. Approximately 5–10% of NAFLD patients in the US are within the normal limits for BMI and are commonly referred to as having lean NAFLD (Iqbal, 2019).

There is a high prevalence of NAFLD in individuals with type 2 diabetes mellitus. A recent systematic review conducted by Younossi (2019) estimated the global prevalence of NAFLD in diabetic patients to be around 58%. Specifically, the prevalence of NASH in diabetic patients has been demonstrated to be close to 65% (Younossi, 2019).

Age is another important consideration with regard to NAFLD. Age is a risk factor in women but not in men. The NAFLD prevalence appears to increase with age, with most patients diagnosed between 40 to 50 years of age (Iqbal, 2019). Although NAFLD is associated with an increased mortality risk for 60–74-year-old individuals, this risk was not raised in those older than 74 years (Golabi et al., 2019).

The prevalence of NAFLD in men is two times higher than in women. Although controversial, the male sex has been considered a risk factor for NAFLD (Chalasani et al., 2018). Men are at a higher risk of severe fibrosis when compared to premenopausal females. The risk,

however, is similar in post-menopausal females, suggesting that female hormones may have protective effects on hepatic fibrosis (Iqbal, 2019).

### ***Pathogenesis of Non-alcoholic Fatty Liver Disease***

A better understanding of the pathogenesis of NAFLD is essential to establishing efficient and sustainable therapeutic interventions in managing this disease. NAFLD was first thought of as a benign, non-progressive disease until Dr. Jurgen, a pathologist at the Mayo Clinic, introduced the concept of NASH (Tanaka et al., 2019). Patients diagnosed with diabetes, dyslipidemia, hypertension, and obesity displayed histologic findings similar to alcoholic steatohepatitis even without excessive alcohol consumption.

According to liver pathology, NAFLD is classified into two categories: nonalcoholic fatty liver (NAFL), also called simple hepatic steatosis, and NASH. NAFL is characterized as macrovesicular steatosis without ballooned hepatocytes, while NASH is defined as the presence of macrovesicular steatosis with hepatocyte ballooning degeneration, lobular inflammation, and fibrosis (Tanaka, 2019).

According to Arab et al. (2018), the pathogenesis of NAFLD involves a complex interaction among environmental factors such as the Western diet, obesity, changes in microbiota, predisposing genetic variants, and an excessive accumulation of triglycerides and other lipid species in hepatocytes. Statovci et al. (2017) noted that the western diet, defined as a high dietary intake of saturated fats and sucrose and low fiber intake, has become a growing health risk contributing to the increased occurrence of metabolic diseases.

The pathophysiologic hallmark of NAFLD is insulin resistance. Arab et al. (2018) describe insulin resistance as the central mechanism that leads to lipotoxicity, endoplasmic reticulum stress, and disturbed autophagy. Insulin resistance ultimately leads to hepatocyte injury

and death that triggers hepatic inflammation, hepatic stellate cell activation, and progressive fibrogenesis, thus driving disease progression. The most crucial gene variant that predisposes to NAFLD by enhancing fat accumulation in the liver is the PNPLA-3 (Riazi, 2019). This gene variant is a key regulator of lipid droplet turnover in hepatocytes and hepatic stellate cells. The sequence variation is believed to be the most vital genetic determinant of the full spectrum of NAFLD, from fatty liver formation to NASH and HCC (Riazi, 2019).

### **NAFLD in HCV Infection**

With the high prevalence rates of NAFLD and CHC, it is expected that these two disease states will occur together in a particular proportion of patients. Adinolfi et al. (2016) reported that the mean prevalence of NAFLD in chronic HCV infection is about 55%, ranging from 40% to 86%, which is significantly higher than each disease entity's prevalence rates individually. The exact mechanism for developing hepatic steatosis in the setting of HCV infection is not very well understood. Still, the association is dependent on both host and viral factors (Adinolfi, 2016). NAFLD in HCV genotype 3 infected patients is strictly associated with serum viral load (Patton et al., 2004; Poynard et al., 2003); thus, steatosis in this setting is considered of viral origin called "viral steatosis". In HCV non-3 genotype infected patients, NAFLD is linked to host factors such as obesity, particularly visceral obesity, insulin resistance, and type 2 diabetes mellitus, called "metabolic steatosis" (Hickman et al., 2003). The host's genetic background predisposes them to the development of steatosis. HCV's lipid and glucose metabolism impairment cause fatty liver accumulation; this seems to be a viral strategy to optimize its life cycle (Adinolfi, 2016). The interplay between CHC and hepatic steatosis has been shown to have implications in response to antiviral therapy, rate of disease progression, and risk of developing HCC. It is only recently that the significance and relationship of steatosis to HCV have begun to

be understood. The combination of metabolic steatosis and viral steatosis leads to a more rapid progression of scarring or fibrosis and increases the risk of disease progression in HCV infection. They also reduce the likelihood of responding to hepatitis C treatment and may contribute to the development of HCC in people who have cirrhosis (Hepatitis C Trust, 2021).

### *Lifestyle Modifications for NAFLD*

The ultimate goal in the treatment of NAFLD is to extend overall survival and improve life (Tanaka, 2019). Although lifestyle modifications and medications for underlying conditions have the potential to alter their natural course favorably, the optimal lifestyle intervention for NAFLD remains controversial (Dhaliwal et al., 2021, Katsagoni et al., 2016). Implementing lifestyle modifications covers a broad spectrum of interventions, from recommending diet changes and physical activity to nutritional and exercise counseling and cognitive-behavioral treatment, including psychological support. The majority of health care professionals are not adequately trained to implement these behavioral procedures effectively.

Clinical practice guidelines for the treatment of NAFLD from the AASLD and the European Association Study for Liver Disease (EASL) indicate that any attempt should be pursued to modify lifestyle and achieve substantial weight loss (Petroni et al. 2019). Weight reduction through diet modification and increased physical activity is the most established treatment for NAFLD and NASH. In a meta-analysis of eight randomized controlled trials (RCT), those who could lose at least 5% of body weight had improved hepatosteatosis. In contrast, those lost 7% of body weight were associated with an enhanced NAFLD Activity Score (NAS), a histological scoring system for steatosis, lobular inflammation, and ballooning (Chalasani et al. 2018).

A meta-analysis study conducted by Katsagoni et al. (2016) showed strong evidence that exercises alone or combined with a dietary intervention improves serum levels of liver enzymes, intrahepatic fat content, or even liver histology in patients with NAFLD. Among different diet approaches proposed to treat NAFLD, the Mediterranean diet has been suggested as the diet of choice for NAFLD treatment. It improves metabolism, mainly by reducing insulin resistance and lipid serum concentrations (Torres et al., 2019).

### ***Adherence to Lifestyle Intervention***

The World Health Organization (2001) defines treatment adherence as how a person's behavior in taking medication, following a diet, and executing lifestyle changes corresponds with the agreed recommendations from a healthcare provider. The utility of lifestyle-based health promotion interventions is directly impacted by patients' adherence to prescribed behavior changes (Middleton, 2016). However, compliance rates vary widely across different patient populations, treatment regimens, and disease types. About 25% of patients do not adhere to preventive and management activities, including medication taking, appointment keeping, screening, exercise, and dietary changes; for chronic disease management, nearly 50% of patients fail to adhere to their medical advice (Miller, 2016).

Dietary and lifestyle modifications to achieve sustained weight loss represent the main focus of NAFLD management, but long-term compliance is poor. Adherence to treatment recommendations is imperative in NAFLD for successful long-term outcomes. Although treatment adherence is a complex behavioral issue, willingness to undergo treatment is the starting ingredient for adherence (Dhaliwal, 2020). Miller et al. (2016) noted that adherence is driven by patients' lack of understanding of their disease and associated treatment, beliefs about the benefits and efficacy of prescribed regimens, and real or perceived barriers. To improve



adherence, patients need to clearly and appropriately understand health information related to their specific illness or disease (Miller, 2016). Gulati et al. (2018) noted that in people with Hepatitis B, Hepatitis C, and cirrhosis, simple but formal education sessions significantly improved patient knowledge about their liver diseases. It has been shown that a patient's compliance to treatment is better when patient literacy is taken into account.

### ***Care Management Challenges***

There is ample evidence that behavioral intervention targeting diet and physical activity effectively treats NAFLD (Arora et al., 2018). Since patients remain asymptomatic until they have end-stage liver disease, the management of NAFLD poses a significant challenge for both healthcare providers and patients (Dhaliwal, 2021). Engaging asymptomatic patients in intensive lifestyle protocols may be challenging because they do not think of themselves as sick individuals (Zelber-Sagi et al., 2017). According to Arora et al. (2018), the primary reason for the reluctance of NAFLD patients to lifestyle modification is inadequate awareness about the progression and possible consequences of the disease. Patients also find it challenging to provide their views on what they believe would be helpful due to not knowing what NAFLD is and how they could manage it. Secondly, patients are advised to lose weight without meaningful and continuous support to change their lifestyles. Hallsworth et al. (2020) noted that most of these patients are monitored for disease progression annually and are not actively managed by their health care provider. The negative attitudes of health care providers and low levels of emotional rapport towards obese patients have diminished patients' adherence to recommendations and decreased the effectiveness of behavior change counseling (Arora et al., 2018). Furthermore, many health care providers do not recognize NAFLD as a clinically relevant diagnosis, and this gap in awareness and perception can be detrimental to optimizing patient care.

It is essential to know that the outcome of treatments depends largely on patients' behavior. Dhaliwal et al. (2021) emphasized that their health beliefs and illness perception determine the degree to which patients follow treatment recommendation. Healthcare providers' clinical perspectives often exhibit discordance from patients' perspectives and ignore patients' ideas and beliefs concerning their illness (Dhaliwal et al., 2021).

### **Problem Statement**

The problem statement for this CI project is that the health beliefs among patients with CHC who are newly diagnosed with NAFLD are not known. The current management of NAFLD is recommending dietary modifications and increasing physical activity targeted towards weight loss (Riazi, 2019). Maintaining long-term adherence to behavior change represents a problem of enormous clinical significance (Middleton et al., 2016) especially among patients with NAFLD at the clinic site where this study is being conducted. The removal of barriers hampering adherence and successful maintenance of weight loss is central to effective treatment (Petroni, 2020).

### **Purpose Statement**

The purpose of this DNP CI project was to explore health beliefs about NAFLD among patients with CHC with the intent to enhance understanding of patient health literacy in a group at risk for non-adherence to treatment. The Health Belief Model theory suggests that a person's belief in the personal threat of a disease, together with a person's belief in the effectiveness of the recommended health behavior, will predict the likelihood the person will adopt the behavior (LaMorte, 2019). The BIPQ was used to assess patients' cognitive and emotional representation of illness. It is expected that appreciating these constructs will improve the gap in the care management and health outcomes of NAFLD patients in this clinic.

**PICOT Question**

How do CHC patients (P) with new diagnosis of NAFLD (I) perceive their illness and treatment management (O) at the time of diagnosis (T)?

**Needs Assessment*****Objective***

The Needs Assessment was conducted to ascertain a gap in care management of patients with CHC newly diagnosed with NAFLD and assess readiness for change on behalf of the staff at the site. Currently, there are low indicators of disease management by the providers of this clinic.

***Participants***

The key informants in this Needs Assessment included the healthcare team that manages patients diagnosed with NAFLD and the clinic staff involved in implementing the DNP project. This group consisted of two gastroenterologists, three nurses, and the clinic manager. The key influencer is the gastroenterologist who has practiced since 2004. The other gastroenterologist has practiced since 1990. All nurses are RNs and have worked in the clinic for 2 to 15 years. The manager has worked in this clinic for 15 years and has taken the administrative role in the last five years.

***Rationale and Purpose of Needs Assessment***

NAFLD has become the leading cause of liver disease worldwide (Saeed, 2019). The rising epidemic will be the leading cause of cirrhosis, HCC, and liver transplant within the next decade (Tanaka, 2019). The mainstay of therapy remains lifestyle modifications targeted towards weight loss: a valuable objective more often wished for than achieved. Unfortunately, many patients are not successful in instituting these changes and even those who do, find it difficult to

sustain over the long term. Providers have expressed their frustrations about patients' poor adherence to recommended lifestyle modifications. The purpose of the Needs Assessment was to identify the barriers causing the gap in the management of these patients. It is essential that the results must be shared with the key informants, and use this information to engage these patients in health-promoting behaviors, thus improving health outcomes. An in-depth understanding of the barriers contributing to the gap can lead to interventions that can affect long-term change towards optimal practice and care.

### ***Data Collection***

The Needs Assessment utilized a non-structured interview method to collect data from the key informants. During the interview, guided questions using a questionnaire were asked to determine concepts to be collected. These concepts included informants' opinions on the patient population that needed improvement in care. Key informants discussed their role in improving and managing these patients, the rationale for the poor outcomes related to NAFLD, the importance of lifestyle modifications and their benefits, and past experiences with effective lifestyle interventions. Influential factors that affect these concepts include the key informants' perceptions, readiness to participate, and willingness to incorporate change. Potential challenges include barriers to implementing planned actions such as patient and provider noncompliance and the lack of adequate, specific evidence-based interventions for NAFLD patients. The staffs' readiness to change is crucial to ensure the project can be executed successfully. The information provided from the questionnaires was used to develop this DNP project to improve the care of these patients.

### ***Sample, Sample Size, and Sample procedure.***

The participants in the interview were the previously identified key informants. A purposive sampling method was used for this interview. Robinson (2014) defines purposive sampling as an intentional selection of informants based on their ability to elucidate a specific theme, concept, or phenomenon. Six interviews took place in the clinic with the providers, nurses, and the clinic manager. All interviews were approximately 30 minutes long and completed on February 1<sup>st</sup>, 2021, and February 5<sup>th</sup>, 2021.

### ***Implementation and Analysis***

The interviews were conducted at the clinic based on the providers, nurses, and the manager's schedule. The questionnaires used in the interview were analyzed. The respondents confirmed that patients with asymptomatic lifestyle-associated diseases such as NAFLD have limited readiness to change and have poor health outcomes. The providers have recently seen an increase in referrals of NAFLD patients to this clinic from primary care, and all informants believe there is a need to improve the care of these patients. The only recommended treatments are lifestyle modifications; no approved pharmacological treatment is available. Diabetic patients are referred to dietitians for diet counseling to achieve glycemic control, while most patients are instructed to access online resources for diets appropriate for weight loss. Patients' conditions are monitored but not managed; they are only seen once to twice a year, resulting in a lack of support to make lifestyle changes. The overall response for the rationale for poor outcomes was noncompliance with recommended lifestyle modifications. The barriers identified during the interview included: a gap in patient's knowledge and consequences of their illness, lack of lifestyle behavior change resources during the consultation, and lack of external lifestyle behavior change support services to help achieve their goals, such as access to affordable healthy food and gyms to exercise. Key informants also reported that providers might not be addressing

the etiology of the disease and therefore are not prescribing the proper treatment. Providers also expressed limited time during consultations to adequately target lifestyle behavior change. One provider noted that most of these patients do not think of themselves as sick and are not ready to change their lifestyles. The AASLD guidelines indicate that any attempt should be pursued to modify lifestyle and achieve substantial weight loss among NAFLD patients. (Petroni et al. 2019). Some patients showed improvement in their steatosis with weight loss; the question is if they can maintain and sustain their goal. Key informants agreed that improving illness understanding, believing in treatment effectiveness, and enhancing self-efficacy are vital for successful treatment. These factors will likely improve effective lifestyle interventions and achieve long-term engagement of NAFLD patients. The participants were willing and ready to implement this recommended action plan.

### **Aims and Objectives**

The overall aim for this DNP project was to improve the care management of patients who have CHC and were newly diagnosed with NAFLD by understanding their perception of illness and willingness to adhere to treatment. The objectives were as follows:

- To conduct a survey on patients' perception of illness
- To explore patients' willingness to adhere to treatment
- To explore patients' perception of the causal factors of illness
- To disseminate information on health beliefs that will provide scientific evidence for planning and implementing effective lifestyle interventions for NAFLD

### **Review of Literature**

A literature review was conducted to garner information about nonalcoholic fatty liver disease, its diagnosis, and treatment. The research librarian was consulted when conducting this

review of literature. The databases searched included CINAHL, PubMed, Google Scholar, and MEDLINE. Keywords encompassing this search contained terminology including but not limited to nonalcoholic fatty liver disease, lifestyle modification, barriers and facilitators, health beliefs, perception of illness, and self-efficacy. Appendix B provides an evidence grid of the evaluated articles. Data was limited to a five-year search span from 2016 to 2021, except for landmark studies using English-only documents from peer-reviewed journals. Approximately 34 results were found with these search stipulations and 30 studies were included. The inclusion criteria comprised of original research of any geographical locations and healthcare surveys. Exclusion criteria included non-English texts, studies including participants <18 years old, editorials, blogs, theses, and dissertations.

### **Perception of NAFLD**

Many patients diagnosed with NAFLD struggle with implementing and maintaining lifestyle interventions targeted toward weight loss in clinical practice. There have been limited investigations of specific patient-related factors affecting treatment for NAFLD. Studies have shown that patients reported a lack of information about their diagnosis and a gap in knowledge related to lifestyle modifications as the primary treatment for NAFLD (Avery et al., 2017; Hallsworth et al., 2020; Cook et al., 2019; Haigh et al., 2019). A study on NAFLD patients' illness perception, attitudes and behavior toward diet and physical activity, and impact of their disease on health-related quality of life (QOL) could inform potential interventions and address the gaps in care delivery and management of NAFLD (Tincopa et al., 2021).

Perception of illness is a patient's cognitive appraisal and personal understanding of a medical condition and its potential consequences (Broadbent et al., 2015). The study of illness perception emerged from previous research on the Common Sense Model (CSM) of illness,

examining the effect of fear on health behaviors. Leventhal et al. (1971) found that neither a threat message nor an action plan alone was sufficient to lead to health behavior change, but they did motivate health behavior change when combined. Illness perception focuses on how individual experiences and mentally frames living with a disease (Weinman and Petrie, 1997). This may include positive and negative illness beliefs that can influence the ability to cope with the illness and perceive it as manageable or threatening (Bonsaksen et al., 2015).

Hundreds of studies have investigated the association between illness perceptions, coping, and illness outcomes in many different populations. A meta-analysis review of 45 studies showed that worse consequences and identity beliefs were consistently associated with worse physical and social functioning, high distress, lower well-being, and vitality. In contrast, higher control beliefs were associated with better social functioning and well-being, lower distress, higher vitality, and better disease state (Hager & Orbell, 2010). Experimental studies provide the most robust evidence that illness perception can modify behavior, and several studies have shown that interventions designed to alter illness perception can improve health outcomes (Broadbent et al., 2009; Cunningham et al., 2012; Davies et al., 2008; Keogh et al. 2011; Petrie et al., 2012).

Evidence shows that positive illness perceptions are associated with better treatment adherence in asthmatic and diabetic patients. Negative illness perceptions have been associated in occupational illness groups with increased future disability and prolonged sickness absence independent of the severity of the medical condition (Basu, 2016).

Due to the indolent nature of NAFLD, patients often misperceive the danger the disease represents over time (Goh et al., 2016). Previous studies that have evaluated the perception of NAFLD in the general populace have demonstrated an overall indifferent attitude toward the



condition, as the participants were either uneducated about the disease or did not consider themselves at risk (Goh et al., 2016). A cross-sectional study to explore the awareness and perceptions of NAFLD in the Singapore general population found that majority of the subjects had superficial awareness of NAFLD and did not perceive the risk of developing this disease. The authors highlighted that enhanced public education is warranted to improve understanding, and further exploration into awareness and attitudes of NAFLD is needed to develop strategies for combatting this disease (Goh et al., 2016).

A study carried out in the United States showed a lack of awareness about NAFLD among many patients who reported that health care providers never discussed their disease with them (Ghevarija et al., 2017). This study showed the urgent need for the general population and health care providers to increase their awareness about liver disease. The result underlines the fact that there is a dire need for researching self-rated health perception among NAFLD patients (Arora et al., 2018).

Butt et al. (2021) examined the perceptions of NAFLD among a diverse group of people from urban centers in Pakistan. They concluded that patients harboring NAFLD had little to no knowledge about the disease and its nature and did not think they were suffering from it despite being diagnosed clinically. Furthermore, while the general populace was willing to accept being overweight and having unhealthy eating habits, their willingness to initiate lifestyle modifications to manage NAFLD was lacking. They reported that disinformation and flawed perception primarily influenced this reckless behavior toward a potentially deadly disease. Incorrect perceptions about the condition can lead to irresponsible behaviors with detrimental actions. Further exploration of the awareness of and attitudes towards NAFLD is needed to develop effective strategies for combatting this disease in Pakistan (Butt et al., 2021).

A case-control study conducted by Mlynarsky et al. (2016) reported that fatty liver without clinically significant liver disease does not have an independent impact on self-health perception. The findings indicated that NAFLD diagnosis is not associated with higher healthcare utilization. NAFLD does not seem to predict health perception deterioration over the years and is not considered a disease in the eyes of the NAFLD beholder until the advanced stage (Mlynarsky, 2016).

Zelber-Sagi et al. (2017) demonstrated that nutritional habits and lifestyle modifications among NAFLD patients might be associated with their perception of illness and self-efficacy regarding their ability to change their lifestyle. A belief in severe consequences, a strong illness identity, and higher perceived treatment control was significantly associated with the willingness to undergo treatment for NAFLD (Dhaliwal et al., 2020). Correct perception of this growing epidemic and adopting an interdisciplinary and multifaceted approach for effective treatment can go a long way in controlling NAFLD (Arora et al., 2018).

### **Cognitive Behavior Therapy**

Cognitive Behavior Therapy (CBT) is a promising component that should be added to the interdisciplinary approach to treating NAFLD (Arora et al., 2018). According to Miltenberger (1994), behavioral treatment should give patients the practical instruments to achieve their eating and exercise goals, incorporate them into their lifestyle, and maintain the results for extended periods. In a meta-analysis of 29 long-term weight loss studies, patients regained more than half of the weight loss within two years, and by five years, more than 80% of weight loss was regained (Hall & Kahan, 2018).

A few studies have explored the effect of the behavioral approach in NAFLD patients. A 2004 study by Hickman et al. demonstrated that a weight loss behavioral intervention in

overweight patients with liver disease resulted in a sustained improvement in liver enzymes. They compared the effects of CBT with the results achieved by prescriptive dieting at 6 months and 2 years in a tertiary referral outpatient department for NAFLD treatment. CBT was associated with a higher probability of reaching the weight loss target and a higher probability of normal liver enzymes (Moscatiello et al., 2011). Similar trends were observed in the number of components of the metabolic syndrome, confirming that a CBT program produces a significant improvement in liver parameters and overall metabolic abnormalities accompanying NAFLD (Centis et al., 2013). If added along with regular dietary and lifestyle counseling, CBT can help improve dietary compliance and lead to sustained weight loss over a more extended time (Arora et al., 2018).

### **Impact of NAFLD on Quality of Life**

Over the past few decades, advances in behavioral health medicine have demonstrated the important role of behavioral health treatments in improving patients' health and QOL. Chronic diseases and their treatments can be disruptive and negatively affect QOL (Sawyer, 2019). Haas (1999) describes QOL as a multidimensional concept that includes physical, psychological, emotional, and spiritual well-being given the context of life circumstances, cultural norms, and personal values. Patient related outcomes (PRO) such as poor health-related quality of life (HRQOL) from NAFLD play a significant role as study endpoints in the development and evaluation of new therapies (Golabi et al., 2016, Younossi et al., 2015). HRQOL addresses how illness, injury, and treatment affects well-being and prior experiences of normalcy (Golabi et al., 2016). In a study to assess HRQOL in patients with NAFLD, data analysis showed that NAFLD patients experienced significant impairment of their HRQOL (Golabi, 2016). They had more impairment of their physical health than their mental health.

Although not fully understood, NAFLD patients' reported poor physical health might be related to chronic fatigue. Golabi reported that impairment of HRQOL in NAFLD was less pronounced in those with HCV. The mental health aspect of patients' outcomes was more profoundly affected by HCV than NAFLD. It is not a surprise, given the strong association of HRQOL with depression in patients with CHC (Cinar, Ozdogan, & Alahdab, 2015).

When assessed by the Illness Perception Questionnaire instrument and its versions, illness perception domains are often associated with QOL. Ozawa et al. (2020) examined the structure of quality of life and associated factors, including illness uncertainty among individuals with NAFLD. Patients who progressed from NAFLD to cirrhosis and liver cancer had disease uncertainty. In patients with CHC and advanced liver disease, higher levels of uncertainty about the condition were associated with lower levels of QOL. Perceiving an illness to have negative consequences, not surprisingly, has been associated with lower emotional QOL (Sawyer, 2019).

Tiemensma et al.'s (2016) study on COPD patients utilized the Brief IPQ to assess illness perception. They found that the concern, consequences, emotional representation, and identity domains were associated with lower QOL. Vaske et al. (2017) found that a higher score on the Brief IPQ, indicating a more threatening illness perception, was associated with worse mental QOL in COPD patients.

### **Brief Illness Perception Questionnaire**

The BIPQ measured participant's illness perception in this study. The questionnaire, which assesses patients' cognitive and emotional representation of illness, was first examined in research on health threat communication in the 1960s (Broadbent, 2015). Succeeding research led to the development of Leventhal's (1977) common sense model. The theory is used to understand people's response to illness and proposes that illness perceptions directly influences

coping strategies and outcomes. The cognitions and emotional responses motivate people to take specific behaviors to regulate their emotions and improve the outcome of their condition (Broadbent et al., 2015).

The BIPQ includes eight 11-point Likert items and one open-ended question item. The eight items are 1. consequences, 2. timeline, 3. personal control, 4. treatment control, 5. identity, 6. illness concern, 7. coherence, and 8. emotional representation. A higher score for items 1, 2, 5, 6, and 8 represents a worst disease perception. A lower score for items 3, 4, and 7 represents worse disease perception. The BIPQ total score ranges between 0 and 80 points and represents how threatening the illness is perceived. Higher scores reflect a more threatening perception of the related illness. The last item, an open-ended question, is on the perceived cause of illness, in which respondents rank the three most important causes of their illness (Broadbent, 2015).

Multiple studies have investigated associations between illness perception, coping, and illness outcomes in many different populations. A systematic review and meta-analysis of the BIPQ were conducted by Broadbent et al. (2015). The review results showed that the BIPQ is a versatile measure of illness perceptions. The tool has been used in many illness population studies such as cancer, metabolic diseases, mental and behavioral disorder, circulatory system disease, digestive system diseases, respiratory diseases, and musculoskeletal and connective system diseases. The BIPQ has also been used in 36 countries and administered to patients aged 8 to over 80. Meta-analysis showed that the scale has good concurrent validity. Predictive validity was demonstrated in 19 of 20 longitudinal studies for a several mental and physical health outcomes. Randomized controlled trials have shown that all items can assess changes in illness perception after an intervention. To examine concurrent validity, Broadbent concentrated on associations reported in cross-sectional studies between BIPQ and anxiety, depression, higher

HbA1c, and quality of life. Higher consequences, emotional representation, and identity were moderately to strongly associated with higher depression and anxiety, higher HbA1c with worst control of diabetes, and lower quality of life dimensions. Concern perceptions had similar results but were inconsistent. Personal control and treatment control had small negative correlations with anxiety and depression and small to moderate correlations with better quality of life. The studies that included the open-ended causal question categorized and described the most frequent responses and some investigated associations with diagnostic and demographic factors or outcomes. These associations largely support the validity of the causal item (Broadbent et al., 2015).

Dhaliwal et al. (2020) used the BIPQ to study the various determinants of illness perception among patients newly diagnosed with NAFLD and its association with willingness to undergo treatment. The mean BIPQ score was comparatively higher in females than males but did not reach statistical significance. The mean BIPQ score was also significantly higher in patients with a family history of liver disease, transaminitis, obesity, diabetes, metabolic syndrome, and medications. The group was willing to undergo the long-term program of comprehensive management of NAFLD. For the open-ended question to identify causal factors of illness, dietary factors, pollution, lack of physical activity, and emotional stress were the most identified frequent causes.

A study using the BIPQ to determine the relationship between illness perceptions and QOL among people with multiple chronic conditions (MCC) living in China found that illness perceptions accounted for significant physical and mental health (Cheng et al., 2019).

Consequences, timeline, and personal control were predictors; illness perceptions formed by people with MCC differ from those with a single long-term condition due to the complexity of

the disease course and treatment. This finding highlighted the importance of assessing and understanding illness perceptions due to the significant association with health status (Cheng et al., 2019).

### ***Research Survey***

A variety of methodologic approaches exist for researchers in conducting research, but surveys have been proven to be one of the most effective and trustworthy methods of research (QuestionPro, 2021). This DNP project used an online survey to explore the health beliefs of CHC patients with a new diagnosis of NAFLD at a gastroenterology clinic in North Central Arkansas. Although the survey is a quantitative measure of the five components of illness representations, it includes a qualitative component with two open response questions. Participants were asked to rank the three most important causes of their disease and indicate if they were willing to undergo treatment.

Survey research is a type of research that collects information from a sample of individuals through their responses to questions (Ponto, 2015). Survey research uses various data collection methods, the most common being questionnaires and interviews. Psychometric properties, which refer to the validity and reliability of a survey tool, are important aspects to consider in developing and testing any survey instrument for gathering data. The BIPQ has been demonstrated to have appropriate psychometric properties to explore health beliefs. Attention to these considerations helps to ensure the quality of the survey instrument and the data collected for analysis and use (Jang, 2020). Reviews examining survey response rates have reported that response rates vary from 10.3% to 61%. Booker (2021) listed several factors that can impact response rates: survey length, content, mode of transmission, incentives, and several follow-up surveys. Using previously validated instruments that are shorter in length has shown to increase

response rates when conducting research (Booker, 2021). The BIPQ is a short and simple measure of illness perception, which could be particularly helpful in ill populations, large-scale studies, and repeated measures research designs. While traditional modes of administration such as in-person pen and paper, telephone, and mail have the advantage of familiarity and ease of providing incentives for survey completion, web-based surveys are convenient and easy to complete on technological devices (Booker, 2021).

### **Theoretical Framework**

One of the best frameworks to inform the development of interventions that improve health behaviors is the Health Belief Model (Nourian, 2020). The Health Belief Model (HBM) postulates that people will take action to prevent illness if they regard themselves as susceptible to a condition, if they believe it would have potential serious consequences, if they believe a particular action would reduce the severity of illness and lead to positive outcomes, or if they perceive negative attributes related to the recommended health action (Jones et al., 2016). Scholars later suggested that self-efficacy, the belief that one can successfully perform a behavior, should be added to the HBM (Rosenstock, Strecher, & Becker, 1988). However, in actual HBM studies, self-efficacy is rarely included (Carpenter, 2010). The model suggests that specific cues, such as environmental factors, can affect the final action one will take towards their illness, but this construct has also been less investigated. (Champion and Skinner, 2008).

The HBM was the guiding theoretical framework for this DNP project. The HBM serves as an appropriate framework for understanding how individuals acquire health knowledge about their illness, how they are personally impacted by such knowledge, and how they are best prompted to implement behavioral changes (Burnham et al., 2015). In any busy clinical practice setting, health care providers should find time to routinely ask patients and their family members



what matters most to them in their experience of illness and treatment. They should use this crucial information to plan high-quality patient-centered care and implement effective interventions (Hallsworth, 2020).

### **Origins of the Health Belief Model**

The HBM was considered one of the first models to adapt theory from the behavioral sciences to address health problems. Social psychologists working in the United States Public Health Service developed the model in the early 1950s after being influenced by a widespread failure of people partaking in low-cost or free-of-charge programs. They theorized that the peoples' readiness to act was influenced by their beliefs about their susceptibility to the disease and their perceptions of the benefits of trying to avoid it (LaMorte, 2019). Others later extended the HBM to study patients' responses to symptoms and compliance with medical treatments. Since then, the HBM has evolved to address public health concerns and applied to a broad range of populations and health behaviors. The major strength of the HBM lies in the fact that it was developed by researchers directly working with health behaviors. Many of the model's concepts possess face validity and measure what it is supposed to measure for those working in this field (Conner, 2021).

### **Constructs of the Health Belief Model**

The Health Belief Model purports to explain why people do or do not engage in a preventive health action plan in response to a specific disease threat. Understanding people's behavior and the likelihood of changing their behavior is essential in understanding each construct of the health belief model (LaMorte, 2019). Additionally, the HBM theory considers demographical, socio-psychological, and structured variables as potential modifying factors that can influence people's perceptions of illness and the benefits of preventive action.

A meta-analysis was conducted between 1974 and 1984 to assess the validity of the HBM and its constructs in predicting behavior (Becker, 1974; Janz & Becker, 1984). Perceived barriers were the most powerful single predictor of preventive health behavior across all studies and behavior, and perceived severity was the least powerful predictor. Perceived susceptibility and benefits were essential predictors of protective health behavior, and perceived susceptibility was a stronger predictor of preventive health behavior. In terms of the model's overall impact and predictive power in its entirety, an analysis by Zimmerman and Vernberg (1994) found that the HBM was able to predict future behavior. Carpenter (2010) found in a meta-analysis of 18 studies that perceived benefits and barriers were consistently the strongest predictors of health behaviors.

### ***Perceived Susceptibility***

Patients most susceptible to CLD are persons with health disparities, those who lack knowledge, or those with negative behaviors (Burnham et al., 2014). Of growing concern is NAFLD, which is highly correlated with obesity and diabetes. NAFLD is asymptomatic and is often detected incidentally (Arora et al., 2018). There is low awareness of NAFLD as a disease entity, its progression to end-stage liver disease, and its relationship with other metabolic conditions.

Individuals are believed to vary widely in their perceived susceptibility to a condition (Rosenstock, 1974). For example, an individual might deny the possibility of contracting a given condition, another individual may admit to the “statistical” possibility of contracting the condition but will not likely happen, and another individual may actually express a feeling that they are in real danger of contracting the condition. In short, susceptibility refers to the subjective risks of contracting a condition (LaMorte, 2019).

NAFLD patients are mostly unaware of why they have the disease and how they developed it (Hallsworth, 2020). Increasing awareness of NAFLD progression and its relationship with diabetes and obesity could facilitate the development of primary and secondary prevention programs and promote adherence to lifestyle interventions by influencing NAFLD threat perceptions (Alemany-Pages et al., 2020).

### ***Perceived Seriousness***

The belief concerning the seriousness of a condition varies from person to person. Understanding how patients view NAFLD's health and social consequences is essential because patients who perceive the threat to be serious might be more inclined to follow lifestyle recommendations. Rosenstock (1974) explains that the degree of seriousness may be judged both by the degree of emotional response created by the thought of a disease and by the difficulties the condition will create for the individual. Understanding NAFLDs' medical and clinical consequences can make patients realize that the disease could cause death, reduce physical and mental functioning, and permanent disability. However, the perceived seriousness of a condition may include broader and more complex implications, such as the effects of the disease on their job and family life (Rosenstock, 1974). Thus, a person may not believe that NAFLD is medically serious, but its occurrence could be serious if it creates psychological and economic tensions within his family.

HBM constructs could function as causal chains. One of the HBM constructs serves as a moderator for the influence of the other HBM variables (Hayes, 2012). Champion and Skinner (2008) argued that increased seriousness is required before susceptibility can significantly predict behavior.

### ***Perceived Benefits and Barriers to Taking Action***

Awareness of one's susceptibility to a specific disease that is believed to be serious may provide motivation that leads to action. Jones et al. (2015) suggest that perceived benefits and barriers may better predict behavior when threat perception is more significant. Rosenstock (1974) suggests that behavior depends upon how beneficial an individual believes the recommended health action will be and if it relates subjectively to reducing one's susceptibility to or seriousness of an illness. A person's beliefs about the availability and effectiveness of various courses of action, not the objective facts about the action, determine what course he will take.

The health and social benefits of losing weight, the cornerstone of therapy for NAFLD, can be strong motivators to change eating habits and physical activity levels. Higher perceptions of understanding the illness are positively related to better nutritional habits in patients with NAFLD (Zelber-Sagi, 2017). Improving the awareness about the benefits of a healthy lifestyle and the consequences of abusing one's body could help avoid NAFLD later in life (Burnham, 2014).

An individual may believe that a given action will effectively reduce the threat of disease while seeing that action itself is inconvenient, expensive, unpleasant, painful, or upsetting. These negative aspects of health action serve as barriers to action (Rosenstock, 1974). The lack of or inadequate health insurance, high cost of care, general lack of knowledge, negative attitudes and emotions, and low economic status have been identified as barriers to treatment of NAFLD (Burnham, 2014). Lack of access to medical care due to high costs and high rates of uninsured individuals are the leading barriers to care (Tolbert and Orgera, 2020). Simply having medical insurance does not guarantee adequate medical care. High co-payments, limitations on covered

procedures and medications, and the insurance companies' denials of specific treatments are identified as barriers to care for NAFLD.

### ***Cues to Action***

The combined levels of susceptibility and severity provide the force leading to action, and the perception of benefits provides the preferred path of action. However, these combinations may still not result in overt action unless some instigating event occurs to set the process in motion (Rosenstock, 1974). The amount of cues needed for action is related to the level of readiness. A high level of readiness requires a slight cue action, whereas low psychological readiness requires a more intense stimulus (Rosenstock, 1974).

In the healthcare area, events or cues might be internal or external such as perception of bodily states, interpersonal interactions, the impact of media on communication, advice from others, or illness from health members (LaMorte, 2019). A study exploring the readiness of NAFLD patients for behavioral changes reported low motivation to adopt healthier lifestyles regarding nutrition and physical activity (Alemany-Pages et al., 2020). Patients' awareness of their stage of fibrosis, degree of steatosis, and risk for progression to cirrhosis are stimuli that can elicit engagement with the health-promoting behavior (Dhaliwal, 2020). Additionally, conceiving that NAFLD would have severe consequences in the long run and believing that treatment can help their illness are critical predictors of willingness to undergo treatment.

### ***Self-Efficacy***

Self-efficacy is defined as an individual's confidence in their ability to make behavior changes necessary to achieve goals across various situations (Bandura, 2004). Health behavior theories suggest that increasing self-efficacy over time will change behavior. It has been widely studied as a psychosocial correlate and predictor of changes in weight and weight-related

behaviors (Nezami, 2017). For NAFLD patients, strategies to enhance self-efficacy should be incorporated into their care management to promote improvement in dietary intake, physical activity, and weight loss. Studies have shown that individuals with high self-efficacy showed greater willingness to participate in challenging behaviors and offered a better interpretation of health and well-being (Javanmardifard, 2017). Since self-efficacy in nutritional behavior and physical activity are essential factors in achieving the expected outcomes for NAFLD patients, designing self-care programs based on patients' self-efficacy can improve their conditions and prevent complications and hospitalization (Javanmardifard, 2017). The practical implication is that assessing self-efficacy in people with NAFLD may be a first step in developing individually tailored interventions.

## **Methodology**

### **Project Description**

The management of NAFLD has posed a significant challenge for both patients and healthcare providers in this clinic. The primary reason for the reluctance of NAFLD patients to lifestyle modification is inadequate awareness about the progression and possible consequences of the disease. Assessing their illness perceptions and implementing effective interventions to address unhelpful negative perceptions can increase adherence to lifestyle modifications. A cross-sectional survey was implemented to investigate the illness perception of patients with CHC who were newly diagnosed with NAFLD and their willingness to adhere to treatment. The survey provided the means to meet the objectives of the study, to explore patients' perception of illness, their willingness to adhere to treatment, and their perception of the causal factors of illness. The results of the survey were disseminated with the intent to create a program that endorses effective and sustainable NAFLD-tailored lifestyle interventions.

## **Project Design**

The project used a validated instrument for a survey, the BIPQ, to explore the cognitive and emotional representation of illness. Permission was received to use the BIPQ as a survey tool from Dr. Elizabeth Broadbent. Data for this DNP project was collected through Qualtrics, a secured online survey platform that served as the modality for disseminating survey questions. SPSS was used to analyze qualitative and quantitative elements of results. The analysis identified participants' beliefs regarding causes, consequences, control concerns, and the willingness to undergo and adhere to comprehensive treatment. It also identified the relationship between sociodemographic, anthropometric measures, fibrosis and steatosis scores with BIPQ scores. See Appendix N for the BIPQ survey form.

## ***Setting***

The survey was conducted online for easy access to respondents and was available from November 1, 2021, to January 15, 2022. Participants who did not have email accounts completed the survey by phone or at the clinic. Before analysis, the ExpertReview, a feature in the Qualtrics platform, was used to check the overall quality of the data collected.

## ***Study Population***

The study population for this project involved patients treated for CHC and had incidental findings of hepatic steatosis (CAP score  $\geq 238$ ) through transient elastography. Convenience sampling was conducted through the gastroenterology clinic in North Central Arkansas. Adult patients aged  $>18$  years were screened for participation in the survey. The exclusion criteria included pregnant females, previous history of hepatic decompensation, history of alcohol abuse, cancer, cognitive impairment, severe psychopathology, and refusal to provide informed consent to participate in the study. Based on the data from EClinicalWorks, the

electronic health record system used by the clinic, there were 102 patients diagnosed with Chronic Hepatitis C with NAFLD since January 1, 2020. To get a 95% confidence level with a confidence interval of 5% for this population, a sample size of 80 participants was needed to run statistical testing. The sample size included all respondents from the implementation period between November 1, 2021, and January 11, 2022.

### ***Subject Recruitment***

from a gastroenterology clinic in North Central Arkansas. Patients who were seen from January 1, 2020, to December 31, 2021, for CHC treatment and had incidental findings of hepatic steatosis through transient elastography were contacted by telephone to provide information about the study. Contact information for these participants was ascertained through demographic data from EClinicalWorks. A web link through Qualtrics was sent to patients who agreed to participate to obtain consent and access the questionnaire. Participants who did not have an email address were included; the survey was conducted by phone or at the clinic using the anonymous link. Please see Appendix E for the subject recruitment telephone script.

### ***Consent Procedures***

Consent forms were obtained through the web link prior to starting the survey through Qualtrics. Respondents were not able to progress to complete the survey if the consent form was not completed. See Appendix F for the informed consent form.

### ***Study Measures***

**Conceptual Definitions.** The following conceptual definitions for the purpose of this DNP project are:

- *NAFLD* is a chronic liver disease characterized by fatty infiltration in the liver, which can manifest in a spectrum of diseases ranging from benign hepatic steatosis to NASH to



advanced fibrosis, cirrhosis, and hepatocellular carcinoma. Imaging or histology must show evidence of hepatic steatosis and a lack of secondary causes of hepatic fat accumulation, such as significant alcohol consumption, long-term use of steatogenic medication, or monogenic hereditary disorders.

- *Illness Consequence* is defined as the believed consequence of an illness.
- *Illness Timeline* is defined as the believed time trajectory.
- *Personal Control and Treatment Control of Illness* is defined as whether something can be done to control the threat.
- *Illness Identity* is defined as the name or label of a threat.
- *Illness Coherence* is defined as how well the patient understands their illness,
- *Emotional Representation* is defined as how much does the illness affects the patient emotionally. Does it make them angry, scared, upset, or depressed?
- *Illness Cause* is defined as the threat's causal mechanism.
- *Treatment Adherence* is defined as the extent to which the patient follows medical instructions.

**Operational Definition.** The operational definitions for this project consisted of the following:

- *NAFLD* was diagnosed by quantifying the degree of hepatic steatosis through transient elastography with a controlled attenuation parameter (CAP) value of 238 dB/m and greater.
- *Illness Consequences* was examined in question 1 to explore how the illness affected their life.

- *Illness Timeline* was examined in question 2 to explore the perception of how long the illness will continue.
- *Personal Control and Treatment Control of Illness* were examined on questions 3 and 4 to explore how much control they have over their illness and how much the treatment could help them.
- *Illness Identity* was examined in question 5 to determine how many symptoms were experienced from the illness.
- *Illness Concern* was examined in question 6 to explore how concerned patients were about their illness.
- *Illness Coherence* was examined in question 7 to explore how well the patients felt they understood their illness.
- *Emotional Representation* was examined in question 8 to explore how their illness affected them emotionally.
- *Illness Cause* was examined in question 9, asking patients to identify the most important causes of their illness.
- *Treatment Adherence* was examined in a question asking patients if they were willing to adhere to lifestyle modification.

The first 8 items on the questionnaire were rated on an 11-point Likert scale ranging from 0 to 10; item 9 was an open-ended question asking patients to rank the three most important causal factors of their illness.

**Outcome Measures.** The main outcome measures for this project were to assess the illness perception of CHC patients with a new diagnosis of NAFLD and their willingness to adhere to treatment. This was assessed using the Brief Illness Perception Questionnaire,

measuring illness's cognitive and emotional dimensions. Cognitive aspects included the patient's perception of the effect of life, duration of illness, experience of symptoms, control over illness, beliefs about the effectiveness of treatment, and experience of symptoms. Emotional aspects included concern about illness and a multifaceted question about mood. The willingness to adhere to treatment was asked. An open-ended question asked respondents to rank the three most important factors causing their illness. Sociodemographic data assessment included age, gender, race, level of education, marital status, employment, and socioeconomic status. Anthropometric measurements included height, weight, body mass index, steatosis score on transient elastography, and median liver stiffness measurement.

**Process Measures.** The process measure of this project was the survey completion rates. The sample size was assessed weekly during the implementation phase. The goal response rate was 80%. The average survey response rate is 5% to 30%, a survey response rate of 50% or higher is considered excellent in most circumstances. A high response rate was expected because of the strong professional relationship between me and the respondent (CustomerThermometer, 2021). Plan Do Study Act cycles were executed during the implementation phase, to improve response rates, and a run chart was used to track response rates over time.

**Balancing Measures.** Balancing measures determine whether changes designed to improve one part of the system affect other parts of the system (IHI, 2021). Significant impacts from this study include improvement of physician-patient communication, development of a satisfactory physician-patient relationship, and enhancement of patient-centered care among CHC with a new diagnosis of NAFLD. Exploring illness perceptions can foster adequate communication that will allow patients and physicians to engage in appropriate information exchange, decide on a treatment plan, and ensure treatment adherence. Understanding illness

perceptions in the NAFLD population can provide scientific evidence for planning high-quality patient-centered care and implementing effective interventions, thus improving health outcomes. This balancing measure can be assessed during a patient's follow-up clinic visit.

### ***Benefits and Risk***

There was a small risk of a breach of privacy and confidentiality of survey responses. While names and specific data were not collected, respondent identity could be discovered using an IP address. To minimize this risk, no email information was collected for potential follow-up. There were no economic harms of participation in this survey aside from the time spent completing the survey. The approximate survey completion time was projected to be 5 to 10 minutes.

Benefits related to this study included a better understanding of CHC patients' illness perception of NAFLD and their willingness to adhere to treatment. Understanding illness perceptions in the NAFLD population will provide sound scientific evidence for planning high-quality-patient-centered care and implementing an effective intervention.

### ***Subject Cost and Compensation***

There was no cost to respondents for participating in the survey, and no compensation was provided to respondents.

### ***Resources Needed and Economic Considerations***

There was a limited cost associated with the survey related to data analysis. Rental for SPSS software was \$85 for 1 year. The BIPQ survey tool was publicly available. Resources for this project included a computer with internet availability and access to Qualtrics. These resources were at no cost to the participants or me.

## **Implementation**

## **Study intervention**

I conducted an online survey through Qualtrics using the individual link for participants who had email accounts and the anonymous link for participants who did not have email accounts. The survey was composed of questions regarding sociodemographic and anthropometric measures, a structured questionnaire on the perception of illness (BIPQ), and a question on willingness to adhere to treatment of NAFLD. The implementation process involved recruiting potential patients to participate in the survey and surveillance of survey responses to achieve a good response rate. I used the Plan-Do-Study-Act (PDSA) cycles throughout the implementation phase to ensure process and outcome measures were being met.

### ***Pre-Implementation Phase***

Prior to implementation, I identified potential study participants by obtaining a list of CHC patients newly diagnosed with NAFLD from eClinicalWorks. IRB determination was submitted on September 29, 2021, and approval was received on November 1, 2021. After IRB approval, participants were recruited by telephone and given information about the study. Survey questions were transcribed into Qualtrics after a small survey pilot test was administered. A face-to-face encounter with two patients was conducted at the clinic site to assess for technological glitches, formatting, clarity of questions, and data transferability. Testing the survey site, using the Qualtrics Preview Survey and Send Test Email features, was performed to see the survey's overall flow and verify the email content.

### ***Implementation Phase***

The survey implementation began on November 1, 2021, and concluded on January 11, 2022. The plan was to conduct the survey until March 31, 2022, but the goal for an 80% survey response rate was achieved by January 11, 2022. The survey was available online 24 hours a day

and seven days a week through Qualtrics. Recruitment of potential study participants was conducted by telephone to enhance participation. A web link to the survey was disseminated to eligible participants who had email accounts. The survey was conducted by phone or at the clinic site using the anonymous link for participants who did not have email accounts. Survey responses were monitored weekly during the study period, and reminders were sent through direct emails or phone calls when no responses or incomplete responses were observed. Data was evaluated weekly to assess the response rate and the need for continued recruitment. A continuous visual display of response frequency was available in Qualtrics; however, the raw data were exported to Excel to create a run chart. The potential study participants obtained from the chart review were 102 patients; only 81 patients responded to the survey. For surveys conducted through individual links by email invites, 60 were sent, 52 were started, and 48 were completed, yielding a 92% completion rate. There were 33 surveys conducted through the anonymous link by phone and at the clinic site. The overall response rate from individual and anonymous links was 80%.

**Plan-Do-Study-Act Cycle.** For the proposed implementation, I used Qualtrics to disseminate the survey. An appropriate number of responses was one of the main goals of implementation. The target goal for recruitment of participants was 80% and for the survey completion rate was 100%, with the idea that these potential study participants, who were established patients at the clinic, would be willing to participate in the survey. However, the target goal of survey completion was changed to 80% to be realistic. Out of the 102 potential study participants, only 81 responses were completed. Recruitment and surveillance were the key components of the implementation phase to ensure that adequate responses were received. Data was evaluated weekly to assess for trends and the need for continued recruitment.

**Recruitment.** One of the essential components for a successful implementation phase is recruitment. Patients with CHC have difficulties adhering to treatment and follow-up recommendations (Younossi, 2016). To compensate for this poor compliance, I recruited participants by telephone to provide a more personal invitation to the survey. Telephone recruitment was determined to be the most appropriate method to explain to respondents the purpose of the survey, how long the survey will take, and how their feedback will be used.

Recruitment started on November 1, 2021, and the plan was to contact five participants in the evening during the week. As phone calls were made, it was discovered that some of the listed phone numbers were disconnected, and some potential study participants would not answer their phones. Participants claimed they hesitated to answer calls if they did not recognize the caller ID on their phones. I left voice mails to identify myself and the reason for calling, which prompted participants to call back. For those who did not have a working number, I was able to reach some participants using their other contacts listed in their registration. Unfortunately, some potential participants could not be reached. Calling on Wednesdays was unproductive and discontinued because most people attended church services and were not answering their phones. I decided to add weekends for recruitment based on PDSA cycle findings.

Some participants did not provide their email accounts in their registration form; I was able to verify or obtain their email addresses from the telephone encounter. For those who did not have an email account, I was able to conduct the survey over the phone using the anonymous link. Most participants did not keep their Fibroscan report on fibrosis and steatosis scores and did not have portal access to their health records; I was able to provide this information over the phone.

***Surveillance.*** Surveys are one of the most frequently employed methods in primary care research, but the validity of their findings is dependent on the sample size representing the target population (Booker, 2021). There were 102 potential study participants; the goal was to recruit 20 participants per week and have at least 10 completed surveys returned. Surveillance of response rate started a week after the survey was launched and was conducted weekly. From November 1, 2021, to November 5, 2021, 20 participants were already recruited, and 10 surveys were completed. When email reminders were sent, three more surveys were started, and seven more were completed. A follow-up phone call was used for some participants who were not responding to multiple email reminders, which also generated additional survey completion. Participants who did not respond to both email and phone call reminders were asked to respond to the survey in the clinic during their scheduled appointment. Recruitment continued until all potential participants were contacted. The survey closed on January 11, 2022, with a total of 89 participants recruited. Despite constant reminders by email and phone calls, only 81 participants completed the survey.

### ***Post-Implementation Phase***

After the survey data collection period ended, I analyzed data for trends in sociodemographic, anthropometric, and illness perception responses. The raw data were exported to SPSS, where descriptive and inferential statistics were used to evaluate survey response averages, frequencies, correlations, and statistical significance. Categorical variables were expressed as frequencies or percentages, and continuous variables were expressed as the mean  $\pm$  standard deviation. A point-biserial correlation was used to correlate the BIPQ score with the willingness to adhere to treatment. Pearson correlation was used to correlate the BIPQ score with anthropometric variables. T-test was used for two groups and Analysis of Variance (ANOVA)



for more than two groups to correlate the relationship between BIPQ score and demographic variables.

Descriptive analysis of data was presented to the providers of the gastroenterology clinic using the histogram as a visual display. Final data analysis will be disseminated to the providers and staff of the clinic to provide sound scientific evidence for planning high-quality patient-centered care and implementing effective interventions. Further dissemination can guide other professionals and providers, payers, and policymakers towards NAFLD-tailored, patient-centered care in real-world practice.

### **Project Timeline**

I presented the proposal to the DNP project committee on September 8, 2021, and was approved for submission to IRB. There were only a few changes in the proposed timeline throughout the implementation phase. Survey development was started on July 18, 2021, and was completed on September 8, 2021, when consent to use the BIPQ was granted by Dr. Elizabeth Broadbent. The identification of eligible participants was started sooner than proposed, on August 1, 2021, instead of October 1, 2021. The application for IRB determination was sent on September 29, 2021. I made minor revisions requested by IRB and resubmitted; IRB approval was granted on November 1, 2021. A pilot survey was conducted at the clinic site to identify potential problem areas of the survey. The survey was published in Qualtrics and sent to eligible participants the same day. Data collection was expected to continue until March 2022 but was completed earlier, on January 11, 2022, when all potential participants were recruited. See Appendix H for the proposed Gantt Chart and Appendix K for the revised Gantt Chart.

### **Evaluation Plan**

#### **Data Maintenance and Security**

To keep project data secure, I saved the survey results on one password-protected computer with access only to me. Participant information, including names, phone numbers, and addresses, were obtained from eClinicalWorks, the electronic health record system of the gastroenterology clinic. I did not transfer data through any other devices. Electronic consent through the web link was required before completing the survey. I will destroy participants' information after exporting data results to SPSS to prevent breaches of confidentiality.

Data collection for the project involved the utilization of Qualtrics for surveying participants. Qualtrics complies with applicable data privacy laws in its role as a data controller of its data and as a data processor of customer data (Qualtrics, 2021). Specifically, Qualtrics is GDPR (General Data Protection Regulation) and CCPA (California Consumer Privacy Act) compliant and provides technology that enables their customers to be compliant, as well (Qualtrics, 2021). Qualtrics retains a data deletion feature that allows me to request the deletion of individual contacts, responses, entire survey projects, and all related data and associations. All data collected throughout this DNP project will be deleted by May 2022.

### **Data Analysis**

I implemented a cross-sectional study to obtain the aim of the study, which, is to improve the care management of patients with Chronic Hepatitis C. The exploratory nature of this research achieved the objectives of this DNP project: to survey patients' understanding of NAFLD illness and its causal factors, the perceived susceptibility and severity, benefits and barriers of treatment, and to explore the willingness to adhere to treatment. The data gathered included detailed sociodemographic data, anthropometric measurements, illness perceptions and willingness to adhere to treatment. Sociodemographic data assessment included age, gender, race, level of education, marital status, employment, and socioeconomic status. Anthropometric

measurements included height, weight, body mass index, steatosis score, and median liver stiffness measurement from transient elastography. The BIPQ was used to assess patients' cognitive and emotional representations of illness. The question on patients' willingness to adhere to treatment was included to explore the relationship with the BIPQ score. The categorical variables were expressed as frequencies or percentages. Continuous variables were expressed as mean  $\pm$  standard deviation. A point-biserial correlation was used to correlate the BIPQ scores with the willingness to adhere to treatment. Pearson correlation was used to correlate the BIPQ scores with anthropometric continuous variables. T-test was used for two groups and Analysis of Variance (ANOVA) for more than two groups to correlate a relationship between BIPQ score and demographic variables. All tests were two-tailed, with a significant P value defined as  $<0.05$ , and analysis was carried out with SPSS v.28 software.

### ***Outcome Measures***

The main outcome measures for this project were the illness perceptions of CHC patients with new diagnoses of NAFLD and their willingness to adhere to treatment. This was assessed using the BIPQ, measuring the cognitive and emotional dimensions of illness. Cognitive aspects included the patient's perception of the effect of life, duration of illness, experience of symptoms, control over illness, and beliefs about the effectiveness of treatment. Emotional aspects included concerns about illness and a multifaceted question about mood. The willingness to adhere to treatment was asked. An open-ended question was asked respondents to rank the three most important factors causing their illness.

I used both descriptive and inferential statistics to analyze data. Descriptive statistics were used to analyze the frequency distribution of demographic variables. The baseline sociodemographic parameters are presented in Table 1, and their anthropometric and radiological

results are shown in Table 2. Among the 102 chronic Hepatitis C patients identified with NAFLD, 81 patients completed the structured survey and were enrolled in the final analysis. More females (54.3%) participated in the survey than males, and most participants were older than 50 years old (70.4%). The level of educational attainment was equally represented; high school or no formal education was 50.6%, and college or higher education was 49.9%. For income, participants making less than \$25,000 annually (55.6%) were represented by a higher percentage than those making over \$25,000 annually (44.4%). The clinic provides services to the surrounding counties of North Central Arkansas; the participants in this survey are predominantly white (90.1%), which is the largest ethnic group in this community. There were more respondents who were married (48.1%) than divorced/widowed/separated (27.2%) or single (24.7%). Retired patients (42%) completed the most survey, followed by employed (37%) and unemployed (21%).

**Table 1 - Baseline demographics of participants enrolled in the survey**

Variables	N=81
Gender	
Male	37 (45.7%)
Female	44 (54.3%)
Age (years)	
< 50	24 (29.6%)
>50	57 (70.4%)
Education	
No formal education/High School	41 (50.6%)
College/Graduate	40 (49.9%)
Income	
<\$25,000	45 (55.6%)
>\$25,000	36 (44.4%)
Ethnicity	
Caucasian	73 (90.1%)
Non White/Non White/Other	8 (9.9%)
Marital Status	
Married	39 (48.1%)
Divorced	22 (27.2%)
Single	20 (24.7%)

Employment	
Unemployed	17 (21%)
Employed	30 (37.0)
Retired	34 (42%)

To analyze anthropometric measures, data were expressed as mean  $\pm$  standard deviation. The mean BMI was  $31.59 \pm 8.31$ , consistent with obesity, the mean steatosis score was  $298.28 \pm 38.11$ , consistent with Brunt Grade 3 (significant steatosis), and the mean fibrosis score was  $10.49 \pm 9.43$ , consistent with Stage 3 liver disease (severe liver scarring). Most participants (N=76/81, 91.4%) were willing to adhere to treatment recommendations for NAFLD. Those not willing (5/81, 6.2%) did not believe there was a treatment that was effective and sustainable. For the open-ended question to identify the most important causal factors of NAFLD, 79 (98%) mentioned a cause, while the remaining two (2%) could not identify a cause. The most frequent causes identified were diet factors (57/81, 70%), Hepatitis C (37%), lack of exercise (28%), and obesity (26%) (Table 3).

**Table 2 – Anthropometric and radiologic characteristics of participants enrolled in the survey**

Variable	N=81
BMI	$31 \pm 8.31$
Fibrosis Score	$10.4 \pm 9.43$
Steatosis Score	$298 \pm 38.11$

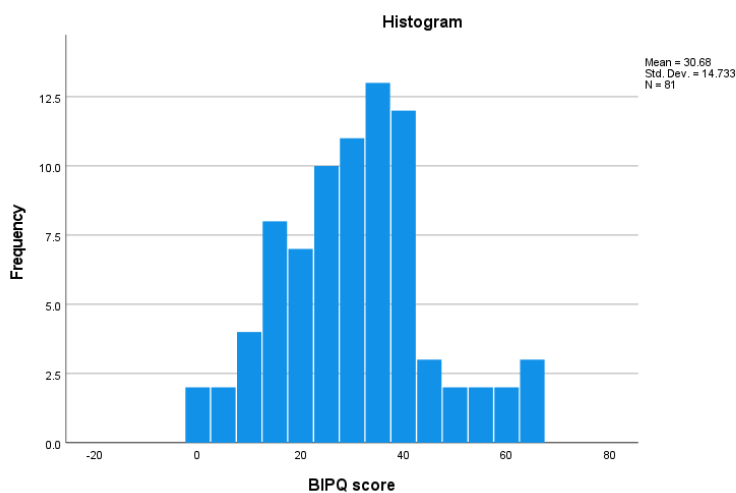
**Table 3 – Causal factors for NAFLD**

Causes	N= 81
Poor diet	57 (70%)
Lack of exercise	23 (28%)
Hepatitis C	30 (37%)
Obesity	21 (26%)
Alcohol	16 (19%)
Drug Use	13 (16%)

Hereditary	9 (11%)
Medication	5 (6%)
Insulin Resistance/Diabetes	3 (3.3%)
Smoking	2 (2.5%)
High Cholesterol	1 (1.2%)

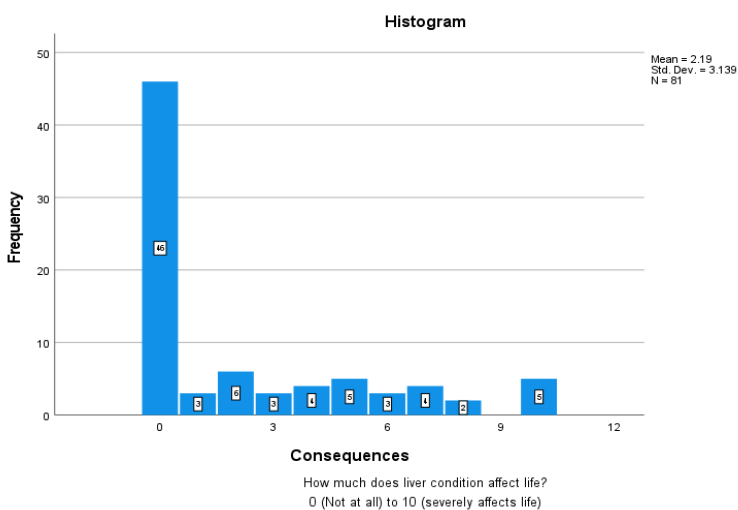
I used a histogram to graphically present the Likert score for the BIPQ individual domains and the total BIPQ score and show the distribution frequency. The BIPQ assessed the cognitive dimensions represented by items 1, 2, 3, 4, and 5, the emotional dimensions by items 6 and 8, and comprehensibility by item 7. A higher score on each item indicates a more threatening view of illness. To calculate the total BIPQ score, items 3, 4, and 7 scores were first reversed. Figure 1 visually displays the total BIPQ score, and Figures 2 to 9 display the individual domain scores. Missing data were identified on the perception of personal control and treatment control of illness.

*Figure 1: BIPQ Score*

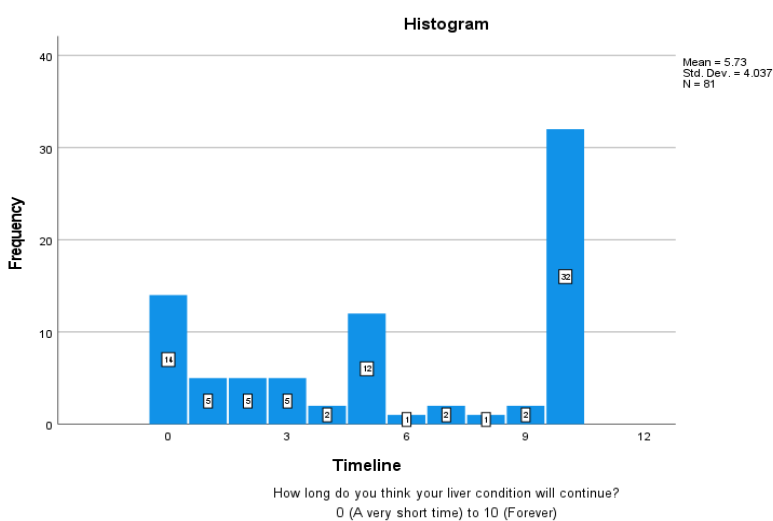


The mean and median total BIPQ score was  $30.68 \pm 14.73$  and 30.0, respectively. A higher total BIPQ score indicates a greater perceived psychological burden of illness (range: 0–80).

*Figure 2: Illness Consequence*



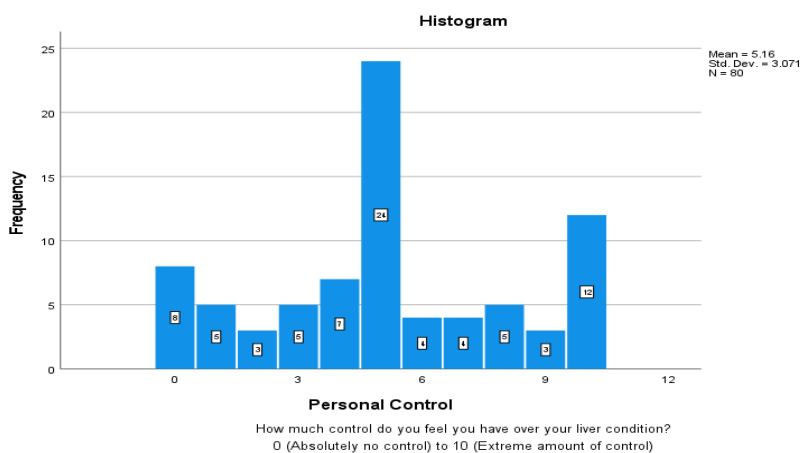
The illness consequence domain explores how the illness affects life. In this survey, 46 (56.8%) participants reported that their fatty liver condition did not affect their lives at all, while 5 (6.2%) reported that it severely affected their lives.



*Figure 3: Illness Timeline*

Illness timeline explores the perception of how long the illness will continue. In this survey, 14 (17.3%) participants reported that their fatty liver condition would only last for a very short time, while 32 (39.5%) reported it would last forever.

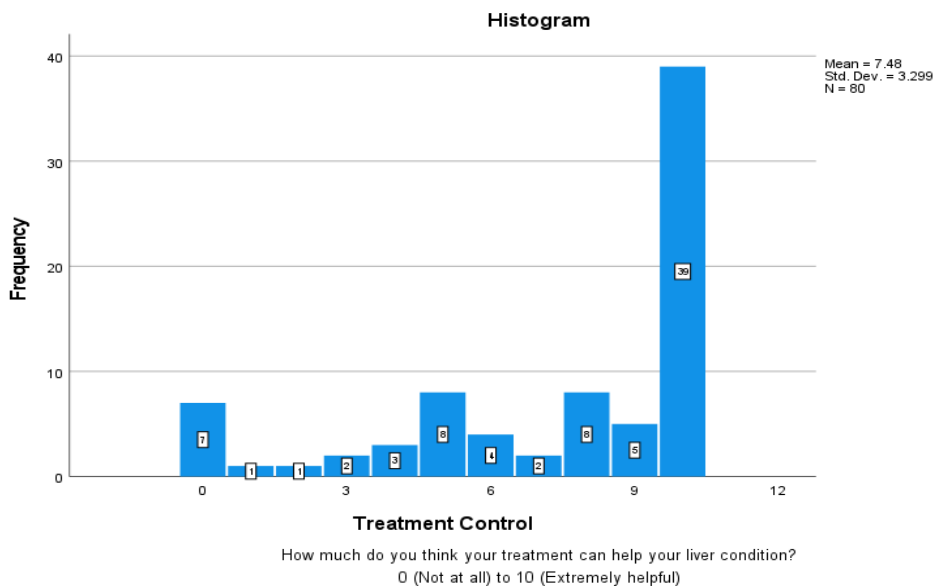
*Figure 4: Personal Control of Illness*



Personal control explores how much control patients have over their illness. The survey data shows 8 (9.9%) reported they had no personal control of their fatty liver condition, while 12 (14.8%) reported extreme control.

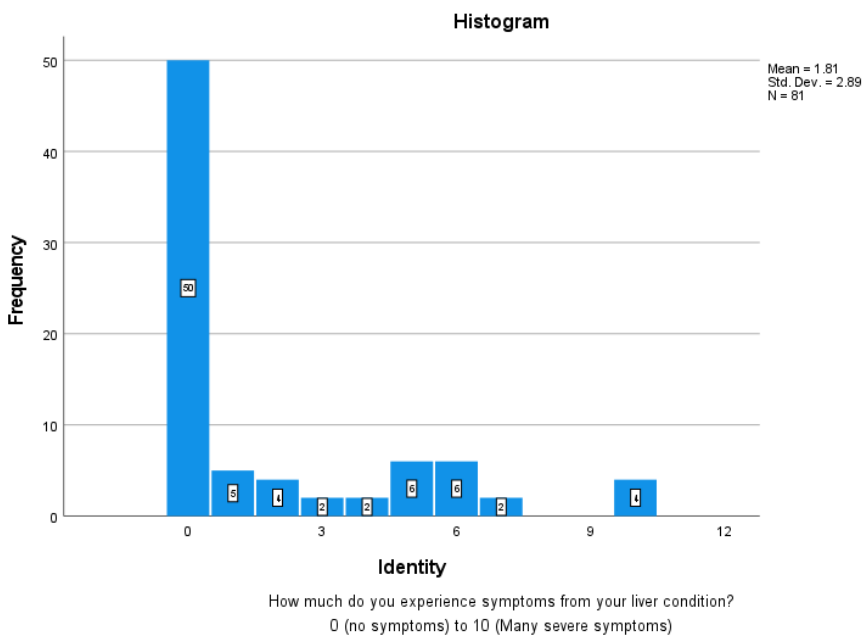


Figure 5: Treatment Control of Illness.



Treatment control explores how much the treatment can help the illness. For treatment control, 7 (8.6%) participants reported that the treatment would not be helpful at all, and 39 (48.1%) reported it would be extremely helpful.

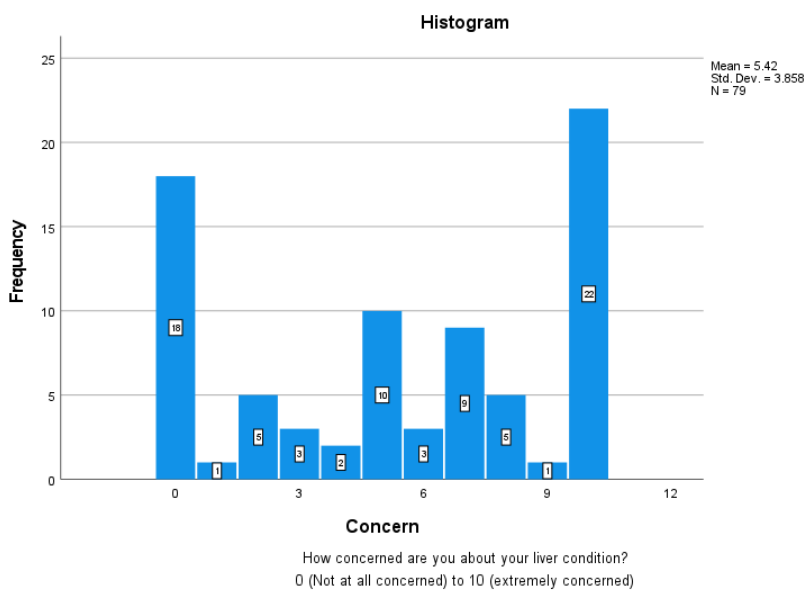
Figure 6: Illness Identity



The illness identity domain explores how much symptoms are experienced from the illness.

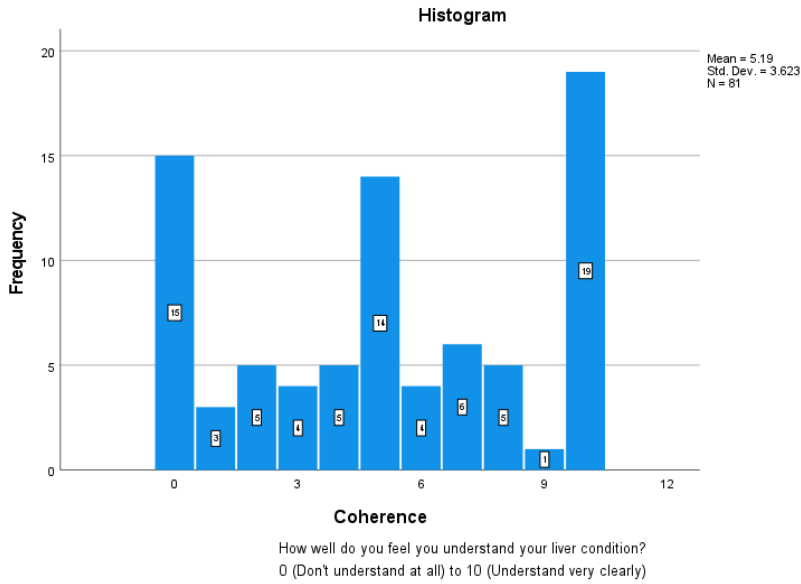
In this survey, 50 (61.7%) participants reported they did not experience symptoms at all, and 4 (4.9%) reported many severe symptoms.

*Figure 7: Illness Concern*



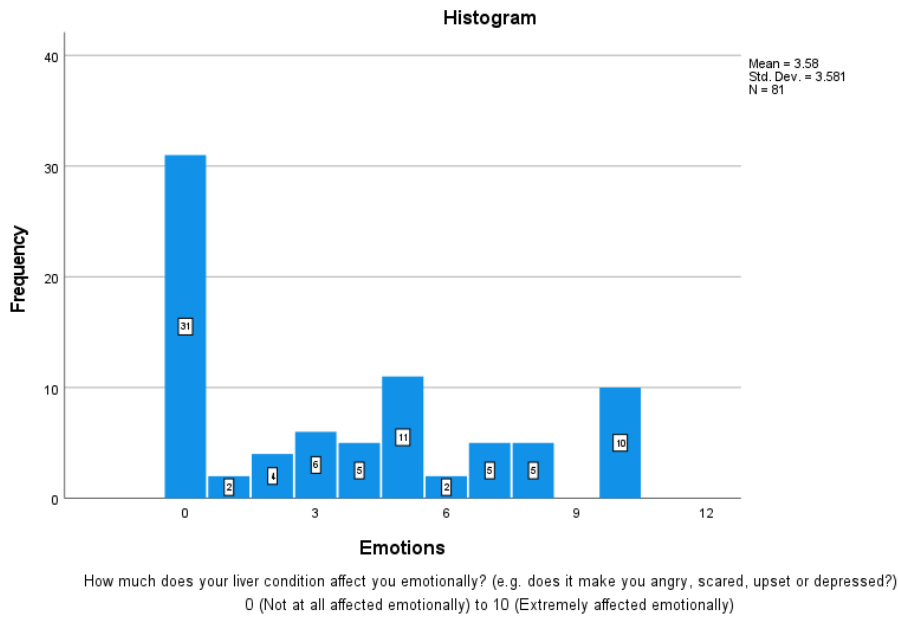
The illness concern domain explores how patients are concerned about their illness. The survey shows 18 (22.2%) participants were not concerned at all about their fatty liver condition, and 27.2% were extremely concerned about it.

*Figure 8: Illness Coherence*



Illness coherence explores how well the patients feel they understand their illness. For illness coherence, 15 (18.5%) reported they do not understand their fatty liver condition, and 19 (23.5%) reported they understood it very clearly.

Figure 9: Emotional Representation



Emotional representations explore how the illness affects the patient emotionally. Does it make them angry, scared, upset, or depressed? For emotional representation, 31 (38.3%) are not at all affected emotionally by their liver condition, and 10 (12.3%) reported they are extremely affected emotionally.

Inferential statistics were used to determine correlations between BIPQ scores and demographic variables, anthropometric variables, and willingness to adhere to treatment. An independent t-test showed that the mean BIPQ score for males was comparatively lower than in females; this difference reached a statistical significance ( $t_{79}=-2.80, p=.01$ ). The mean BIPQ score was higher among patients younger than 50 years of age than those older than 50; however, this difference did not reach statistical significance ( $t_{79}=1.41, p=.16$ ). In education, the mean BIPQ score was higher in patients with college and more advanced degrees than those who only had high school education or less, but no statistical significance was reached ( $t_{79}=-1.07, p=.29$ ). For income, the mean BIPQ score was higher for patients who earned less than \$25,000/year than those who made more than \$25,000/year. This difference also did not reach statistical significance ( $t_{79}=0.52, p=.60$ ). For ethnicity, Caucasians had a lower mean BIPQ score than non-Caucasians; this difference also did not reach statistical significance ( $t_{79}=-.47, p=.64$ ). A one-way ANOVA test showed no statistical significance in the mean difference among married, single and divorced/separated/widowed patients for marital status. The mean BIPQ score was highest in divorced/separated/widowed patients than in single and married patients ( $F_{2,78} = 1.51, p = .28$ ). For employment, the individuals who reported being unemployed had the highest mean BIPQ score compared to those who were employed and retired/disabled. There is no statistical significant difference in BIPQ score with respect to employment status ( $F_{2,78} = .924, p = .40$ ). The Pearson correlation was used to determine the relationship between BIPQ scores with

steatosis score, fibrosis score, BMI, and willingness to adhere to treatment. The Pearson product correlation of fibrosis score and BIPQ score was found to be a very low negative correlation and was not significant ( $r = -.12, p=.27$ ). The correlation between the steatosis score and BIPQ score was a negligible positive correlation and was not significant ( $r = .08, p=.46$ ). For BMI and BIPQ scores, the Pearson correlation was also a negligible negative correlation and was insignificant ( $r = -.01, p=.92$ ). The point biserial correlation between BIPQ score and willingness to adhere to treatment was a very low positive correlation and was insignificant ( $r = .11, p=.33$ ).

### ***Summary***

The data suggest that most study participants do not fully understand their NAFLD diagnosis. More than half of the participants did not experience symptoms and did not think their illness affected their lives. Although most of them perceived NAFLD as a long-term condition, the majority believed that they do not have personal control over their illness. Less than half of the participants think there is some form of treatment that could help with regression or resolution of their NAFLD, but almost all are willing to adhere to treatment recommendations. Regarding emotional representation, most participants reported low levels of concern regarding their illness and were not extremely affected emotionally. Perceptions regarding causal factors were believed to be related to lifestyle behavior such as dietary habits, obesity, lack of physical activity, and Hepatitis C from illicit drug use. For the correlation between demographic variables, anthropometric measurements, and Fibroscan scores with the BIPQ scores, only the gender variable showed a statistically significant difference in the mean score. Females have a higher BIPQ score and have a greater perception of the psychological burden of their illness. In general, the total BIPQ score of each participant did not correlate with any other variables measured in this study. This clinical inquiry project tried to assess the various determinants of

willingness to adhere to treatment and did not find an association with a range of illness perceptions.

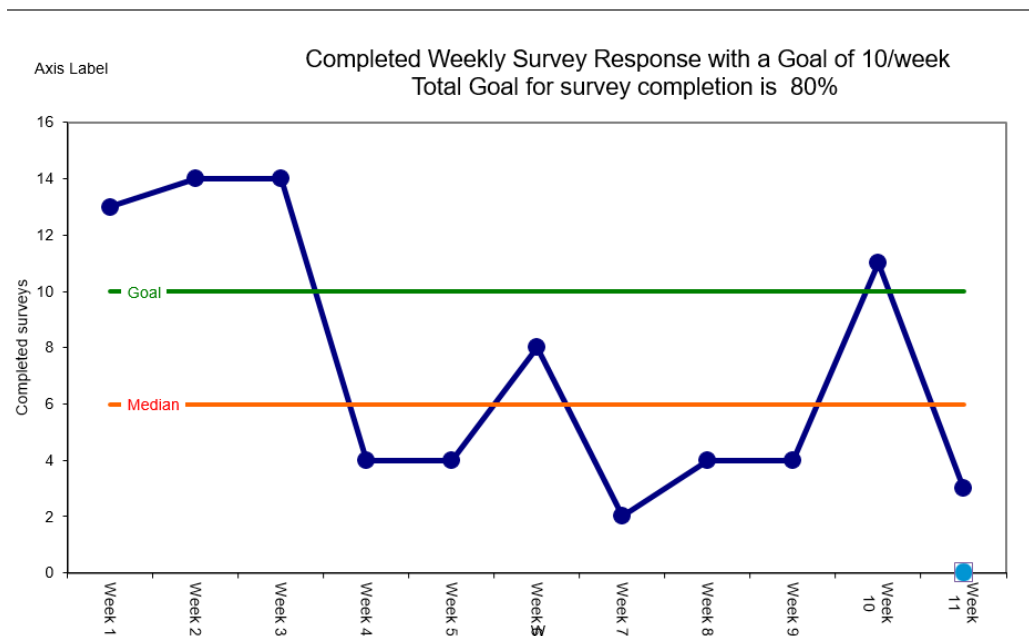
Not all data were consistent with the previous research conducted by Dhaliwal et al. (2021) and Zelber-Sagi et al. (2017). Dhaliwal's study on illness perception and its association with treatment willingness in patients newly diagnosed with NAFLD showed that a belief in the serious consequences of illness, a strong illness identity, and a higher perception of treatment control were significantly associated with the willingness to undergo comprehensive treatment for NAFLD. In this study, participants were willing to adhere to treatment recommendations despite low perceptions of cognitive and emotional dimensions of their fatty liver disease. Zelber-Sagi et al. (2017) assessed the relationship between illness perception, self-efficacy, and healthy lifestyle maintenance of NAFLD patients. They concluded that higher illness perception and higher self-efficacy were positively related to better nutritional habits.

### ***Process Measures***

The process measure of this project is the survey completion rates. An appropriate number of responses was one of the main goals of implementation. To get valid results, 80 responses were needed. Initially, the target goal for the survey completion rate was 100%, with the idea that these potential study participants, who were established patients at the clinic, would be willing to participate in the survey. However, the target goal was changed to 80%. Out of the 102 potential study participants, only 81 responses were completed. Incomplete survey responses were likely due to the participant closing the web browser without finishing the survey and not coming back to finish the survey within the allotted time frame. The sample size was assessed weekly during the implementation phase. The PDSA cycles were executed to improve respondents' rates. The goal for the completed survey response rate was 10 responses/week with

a total completion rate of 80%, which was achieved. A run chart is used to track response rates over time.

*Figure 10: Run Chart*



## Balancing Measures

There were no unintended challenging consequences associated with the DNP project. The project's potential benefit was the contribution to the development of NAFLD-tailored lifestyle interventions. The project will not only allow physicians to understand the illness perception of NAFLD patients to provide evidence-based patient-centered care, exploring illness perceptions can foster adequate communication that will allow patient and physician to engage in proper information exchange, decide on a treatment plan, and ensure treatment adherence. The project will also allow physicians to make an impact on the health illiteracy epidemic on NAFLD and improve the patient's understanding of their illness and outcomes.

## Recommendation and Discussion

### Economic and Cost Benefits

There is uncertainty around the economic burden of NAFLD. Because it can progress to a more serious condition if left untreated, it can result in higher utilization and cost of medical services (Younossi, 2019). In the United States, over 64 million people are projected to have NAFLD, with annual direct medical costs of about \$103 billion, averaging about \$1,613 per patient, and another \$188 billion in societal costs (Younossi, 2016). Knowledge about the cost of illness can help policymakers decide which diseases need to be addressed first by health care and prevention policies. The current lack of approved drug treatment for NAFLD and the shortage of organs for liver transplants emphasizes the need for comprehensive primary prevention measures to reduce the future health and economic costs associated with NAFLD (Younossi, 2016). Targeting lifestyle behavior change is imperative in the treatment of NAFLD for successful long-term outcomes. The survey shows that most participants have low cognitive and emotional perceptions about their illness. Their illness perceptions are important deterrents as well as determinants of their health-seeking behavior; therefore, effective interventions that change illness perceptions are needed to improve adherence to lifestyle modifications and reduce NAFLD's health and economic burden.

### **Healthcare Quality Impact**

The survey results indicated that most participants exhibited low literacy levels and low emotional perceptions about their fatty liver disease. Nguyen et al. (2021) found that low health literacy is associated with poorer access to care and health outcomes. A negative perception of illness is associated with poor adherence to treatment (Basu & Poole, 2016). The information obtained from this clinical inquiry will be used to plan high-quality patient-centered care and develop NAFLD tailored interventions to improve the health outcomes of patients in this GI clinic. Assessing knowledge of the disease, risk factors, willingness to adhere to treatment, and



potential areas for health literacy improvement will not only improve health outcomes, it can serve as preventative measures for disease progression and complications. This DNP project will therefore help attain the Triple Aim of the Institute of Healthcare Improvement, to improve the population health of NAFLD patients, to reduce the per capita cost of healthcare, and to improve the patients' experience of care. Organizations that attain these aims have healthier populations (IHI, 2021). NAFLD patients are at high risk for poor health outcomes because effective treatments depend to a large extent on behavioral change. Interventions that address unhelpful negative perceptions and low awareness of NAFLD can lead to better health outcomes in this population.

### **Policy Implication**

Healthcare professionals and policymakers tend to ignore patients' ideas and beliefs about their illnesses (Hallsworth, 2020). Data from the survey showed that most of the participants had low perceptions of their condition's cognitive and emotional domains. Patients' perceptions and beliefs of their illness are not static; they can be favorably modified by targeted interventions such as patient education courses to improve their health outcomes (Dhaliwal, 2020). Without adequate knowledge about disease and treatment perceptions among this population, building and implementing efficient and sustainable lifestyle modification programs can be challenging. Policymakers should support the development and promotion of sound scientific interventions based on patient's cognitive and emotional representations to bring out the maximum benefits of these programs (Dhaliwal, 2020). The information obtained from the survey will be used to guide professionals, providers, insurance payers, and policymakers towards NAFLD tailored patient-centered care in real-world practice.

### **Translation**

Data analysis from the survey provided a greater understanding of illness perception among patients with NAFLD. This information is crucial in planning effective and sustainable lifestyle interventions because treatment adherence is determined by patients' health beliefs and illness perceptions. NAFLD has become a common liver disease worldwide, and many patients are followed by clinicians other than gastroenterologists and hepatologists, such as cardiologists, endocrinologists, and primary care providers. Therefore, gastroenterologists and hepatologists should aim to establish clear and straightforward guidelines for the effective and sustainable treatment of NAFLD for non-specialists. This information will be used for evidenced-based training for providers to address barriers in the care management of NAFLD patients. It can also be translated to researchers who want to explore any chronic diseases' illness perceptions.

### **Sustainability**

The survey results and data analysis from this project has provided insight into future steps that will include the development of a Fatty Liver Clinic in the surrounding counties of North Central Arkansas. The clinic will offer point-of-care evaluation (e.g., elastography staging of disease), diagnosis, and evidence-based treatment plans that target lifestyle behavior change to improve patient health. The program will be supported by a multidisciplinary team of gastroenterologists and nurse practitioners, registered dietitians, and lifestyle coaches who will collaborate to provide more comprehensive care management than what is offered now in this GI clinic. It will provide a more personalized treatment plan to help patients adapt, maintain a healthy lifestyle, and improve their condition. Patient education courses will be offered to enhance awareness and knowledge of the disease and its consequences.

### **Dissemination**

This study provides critical information that can be used and disseminated among key stakeholders, primary care providers, specialists, and other clinicians who follow patients with NAFLD. The clinical inquiry project aimed to improve the care management of patients who have CHC with a new diagnosis of NAFLD by understanding their perception of illness and willingness to adhere to treatment. Research has highlighted a discordance between published guidelines and clinical practice in managing NAFLD, and a gap remains between the recommended clinical care behaviors and actual care delivery (Hallsworth, 2020). The role of illness perception has received little attention, particularly in the treatment of NAFLD. It is important to disseminate the results of my project because by understanding patients' perceptions of their illness, better ways of implementing lifestyle interventions can be developed. Studies have shown that favorable illness perceptions are associated with better health outcomes, while unfavorable illness perceptions are associated with worse outcomes (Sawyer, 2019). Data from the survey showed that most participants have low perceptions of timeline, consequences, concerns, personal and treatment control, and identity of their illness, which poses a significant challenge for both patient and provider in managing the disease. Therefore, this study can serve as a model for other studies seeking to identify what domains of illness are associated with greater willingness to treatment adherence and studies that assess the effectiveness of interventions to change illness perception.

The survey results and data analysis will be presented to the DNP committee, the staff and providers of the gastroenterology clinic, the University of Arkansas, and the Eleanor Mann School of Nursing in April 2022. I will also attend the research poster presentation on May 13, 2022, at the University of Arkansas Union Hall in Fayetteville, Arkansas. I want to present my poster at the annual conference of the Arkansas Nurse Practitioner Association and the Baxter

County Health Fair in Mountain Home, Arkansas, to increase awareness of NAFLD among the general population.

### **Professional Reporting**

Dissemination of results and data analysis from the survey will be shared among the healthcare community in North Central Arkansas. Plans for possible publication include submission to the *World Journal of Gastroenterology, Digestive Diseases and Sciences*, or the *Journal for Nurse Practitioners*. The first two selected journals have previously published research on illness perception in lifestyle modifications among NAFLD patients. *The Journal for Nurse Practitioners (JNP)* has published high-quality, peer-reviewed clinical articles and original research that helps practitioners excel as providers of primary and acute care across the lifespan. It is included in Scopus, CINAHL, and the Journal Citation Reports. The *JNP* supports advocacy by demonstrating the role that policy plays in shaping practice and delivering outcomes. Topics on NAFLD and its implications for clinical practice, health promotion, and evidenced-based management have been included. These scholarly publications are appropriate outlets to include in the dissemination process.

### **Strength and Limitation**

The primary strength of the study was its high survey response rate, 80% of the identified potential participants completed the survey. Participants were willing to participate in the study because they had established rapport with me when they were treated for their CHC. To my knowledge, this is the first study to explore the perception of illness and its association with willingness to adhere to treatment among CHC patients who had incidental findings of NAFLD. The data on the perception of illness were collected using the BIPQ. The validated and time-

tested instrument has been demonstrated to have appropriate psychometric properties to explore the various chronic diseases' cognitive and emotional representation.

Although attempts were made to ensure a strong study design, there are a few recognized limitations. The diagnosis of NAFLD was based on the findings from transient elastography. The technical limitations of this test can preclude its use in individuals who are morbidly obese and patients who have large amounts of chest wall fat. In these groups, the results may not be reliable. Although the current gold standard for diagnosing NAFLD/ NASH is still by liver biopsy, it also has several limitations. In addition to being invasive, sampling error, inter-observer and intra-observer variability were also identified. Evidence suggests that ultrasound is a suitable method for detecting patients with liver steatosis, obviating liver biopsy and Fibroscan (Kamali et al., 2019).

Another limitation of the study is the lack of diversity among participants. Research participants should reflect the diversity of culture and conditions, taking into account race, ethnicity, gender, economic status, and age. The lack of diversity among research participants can impede the ability to generalize study results (Palmer & Burchard, 2022). Majority of the participants in this study were females, Caucasians, had low socioeconomic status, and were older than 50 years old. It has been known that there are social and ethnic differences in illness perception (Dhaliwal, 2021); therefore, the causality and the direction of the association in this study cannot be established and ascertained. More studies would be required in different ethnic populations to validate my findings externally.

### **Conclusion**

This project has provided insight into improving the care management of patients with CHC who are newly diagnosed with NAFLD. Although pharmacological agents are being tested

in clinical trials for their ability to reverse the effects of fatty liver, lifestyle modifications focusing on dietary changes and exercise targeted towards weight loss remain the only effective therapy. Despite the compounding evidence supporting lifestyle interventions in the management of NAFLD, many patients struggle with implementing and maintaining these recommendations. Provisions of evidence-based lifestyle behavior change interventions are needed. Based on this study, health literacy, illness perception, and awareness of the disease seem to drive their health behaviors. Interventions targeting patients' knowledge and their emotional responses to illness can motivate them to take specific health behavior (Dhaliwal et al., 2021). Although the data demonstrated low levels of illness perception among the participants, it was not directly associated with willingness to adhere to treatment. Participants were willing to adhere to therapy despite their lack of knowledge and awareness of their diagnosis and their low perceptions of their disease's cognitive and emotional representation. Patients' perceptions of illness are not fixed and can be modified by raising awareness of the disease to improve treatment outcomes. I would advocate for a Fatty Liver Disease program that will offer patients educational courses to improve health literacy and personalized treatment plans tailored to their perceptions to help them adapt and maintain a healthy lifestyle. These recommendations aimed at policymakers and practitioners who design and implement models of care can help address the increasing need for good practice care for patients with NAFLD. Future research should aim to identify optimal behavioral strategies that can increase low levels of illness perception to improve patients' adherence to lifestyle modifications.

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## Appendix A

### Global Aim

College of Education and Health Professions  
*Eleanor Mann School of Nursing*

#### Write a Theme for Improvement:

The care of patients with non-alcoholic fatty liver disease

#### Global Aim Statement

Create an aim statement that will help keep your focus clear and your work productive:

We aim to improve:

The care management of patients with Non-alcoholic Fatty liver disease across culture.  
 (Name the process)

In:

Baxter Regional Medical Center Gastroenterology Clinic  
 (Clinical location in which process is embedded)

The process begins with: exploring the health beliefs and perspectives of patients with NAFLD  
 (Name where the process begins)

The process ends with evaluating and analyzing of patients' responses to understand their perception of their disease, the severity, and barriers related to their health behavior so their management could be tailored to their personal needs.

(Name the ending point of the process)

By working on the process, we expect: Patients to be more engage in the recommended lifestyle modifications for treatment of NAFLD.  
 (List benefits)

It is important to work on this now because:

The cornerstone therapy for NAFLD is lifestyle modification and in order to engage patients to this, an understanding of the health belief of their illness is a key factor that could influence their health behavior.

#### Create Flowchart

#### Specific Aim Statement

We will: Improve

The quality of care given to patients with NAFLD by the providers of BRMC Gastroenterology Clinic by understanding the patients' health beliefs and perspectives of their illness measured by improvement or resolution of their fatty liver.

From: \_\_\_\_\_  
 (baseline state the number/amount/percentage)

To/By: \_\_\_\_\_  
 (describe the change in quality or state the number/amount/percentage)

By: March, 2022  
 (Date)



## Appendix B

### Evidence Table

Author	Y E A R	Coun try	Theo- ry guiding the study	Indepen dent variable	Depen dent Variable	Resear ch Design	Sam ple Metho d (n)	Data collec tion process	Brief Summary or results	Stren- gth of eviden ce
Beckwith, V., & Beckwith, J.	2020	US	Motivational interviewing. A collaborative communication style to improve conversations and serve as a catalyst for behavior change	NA	NA	NA	NA	NA	MI is both a treatment philosophy and a set of methods employed to help people increase intrinsic motivation by exploring and resolving ambivalence about behavioral changes	NA
Broadbent et al.	2015	US	Health Belief Model. The use and performance of the Brief Illness Questionnaire	None	The BIPQ's concurrent validity, predictive validity, sensitivity to change, discriminant validity and mean scores for different populations	Systemic review and meta-analyses	188 articles	Electronic database search	The Brief IPQ is widely used and has good psychometric properties	Level I

Burnham, B., et al	2015	US	Health Belief Model. Perception of illness susceptibility, threat, benefits and barriers to care among patients with Chronic liver disease	No treatment variable	Knowledge, attitudes behaviors and barriers to care	Qualitative study	13 focus groups	Interview lasting 60 minutes. The moderator utilized response reflection and natural inquiry	Their findings reveal the utility of the Health Belief Model as an exploratory lens for understanding perceived causes susceptibility prevention and attitude related to CLD	Level III
Dhalwal, H. et al.	2021	US	Health Belief Model. Illness perception and association with treatment willingness	Illness perception	Willingness to treat	Cross Sectional Study	264 patients	Survey	A belief in serious consequences, a strong illness identity, and high perceived treatment control were significantly associated with willingness to undergo treatment	Level IV
Dobber, J. et al.	2019	Netherlands	Motivational Interviewing	Motivational Interviewing	Increase intrinsic motivation of patients with CAD	Before and after study of a learning strategy	24 nurses	Audio recorder conversation	A 1 year follow-up on Mo-Int workshop with feedback and coaching improves motivational skills of nurses	Level III
Katsogianni, C. et al.	2020	Greece	Lifestyle interventions remain	Lifestyle intervention with	Liver Function outcomes	Meta-analyses	20 RCTs	Literature from Scopus	Exercise alone or combined	Level II Low

	16		the cornerstone therapy for NAFLD. This study investigate the effect of Mediterranean diet, Mediterranean lifestyle along with weight loss in NAFLD patients	diet and exercise				and US National Library of Medicine	with dietary intervention improves serum level of liver enzymes and liver fat or histology	quality insufficient sample size
Mazotti, A. et al.	2018	Italy	Interventions aimed at lifestyle changes are pivotal for the treatment of NAFLD and web based programs might help remove barriers in both patients and therapist	Motivational interviewing and group-based intervention or web based intervention	Primary: Weight loss 10% or greater Secondary: ALT within normal limits, changes in style, weight, weight. Surrogate markers of steatosis and fibrosis	Quasi experimental not randomized	Group based intervention n=438 Web based intervention N=278	Interview	The study shows that by following a structured approach, a web based interactive intervention coupled with a 6 month face to face meetings is not inferior to a standard group based intervention	Level II
Mlynarsky, L. et al.	2016	Israel	Health Belief Model. Perception Illness of NAFLD	NAFLD	General Health perception	Cross sectional and prospective follow-up	N=349	Survey	Fatty liver without clinically significant liver disease does not have independent impact on self-	Level IV

									health perception	
Nouredin, M. et al	2018	US	To determine steatosis and fibrosis prevalence in Hepatitis C patients after sustained virological response achieved with direct acting antiviral	Hepatic Steatosis and fibrosis	Hepatitis C antiviral treatment	Prospective cross sectional study	N=101 patients	After achieving an SVR, patients were invited to undergo standardized history and anthropometric examination, laboratory testing and transient elastography	There is a high prevalence of fatty liver with continuing fibrosis in patients with steatosis despite normalization of liver enzymes after antiviral treatment. Therefore, post SVR assessment of steatosis and fibrosis in those with abnormal BMI or risk factors typical of NAFLD is recommended	Level IV
Nourian, M.	2020	Iran	Health Belief Model is one of the best framework to inform the development of interventions to improve health behaviors	Educational intervention on lifestyle modification based on the HBM	Health Belief Model variables and knowledge. Liver enzymes and liver steatosis	Parallel randomized control trial	N=82 patients	Patients were recruited and allocated to intervention or the control group. After 2 months of intervention, HBM variable	This HBM-based lifestyle modification on education could be effective not only in the HBM domains but also in the improvement of NAFLD	Level II

								were assessed with questionnaire. Liver enzymes and sonographic findings were measured	parameters.	
Ozawa, N. et al	2020	Japan	Health Belief Model. Individual perception of health	NAFLD	Quality of Life and Illness uncertainty	Cross sectional study	N=168 NAFLD patients	Survey	Patient who progress from NAFLD to cirrhosis and liver cancer have disease uncertainty. Patients with chronic Hepatitis C and advance liver disease have higher level of uncertainty associated with lower levels of QOL.	Level IV
Sawyer, A. et al.	2019	US	Health Belief Model	Illness Perception	Health outcome	Quantitative Methodology, systematic review	31 studies	A search of MEDLINE via PubMed PsycINFO, and CINAHL was conducted.	Review showed that favorable illness perception has been associated with better health	Level I

									outcomes, while unfavorable illness perception has been associated with worse outcomes.	
Tiemsma, J, et al.	2016	Netherlands	Health Belief Model	Illness perception	Quality of Life	Qualitative study	N=100 patients	Survey/ Questionnaire	Patients with better understanding of COPD utilized more proactive coping strategies. A self-management intervention targeting patients' illness perceptions leads to improved QOL.	Level V
Ubaidi, A.	2017	Kingdom of Bahrain	Motivational Interviewing. Applying the principles and essence of MI in everyday primary care practice	Motivational Interviewing	Adherence to recommended lifestyle modification for NAFLD	Qualitative study	1 patient case study	Interview	Using the MI style of communication to enhance adherence to recommended lifestyle modification for NAFLD will seek to uncover an individual's internal motivation	Level IV

									n to changes by focusing on their strength and desired change, rather than advising them what's best	
Vaske,	2017	Germany	This study investigated the effects of illness perceptions and coping with disease on health-related quality of life in chronic obstructive pulmonary disease.	Illness perception and coping with disease	Health related Quality of life	Qualitative research	N=444	Survey questionnaire	It is concluded that in order to prevent decreasing health-related quality of life in chronic obstructive pulmonary disease, treatment may be adjusted by promoting coping with disease and functional illness perceptions.	Level IV
Zelber-Sagi, et al	2017	Israel	Health Belief Model Role of Illness perception	NAFLD patient's perception of illness	Nutritional habits and healthy lifestyle	Cross sectional study	N=87 patients	Survey	Higher perception of understanding illness and higher self-efficacy are positively related to	Level IV

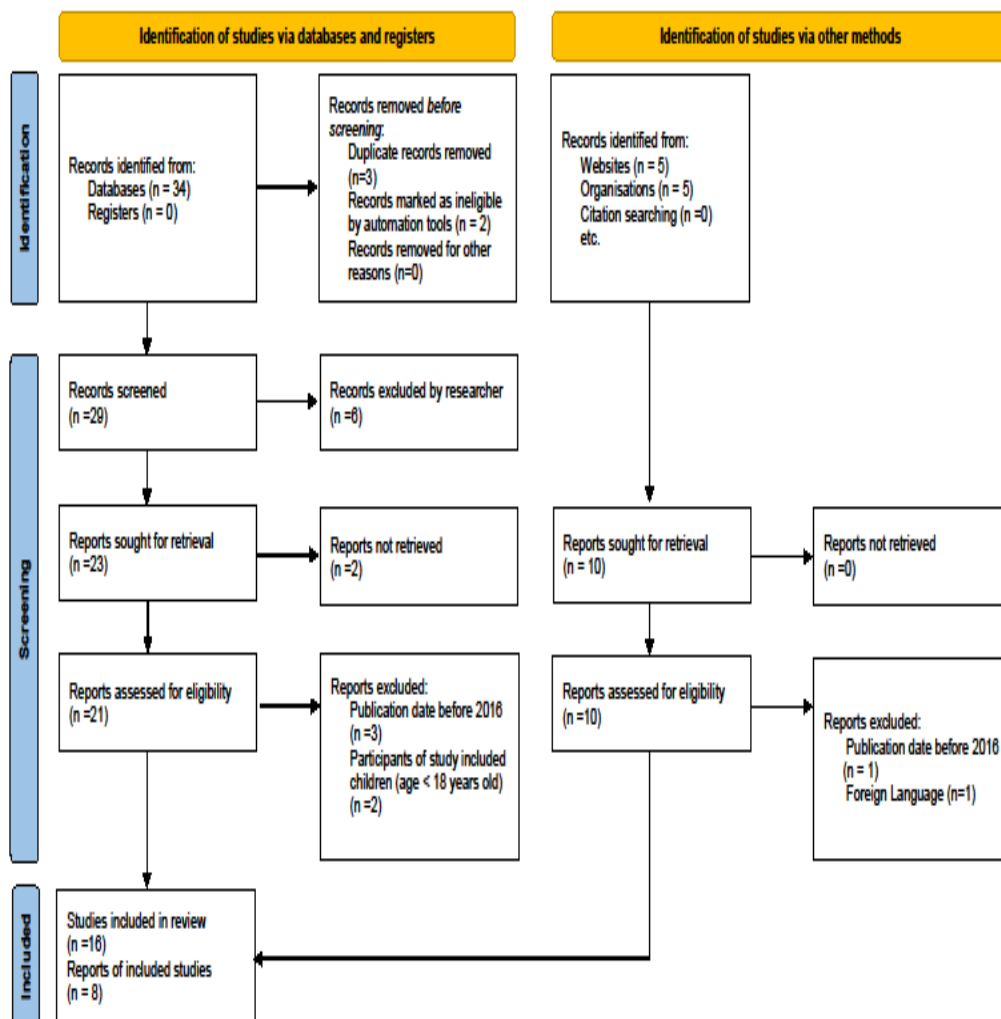
									better nutritional habits	
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## Appendix C

### PRISMA Flowchart

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources



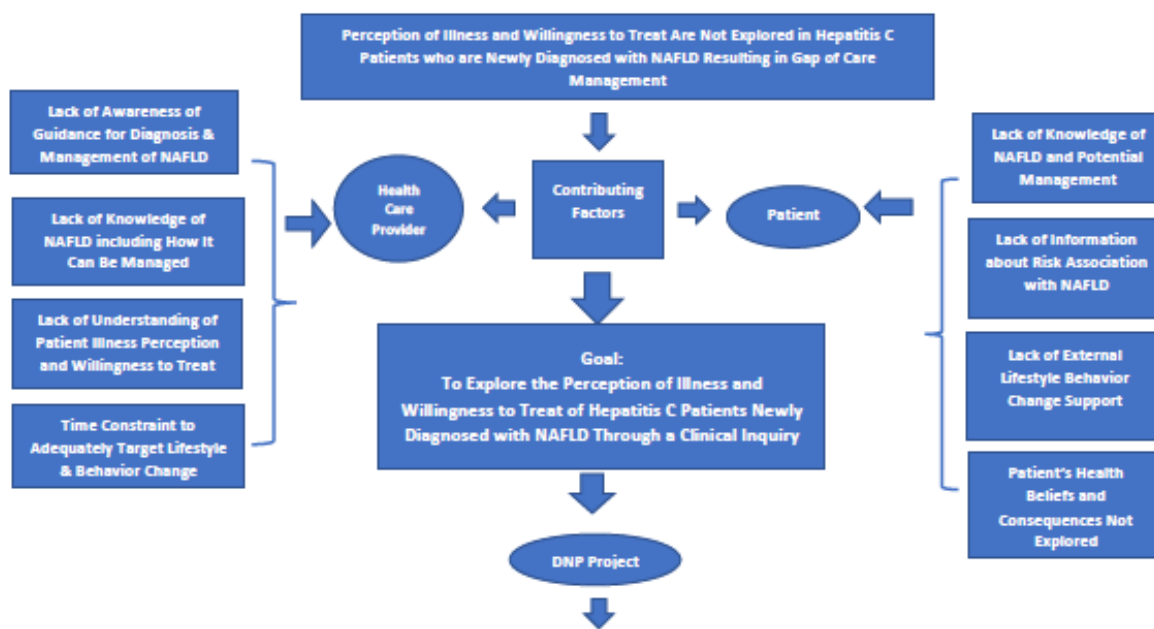
\*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/register).

\*\*If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

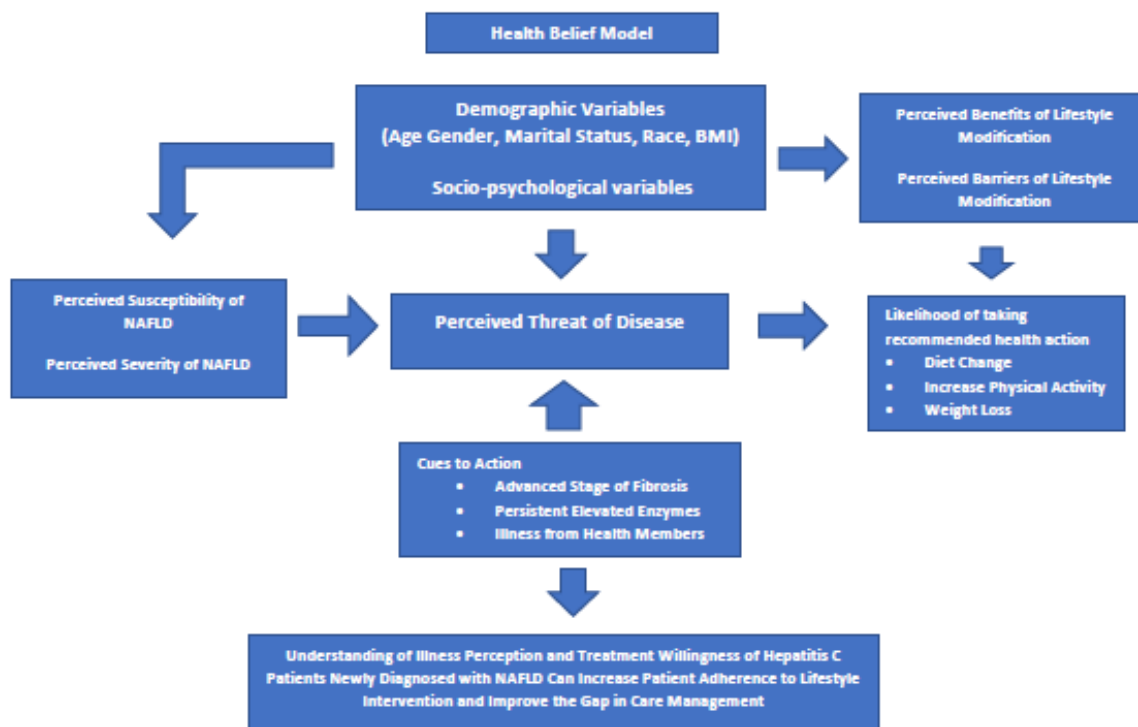
From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: <http://www.prisma-statement.org/>

## Appendix D

### Concept Map



### Theoretical Framework



### Expected Outcome

**Understanding of Illness Perception and Treatment Willingness of Hepatitis C Patients Newly Diagnosed with NAFLD Can Increase Patient Adherence to Lifestyle Intervention and Improve the Gap in Care Management**

## Appendix E

### Recruitment Telephone Script

Hello \_\_\_\_\_,

My name is Carmel Kruse, and I am a student at the University of Arkansas' Doctor of Nursing Practice program in Fayetteville. I am working with the Eleanor Manning School of Nursing on conducting a survey to investigate the health beliefs and perception of illness of patients with Chronic Hepatitis C diagnosed with nonalcoholic fatty liver disease at our clinic, Baxter Regional Gastroenterology Clinic. The survey is focusing on your understanding of the illness, such as how you would describe the illness, the cause, consequences, cure, timeline on how long you think the disease will last, and how you think you can control or recover from it. The survey will also ask for your body mass index (BMI) and the scores obtained from the Fibroscan. You can obtain this information in the diagnostic imaging category of your medical records through your patient portal. If you have not set up for this, I can give you this information now. The survey should take approximately 30 minutes and will provide our clinic with valuable insight on how we can improve the care management and health outcomes of our patients such as yourself. I will be sending you an email to ask for your consent and to access the survey questionnaire if you agree to participate. I will need to verify your email address. Your participation would include completion of a survey on your background information and a brief illness perception questionnaire. Your information will be kept anonymous and results will only be shared with no identifiable information. Participation is voluntary. Refusing to participate will not adversely affect any other relationship with the University, the researcher, or Baxter Regional Gastroenterology Clinic.

Principal Investigator

Contact Information:  
Carmel Kruse  
University of Arkansas Eleanor Mann School of Nursing  
606 N. Razorback Road  
1-870-421-0010

Co-Investigator/Faculty Chair

Dr. Allison Scott  
University of Arkansas Eleanor Mann School of Nursing  
606 N. Razorback Road  
1-479-575-3761

## Appendix F

### Consent Form

#### PRINCIPAL INVESTIGATOR

Carmel Kruse  
University of Arkansas Eleanor Mann School of Nursing  
606 N. Razorback Rd.  
1-870-421-0010  
[ckruse@uark.edu](mailto:ckruse@uark.edu)

#### FACULTY ADVISOR

Dr. Allison Scott  
University of Arkansas Eleanor Mann School of Nursing  
606 N. Razorback Rd.  
1-479-575-3761  
[Als002@uark.edu](mailto:Als002@uark.edu)

#### PURPOSE OF PROJECT

You are being asked to take part in a DNP project. Before you decide to participate in this project, it is important that you understand why the project is being done and what it will involve. Please read the following information carefully. Please ask the principal investigator if there is anything that is not clear or if you need more information.

The purpose of this project is to survey the health beliefs and illness perception of Chronic Hepatitis C patients who have nonalcoholic fatty liver disease (NAFLD) at Baxter Regional Gastroenterology Clinic.

The project's aim is to develop more knowledge and understanding of the health beliefs and illness perception of Chronic Hepatitis C patients with NAFLD to improve the care management and health outcomes by planning high quality patient-centered care and implementing effective NAFLD-tailored lifestyle interventions.

#### PROJECT PROCEDURE

Participation in on-line survey.

#### RISK

- Risk I participation this survey is limited. A loss of confidentiality of data will be limited through protected data software.

#### BENEFITS

Benefits to participating in this survey include:

- Contributing to furthering the knowledge and understanding of the health beliefs and illness perception of Chronic Hepatitis C patients to develop NAFLD-tailored lifestyle interventions.
- Identifying barriers and facilitators in the management of NAFLD to improve health outcomes
- Opportunity to reflect on your understanding about the disease and treatment of NAFLD

## **CONFIDENTIALITY**

Your responses to the survey will be anonymous. Please do not include any identifying information on your survey. The principal investigator will keep data in a computer that is password-protected. Any identifying participant information will be secured in a data-encrypted file within the computer belonging to the principal investigator. All information collected will be kept confidential to the extent allowed by law and University policy. This includes, but is not limited to, cases where the principal investigator is legally obligated to report specific incidents such as abuse or suicide risk.

## **CONTACT INFORMATION**

If you have questions at any time about this project, or you experience adverse effects as the result of participating in this project, you may contact the principal investigator, whose contact information is provided on the first page. If you have questions regarding your rights as a study participant, or if problems arise which you do not feel you can discuss with the principal investigator, please contact the University of Arkansas Institutional Review Board at 479-575-2208.

## **VOLUNTARY PARTICIPATION**

Your participation in this project is voluntary. It is your decision whether or not to take part in this project. After you agree to participate, you are still free to withdraw at any time and without giving a reason. Withdrawing from this survey will not affect the relationship you have, if any, with the principal investigator or clinic. If you withdraw from the survey before data collection is completed, your data will be destroyed.

## **CONSENT**

I have read and I understand the provided information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without cost.

Please provide your consent to participate:

	Yes	No
I consent to participate	[ ]	[ ]

## Appendix G

### Survey Question

#### Demographics

What is your age?

- (21-29)
- (30-39)
- (40-49)
- (50-59)
- (60-69)
- Over 70
- Prefer not to say

What is your gender?

- Male
- Female
- Prefer not to say

What is your level of education?

- No formal education
- High School
- College/University
- Graduate School
- Prefer not to say

What is the level of your annual income?

- Less than \$25,000
- \$25,000 to \$49,000
- \$50,000 to \$99,000
- \$100,000 to \$200,000
- More \$200,000
- Prefer not to say

What is your ethnic background?

- White/Caucasian
- African American
- Hispanic
- American Indian
- Mixed race
- Other





7. How well do you feel you understand your liver condition?

0      1      2      3      4      5      6      7      8      9      10  
 Don't understand      Understand very  
 at all      clearly

8. How much does your liver condition affect you emotionally (e.g. does it make you angry, scared, upset or depressed)?

0      1      2      3      4      5      6      7      8      9      10  
 Not at all      Extremely affected  
 affected emotionally      emotionally

Please list in rank-order the three most important factors that you believed caused your liver condition

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

Are you willing to adhere to treatment recommendation for NAFLD?

Yes \_\_\_\_\_ No \_\_\_\_\_

Anthropometric Measurements

Height \_\_\_\_\_

Weight \_\_\_\_\_

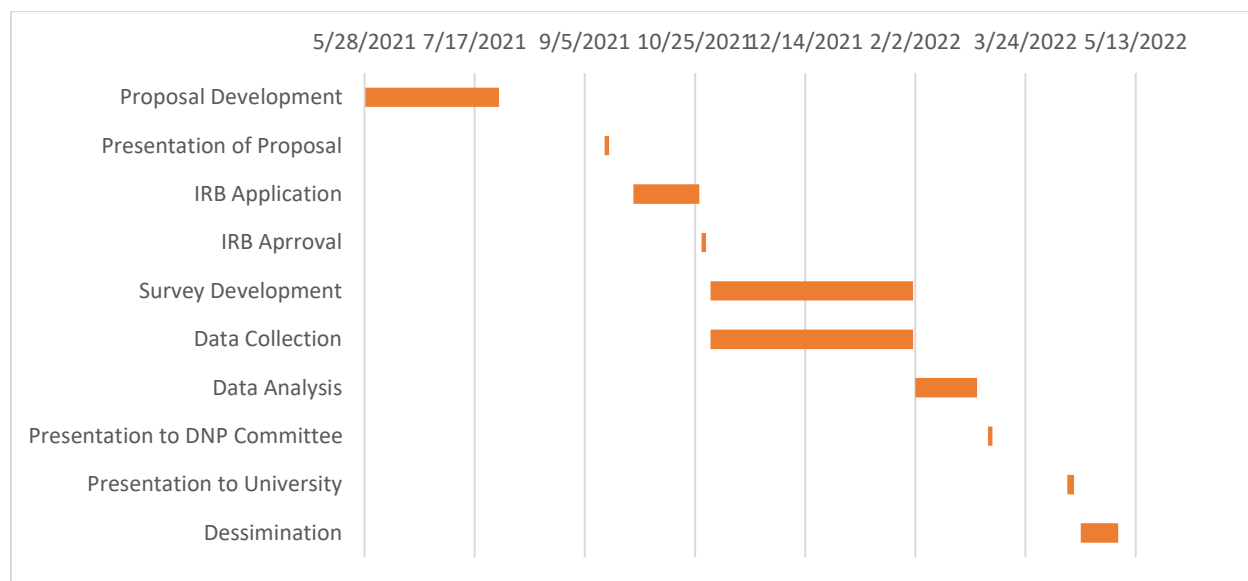
BMI \_\_\_\_\_

Steatosis Score (CAP) \_\_\_\_\_

Fibrosis Score (kPa) \_\_\_\_\_

## Appendix H

### Proposed Gantt Chart



## Appendix I

### Letter of Support

September 8, 2021

RE: DNP Project-Illness perception and its association with willingness to adhere to treatment among Chronic Hepatitis C patients with a new onset of Non Alcoholic Fatty Liver Disease.

Dear Carmel Kruse

As the office manager of Baxter Regional Gastroenterology Clinic, I have read your research proposal; I support the involvement of our Gastroenterology clinic in this project, and look forward to working with you.

Sincerely,

  
Jennifer Helms, office manager

Bodunrin S. Badejo, MD | William S. Dyer, MD | Peter A. MacKercher II, MD  
William G. Silber, MD | Carmel Kruse, APRN, FNP-BC  
228 BUCHER DRIVE, MOUNTAIN HOME, AR 72653  
PHONE (870) 425-4416 | FAX (870) 425-8615 | [www.baxterregional.org](http://www.baxterregional.org)



**BRMC Gastroenterology  
& Advanced Imaging**

## Appendix J

### Approval to Use BIPQ



---

**Date:** Wednesday, September 8, 2021 2:29 AM  
**From:** Elizabeth Broadbent <e.broadbent@auckland.ac.nz>  
**To:** Carmel kruse <carmelkruse@suddenlink.net>  
**Subject:** Re: Request to use the The BIPQ

---

Dear Carmel

Yes you may use it for your study,

Kind regards  
Liz

> On 8/09/2021, at 4:50 PM, Carmel kruse <[carmelkruse@suddenlink.net](mailto:carmelkruse@suddenlink.net)> wrote:  
>

> Good day. I am a student of a DNP program at the University of Arkansas In Fayetteville here in the US. My project's title is The perception of illness and it's association with treatment willingness among patients with chronic hepatitis C who are newly diagnosed with NAFLD." I have been trying to find where I can ask permission to use the BIPQ or is it public domain? If it has a copyright may I ask your permission to use it for my research survey? Thank you for your assistance on this matter.

> Carmel Kruse MSN FNP BC

> My number is (870) 421-0010

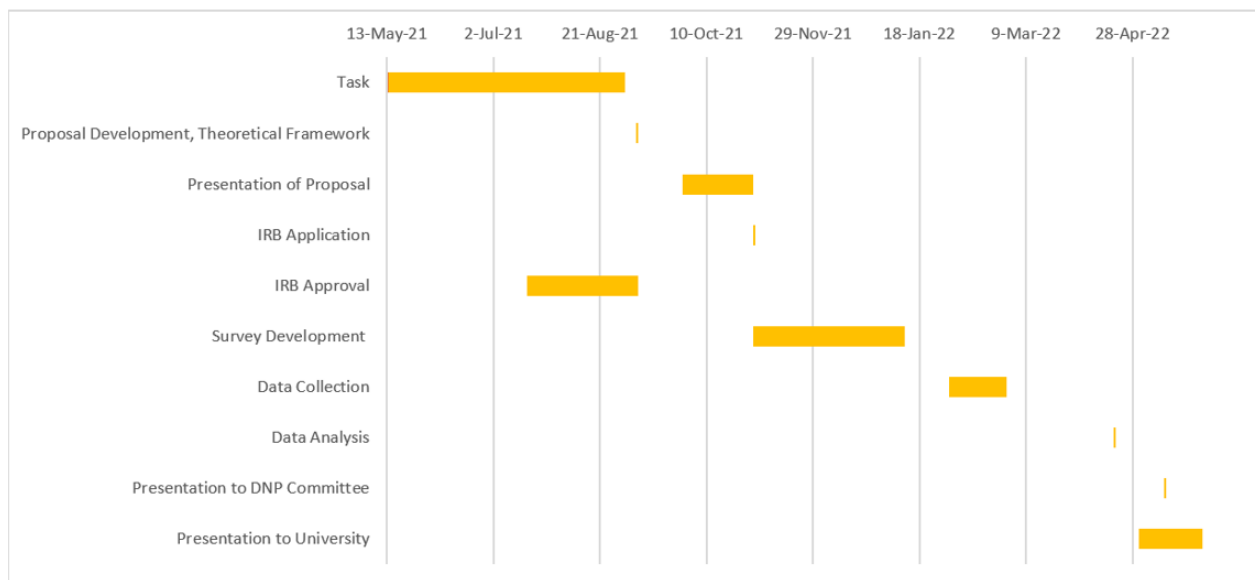
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## Appendix K

### Revised Gantt Chart



## Appendix L

### Implementation Table

Dates	Description	Modifications	Intervention
July 18, 2021 – September 8, 2021	The BIPQ was used to inquire patients perception of illness about NAFLD. Permission to use the questionnaire was granted by Dr. Elizabeth Broadbent. Demographic and anthropometric questions created	In the BIPQ, instead of using the word “illness”, fatty liver condition was used for clarity of question as recommended Dr. E. Broadbent	Development of Survey
September 29, 2021 November 1, 2021	Project proposal submitted to IRB	Specific minor revisions were required by IRB, and resubmitted	IRB determination and approval
August 1, 2021 to August 31, 2021	Eligible participants were identified and obtained from eClinicalWorks, the clinic’s EHR	Chart review was started earlier than anticipated	Identification of eligible respondents
November 1, 2021	Two patients completed the survey in the clinic, no technological glitches were noted	No changes were made in the survey questionnaire	Small pilot survey conducted
November 1, 2021	After participants were recruited by phone, survey was disseminated through email. For participants without email accounts, the survey was conducted at the clinic or by phone	Recruitment of participants was to be conducted in the evening during the week. The goal was to recruit 25 patients per week and obtain 10 completed surveys. Recruiting on Wednesdays was discontinued because patients were not	Initiation of survey implementation

		answering their phone	
November 7, 2021 – January 11, 2022	Weekly surveillance was conducted to monitor response rate	Reminders were sent through email and telephone calls. For patients who did not respond to these reminders, the survey was offered in the clinic during their scheduled clinic visit	Monitoring of respondents
February 7, 2022	Descriptive analysis of data from survey was presented to the staff and providers using visual displays such as histogram and pie chart	Only descriptive analysis was presented, inferential analysis was not performed yet. Collaborating with SMSS for inferential analysis tutorial session.	Collaboration with clinic provider and staff to share descriptive analysis of data obtained from the survey

## Appendix M: PDSA Cycle

PDSA Cycle # 1		
Objective: There were 102 eligible patients for the study. The objective is to recruit 25 patients a week by phone and attain a 100% participation rate		
Change Idea: Begin recruitment of participants and disseminate survey questionnaire by email		
	Person Responsible	Due Date
Plan: Start survey recruitment by phone to explain the purpose of the study, how long the survey will take, and how their feedback will be used. The plan was to recruit 5 patients in the evening during the week and have participants return completed surveys.	Carmel Kruse (PI)	November 1, 2021
Do: Survey was disseminated by email through Qualtrics to patients who agreed to participate	PI	
Study: Recruited only 20 participants from November 1, 2021 to November 5, 2021 instead of anticipated 25. Unable to recruit on Wednesday as patients were not answering their phone, most probably because of church services. Conducted a review of the survey response from this week, 10 completed responses were received.	PI	November 5, 2021
Act: Send reminders using Qualtrics mailer and monitor response by November 14, 2021	PI	November 14, 2021
PDSA Cycle # 2		
Objective: To attain a 100% participation among recruited patients from November 6 to November 19, 2021.		
Change Idea: To increase survey response rate		
	Person Responsible	Due Date
Plan: Use Qualtrics mailer to send reminders to enrolled participants; conduct survey through anonymous link or on site to enrolled participants who do not have an email account.	Carmel Kruse (PI)	November 14, 2021
Do: Send reminders from November 7, 2021 to November 14, 2021 to 20 enrolled participants who did not start the survey and call 8 enrolled participants who do not have email accounts to conduct survey by phone; and conduct survey on site to 2 participants during their clinic visit.	PI	
Study: Reminders sent using Qualtrics mailer from November 7, 2021 to November 14, 2021, 7 more participants completed the survey and 3 more just started the survey but did not finish. 10 more participants who did not have an email account completed the survey through anonymous link.	PI	
Act: Will check Qualtrics survey response rate on November 21, 2021 to send reminders again to participants who did not start the survey in order to increase survey participation.	PI	November 21, 2021



PDSA Cycle #3		
Objective: To attain 100 % participation among recruited patients from November 21 to November 27, 2021.		
Change Idea: To increase survey response rate		
	Person Responsible	Due Date
Plan: Use Qualtrics mailer to send reminders to enrolled participants and call those who did not respond despite 2 reminders sent; conduct survey through anonymous link or on site to enrolled participants who do not have an email account.	Carmel Kruse (PI)	November 27, 2021
Do: Send reminders on November 27, 2021 to 25 participants who have not completed the survey. Call participants who did not respond to 2 reminders and conduct survey through anonymous link if participants don't have email account.	PI	
Study: Reminders sent using Qualtrics mailer November 27, 2021, only 1 more participant completed the survey, I called participants who already received 2 reminders and still did not respond, the reasons given were they were busy during the Thanksgiving holiday week or they never received the email reminder. Qualtrics did not show any emails sent that bounced. Another reason, one participant decided not to consent to the survey after he received the web.	PI	
Act: Will check Qualtrics survey response rate on December 3, 2021 and send reminders again in order to increase survey participation. I will continue to recruit newly referred Hepatitis C patients with hepatic steatosis diagnosed through the Fibroscan to increase research sample size.	PI	December 3, 2021

PDSA Cycle # 4		
Objective: Decrease goal for participation rate from 100% to 80%		
Change Idea: Some potential participants were not reachable by phone for recruitment, 100% participation rate was not achievable		
	Person Responsible	Due Date
Plan: Change participation target goal to 80%. Continue recruiting eligible participants who are newly referred to the clinic.	Carmel Kruse (PI)	January 1, 2022
Do: Recruited new patients referred to the clinic who met the inclusion criteria for the study	PI	
Study: New eligible patients consented to participate in the survey, 11 more completed surveys were obtained from January 2, 2022 to January 8, 2022	PI	January 11, 2022
Act: Survey will be closed if 80 survey responses is obtained by January 15, 2022	PI	January 15, 2022

## Appendix N

### BIPQ Form

For the following questions, please circle the number that best corresponds to your views:

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How much does your illness affect your life?	0	1	2	3	4	5	6	7	8	9	10
no affect at all											severely affects my life
How long do you think your illness will continue?	0	1	2	3	4	5	6	7	8	9	10
a very short time											forever
How much control do you feel you have over your illness?	0	1	2	3	4	5	6	7	8	9	10
absolutely no control											extreme amount of control
How much do you think your treatment can help your illness?	0	1	2	3	4	5	6	7	8	9	10
not at all											extremely helpful
How much do you experience symptoms from your illness?	0	1	2	3	4	5	6	7	8	9	10
no symptoms at all											many severe symptoms
How concerned are you about your illness?	0	1	2	3	4	5	6	7	8	9	10
not at all concerned											extremely concerned
How well do you feel you understand your illness?	0	1	2	3	4	5	6	7	8	9	10
don't understand at all											understand very clearly
How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)	0	1	2	3	4	5	6	7	8	9	10
not at all affected emotionally											extremely affected emotionally

Please list in rank-order the three most important factors that you believe caused your illness.

The most important causes for me:-

1. \_\_\_\_\_
  2. \_\_\_\_\_
  3. \_\_\_\_\_
-