WHAT CAN WE LEARN FROM PAIN NARRATIVES?

AN INVESTIGATION OF THE ETHICAL GAPS IN THE TREATMENT OF PATIENTS WHO SUFFER FROM CHRONIC NON-CANCER PAIN THROUGH THE PERSPECTIVE OF PATIENT NARRATIVES

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ABSTRACT

What Can We Learn from Pain Narratives?

An Investigation of The Ethical Gaps in The Treatment of Patients Who Suffer from Chronic Non-Cancer Pain Through the Perspective of Patient Narratives

Doctor of Medical and Health Humanities Dissertation by

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Chronic Pain effects 20% of the adult US population. Those afflicted with chronic pain are not treated the same. The World Health Organization designated the alleviation of pain a human right in 1995. Adults suffering from chronic non cancer pain receive unequal treatment due to a variety of factors. These factors are determined by a variety of sources intrinsic to the individual. These sources include demographics, cultural and societal norms that each participant personally brings to bear. Factors explored in this project include the normal demographics and the lives of the participants and how they relate to the pain treatment regimens that help get them through the day. In this study we saw that all participants did have adequate insurance which did not impede their ability for treatment or ability to try multimodal techniques for pain relief. Spirituality played a role for many in helping to alleviate some aspects of pain and to help the participants make it through the day. There were not any members of this surveyed population who were below the Federal Poverty Level, and all participants had the ability to travel for treatments, although there were times when this was difficult, not due to resources but due to the constraints of pain. A statistically relevant finding was that married men do

have a better quality of life and less pain than married women or single men or women. The COVID pandemic, which was ongoing when this survey took place, did make treatment less available but participants were able to manage to access what was necessary to abate the more severe symptoms of pain.

The most disturbing outcome of the COVID-19 crisis for my participants was the continued disruption of medication for patients due to the opioid crisis and supply chain issues. Many participants had their doses reduced and consequently less pain control since 2016 when the new CDC guideline was published. Even with an update in 2020 which relaxed and clarified the 2016 restrictions, physicians remained afraid to prescribe sufficient doses of therapeutic agents to adequately control symptoms of pain. A quality-of-life survey is a starting point to aid participants to think about their own situations with follow-up interviews to solidify the participant's narrative. An ongoing narrative between a Health Care Provider (HCP) and the participant could continue to expand and deepen the trust, understanding, and as well as empathy and respect.

DEDICATION

I dedicate my work to all those who suffer from chronic pain, particularly my family members, but especially my spouse Ellen Pinkus. Ellen has been an inspiration to me in this program. Her strength in just getting through a day with the amount of pain she endures is astounding and her support of my work is unwavering.

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INTRODUCTION

WHAT IS CHRONIC PAIN?

CURRENT THOUGHTS ON CHRONIC PAIN

A study by the Centers for Disease Control (CDC) conducted in 2018 revealed that fifty million Americans (just under 20% of the age-adjusted adult population) suffered from chronic pain, defined as "pain on most days or every day in the past 6 months." Nearly 20 million (about 7.5%) experienced high-impact chronic pain, defined as "limiting life or work activities on most days or every day in the past 6 months (Dahlhamer J. et al, Sept 2018). An updated 2021 CDC survey has shown an increased percentage of those in chronic pain now at 21% and effecting 51.6 million Americans and those effected by high impact chronic pain dropping slightly to around 7% or 17.1 million Americans (Rikard, S.M. et al., 2023).

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage. The perception of pain is subjective and varies from person to person. A patient experiencing pain has multiple psychological and physiologic responses that can have negative effects on the body. Pain generates a sympathetic response that causes an increase in heart rate and blood pressure. Cortisol, sometimes called the stress hormone, increases in the body during events of pain. The long-term effects of high cortisol levels can lead to alterations in blood pressure, and alterations in blood glucose levels, which slows wound healing (Edgerly, D. 2016). Scarry, in her book *The Body of Pain* states that the cause of suffering is the lack of pain control, and that chronic pain can mean an entire lifetime of suffering due to the inability to obtain pain relief (Scarry, E. 1985).

Uncontrolled pain or inadequately controlled pain is frequently due to rules and norms of society as detailed in some of the sections discussed later following possible participant burdens due to race, education, culture ,finances and possible biases from Health Care Practitioners The burden of suffering on many of the fifty million afflicted patients is due to a lack of access to healthcare for all. There are many ethical issues involved. Uncontrolled pain places a burden on our society how responsible is our healthcare system to provide the best treatment to alleviate pain, to investigate the cause of pain and provide comfort for those who continue to suffer pain as well as continue to investigate situations that need to be addressed. Do we ethically use all the resources available to provide a suitable quality of life for those who suffer from chronic pain despite established standards of care? The World Health Organization has not only identified pain control as an essential component of patient care but also as a basic human right (Brennan F, et al., 2007).

Patients who suffer chronic pain also need more than just the treatment of symptoms. Major physicians and nurse associations uniformly acknowledge the need for chronic pain treatment. This resolve does not always come through to the patients. Nurses are “ethically obligated to take action against the disparities associated with access to pain management” (American Nurses Association and Association of Pain Management Nursing 2017, p25) and all physicians have an obligation to address acute and persistent pain (AAPM Council on Ethics, 2005).

An important first step in providing ethical care (beneficence, non-maleficence) for patients with pain is for healthcare professionals to assess their own beliefs, experiences, and possible biases about pain, patients experiencing pain, and pain behaviors (Quinlan-Colwell, A., 2013, p66).

PERSONAL CONNECTIONS TO THOSE WITH CHRONIC PAIN

Many of us are acquainted with family and friends who suffer from chronic pain. The current research has been an exercise in exploring the personal attitudes and lifestyles of those who suffer from chronic pain. This exploration dealt with participants who suffered from lifelong, non-cancer, chronic pain. Much was learned through direct interaction with participants through personal interviews by collecting of a directed pain narratives also known as narrative interviews (Jovchelovitch,S, and Baur, M., 2000, p57). Some of the most powerful interactions in exploring chronic pain are from my own family members. I have a deeper understanding of their pain and suffering due the chronic pain they endure. The closer and more frequent, the more one can understand the many facets of chronic pain. ,

Familial interactions have an effect on chronic pain. Longitudinal studies over 10 years of time have shown that supportive interactions actually lessen some of the perceived feelings of pain for the sufferer as well as for the family and friends who are providing the support (Woods, S.B. et al, 2024). Familial support can build or regress due to preexisting relational patterns. Poor communication and behaviors between family members tend to exacerbate and add stressors to the person suffering from chronic pain while those with good relationships tend receive more support from their familial support systems (Rolland, J.S., 2018). Various issues associated with chronic pain are discussed in publications such as in Mills et al 2019 discussion of issues that emanate from chronic pain such as pain’s influence on lifestyle and behaviors. Mills discusses a compendium of issues from nutrition, sleep, physical activity, mental health and even participants own feelings on chronic pain effect how the participants in these studies felt about themselves (Mills, S.E.E. et al, 2019). As a close family member, I was able to observe the everyday trials, failures and successes which depict the very real story of those in chronic pain. Pain is an affliction that cannot easily be seen externally, because pain is the bodies signal that something is wrong. One does not become aware of pain until the body processes the signal. If pain is a reaction to physical stimulus, the brain signals the body to react. Stimuli that signal pain are not always visible to those external to an afflicted person. Pain sometimes has a clear cause, such as an acute injury, a long illness, or damage to and dysfunction of your nervous system. Sometimes it even happens without any obvious reason (NIH, 2023 p38).

The daily interactions with my family members have allowed me a view of how chronic pain can make achieving the simplest things be an incredible feat. Some days just getting out of bed can be an accomplishment. Of the three family members who are directly related to me, two of them are no longer able to work due to their chronic pain and the third member works by pushing himself through a tremendous amount of pain. None of the three family members have acquired their afflictions in the same manner. One suffers from a congenital disease; the other two members were as the result of injury due to accidents. One was an industrial accident, the other resulted from an automobile accident. Their stories show the power of the narrative for understanding them and the lives they negotiate. Their narratives also have a greater impact because their lives are so well known to me. The window of their lives looms larger for me than for most clinicians than would have in a health care professional-patient relationship only supports the premise that a greater understanding of the invisible disease can be better reconciled through ongoing and caring discussions that lead to a fleshing out of the finer points of those who suffer from chronic pain.

The close contact and interactions with my family also allow me a better vehicle to utilize a tool by Meynadier from *Invasion of Speech by Pain*. (Carr D.B. et al, 2005). Carr et al. describe how chronic pain invades one's daily speech patterns depending on how much pain the sufferer has and how it affects their daily living. I have asked the participants of this study to describe their relative assessment of pain invading their speech patterns, as an way to orally detect the amount of pain a person is suffering as detailed by Meynadier in the book: *Narrative, Pain and Suffering* (Carr, D.B., 2005), however I now better understand that the reporter and reportee determine the outcome of the assessment. In this situation the participant is not the best reporter. Having a family member assess this parameter would have been more insightful rather than having the participant asses their own invasion of speech by pain.

Narrative competence as described by Charon describes how different reporters give varied accounts of a participants narrative due to their relationship to the participant and the amount of information the participant is willing to share based on that relationship. (IBID) I can much more adequately assess the speech invasion of pain parameters from my family as I have much more frequent interaction and understanding of the individual in various states of pain. One can literally interpret how bad a person is feeling by how they speak about their chronic pain. A better day has less invasion of speech by less references to their pain. My interactions with the person in pain would be a more objective an assessment than posing the question to the participant. An observational account would have required additional consent of a secondary source of data.

REVIEWING THE ISSUES THAT PLAGUE PAIN MANAGEMENT

In the US, the current racial demographics as of 2022 as extrapolated from 2020 US Census data were: White/Caucasians: 58.4%, Hispanic/Latino: 19.5%, Black (non-Hispanic): 12.6%, Asian (non-Hispanic): 6.4% and all others: 3.1%. (US Census Bureau 2024). As the population becomes more diverse, western society and Caucasian cultural practices will create a wider gap in the ability to manage pain across a more diverse society. There currently exists research along the lines of demographic differences in pain treatment. This investigation includes a review of demographic surveys to better facilitate the collection of personal narratives. I will be particularly interested to determine how the current climate of the opioid crisis coupled with the COVID 19 pandemic has affected the pain treatment programs of chronic pain participants. I will more importantly try to detect any effect on the quality of life of the participants that are interviewed. I will also investigate if administration of these revised treatment programs that were due to the current crisis conditions were conducted in an ethical way. In addition to the recent pandemic and the ongoing opioid crisis, there exist the societal and cultural biases in the treatment of chronic pain. Gender, race, culture, economic status as well as education all play a part in how a patient receives healthcare in the US. Since the US does not have universal health care, these biases seem to be even more determined by when and where participants access health care are more highlighted by what one can afford and what quality is locally available.

COVID 19

The detailed timeline for the COVID 19 pandemic is referenced for the following section from a 2023 CDC archive document last updated in March of 2023 (CDC Museum Archives 2023).

The COVID 19 pandemic was caused by SARS-CoV-2 virus. In December of 2019 information concerning a group of patients in Wuhan China that began to experience flu like symptoms that were not related to any known infection became known. By early January of 2020, the group of infected patients in China had grown to forty. Soon after the virus was identified as a Novel Corona Virus and was completely sequenced. Later in January 2020, the virus had spread to the US and other countries around the globe. By March of 2020, the World Health Organization (WHO) has declared the COVID 19 outbreak as a pandemic. There were no known treatments or preventatives initially and the world went into a lockdown situation. The population wore masks when in the presence of others and practiced social distancing to try to still be unscathed by COVID 19. A diagnostic test was developed to help contain and quarantine the infected. Several major pharmaceutical companies began to use the sequenced virus data to develop targeted vaccines. The pandemic raged through all of 2020. The first dose of vaccine administered outside of clinical trials was December 14, 2020.

In the second quarter of 2021, vaccines became available to the general public. This research project was approved in the second quarter of 2021, and as a result of COVID 19 all the interviews for this project were conducted using video calls. The technology has become comfortable for many to use as a result of the pandemic as many health care providers have resorted to this technology for more routine visits utilizing telehealth. This technology additionally serves as a barrier to disease as it limits the need to visit an HCP. This was especially a boon for those who suffered from chronic pain. Those who receive opioid prescriptions can only receive a 30-day supply. This means that previously a patient would have to have an office visit every month as well as be subjected to random drug screenings. The telehealth health option reduced the need for contact with others and reduced the risk of infection from COVID 19. The one positive outcome from the COVID 19 pandemic is that many health care providers have discovered that the use of telehealth for some routine visits can successfully replace office visits with compromising care. Telehealth visits often provide a longer window for discussion than might have been available through an office visit. As COVID 19 has still not been eradicated as of 2024 and continues to mutate, the opportunity to avail patients to telehealth has not reduced and has now become a staple in the treatment arsenal for chronic pain.

THE OPIOID CRISIS

The Opioid Crisis has exacerbated treatment biases and has led to inadequate treatment for many patients who suffer from chronic pain (Dasgupta, N. et al, 2017). It is evident that this bias was not always true prior to there being a renewed interest in opioid drug abuse.

> In November of 1996, the president of the American Pain Society coined the phrase “pain as the 5th vital sign” to elevate the awareness of treating those with pain.
>
> Vital Signs are taken seriously. If pain were assessed with the same zeal as other vital signs are, it would have a much better chance of being treated properly. We need to train doctors and nurses to treat pain as a vital sign. Quality care means that pain is measured and treated. *James Campbell, MD Presidential Address, American Pain Society November 11, 1996* (Campbell, J., 1996*).*

In conjunction with Dr. Campell’s declaration of assessing pain more accurately and timely, a new type of opioid was coming to market from Purdue Pharma that would supposedly alleviate pain and would have a lower incidence of addiction. The massive marketing of this drug and others that followed in its wake were the beginning of the opioid crisis (Nadeau, S.E. et al, 2021).

HCPs were becoming more accustomed to treating patients for pain. Relief from pain was designated a human right by the WHO in 2004 (Brennan F. et al., 2007). The use of opioids to treat the symptoms of chronic pain was one of the major therapies in the toolkit to bring some pain relief. As always, the education of the use of opioid therapies was not well understood and opioid therapy was frequently over prescribed. Those that suffered from short term pain often had unused prescriptions in their homes or the prescriptions were diverted to those who abused the compounds (Kertesz S. et al, 2017).

As the 2000s progressed and the use of opioid treatment became more commonplace, the number of opioids that were availble became more common. The incidence of “Pill Mills,” clinics that catered to those seeking opioids, grew at an alarming rate. As the rate of overdose deaths steadily climbed in the US, a panic began to grow in society.

In 2017, Chris Christie the former governor of New Jersey, was tasked with an evaluation of the opioid crisis. He led a blue-ribbon panel and presented a report titled *The President's Commission on Combating Drug Addiction and The Opioid Crisis*. Christie noted that in 2015 enough opioids were prescribed so that every American could be medicated for three weeks (Christie C., 2017). During this timeframe in 2016, the CDC rolled out *CDC Guideline for Prescribing Opioids for Chronic Pain — United States, 2016*. The combination of the two documents and the involvement of insurance companies to restrict opioid prescriptions began to slow the number of opioid prescriptions being written.

Prescription Benefit Managers (PBMs) started to require that doctors not prescribe over a certain level of opioids per day, ninety morphine equivalents . This led to reductions in the number of opioids being prescribed to those who were above that level and were functioning at a steady state. These forced reductions led to patients who were just barely managing their pain to now being reduced to having to tolerate a higher level of pain and subsequent reduction in their daily activities. The PBMs were taking away the ability of HCPs to effectively treat their patients (Zimmerman, B., 2017). The DEA was also closing in on "Pill Mills" and unscrupulous pharmaceutical companies and their agents for "pushing" prescriptions of opioids for profit and kickbacks. Recent convictions in Florida lead the way for future pill mill prosecutions (Duret, D., 2017). Once the ball was rolling against producers of opioid drugs, states began to file suit against any producer and PBM that had to do with the production and manufacture of opioids (Tanne, J.E., 2022). These suits are currently winding their way through the courts and the producers and PBMs as well as some pharmacy chains are paying a high price in the form of fines and restrictions on the number of opioids that that can be sold through their retail outlets. The upside of these enforcement tactics has made prescriptions less available to the general public and consequently reduced early access and possible addiction to those who would access and abuse pharmaceutical grade opioid compounds. The downside is that with fewer pharmacies carrying opioid compounds and many manufacturers also dropping out of producing these compounds, it is harder for those who truly need these compounds access to the medications they need to make it through the day.

Pharmacy shopping is a reality (Morrison, R.S., 2000). Pharmacies have a quota of how many patients using opioid therapy can be serviced at one location. Even though in 2020, the 2016 CDC guidelines were clarified and somewhat relaxed (Greenspan, A.I., 2022), HCP prescribing patterns have not rebounded. Those who had a reduction in their opioid prescriptions can still not obtain what they previously had to alleviate their pain symptoms. Patients feel like they are being treated like addicts. The reductions in pain relievers have resulted in depression, anxiety, and suicide (Ramsey, L., 2018).

The current reduction in pharmaceutical grade opioids has also led to another destructive societal issue, the abuse of street opioids such as the more powerful drug fentanyl. Fentanyl is one hundred times more potent than heroin and has caused a large upward curve in deaths for the last ten years. 2023 is the first year that there has been a reduction of deaths by fentanyl from the previous year high record number of deaths (CDC/NCHS, 2024). This reduction in deaths is hopefully the result of the corresponding reduction of the number of opioid prescriptions written. It may also be due to the increased availability of Narcan. The State of NJ has required since 2021 that all opioid prescriptions that are over 90 MME also co-prescribe Narcan (NJ 13:37-7.9a, 2021). New publications have shown that since the availability of over-the-counter Narcan, the use of this opioid receptor blocking agent has reversed many overdoses. The article also notes that 43% of those administering the Narcan are not healthcare or emergency response workers (Gage, C.B., 2024). It has also been reported that some drug dealers even supply Narcan with their sales (Goldman, J., 2024). Both of these new developments are showing a positive spin on the use of Narcan providing a for the importance of public health campaigns to save lives.

The newest aspect of the opioid crisis is that although HCPs have been closely following the CDC guidelines, they seem to be even more closely following the legal ramifications of prescriber prescription practices. The HCPs are now challenged by the pharmacy benefit managers (PBM). There are patients who have been on stable doses of medications for years for chronic non cancer pain and the PBMs have been denying coverage of the full prescriptions. The PBMs are continuing to face lawsuits on the number of opioid prescriptions that they have reimbursed. The PBMs will only pay for what is the limit of the current CDC guidance so that there will not be a legal challenge to their institutions. This is a reduction in benefits in a way that will unfairly affect the members of a particular benefit plan.

The members who have fewer financial means will suffer the greatest. It is still possible to get your full prescription, but the PBM will only now pay up to the new restricted limit. I am not sure if this is a universal across all PBMs, but this is a recently instituted action taken by CVS/Caremark PBM. The denial form is very limited, and the appeals process is, of course, a nightmare. Most insureds still get denied as the PBMs are holding fast to their apparent resolution to protect themselves from liability by denying benefits to their membership. Even with the HCP intervention in a peer-to-peer review process, the HCP could not resolve the impasse of a denied appeal. This is another blow to those who need opioid prescriptions to relieve them from the symptoms of chronic pain.

As an extra bonus to the opioid crisis, there is a section of the CDC document that has reference to the use of anxiolytics and antidepressants in conjunction with opioids for the treatment of chronic pain. It is well known that co-morbidities of chronic pain can be reflected in participants with additional symptoms of depression and anxiety. Mood disorders, especially depression and anxiety, play a significant role in the exacerbation of pain perception in all clinical settings.

Depression commonly occurs as a result of chronic pain and needs treating to improve outcome measures and quality of life. Anxiety negatively affects thoughts and behaviors which hinders rehabilitation. Anxiety and depression in acute hospital settings also negatively affect pain experience and should be considered in both adults and children. Poor pain control and significant mood disorders contribute to the development of chronic pain (Woo, A.K., 2010). To this end, HCPs now also need to contend with a restriction on the amount and type of prescriptions that can be used to treat these co-morbidities. Major healthcare institutions are requiring physicians to administer an ancillary document akin to the pain management contracts. This document is as stringent as the pain management program and has similar caveats and outcomes. The document known as the Non – Opioid Controlled Substance Prescription Agreement is displayed as *Appendix 9*. The agreement is used for those who require treatment for anxiety and/or depression. The patient is under threat of expulsion from the program for any variety of reasons deemed appropriate by the institution, can require random urine and blood tests and to the requirement be seen in person every 90 days. The chronic pain patient finds life less aided by the HCP but actually more controlled by more required visits and rules to remain in a treatment program.

SOCIETAL ISSUES IN PAIN MANAGEMENT

Societal structure influences how patients access and are treated for their chronic pain. The biases of gender, race and culture play a large part in how and when chronic pain patients are treated for their symptoms. With the future trends of an increasingly diversified population in the US, the current philosophy of treatment will have to shift to allow for the more diverse cultures to be adequately treated for chronic pain.

GENDER BIAS

Gender bias have throughout time been an issue for females to receive equitable treatment. Women who are suffering have universally been seen as less than and not receiving the treatment they deserve. Equating actual issues as hysteria or mental instability and resultingly not be taken seriously for their ailments (Hoffman, D.E. and Tarzian, A.J., 2001).

Seventy percent of the people chronic pain impacts are women. And yet, 80% of pain studies are conducted on male mice or human men. One of the few studies to research gender differences in the experience of pain found that women tend to feel it more of the time and more intensely than men. While the exact reasons for this discrepancy have not been pinpointed yet, biology and hormones are suspected to play a role (Blog, H.H., 2017).

In a study from 2021, researchers found that when male and female patients expressed the same amount of pain, observers viewed female patients' pain as less intense and more likely to benefit from psychotherapy versus medication as compared to men's pain, exposing a significant patient gender bias that leads to disparities in treatments (Zhang L. et al, 2021). In another study it was found that men and women who were in the same intensity of pain did not receive the same medical treatment. Men received treatment to help with pain while women were more often prescribed sedatives (Hoffman, D.E. and Tarzian, A.J., 2001). My research will probe the differences in gender and the quality of life as well as if there continue to be gender bias in the treatment of chronic pain.

RACIAL BIAS

Racial bias in the treatment of chronic pain is well known and continues on as reported in many articles and blogs (Ringwalt, C. et al, 2015) , (Ezenwa, M.O., 2012). Investigations have revealed that a substantial number of white laypeople and medical students and residents hold false beliefs about biological differences between blacks and whites and demonstrate that these beliefs predict racial bias in pain perception and treatment (Hoffman, K.M., 2016). Individual accounts and studies show how pervasive these bias remains.

One of the most blatant biases occurs in the treatment of sickle cell disease which predominantly effects populations from Africa. One in thirteen African American babies are born with sickle cell trait and one in 365 children are born with sickle cell disease (NIH: NHLBI, 2018). Sickle cell disease is reported to be an adaptation to malaria which is carried by mosquitoes in the equatorial areas of the world. Sickle hemoglobin is not like normal hemoglobin. It can form stiff rods within the red cell, changing it into a crescent, or sickle shape. Sickle-shaped cells are not flexible and can stick to vessel walls, causing a blockage that slows or stops the flow of blood. When this happens, oxygen cannot reach nearby tissues. The lack of tissue oxygen can cause attacks of sudden, severe pain, called pain crises. These pain attacks can occur without warning, and a person often needs to go to the hospital for effective treatment (IBID). The pain that comes from an attack from sickle cell disease can be particularly debilitating. Many times, when a patient presents with sickle cell disease, they are thought by the physician on call to be drug seeking. Externally the Physician note that the patient presents no obvious symptoms or visible reason to be suffering from pain. The patient tries to explain the issue and if a blood test is not performed, the patient will languish in the ER or be turned away.

In a large study in 2012 of 891 participants, 201 African Americans and 690 Caucasians were surveyed for experiences with their treatment for pain. African Americans compared to Caucasians had higher perceived discrimination. Perceived discrimination was positively associated with hopelessness, and higher hopelessness was associated with worse pain management. The study also found worse pain management of the patients predicted worse quality of life outcomes (Ezenwa, M.O. and Fleming, M.F. 2012).

ECONOMIC BIAS

Economic considerations for chronic pain treatment in a country without universal healthcare are very real. Those without health insurance currently are 7.7% of the population in the US or 25.6 million individuals. This is down from pre–Affordable Care

Act levels of 16% in 2010 and pre-pandemic levels of 9.7% in 2019 (Tin, A., 2024). The uninsured who do not have economic means simply cannot get continued pain relief from a medical setting. It is possible in an emergency setting for patients to be treated as indigent care but for those who suffer from chronic pain and need long term care, the process is bleak. Many hospitals and HCP offices deny care for those who have only Medicaid. Medicaid is the health insurance for those who are too young for Medicare but meet the lower economic standards established by the US government to receive free medical care. Since hospitals are many times privately funded, they can and do refuse government insurance programs because they believe they will not receive adequate payment for their services. For people who have insurance or can afford to pay out of pocket, there are still excessive costs associated with treatment for chronic pain. In some instances, even if one can pay out of pocket, the hospital is many times unwilling to accept cash payment. They believe insurance provides a more transparent audit record. If a patient requires opioid treatment, they are required by NJ State law to complete a pain management contract (*Appendix 7*) (Wheeler, T., 2017) and have monthly office visits as opioid prescriptions are only valid for 30 days with no refills. This policy is also required by NJ State law (NJ 13:37-7.9a, 2021).

Some opioid compounds that are designated extended or time release doses are more expensive. The extra expense is to compensate for the slow-release technology. This technology is preferred over cheaper short acting drugs. Other pain medicines that are used to treat chronic pain can be cheaper such as muscle relaxants and fast acting opioids. Nerve pain blockers such as gabapentin are now generic but still command a prohibitive cost as the synthesis process and raw materials for manufacture remain expensive. Alternative therapies such as acupuncture, massage, and water therapies are often not covered by insurance leading to the fact that only those with economic means have access to these types of treatments.

There are other more invasive therapies that may be covered by insurance but have more risks associated with their use. These other invasive therapies can require several outpatient hospital or clinic visits. These therapies include Radio Frequency Ablation, where tiny needles actually burn affected nerve endings, epidural and facet joint injections that hope to sooth inflamed nerves by bathing them in a steroidal solution, similarly trigger-point injections at certain nerve bundles to reduced inflammation and lastly there are electronic pain stimulators that are surgically implanted in the spine to reduce or neutralize the nerve pain signals to the brain (Institute of Medicine 2011). Overall chronic pain treatment demands continued medical care as well as therapies to help alleviate pain and this continued care is costly and time consuming.

EDUCATION AND CULTURAL BIAS

Healthcare in general and especially those who suffer from chronic pain work from a script that is provided by societal norms and the sufferer’s educational background. As technology has evolved, the process of applying for healthcare has become increasingly reliant on computer technology. Generational roadblocks through technology tend to effect older generations. Those who are suffering from chronic pain are generally of a higher incidence in rural areas and areas of less affluence. The work done in rural areas tends to be more manual labor oriented and leads to a higher prevalence to physical injury (Rikard, S.M. et al, 2023). The rural areas tend to have less access to HCPs locally and travel to seek treatment is prohibitive. There is also a prevalence of protected groups (LGBTQI, disabled, and prisoners) having less access to healthcare that arises from a history of society treating these protected groups as less than . These protected groups understand this bias and are unfortunately less likely to seek treatment. Minority groups as well are often not treated with the same veracity as their Caucasian counterparts which also leads them to avoid seeking out medical attention due the biased treatment they receive from HCPs (Nguyen, L.H. et al, 2023).

The more education a patient has, the more likely they are to seek medical attention, even if they belong to a group that traditionally might not seek treatment. The more education a patient has the less likely they are to have chronic and even high impact pain. Those below college level education have greater than 22% of the pain for the following levels of pre-college graduate: no HS diploma, HS Diploma, and some college. The level drops to 15% for those who have a bachelor’s degree or higher. A similar effect is seen for high impact pain. Nearly 9% for each of the previously mentioned precollege graduate groups and only 3.4% for those with a bachelor’s degree or better (Rikard, S.M. et al, 2023). This may be due to the fact that a higher education leads to more opportunities of employment that are less demanding on the body and that when an issue arises, the more educated person may understand better the need to take corrective action or be more able to afford treatment.

Cultural norms play a part in seeking treatment. In some societies it is seen as a sign of weakness to show an affliction of pain. Statements like “shake it off” and “power through it “or “tough it out” lead to patients suffering in pain when they do not have to. The ignoring of pain issues that are originally not chronic pain but are left untreated can become chronic pain. Many patients and some cultures or social groups believe that pain is an inevitable part of their diseased state, or that bearing pain may be admirable or honorable in some way, or that complaining about pain may be seen as a weakness (Zuccaro, S.M. et al, 2012).

The African American community has long distrusted the medical care providers and associated governmental agencies due to events that resulted in the Tuskegee study which left hundreds of black men untreated with syphilis for 40 years after a known treatment could have been provided. The study started in 1932 with a known treatment for syphilis becoming availble 11 years later in 1943. However, no treatment was provided as a part of the clinical treatment, and the study continued until 1972. The study was so clearly egregious against the study participants, that it led to the 1972 Belmont report which is a bedrock for ethics in current clinical trials. The long-term effects of syphilis were better understood due to the unwitting and deceived participants (CDC Timeline Series, 2022).

Stereotypic thinking about people of African American heritage having thicker skulls, being less sensitive to pain and having a lower need for analgesia were continued to be promoted in medical schools well into the 20th century (Nguyen, L.H. et al, 2018). This kind of thinking from HCPs led to a continued distrust in the African American patient community that their concerns are being heard and that even seeking pain treatment that their concerns may not be treated respectfully and honestly.

In Hispanic cultures, pain and illness are viewed as disharmony with or punishment from God. This theme emerged during interviews with patients living with chronic pain. Pain was discussed as a loss of spiritual connectedness or as conflict with God, while God was also viewed as the provider of help from pain. Certain types of religious coping mechanisms are associated with more pain sensitivity. Hispanic populations seem to exhibit more severe chronic pain as opposed to Caucasian and African American participants. The understanding the cultural aspect of religion may play an important part in issues of treating chronic pain in Hispanics (Hollingshead, N.A. et al, 2015).

Also reported in Hollingshead was the facet of stoicism in Hispanic populations. It is believed that stoicism is family learned as a way to cope with pain. This coping mechanism is strongly used by men so as they do not show that they do not feel able to fulfill one’s societal obligations or need to depend on others for any help. This is a similar mechanism for women but not as broadly discussed. Women in a machismo environment are given some ability to express signs of pain as they are the weaker sex. Childbirth, as would be expected, is one of those opportunities for women to express their feelings of pain (IBID).

In many Asian cultures, patients might not seek medical help because chronic pain is regarded as an expected part of life and a normal ageing process that should be endured. The cultural aspects of life are also reasons why Asians may have chronic pain. Low back pain and arthritis can be the result of lifelong practices. Sitting cross legged and on the floor as well as jobs that require much bending at the waist such as agriculture tend to be a causation for pain (Zaki, M.F., 2015).

The experience of pain led to more empathy toward others. Pain was seen to be part of the natural flow in the rhythm of life (Lewis, G.N. et al, 2023). Culturally, families are a source of strength to endure pain. Confucian beliefs in that the desire for harmony and self-restraint are put above the need to express discomfort or unhelpful emotions. Pain was needed to be managed by the self and not to disturb others with your emotional baggage. Even if the person were struggling with pain in a healthcare setting, there would be no requests that might burden another to provide relief to the patient (IBID). Many Asian participants feel western medicine does not help them as much as cultural traditions for pain relief. A major source of relief is massage. Family and friends would provide these massages known as “Gua Sha” at periods of intense pain. A participant would seek out a professional massage therapist if their family or friends were not available (IBID). Chronic pain is usually not treated with analgesics in the Asian community. During the opioid epidemic, opioid prescriptions were four times less than that of other counties. (Lancet Editorial, 2023).

Part of the rational for this lack of analgesic treatment goes along with a 2020 survey by Z. Yongjun et. al. that showed of the Asian participants who suffered chronic pain, 24% did not seek medical help and 36 % did not receive treatment because they did not believe chronic pain is harmful (Yongjun, Z. et al, 2020). Additionally, it was found that Asian patients with chronic non-cancer pain are more willing to report their pain when it becomes more severe and when they have sufficient time to talk with physicians. Narrative medicine would improve regular pain measurement and assist physicians in pain management by a shift the focus towards holistically relieving pain and not just treating diseases causing pain (Cheung, C.W. et al, 2019).

PAIN MANAGEMENT FACILITIES ISSUES

Some of the bedrock of pain management is the pain management program. These programs are generally administered by specialist in the field of anesthesiology. Patients usually come to these programs referred for specialized pain care. Not all patients are chronic pain patients. Most patients coming to the programs are usually referred from a surgeon or others are possibly referred by primary care physicians to treat pain after a procedure or complaints of chronic pain. The pain management HCP has many tools available to treat pain. The HCPs seem to see opioids as a last resort, although insurance companies believe that as opioids are cheap therapy they should be used as first-line therapy. The HCPs try to use a variety of current known techniques for pain relief.

Some techniques are mechanical such as massage, physical therapy, and acupuncture. There are techniques that involve ways to deal with pain on a more metaphysical way using meditation, breathing exercises and guided imagery to help relieve the symptoms of pain.

Other specialized techniques that are more pain management facility based involve injections to the spinal cord (an epidural) to bathe the affected area with anesthetic and steroids to briefly relieve pain and reduce inflammation of tissue or more specifically nerves. Pain management HCPs administer agents to block nerve pain, some are injected or taken orally. A semi-permanent method of nerve block used by pain management practitioners is Radio Frequency Ablation, this technique can be used to actually burn nerve endings by applying a radiofrequency through a needle and creating a cloud of energy at the tip to burn the nerve endings to stop receiving nerve pain signals. A major surgery that is used to block pain on a constant basis are nerve chord stimulators. These devices are embedded in your back and try to block pain along your spinal column by targeting specific nerve bundles that are thought to be responsible for pain (Institute of Medicine, 2011).

In conjunction with and many times after exhausting the techniques above for the treatment of long-term chronic pain, the most common course of action becomes pharmacologic interventions. There are many different types of pharmacologic interventions: Steroids to reduce inflammation, non-steroidal anti-inflammatory (NSAID), gamma aminobutyric acid (GABA) analogues. GABA reduces the excitability of nerve cells (neurons) in the brain, general muscle relaxant compounds and last but not least, opioid compounds (Alorfi, N.M., 2023).

The opioids are cheap and effective pain relievers but can cause long term side effects. HCPs worry about abuse, addiction, and overdose. There are other major side effects that the patient worries about just as much such as sleepiness, constipation, nausea, and respiratory depression (inability to have deep full breaths). Frequently those who receive long term opioid therapy also receive yearly two doses of naloxone (Narcan) in case of overdose (NJ 13:37-7.9a, 2021). Naloxone, the active ingredient in NARCAN® Nasal Spray, competes with opioids to bind with the same receptors in the brain, reversing the effects of an opioid overdose in 2 to 3 minutes (Narcan PBI, 2015). This additional prescription is a CDC recommendation in the 2016 and 2020 opioid treatment guidelines. The overdose event is not usually the patient but someone who has diverted the chronic pain sufferer’s prescriptions and used them unlawfully.

The patients who are under long term care for chronic pain with opioids are required to sign a pain management contract (*Appendix 7*) . A patient under long term opioid treatment must have monthly visits with the pain management HCP to keep receiving treatment. Prior to COVID, all visits were in person monthly. Since COVID, the ability to reduce in-person meetings to once a quarter is now possible.

The HCP dictates the type of meetings depending on the patient’s stability and needs. In conjunction with the burden of monthly meetings, finding a pharmacy that will fill your prescriptions can also be difficult. Many regular chain pharmacies will not fill the stronger opioids and usually an independent pharmacy will be utilized to fill the prescription. Your pain management HCP will only prescribe to one pharmacy to be sure that there is not any other pharmacy that will supply your medication (Wheeler, T 2017). As an added bonus, many pharmacies have a limit regarding the number of opioid prescriptions that can be filled at their pharmacy. If a person moves to an area that has many patients with chronic pain, they may not be able to fill opioid prescriptions in their immediate area.

All of the rules for being in a pain management program have led to additional biases to overcome. If a person does not have insurance, they cannot be treated. There are restrictions on the type of insurance accepted as well. Even if pain management is covered, plans like Medicaid reimburse at a lower rate and the HCP may not accept this insurance. The same bias as discussed previously for minority patients especially comes to play in pain management. The need for diverse practitioners in pain management is lacking and empathy sometimes is also lacking.

Pain is the invisible epidemic (Morris, D.B.; 1991, p269) and even HCPs whose area of expertise is to treat pain are not always empathetic or even truly listening to the patient. There are quarterly urine tests to be sure the patient is only taking what is prescribed and that they are taking the full amount of their prescription as well as any vitamins or over the counter preparations. Failure in either test can be reason for expulsion from the pain management program as well as being designated as untrustworthy to other possible HCPs (Wheeler, T., 2017). The restrictions are difficult for those in pain but there is not any other choice for honest patients seeking pain relief from pain management programs. Pain management HCPs are the gatekeeper for pain relief by either approving or denying the various treatments, prescriptions, and referrals that are written in an effort to alleviate the patient's pain.

THE OPIOID CRISIS

The opioid crisis also impacted the treatment of opioid treated patients with chronic non-cancer pain. There are not any substitutes that can do a better job of alleviating chronic pain than opioid pain relievers (Nadeau, S.E. et al, 2021). Nadeau has conducted an extensive analytical literature review and found that most pain HCPs were prescribing responsibly and accurately. The 2016 and 2020 CDC guidelines on pain caused HCPs to be fearful of prescribing opioids. Prescriptions rates did drop subsequent to the issuance of the 2016 CDC report. This was at the expense of many chronic pain sufferers (IBID).

The 2016 guidelines suggested no more than ninety morphine milligram equivalents per month of any opioid be prescribed. Insurance companies followed up on this guideline by prohibiting the processing of any prescription for opioids above the ninety morphine milligram equivalents per day limit. The insurance companies and the intermediary companies, pharmacy benefit providers, demanded a second letter from the prescriber detailing the high use of the dose of opioids in the treatment of chronic pain (Pergolizzi J.V. et al, 2019). The 2016 CDC document boldly states that this limit is not a prescribing limit but only a guidance. However, the continuing civil and criminal litigation and the 2016 CDC document directives, there was a definitive reduction in prescribing practices.

There was such a reduction of prescriptions and dosages that there became a constant patient outcry through social media, newspapers and journal articles outlining how this reduction in opioids had reduced the quality of life for many chronic pain sufferers. Articles such as “We Are Treated Like Addicts” (Ramsey, L, 2018) talk about the dichotomy of wanting patients to take less opioids but also not wanting to spend more insurance and patient money on non-narcotic alternatives. The patients have had their dosages lowered and with that lowering comes a situation of uncontrolled pain. Increased uncontrolled pain has led to less physical activity and less ability to mentally focus, that culminates in feelings of depression and even suicide for some patients who feel they no longer a have a quality of life worth living (Petrosky E. et al, 2018). The converse of suicide is also true, where there are instances of patients being so frustrated with the reduced quality of their lives and have been so angered by an HCP who cut down the dosage once prescribed. In one case the patient pleaded repeatedly with the HCP but to no avail. When the patient, now even more frustrated and in chronic pain with no hopeful view toward the future, took the life of the doctor with two gunshots to the head (Kertesz S, and Satel S., 2017).

Continuing in the same article, a physician who had taken a low dose of methadone for 34 years to control a chronic condition of pain was also frustrated. Due to the opioid crisis, her doctor declined to prescribe more opioids in the future. In the end, she did find another HCP to treat her, but it was with great difficulty, and she was a physician herself! Finally, reported in the same *Slate Article* was the patient who had been receiving methadone and oxycodone for 20 years. His physician also cut him off because of the new monitoring standards and this patient did not fare as well, Similar to other reported pain suffers described his pain had worsened, and his future appeared bleak. He lasted 6 weeks and committed suicide (IBID).

The issue here is not only the bias against prescribing (and patients needing) opioids for chronic pain but the fear that has been instilled in HCPs to adequately treat chronic pain at all. The newer guidelines initiated in 2020 did not reduce the fear or the strict monitoring that was started with the *2016 CDC Opioid Prescribing Guidelines*. Pain Management patients need to feel confident that they are being heard and their needs are met to be able to have a way to deal with their pain and to achieve a livable quality of life. The opioid crisis is a genuine issue, but those who are treated for chronic pain under the watchful eye of a pain management HCP should not be penalized. These HCPs are professional and their whole practice is anesthesiology and the management of pain. Most family practice doctors will refer a patient to a pain management center after a short term of offering relief in their office. The pain management HCP monitors the patient through mandatory random drug testing and monthly appointments to continuously monitor the patient’s pain levels, mental health status and behavior.

The current situation is still biased and still leads to patients being thought of as drug seeking by society as a whole. Many HCPs remain suspicious of those requesting opioids. HCPs who are not pain management providers doing chart review of those using opioids for pain relief give a suspicious attitude on intakes for other medical procedures with retorts of “ You can’t be in enough pain to justify the treatments you are receiving” and “How can you feel any pain with the medications you are taking?” (Participant Narratives, 2024).

Pain relief is complex as pain is subjective for every person. No one knows the amount of pain another feels even with newer techniques that use functional magnetic resonance imaging to map portions of the brain in response to stimulus. The same amount of stimulation applied to individuals does not give the same response to mapping in the brain under this imaging technique (Carr, D.B. et al, 2019). The wide divergence between the degree of pain that a patient communicates via body language, voice, culture, ethnicity, and the degree of pain that the HCP understands can be aided by narrative discussions and by developing an ethical framework for treatment (Carvalho, A.S. et al, 2018).

RESEARCH METHODOLOGY

To explore the multifaceted nature of pain, I employed a combination of a survey and narrative interview study to gather experiences of 19 participants suffering from chronic pain which was defined as suffering from pain continually for 6 months or longer.All research was conducted within the continental US and as such was subjected to the norms of US medical and legal regulations. Recruitment of participants was sought utilizing advertisements with an approved flyer from the Drew Institutional Review Board (IRB) in the following settings: a hospital, at a clinical pain management practice, within pain support groups, local pharmacies, family practice physician offices, “Drew this Week; Community Notices”, a dental practice, local grocery store bulletin boards in NJ, and by word of mouth.

The Drew University Institutional Review Board approved this human research proposal and all of its’ associated supporting documents. IRBs must have at least five members and include at least one scientist, one nonscientist, and one member who is not otherwise affiliated with the institution and who is not part of the immediate family of a person who is affiliated with the institution. IRBs have authority to approve, disapprove or require modification of (in order to secure approval), of all research activities covered by the “Common Rule” (Steneck, N.H., 2007). US Federal Regulation 45 CFR 46, Protection of Human Subjects , which is referred to as the “Common Rule”, is an anchor regulatory text on which investigators and IRBs rely and must comply to protect human participants in conducting research (Bankkerty, E.A. et al, 2021 P 91). They are also responsible for conducting continuing review of research at least once per year and for ensuring that proposed changes in approved research are not initiated without IRB review and approval, except when necessary to eliminate apparent immediate hazards to the participant (Steneck, N.H., 2007).

The approved documents included: a study welcome letter (*Appendix 1*), an informed consent (*Appendix 2*), a physical handbill for advertisement of the reseach (*Appendix 4*), as well as the script that was utilized for directing the participant narrative sessions (*Appendix 3*). The IRB approval letter for this proposal is found in *Appendix 5*.

The IRB suggested that the narrative interview could be a mental health stressor for some participants. This was ameliorated by provideding a mental health resource list. Addittionally, I trained and received a certificate from the National Council on Behavioral Health (*Appendix 7*) to provide mental health first aid which enabled me to recommend a number of different mental health resources if this was needed by any of the participants. There was also a link provided in the ICF itself if a participant thought they may need to seek mental health resources on their own.

The flow of the project consisted of the informed consent document being signed by the participant to facilitate the release of their personal protected information. The informed consent was administered prior to the participation or collection of any data for this research project. Two copies of the informed consent were mailed to each particpant. The written instructions contained in the IRB approved welcome letter were to read and sign the informed consent. If there were any issues or questions, the investigator could be contacted to clarify or answer any questions. The participant was also advised that they could seek advice from other members of their family, friends or advisors about their participation in this study. Upon execution of the informed consent, participants were directed to the provided packet of the *World Health Organization Quality of Life* (WHOQOL100) *Survey* and asked to answer the survey questions with the caveat that if they could not answer a question to draw a line through the question so that it would be known that the question was not missed. The completed WHOQOL100 and one copy of the informed consent were returned to the investigator in the postage paid pre-addressed envelope to the investigator. The participant was directed to retain one copy of the informed consent for their own records. Upon receipt of the executed ICF and completed WHOQOL100, an appointment was scheduled to conduct a video interview session as close as possible to within one week of the receipt of the completed survey.

The session utilized the IRB approved script to obtain a directed personal narrative of the particpants pain history. Most interviews lasted for one hour but there were outliers on either end of the spectrum. The interviews were conducted using MS Teams software and the connection was secured through NordLayer Always On VPN. A VPN, or Virtual Private Network, is a tool that encrypts the internet connection to protect the users privacy and security. The recorded audio from the interviews were transcribed and digitized into individual documents and subsequently pooled into one document for data analysis as previously described. All original documents remain stored in a locked steelcase file cabinent and will be retained as per good clinical practice for 15 years.

This research consisted of two parts: a quality of life questionaire that was administered pre-interview and personal interviews which were driven by the IRB approved narrative script to obtain directed narratives of participants that suffer from non cancer chronic pain. The directed scripts were used to steer the conversation of each of the participants through their pain history to lead to a more standard analysis of their pooled narratives. The participant’s information provided a framework for investigating the ethical gaps in the treatment of participants who suffer from chronic non-cancer pain. The investigation also included the effects of the current opioid crisis as well as the COVID 19 pandemic in relation to the demographics of this population including cultural issues, religious affiliation, race, gender, education and age,as well as socio economic background.

Text analysis Artificial Intelligence (AI) software CLAUDE was utilized to determine and to analyze different defining themes of patients suffering from chronic pain, including demographic characteristics of this population, and to correlate the information gathered from the collected oral narratives against the self-reported WHOQOL100 surveys. The transcript data was collected through video interviews using Microsoft Teams application. The individual participant narratives were pooled to make any reference to one particular subject more difficult to re-identify.

CLAUDE is a web based application for mixed methods research developed and created by Anthropic, an artificial intelligence research company based in the San Francisco Bay Area. Anthropic was founded in 2021 by Dario Amodei, Paul Christiano, and others who previously worked at OpenAI. CLAUDE helps organize research data in a wide variety of formats including qualitative data such as text, audio, images, or video; and quantitative data such as spreadsheets, surveys, test scores, ratings or demographics. A subscription to CLAUDE allows a researcher to have their own space with an ability to use the AI algoritym for analysis with their own private workspace. In addittion to the protection of a multifactor authentication algorithym to gain acess to the workspace, Anthropic, the owner of CLAUDE AI is certified HIPPA, GDPR and Brazilian privacy compliant. As an additional confirmation of the product security, a third party review of the system URL was completed. The reviewed yielded an A score as shown in *Appendix 10* that details the areas reviewed and the over score for security of the internet site. The full 42 page report is availble on demand. At the termination of the project, all data has been guaranteed to be deleted from the lockbox .

The provided survey utilized is the WHOQOL100 as previously mentioned. World Health Organization (WHO) defines Quality Of Life (QOL) as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. QOL is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to personally salient features of their environment. The WHOQOL-100 was developed simultaneously in 15 field centers around the world. The important aspects of quality of life and ways of asking about quality of life were drafted based on statements made by patients with a range of diseases, by well people and by health professionals in a variety of cultures. The instrument was rigorously tested to assess its validity and reliability in each of the field centers and is currently being tested to assess responsiveness to change. The WHOQOL instruments can be used in particular cultural settings, but at the same time results are comparable across cultures. The WHOQOL is now available in over twenty different languages and its development in further languages is progressing. The WHOQOL100 was scored and analyzed using the WHOQOL *User Manual* for directions, and in particular MS Excel software for nuumerical scoring of the survey.

This research included the collection of patient narratives that discussed the historical and current status of the participant's treatment and the subject's perception of their treatment goals. Participants were asked if their treatment goals were fully achieved and to describe the possible rationale of their perception that current pain relief measures remained acceptable or unacceptable. A query as to the types of pain relief measures utilized were investigated. This discussion included all treatments for pain methods not just those that were clearly medical in nature. Research dissected the perceptions along demographics especially the areas of culture, socio-economic status, race, age, religion, education and gender. The narrative script doucment is contained in *Appendix 3* of this document. The CLAUDE AI software was utilized to help summarize the answers to the scripted questions to provided overviews of all the narratives collected for these seventeen participants of nineteen participants that completed the narrative portion of the study. These summarries gave an insight into the common issues that surrounded this population of participants who suffered from chronic non cancer pain.

RESULTS

WHOQOL100 DATA

The data obtained for the participants was cross confirmed by using the WHOQOL100 survey as well as the data obtained from the video interview sessions that were collected in both methods of enquiry. The collection of data during the narrative sessions lasted between 45 minutes and 2 hours. The average interview was one hour. The expected time to complete the WHOQOL100 was approximately 90 minutes. The actual time to complete the WHOQOL100 for these participants was unknown.

Subject demographics were compiled from with answers provided in the WHOQOL100 and were cross checked narrative session data. There were nineteen participants in total that were enrolled in this study. Nineteen participants completed the WHOQOL100 while only seventeen participants were able to complete the narrative session. Two participants were lost to follow up and could not be interviewed. Lost to follow up letters were filed and sent to the participants who were then deemed “closed out” from future data collection.

The WHOQOL100 analysis was performed by using the analysis scoring system from WHOQOL100 user manual (World Health Organization, 2012) and actual generation of output data was performed utilizing Microsoft Excel. The Excel software has a statistical analysis package module that was utilized to score the data as well as perform the basic statistical analysis of the generated data. Basic statistical analysis such as mean, standard error of the mean (SEM) which is a statistical measurement that indicates how close a sample mean is likely to be to the population mean and standard deviation (SD) which characterizes typical distance of an observation from distribution center or middle value. If observations are more disperse, then there will be more variability. Thus, a low SD signifies less variability while high SD indicates more spread or variability of data (Barde, M.P. et al, 2012). The mean, SEM and SD were computed using the Microsoft® Excel® for Microsoft 365 MSO (Version 2408 Build 16.0.17928.20114) 64-bit.

The average age was 61.1 years of age +/- 3.6 SEM. There was not a statistical difference in the average age between men and women. The gender division was 57.9 %

female participants versus 42.1% male participants. There were no participants that identified as anything but their biological birth gender. The gender identification question was specifically queried of each participant.

Table 1: Participant Demographics

Demographic variable	**Participants (n=19)**
Age group in years, n (%)	
< 65	8 (42.1)
>= 65	11 (57.9)
>= 75	4 (21.1)
Age (Years)	
Mean	61.6
SEM	3.6
SD	15.8
Male Age (Years)	
Mean	63.9
SEM	3.6
SD	10.1
Female Age (Years)	
Mean	59.9
SEM	5.9
SD	19.4
Gender, n (%)	
Female	11 (57.9)
Male	8 (42.1)
Marital Status	
Married	11 (57.9)
Single	5 (26.3)
Widowed	2 (10.5)
Separated	1 (5.3)
Race, n (%)	
White	19 (100)
Black or African American	0 (0.0)
Asian	0 (0.0)
American Indian or Alaska Native	0 (0.0)
Ethnicity, n (%)	
Non-Hispanic or Latino	17 (89.5)
Hispanic or Latino	2 (10.5)
Unknown	0 (0.0)

Demographic variable	Participants (n=19)
Geographic Location (US state), n (%)	
Florida	9 (47.4)
New Jersey	7(36.7)
New York	1 (5.3)
Georgia	1 (5.3)
Virginia	1 (5.3)

The overall data collected from the WHOQOL100 survey was analyzed and detailed in figure one. Missing data and scoring were assessed using the WHOQOL100 User Manual. No participant skipped more than two questions in the entire questionnaire. It was notable that in the two cases of the nineteen participants surveyed, the only domain in which questions were skipped were questions about sexual quality of life. This domain was considered as part of social relationships and was scored per instructions for missing data and a derived average for that domain was added to the overall score. The one module that was of particular significance to this research above and beyond the overall scoring of quality of life was the pain domain. Analysis was executed to compare the pain module and quality of life scores against social constructs of marriage and participant gender.

Quality of life questionnaires based on a 0-100 scale utilize the following eight labels to describe the scale as follows (Celestine, N., 2019):

95 = Near perfect quality of life

85 = Very good quality of life

70 = Good quality of life

57.5 = Moderately good quality of life

40 = Somewhat bad quality of life

27.5 = Bad quality of life

15 = Very bad quality of life

5 = Extremely bad quality of life

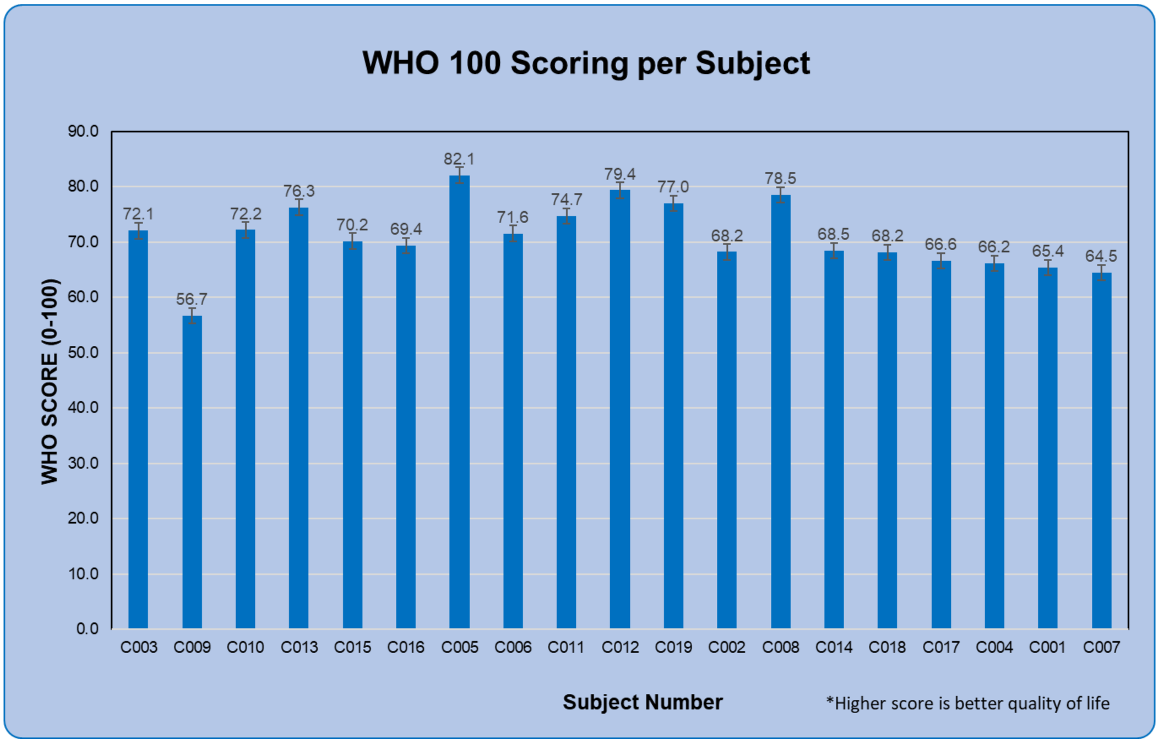

Figure 1: Quality of life scores per participant from the WHOQOL100 survey.

The overall Quality of Life scores per participant in the figure above show a range of somewhat bad to good quality of life for the participants of this study. The average of the study is a score of 70.7 with a standard deviation of 6.1. and a standard error of the mean of 1.0 for nineteen participants.

The data below represents the statistical analysis of the WHOQOL100 based on some general demographic features. Reviewing the analysis of overall quality of life between men and women suffering from chronic non cancer pain who participated in this study we see that there is not any statistical difference between the two genders. The probability score of the t-test is 0.254.

Table 2

WHOQOL100 Score (based on 0-100) Higher score shows a better quality of life. M vs. F

Over- All Score	Male n=8	Female n=11
Mean	69.1	72.2
SEM	1.7	2.2
SD	5.0	6.9
M v F	t-test	*P = 0.254*

The pain module of the WHOQOL100 scoring shows no statistical difference as well between sexes and complements the overall Quality of Life score. The probability score of the t-test is 0.304.

Table 3

WHOQOL100 Score Pain Module (based on 0-5) Higher score shows a less pain. M vs. F

Pain Module	Male n=8	Female n=11
Mean	2.5	2.8
SEM	0.2	0.2
SD	0.6	0.6
M v F	t-test	*P = 0.304*

As the analysis proceeds to look at the marriage status for overall quality of life we see a trend towards marriage providing a possibly better quality of life but in this small sample size it does not achieve statistical significance. The probability score of the t-test is 0.083.

Table 4

WHOQOL100 Score Married vs Non-Married (based on 0-100) Higher score shows a better quality of life.

Over-All Score	Married n=11	Non-Married n=8
Mean	72.6	68.1
SEM	2.0	1.6
SD	6.6	4.4
M v NM	t-test	*P = 0.083*

Marriage does not reflect any trend on chronic pain as the scores are equivalent for married and non-married participants. The probability score of the t-test is 0.305.

Table 5

WHOQOL100 Score pain Module Married vs Non-Married (based on 0-5) Higher score shows a less pain.

Pain Module	Married n=11	Non-Married n=8
Mean	2.8	2.9
SEM	0.2	0.3
SD	0.6	0.7
M v NM	t-test	*P = 0.305*

The analysis for married women vs non married women in the overall quality of life seem possibly better for the married population but do not achieve statistical significance. The probability score of the t-test is 0.130.

Table 6

WHOQOL100 Score Married Women vs Non-Married Women (based on 0-100) Higher score shows a better quality of life.

Overall Score	Married Women n=6	Non-Married Women n=5
Mean	72.2	68.1
SEM	2.2	1.6
SD	6.8	4.4
MW v NMW	t-test	*P = 0.130*

Similar to the overall quality of life, the married women are reporting less pain than non-married women but still are not able to show statistical significance. The probability score of the t-test is *P= 0.306*.

Table 7

WHOQOL100 Pain Module Score Married Women vs Non-Married Women (based on 0-5) Higher score shows a less pain.

Pain Module	Married Women n=6	Non-Married Women n=5
Mean	2.8	2.5
SEM	0.2	0.2
SD	0.7	0.7
MW v NMW	t-test	*P = 0.306*

The break though data is overall quality of life for married men vs non married men. Married-men do show a statistically significant *P= 0.018* value of better quality of life than their non-married counterparts.

Table 8

WHOQOL100 Score Married Men vs Non-Married Men (based on 0-100) Higher score shows a better quality of life.

Overall Score	Married Men n=5	Non-Married Men n=3
Mean	72.7	66.1
SEM	2.2	0.6
SD	7.0	1.2
MM v NMM	t-test	*P* = *0.018*

The pain module also shows a significant difference between married men and non-married men. This follows the above assessment in table 8 for overall quality of life where married men have a better quality of life as well and in this table express less pain.

Table 9

WHOQOL100 Pain Module Score Married Men vs Non-Married Men (based on 0-5) Higher score shows a less pain.

Pain Module	Married Men n=5	Non-Married Men n=3
Mean	2.9	2.2
SEM	0.2	0.2
SD	0.7	0.4
MM v NMM	t-test	*P* = *0.046*

The overall quality of life for married men and women are the same as the p value approaches one signifying correlation between the two groups.

Table 10

WHOQOL100 Score Married Men vs Married Women (based on 0-100) Higher score shows a better quality of life.

Overall Score	Married Men n=5	Married Women n=6
Mean	72.7	72.2
SEM	2.2	2.2
SD	7.0	6.8
MM v MW	t-test	*P = 0.875*

The pain module reflects the overall quality of life module with married men and women showing similar pain scores with a large p value that denotes their similarity.

Table 11

WHOQOL100 Pain Module Score Married Men vs Married Women (based on 0-5 Higher score shows a less pain.

Pain Module	Married Men n=5	Married Women n=6
Mean	2.9	2.8
SEM	0.2	0.2
SD	0.7	0.7
MM v MW	t-test	*P = 0.935*

The non-married men and women also show similar characteristics in overall quality of life. The quality-of-life scores are less than their married counter parts but between the genders there is no difference.

Table 12

WHOQOL100 Score Non-Married Men vs Non-Married Women (based on 0-100) Higher score shows a better quality of life.

Overall Score	Non-Married Men n=3	Non-Married Women n=5
Mean	66.6	68.1
SEM	0.6	1.6
SD	1.2	4.4
NMM v NMW	t-test	*P = 0.342*

The pain scores for the non-married men vs non- married women echo the overall scores for quality of life and show no discernable difference between the genders.

Table 13

WHOQOL100 Pain Module Score Non-Married Men vs Non-Married Women (based on 0-5) Higher score shows a less pain.

Pain Module	Non-Married Men n=3	Non-Married Women n=5
Mean	2.2	2.5
SEM	0.2	0.2
SD	0.4	0.7
NMM v NMW	t-test	*P = 0.341*

NARRATIVE DATA

There were nineteen participants in the WHOQOL100 survey. In the narrative portion of the research, seventeen participants were able to respond. Two participants were “lost to follow-up,” and they were sent the *Appendix 6* form letter after numerous attempts to solicit their response. As an investigator, I left phone and email messages but was not successful in reconnecting. There was not a response to the lost to follow up letters. Much later, one of the respondents did contact me and respond that they were feeling poorly and did need surgery for pain relief.

The participant narrative data was organized following a script of interrogatories to elicit a response regarding the participant’s pain history. The script in *Appendix 3* was used as a guide to help steer the conversation through the participants major history of chronic non cancer pain.

DEMOGRAPHICS

The demographic data from the narratives is already captured in table one. The demographics were reviewed in the narrative but originally captured in the WHOQOL 100 survey document. There were not discrepancies in what was written and what information was gleaned from the narrative session. All respondents were happy to help and believed that their work would further a base of knowledge on those who suffer from chronic pain. The participants responses seemed candid and there did not seem to be a hesitancy to respond.

Not included in the demographic table was the educational component and economic status of the participants. No one in the group was below US Federal Poverty

Level of 15,060 USD per year as per the published Federal Register Notice of January 17, 2024 (DoHHS, 2024). The federal poverty level for one person in 2021, when this data was collected was 12,880 USD (DoHHS, 2021). The actual range of the participants of this study was between 25 and 150K per year. Most were better off than the low end of the spectrum owing to the fact that most participants did not live alone and had better combined resources than had they lived alone (Wheeler, T., 2017). All participants had a HS diploma with most of the participants being college educated with quite a few having advanced degrees such as PhD and JD degrees.

There were no participants that were not enrolled in some form of medical insurance. Those who had retired from the work force participated in the Medicare program. There were participants who were still in the work force and were covered by their own or a spouse's private medical plan. There was one participant who had military insurance for life and felt that it was exceptional. The participants all seemed to feel they had access to adequate medical care. During the discussion, the issue of medical access was investigated. All participants in this study felt that they had full access to medical care and these participants were grateful for the care they were receiving.

Some participants who had lifelong chronic pain did lament the fact that their pain experiences in their younger life were not taken seriously and delayed an accurate medical diagnosis. Getting the right initial diagnosis was often illusive. A portion of the participants did have to investigate multiple times to find an HCP who could help them. The over-whelming consensus of the participants when asked regarding the relationship with their current medical providers was that they felt heard.

Unfortunately, the two participants who did not take part in the narrative portion of the study were the same participants who were in the greatest pain and probably had the least amount of community support. Both participants were living alone and were very much in pain. Preliminary information gleaned from the WHOQOL100 survey showed higher pain scores and lower quality of life scores than the rest of the cohorts who completed the narrative portion. Both participants were seeking surgical intervention to relieve their symptoms, and both were having a challenging time finding the correct medical attention.

RELIGION

The aspect of religion or a spiritual component of the interview gathered as many different answers as there were participants. A sizable portion of the participants were actively practicing some form of organized religion. The few who were no longer actively involved with an organized religion did acknowledge that they formerly were involved with an organized religion and were no longer involved with that religion. Some participants had a deeply religious background including one who is a pastor of a congregation. There were those who were no longer practicing any organized religion at all. All of those interviewed had some attachment to Christian ideology.

More than half the respondents detailed that religion played a part in their lives and influenced their value systems. A few of the participants stressed how religion and reflection had helped them to deal with their pain. Some participants used prayer and the reading of the bible to help get themselves through particularly difficult episodes of pain.

As discussed earlier, some cultures look at pain as a part of life. There was not that feeling from within this group. Those who suffered from pain believed it was the body telling them that there is something wrong. It did not seem as if there were any practices of stoicism in this group. Since there was chronic pain there was felt a need to try and alleviate the symptoms.

The participants who discussed religion fell into two main divisions: those who used religion to help them endure their chronic pain and those who said they had religious beliefs but did not rely on those beliefs as a way to ameliorate the symptoms and thoughts of pain. There did not seem to be any pattern of support system versus religion to describe the dichotomy. Some participants had a dedicated support system and were deeply religious and there were those that had a dedicated support system and did not utilize religion as a means to mediate their chronic pain. Some used prayer and reading the Christian Bible as a way to comfort themselves in times of pain.

DOMESTIC LIVING ARRANGEMENTS AND SUPPORT SYSTEMS

During the narrative interviews with the participants, they all each had identified that they live in secure and safe housing. Their settings are varied with some living in apartments, single family homes and modular homes. The geographies are rural, suburban, and near larger towns. One outstanding finding is that more than half of the respondents had moved to warmer climates in the sunbelt. The participants acknowledged this move south was to help alleviate the increase of pain that accompanies living in a colder climate such as the Northeast. The few participants living in the NE suggested that they may in the future move to warmer climates to be with family and to help alleviate pain.

Support for those in chronic pain comes from HCPs, community, church, family, and friends. Participants in this study all lived in their own homes with no external professional help being provided. Many of the participants in the study had spouses, children, and community members provide who provided support for them in time of distress from chronic pain. Some everyday tasks may seem monumental to those in chronic pain. It was described many times that having a spouse or children living in the home who are willing to provide daily support is invaluable.

During COVID community support was more difficult to obtain. Caregivers were wary of catching or spreading the virus. The public was urged to stay at home and limit contact with strangers unless they were an HCP. Efforts to maintain social distancing, the 6ft separation rule, caused many would be supporters to stay at home. The participants in this study noted that external support during COVID was difficult to obtain. The increase in isolation did lead to more use, of those who were able, to communicate through online social platforms and videochats. Some external essential services provided touchless delivery of goods. Online ordering of goods and delivery of groceries had a large uptick in use. The participants spoke very highly of the healthcare community as being supportive with COVID19 related issues and being supportive overall.

Families were the predominant support for these participants. One participant noted he would be in a nursing home if it were not for the care of his wife. Children were also a major family support. Even if the children were not living home, the children would still make themselves available to help when needed. Some children checked in on a regular basis just to be sure their parents’ needs were being met. It was also mentioned that some extended family could be counted on in case of emergencies. The extended family members may be some distance away from the participants but were counted as reliable resources. A few participants did mention the church community for support, but this support was not really outlined. All of the participants acknowledged the need for emotional as well as physical support. Even the few participants that said they have a challenging time asking for support acknowledged that support in time of distress was welcome and comforting.

DESCRIPTION OF CURRENT PAIN

The key components of this project were to investigate the current level of pain, the etiology of the pain, the duration of the pain and the current regimen of pain treatment. The narrative script is detailed about the current modes of treatment, what works for each participant, and did participants feel that their current treatment regimens were enough to alleviate their chronic pain. Levels of chronic pain vary by day, weather, diet, previous activity, and even the position during sleep.

Pain levels were varied for all participants. The *Wong-Baker Faces Scales* registers pain in face emojis on a scale of one to ten. The scale uses the value of one being the lowest value correlating to no pain and a value of 10 signifying unbearable pain (Wong, D.L. and Baker, C.M. 1988). This scale is depicted as part of the script in *Appendix 3*. On good days, the pain levels were as low as a two on the Wong Scale. For some, pain could at times reach unbearable levels of ten, the highest level on the Wong Scale. Each participant had their own solutions for pain relief .

Medications: Several participants use over-the-counter pain relievers like Tylenol or ibuprofen. Some use prescription medications like meloxicam, gabapentin, and tramadol. Another uses Cymbalta and nabumetone. A few participants require opioid therapy such as morphine, oxycodone, Vicodin, and fentanyl patches. The opioid therapies as well as other therapies can be changed by the HCP for their patient and are usually re-evaluated during each monthly pain management session for those who have a specific pain management HCP.

Non-pharmacological treatments: Heat therapy (heating pads) was mentioned by multiple participants. Cold packs were an option but were not usually favored as they were an extreme when other therapies were not working. Physical therapy and exercises were common, especially for back and joint issues. One participant used a spinal cord stimulator to alleviate back pain. Some participants engage in regular walking or other light exercises. Several described utilizing regular chiropractic adjustments. Daily back exercises were also performed by some participants.

Medical Procedures: Cortisone injections were mentioned by a few participants for joint pain. One participant receives regular IV treatments for lung issues. Also stated were epidural injections, radiofrequency ablation and trigger point injections which are injections that focus on a specific muscle or nerve group and are closely related to facet joint injections in the spine but more general to specific areas thought to be the etiology of the pain symptoms.

Alternative Therapies: A few participants have tried or considered acupuncture but did not report much success. This seemed to be an issue of they tried a few sessions and there was not a perceived relief from pain. One participant uses medical marijuana and reports some relief from pain but not consistent as they had hoped. Some participants also stated that low impact exercise like biking could provide a vehicle to stretching and non-weight bearing exercise that could still build some strength and not do as much damage to some of their painful joints using a slow rhythmic motion with ability to build up to more rigorous exercise if they felt they could do so.

Self-management strategies: Many participants mentioned resting when pain increases. Some modify activities or use assistive devices (like walkers and canes) as needed. One participant, a musician, continues to play piano as a form of therapy for arthritis. Meditation and mindfulness are also used to help alleviate pain in times of flair ups. The ability to control breathing and to be mindful are strategies that a few participants have used to control pain.

The etiology of the pain was varied for each person, but lower back was a predominant feature of many of the participants. The chronic lower back pain evolved in many ways. For some it was a degenerative disease paradigm. For these participants, there was not a known external cause for the chronic degenerative disease and pain. For some, chronic pain was due to various accidents or injuries that have taken a toll on their bodies at one time or over time. Many have suffered for decades with chronic pain, without much relief. Some have had surgical interventions, but those have not been very successful. In one case, a procedure was quite disastrous, which led to infective complications.

Many of the participants have a chronic and progressive disease model in which the pain will only get worse, and pain relief seems out of reach. As previously discussed, most in this survey seem to have their pain at a moderate level but have steadily progressed to higher levels of pain over time. The participants have tried to find ways to accept this progressing pain.

PAIN AFFECTS ON EVERYDAY LIFE

Chronic pain affects everyday life, as described by the participants of this study. Each participant talked about the limitations pain placed on their lives. Some have lost jobs or even the ability to work and are now receiving full disability benefits. Some find a way to deal with chronic pain that seems incomprehensible to me. They have returned to their previous positions and try to keep the pain under control. Every end of shift or workday for this group of participants is spent recovering to get ready for the next day and next onslaught of pain.

Personal relationships with friends and family have taken a toll due to chronic pain. The pain quashes any thought of being in a social situation even when they would really like to attend an event. There are times when family and friends pressure a person to attend an event or function and cannot see the effort or damage that occurs from a person pushing through the pain to deal with these special social requests. Many families and friends do not comprehend the absolute pain endured in these situations and that the person does not seem to be in pain. There is a large guilt component utilized against those in chronic pain. The possible over-exertion at these events can leave days and weeks of exacerbated pain due to trying to appease the requests.

Friendships have faded away due to lack of contact on the part of those in pain. Leaving the workforce due to pain has also caused feelings of anxiety, depression, and a loss of self-worth. Even spiritual communities seem out of reach through lack of contact. Although this was discussed, the above losses did happen, but these participants did have dedicated support systems in place and all participants felt extremely lucky and happy to have the support they were receiving. The two participants that had the least support were the most isolated and endured higher levels of pain as determined from the

WHOQOL100 survey. These two participants were not interviewed and could not be followed up. Neither one had the ability to find a time when they thought they could endure the interview process, both postponed the interviews for when the thought they would feel better, in the end, both stopped responding to requests to be interviewed.

The discussion of daily activities and the limitations caused by chronic pain was a very intense discussion. Listening to participants detail how chronic pain had changed their lives and how they managed to continue to make progress in their lives was very enlightening. Many participants suggested some similar items such as the loss of ability to do the physical tasks that were previously a part of their everyday routines. Household chores were a quite common limitation. Preparing meals, house cleaning, laundry was commonly stated as difficult. Activities outside the home such as shopping and just taking walks were curtailed by chronic pain. The ability to do certain tasks without having a plan about when and where to take breaks and what to do in the case of extreme pain making a task impossible to continue with the task in which they were involved.

Pain also frequently interrupted the sleep cycles of participants. Even with the use of analgesic agents and sleeping medications, participants sleep cycles were often interrupted. Some participants noted they just could not find a way to get comfortable. The poor sleep cycles led to an inability to function during the day and often led to frequent napping and constantly feeling tired as well as in pain. Daily living activities such as walking and sitting for extended periods of time could be difficult. Personal hygiene can be difficult and in turn causes participants to feel anxiety and become depressed that they cannot achieve the self-care they need or want. Adequate self-care can be a barrier to any just getting some outdoor time.

FUTURE THOUGHTS ABOUT PARTICIPANT'S CHRONIC PAIN

Chronic pain curtails most positive thoughts on the future. Many participants stated that they do not see a future without pain. Each has detailed their thoughts, but they all see further limitations to the things they would be able to do in the future versus the present. The loss of independence, not relying on others to achieve goals that once were within their own control is a major issue. Some participants see probable future surgeries will be required and are not looking forward to that prospect. The current level of the pain seems to be a best-case scenario. The pain for most is manageable now with the accompanying treatment regimens but the participants see their conditions as not remaining stable. This amount of pain was not what they were hoping to be dealing with at this point in their lives.

A few participants thought their current levels of pain might remain stable and that they would be able to continue their current activity levels. This was a minority opinion. Most believed their conditions would only continue to worsen. Those who were working still wondered how much longer they could continue to be productive in their profession in their current position. Participants were hoping to remain in the workforce, but they were feeling pressure from their chronic pain and the demands of the job to do things that were physically and mentally difficult due to the symptoms related to the chronic pain. Mobility issues due to pain were a big concern in the future. The additional burden on their families and support systems causes anxiety.

Participants were also worried about the additional issues that come with age such as arthritis being a compounding factor to their mobility and pain issues. Already burdened with current pain issues most see the future as worsening faster than when they were younger. For some participants, the pain had advanced to having some days that getting out of bed could be a challenge. Additional time, now required to deal with everyday life, was a standard. The task of getting ready to leave the home to go to an appointment could be a task that takes hours instead of minutes. The ability to know if one can even get themself ready can be a mental burden and lead to lateness, cancellations, and declinations of invitations. Your friends and family may accept that one may only be day to day to come to an event, but many HCP offices are not so forgiving. HCPs generally have a policy of at least 24 hours prior to an appointment to cancel. Patients who have chronic pain are hoping to make the appointment at all. but It comes down to the last 12 hours if they can muster the fortitude to make it up and out the door on time.

PAIN AND ITS EFFECT ON RELATIONSHIPS

The most consistent ffect of chronic pain was the fact that interpersonal relationships were adversely affected and led to isolation. The isolation occurred due to many types of scenarios, but a large component was self-isolation. When levels of pain were high, some participants would rather be alone. The sufferers would seek refuge away from their families and support because the interactions were just too much to endure. As discussed previously, many techniques are used for pain relief and some need to be practiced in private. This isolation should last until the pain cycle breaks or perhaps medication or another non-pharmacological regimen alleviates the worst levels of pain.

Chronic pain reduces the circle of friends and family. Some loss of friends and support is due to the isolation factor, but many times it is only plain difficulty on focusing outside the pain. Participants lament loss of friends through group activities that they would have previously been involved prior to the intensified chronic pain. Many of these activities were physical ones. The physical activities mentioned by the participants were hiking groups, biking, and basketball. Attending events that were long travel distances or required being in a place where there was not an ability to retreat from the public would make these type events unimaginable.

Visiting family and friends is difficult and the burden is now on the friends and family to come visit the participant as this may be the only way that the chronic pain sufferer has the ability to be around others with the safety net of being able to retreat to a place in the home if the pain reaches an elevated level that the participant requires a break to recover. Familial dynamics change due to chronic pain. Familial relationships can be understanding or surprisingly callous. Marriages have dissolved, familial activities were modified or stopped, and friends are not as available as they once were. Intimate relations are often set aside as they are just unimaginable.

Participants know that their pain leaves them with less patience and tolerance at times and they can seem unhappy or stressed and not treat others like they used to treat them. Some family, friends and support groups know this is an outcome of the pain but is not always easy to accept. These exhibitions of negativity can also lead to isolation to the participant by their support systems. It is a difficult cycle of pain. Each side needing to recover and reset in order to go on to the next day.

Participants have also detailed how some family relationships have grown stronger. Their families know and understand the pain they are enduring and try to be more supportive; the families realize that chronic pain has placed many limitations on their loved ones, and they have stepped up to make the lives of those suffering from chronic pain as good as it can be. Many participants had spoken about how the quality of their lives would not be nearly what it is now had it not been for their significant others. This was also borne out by the WHOQOL100 that showed married participants and in particular to a significant amount, male married participants, had a much better quality of life.

THE MEYNADIER INVASION OF PAIN IN EVERYDAY SPEECH DISCUSSION

In 2005 Jaques Meynadier authored a chapter in the book Narrative, Pain, and Suffering by DB Carr et. al. describing the invasion of speech by pain. In the narrative sessions, I discussed with participants the scale used by Meynadier to rate those who suffer from chronic pain by how often they discuss their pain in their daily speech. The ratings scale was as follows:

0= No complaint even on questioning

1= Complaint only on questioning

2= Spontaneous complaint, infrequent, only addressed to specific people among participant's contacts

3= Partial invasion of speech by the complaint: the participant complaints to everyone but is however able to talk with someone else

4= Complete invasion of speech by the complaint

In this study, the participants were asked to be introspective and self-report on how they felt they would describe themselves on this scale. As always, the audience for this type of analysis would produce different results based on the listeners bias and relation to the participants. None of the participants believed that they were at a point where their only conversations would be about their pain. Most participants tend not to bring up pain in everyday discussions unless necessary. The participants were more likely to mention pain to close family members (especially spouses) than to others. Several participants reported that they actively try to avoid talking about pain to prevent it from defining them. Some participants will discuss pain if directly asked. Pain might be mentioned in the context of needing to modify or stop an activity; they may be tired and need a break; or the pain is too great for them to continue in an activity and may need to drop out. According to the participants, there is a general preference to keep pain private rather than making it a topic of regular conversation. One participant stated that their friends and family know they are in pain, and they feel that they do not need to reiterate what they believe is already known. The participant is not looking for sympathy, they are doing the best they can.

DISCUSSION

OPIOID CRISIS

Chronic pain affects fifty million Americans (just under 20% of the age-adjusted adult population) which is defined as "pain on most days or every day in the past 6 months." Nearly 20 million (about 7.5%) experienced high-impact chronic pain, defined as "limiting life or work activities on most days or every day in the past 6 months (Dowell, D.C., 2016). A proposed 2022 guidelines from CDC is that chronic pain be considered as such at 3 months of continuous pain but this is not yet codified (Greenspan A.L. 2022). Patients that suffer from chronic pain may not show any physical or outward signs of their affliction. The common notion is true that pain is the bodies response to a stimulus telling the brain that something is wrong. The World Health organization tells us that pain control is a basic human right. How do we, as a society, continue to not get this right?

Pain affects everything about the human condition. The CDC lists out that twenty million Americans have such debilitating pain that they are no longer able to participate in the workforce. There is continuous research into ways to alleviate the symptoms of pain. New analgesics, nerve blocks, migraine treatments as well as so many current treatments that are used off label to help reduce the symptoms of pain still are not enough to satisfy the increasing unmet medical needs of those suffering from chronic pain. Still the medical society and government treat pain patients as pariahs (Ramsay, L., 2018). It is frustrating when an HCP can do nothing to cure the pain but only help ameliorate some of the symptoms. The government looks at some of those who take pharmaceuticals as a gateway to illicit use . These points of view are wrong, especially for those who suffer from debilitating chronic pain. Physicians who treat pain feel they should be able to prescribe for their patients what is appropriate (Huang, C.J., 2018) .

Pharmaceuticals in some instances are what keep the other thirty million who are not classified as debilitated from being unable to do what they need to do to be an autonomous functioning member of society. The current CDC guidelines from 2020 have softened and refined the language from the 2016 report, but severe damage has been done. There are numerous accounts from the regional newspapers and headlines like this from VICE; “ *Cracking Down on Opioids Hurts People with Chronic Pain*” (Szalavitz, M. 2017) are only the tip of the iceberg as to what is actually happening in the U.S. Suicides have increased due the reduction of opioid pain relievers. Former functioning patients who had their pain relatively controlled were forced to have their opioid doses reduced to fall in line with CDC guidelines. The reductions forced the patients to retreat into isolation. The pain was now uncontrolled, and they could no longer enjoy the ability to have pain relief.

Some HCPs decided that they would avoid the issues of scrutiny over opioid pain prescriptions and jettison those patients from their practice entirely. The fear of loss of license was a reality. For those patients who were jettisoned, there may not be another local HCP to take on a pain management patient. These patients are some the population that may turn to street drugs because they now have no other alternative. The new policies have caused fewer prescriptions for opioids to be written and that is a good thing. According current 2024 CDC Morbidity and Mortality report, opioid deaths are starting to decrease (CDC National Center for Health Statistics, 2024). The consequence of this prescription reduction could have been the continued uptick in opioid, especially fentanyl, deaths which were more than likely the result of street drugs. There is not a way to know clearly if a drug death is from street drugs or pharmaceutical grade drugs unless an expensive analysis is completed looking at all the excipients in the original drug as well as an exhaustive look at the metabolites found in the body of the deceased.

Many hurtful issues are for those who still are getting prescriptions written but for not enough medicine to control the symptoms of pain. This injustice is easing a bit with HCPs, but the culprits who now continue the problem are the pharmacy benefit managers (PBMs) who are denying coverage of opioids or are only allowing prescriptions up to the CDC recommended amount of ninety milligram morphine equivalents per month. The recent litigation that has been directed at manufacturers and distributors of opioids has become a rational for PBMs to make this decree. A patient can appeal but the appeals are summarily denied. A patient may still get the fully prescribed amount from their HCP, but the PBM will only pay for what the CDC guideline suggests. This does nothing to reduce the number of opioids prescribed, it just shifts the financial and legal burdens to the patient. Those who cannot afford to pay out of pocket are the ones who are the most hurt.

There is also an issue of where chronic pain sufferers can get some prescriptions filled. Many of the big chain pharmacies do not have a full formulary of opioids and a patient needs to seek out more specialized pharmacies to get their prescriptions filled. These specialized types of pharmacies may not be available in your town. If someone finds a pharmacy that could fill their prescription, the prescription still may not be able to have been filled because the pharmacy has reached its limit of how many opioid prescriptions that this pharmacy can currently fill. Once again, the distributors and PBMs are regulating the supply chain. If a prescribed moves from one area to another a new difficulty may arise. The afflicted may have to keep going back to their previous pharmacy to fill a prescription because the prescription is already accounted for in the former pharmacy's monthly allotment of opioid prescriptions. The U.S. D.E.A. also has taken a stronger hand in regulating what opioid products are delivered to a pharmacy. If the pharmacy has been successful in securing approval from the distributor to obtain the products to be delivered to the requesting pharmacy, the DEA reviews the orders as well as the PBM and distributer. The pharmacies are told that it is at their discrepancy to distribute narcotics to customers, but the DEA has become an aggressive reviewer. If a pharmacy adds too many new opioid prescriptions it will trigger a DEA audit of the entire pharmacy. This additional burden is a reason for pharmacies to avoid accepting new prescriptions from chronic pain patients.

COVID PANDEMIC

This research was conducted during the coronavirus disease 2019 (COVID-19) pandemic caused by a global outbreak of the coronavirus – an infectious disease caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). The participants of this study did follow required precautions as well as generally tried to isolate from strangers and large indoor gatherings and were able to make all their medical appointments. Only a few participants had some delays in being able to have their medical needs met. There did not seem to be any issues receiving treatment or prescription medications for pain relief. The pandemic afforded the opportunity for me to utilize a technology that was not previously used as widespread as it was during the pandemic. All the interviews for this study were conducted using applications that allowed video communications. In addition to the video communication, the application allowed for audio transcription. All the participants felt comfortable conducting the interviews in this manner and this I attribute to the pandemic making this type of communication more utilized and accepted. As with all narratives, the bias is between the narrator and the listener. This technology allowed me to see and converse with the narrator in their own safe space. I am hoping this safe space provided my analysis with a less stressful and judgmental atmosphere and that the narrators felt free in their story telling. The responses from the narratives did match up with the responses from the WHOQOL100 survey.

Many of the issues were a direct match and, in most cases, would not normally be an issue for discrepancy. When the discussion turned to more abstract feelings regarding their quality of life, the participants all seemed thoughtful as described in their responses and their relaxed body language. Aside from a face-to-face meeting, the tele-video meetings afforded an opportunity to interview participants thousands of miles away in a more personal setting than just a phone conversation and since recruitment was difficult, this was an exceptional resource.

RECRUITMENT

Recruitment for this study was a challenging task. The ask was a personal look into the attitudes, culture and treatment of the participants suffering from a chronic pain condition. Recruitment advertisements were placed in locations that should have attracted the attention of would-be participants. The recruitment through IRB approved advertisements proved to be fruitless. Only one enquiry was from a non-word of mouth referral. The advertisement referral came from a six-month run in the "Drew University This Week" communication that was emailed to the Drew University community on a weekly basis. The advertisement had all required elements and is shown as *Appendix 4*. The best referrals came from professional colleagues and fellow students who had received a detailed description of the project and were able to refer possible recruits for the study. It is detailed in many sources the reluctance of those to participate in clinical studies. There is a fundamental mistrust of those that conduct human research. There are often times not a direct benefit to those involved in the research project and this is clearly stated in all informed consents. It cannot be guaranteed that a participant can be helped but that others may benefit from the participation of those participants helping to find answers for future research.

The recruitment for this study was not as diverse as the US population but there was a near even split between men and women as well as married and not married participants. All participants were Caucasian in appearance but two were of Latino heritage. Unfortunately, there were no Black, Asian or any other racial background participants. The range of participants did span the U.S. East coast. The participants included some transplants from New England to Florida, actual or long time Floridians, several of the local New Jersey metropolitan area participants and a few participants from the mid-Atlantic region. Their narratives did provide a good basis for this narrative research project.

QUALITY OF LIFE

Quality of life for those who suffer from chronic pain is often the subject of debate. Those who have not experienced chronic pain may find it difficult to empathize with the complex issues associated with such conditionsEven those who suffer chronic pain cannot judge another but may be able to better empathize with fellow sufferers. Pain is personal and no one can say how another feels. With that in mind, this research looked at the quality of life of the participants who were all diagnosed as suffering from chronic pain. The participants were asked to complete a one hundred question validated quality of life instrument, the WHOQOL100. The questionnaire was scored using the derived algorithm that is associated with the instrument. The scores are reported in *Figure 1* above. Most in this study had a “moderate to good quality of life” or better as from the scoring in the publication by Celestine, N 2019, that describes the different values and their associated corollary labels which are detailed in the results section. It is unfortunate that the two participants with lowest scores based on the WHOQOL100 dropped out of the narrative portion of the project. These participants had the lowest quality of life scores and also had very serious pain issues that kept them from completing the narrative portion of the study. Neither participant would respond to attempts to contact them for the narrative portion and were officially considered “lost to follow up” and would have provided more insight for the project.

One of the domains of the WHOQOL100 survey included a domain on pain. This domain did show a correlation between quality of life and pain. The table in the results section reveals some interesting but not unheard-of outcomes. The one statistically significant set of outcomes were that married men with chronic pain had a better quality of life the non-married men as well as better pain scores. The trend was similar for married women vs. non married women but did not meet statistical significance. The analysis also shows the p-value for married women vs married men was close to correlation and more similar than not as the expressed value was 0.875 and a correlation of pain expressed as 0.935 for married men vs married women. It is quite evident that those who suffer from chronic pain and are married have a better quality of life and even though they suffer from chronic pain are able to deal with chronic pain better when they have spousal support.

NARRATIVE ANALYSIS

The participant interviews used to transcribe into participant narratives were recorded sessions from Microsoft Teams and in two instances from ZOOM video calls. The interviews lasted from 45 minutes up to 90 minutes in length and followed the script of *Appendix3*. All the participants were at ease with the interviews and spoke freely as we wound our way through the script driven interview. In all, over 650 pages of total p in single space small font were captured for analysis utilizing the CLAUDE AI algorithm. The patient names were removed and replaced with participant ID numbers and the narratives were pooled to help keep anonymity of the interviews. CLAUDE AI is a cloud-based project that provides a locked area for research of each subscriber so that their projects are kept secure and confidential. None the less, security and privacy are a hallmark of patient data stewardship, and this data needs to be kept secure. The analysis algorithm was able to take the inputted pooled narratives and provide summaries based the interrogatories provided to the algorithm.

The program could research a single participant if asked or it could provide accurate summaries of the data in an aggregate statement. I would review this statement and use its contents to speak to the questions that were originally asked in the interview script. The narratives outcomes are described previously. The outcomes do vary for each person. There are some similarities, but the constant was they all had a consistent level of pain and a similar quality of life readout. It was unfortunate that the two lowest quality of life respondents could not be available for the narrative portion of the project. It validates that the two had a poorer quality of life and lower pain score numbers which translate into having more pain. As part of their lower quality of life scores, the domains for support systems were also lower. The other participants in the study had family, friends, or community support.

The bias in the narrative is that the investigator in this situation is the only reporter. It is known that a different audience can produce a different story. Frequently a doctor hears a different story than a nurse or a chaplain or a family member. I am hoping that this interview will fall on the less reserved side of the paradigm. All participants were advised that their responses were anonymous and that I would be the reviewer and aggregator of their narratives. I tried to consider Maynadier's theory of invasion of speech. I questioned the participants about their thoughts about how pain invades their everyday speech. Most seemed stoic. They believed those who were in their support system knew and understood their chronic pain and that they would rarely talk to strangers about their pain even when asked. The belief was that their pain was private. In the brief time spent with the participants, they would relay the information requested through the interrogatory script but would need to have multiple follow questions to have the participant elaborate on the discussion points. It did seem that indeed they were reserved in their symptoms descriptions until they realized that their information would be helping the investigator understand the participant's life and prospects to facilitate the research questions.

DETERMINING THE ISSUES

The participants in this study revealed the core issues of their everyday lives. The study revealed how pain restricts the participants from physical tasks and at times can be socially isolating. Pain has proven for some to be an issue with mobility. Household chores such as cooking and cleaning, bathing and personal hygiene and walking stairs can be an issue in the home. Externally to the home, pain can be exclusionary from just going outside for fresh air, going shopping for daily necessities and even the thoughts of entertainment or a dinner out can seem out of reach. The participants all had medical insurance that made it possible to receive a comprehensive diagnosis of their conditions and access to the necessary medical care although sometimes getting an accurate diagnosis has taken years. HCPs do not always listen to pain patients to get an accurate picture of the symptoms and consequently provide first glance inaccurate diagnosis. Many of the population in this study are older and have fought to be heard and believe they now have physicians that hear and understand their chronic pain issues. Covid Isolationism was not an issue for most, access was still provided, although wait times for appointments were longer. Some advised that some in person visits were replaced with telehealth appointments. The ability to keep appointments is extremely important for those who need opioid therapy as one needs a new prescription every month.

Opioid treatments were an issue where some participants suffered from reduced dosage due to CDC guidelines as well as some State issued regulations that strengthened the federal policies. The reduction in dosage as well as some HCPs who have dropped patients in their care for needing opioids is a big concern. The number of pain care clinics are diminishing due to increased legal scrutiny and liability issues and as a consequence the former patients are left in a bind. A few participants had their dosages cut in half. This reduction of dose follows a national trend. This interference with treatment regimens has led to more isolationism because the sufferer’s ability to function has been greatly reduced. There are days when any movement causes pain due to the lack of pain control. There have been studies that show that anxiety and depression increase due to this lack of pain control up to the point where some have considered suicide. I do not believe any of these participants fall into that category, but some are suffering from anxiety and depression as co-morbidities of their chronic pain.

Even though the participants in this study do seem to have a current handle on their chronic pain, their future does seem to continue a downward slide. All have acknowledged that they only expect their chronic pain to worsen and are unsure how they will deal with this in the future. Continuous visits and talking with HCPs are what the participants believe will continue to give support for the inevitable worsening of their conditions. All participants have greatly acknowledged the support systems they have in place. They are grateful for the support and acknowledge that their lives would be in a lesser place without the support. One participant detailed that “ I would be in a nursing home if it were not for the support of my wife.” Community, family, and friends support is one of the most important aspects of dealing with chronic pain. As previously discussed, all the issues that surround living with chronic pain are at time reduced to having a system of support that has empathy for the whole person and can understand their needs to help them continue their lives in a way that preserves their dignity and quality of life.

CONCLUSION

Chronic pain as a category may need to be reconsidered. Acute pain is defined as pain that lasts less than 6 months and chronic pain is defined as persists for greater than six months. A new designation may need to be considered for "chronic long-term pain." Some sufferers in what is now termed as chronic pain can see their pain resolve in a finite time span, such as replacement knee or hip surgery. Others considered in the chronic pain category may never achieve relief. In fact, the participants in this study all felt that their pain will continue to worsen throughout their lifetime.

Those who suffer from chronic pain strive to live life in a meaningful way. This is done by receiving the care and relief from some of the symptoms that debilitate them every day. The World Health Organization has not only identified pain control as an essential component of patient care but also as a basic human right. (Brennan F, et al, 2007). As a society we have fallen down on this remit. Chronic pain is an invisible epidemic! From the statistics we see that in the US a full 20 % of the population are afflicted with chronic pain. We have an ethical duty to treat this population and to try to relieve their pain. Chronic pain was being more seriously addressed in the 1990s with the idea of that pain was the fifth vital sign. This was a good progressive stance.

Unfortunately, the new importance of this pain model was the open door for pharmaceutical companies to see pain as a fresh area to target for the development of strong compounds that would alleviate the symptoms of acute and chronic pain. For those who suffered from chronic pain, the newfound emphasis on pain relief was welcome. To some unscrupulous HCPs, peddling pain medicines was a money maker and there became a rise in what was known as “Pill Mills.” Pills Mills were facilities where one could easily obtain prescriptions for pain medications from an HCP. This increase in opioid prescriptions was fueled by a lax regulatory environment in which pharmaceutical companies that manufactured the compounds could incentivize HCPs to prescribe their compounds. Easy access to pain medication provided a route for abuse problems and a prescription drug addiction cycle. Opioid abuse is not new and was an issue in the 20th century with the use of heroin. Since that time, new stronger synthetic molecular derivatives have been developed and made available to the public through prescription routes and many times easier to obtain by the general population by means of diversion, a term to describe the unlawful distribution of narcotics to those who do not have a medical need.

The pendulum has now swung back the other way. A tightening of regulations that reduces the dosages and prescribing guidelines was first set forth in 2016, revised in 2020 and may have another revised document in 2025. The guidelines reduced the number of opioids prescribed for pain for non-chronic treatment from a 14-day supply to 7-day supply with possibility of refill. This one change is welcome to help avoid opioid dependence and divergence. Still if one needs more than 7 days pain relief one can obtain a refill under closer HCP oversite. The hit for those who suffer from chronic pain came in the form of the guidance that no one should be receiving more than ninety milligram morphine equivalents per month. HCPs were thought to be in danger to lose their license if they prescribed more than this amount even though the higher doses were not illegal. State legislature also “took up the call” to insist that this guidance was law. Along with this new guidance, lawsuits were spawning against pharmaceutical companies that manufactured the pain killing drugs, the middlemen distributers who supplied pharmacies and hospitals with the pain killing drugs, pharmacy chains that filled prescriptions for the pain killing drugs and finally, the HCPs who prescribed the compounds. The lawsuit threats caused many HCPs to reduce or even completely stop prescribing opioids. For those who suffer from chronic pain, it was a disaster. Many of those on opioid treatment had been titrated to a stable dose that did allow them to function but were far above the CDC guidelines. HCPs were not willing to risk their livelihood to continue the current treatment regimens.

Some participants in this study were affected by these new guidelines and their journey for pain relief was truly an odyssey. The reduction in dose guidelines as well as HCP's refusal to prescribe opioids made the quality of their lives much worse than they had previously enjoyed. The possibility of finding a new HCP for pain management was even more difficult with HCPs now wishing to distance themselves from this option of treatment. In 2020 the CDC came out with more nuanced guidelines, but the damage was done and there was a reluctance of HCPs to return to previous treatment regimens. The onslaught of state legal victories over distributers and manufactures as well as local and federal prosecutions of HCPs had swung the treatment pendulum far back to more conservative treatment options. If a patient was not willing to receive ancillary interventional treatment (i.e., epidural injections or radio frequency ablations) along with opioids, they were discharged from the program.

HCPs now provide a document for opioid therapy, a contract for pain management. Any infraction could be reason for termination from the program. In conjunction with the Opioid Contract, other contracts had now come into vogue to insulate the HCPs against potential lawsuits in the future. Scheduled drugs (benzodiazepines) that are used in conjunction with opioids also became monitored in the same fashion as opioids. Random urine testing is performed to be sure that all treatments that were prescribed were at therapeutic doses as determined by scientific analysis of the drug and metabolite levels in the urine.

Chronic pain patients often feel they are not heard. The lack of empathy by HCPs and the federal government by those who require treatment for chronic pain are not all embraced. The HCPs need to realize that 20% of the population do suffer from chronic pain. There needs be available and sufficient treatment options for those who suffer from chronic pain. The options for those who suffer outside of the medical community are few and potentially dangerous. For those whose dosages were reduced, there is little hope. Many find that they are reduced to isolation because movement is painful. This can lead to depression and disconnecting from family and friends. There are profound consequences of these increased rates of depression and anxiety with the reduction in pain relief. Suicide rates have risen in the group. The increased pain and suffering that is no longer under control leads to feelings of hopelessness.

Illegal drugs to supplement the reduced dosage will result in expulsion from the pain management programs. Illicit drugs on their own are a major concern due to purity and strength. Street drugs may be cut with unknown and possibly deadly excipients. The strength of the drugs is also unknown. The flood of fentanyl, a drug one hundred times more potent than heroin has shown to be a large component of the overall skyrocket in opioid overdose deaths. 2024 is the first year in over a decade to register a decline in opioid deaths, not necessarily due to a reduction in usage but the widespread availability of Narcan commonly called naloxone which can reduce the effects of an opioid overdose. It is mandatory for all prescribed opioid users to also be prescribed a two pack of naloxone. Naloxone is also available over the counter and many police and EMTs carry this therapy as a matter of course to use in their daily work.

Treatments that are prescribed by HCPs are through agreement between the HCP and the patient. Patients early in their diagnosis may not have a good understanding of their chronic pain status and may not have found an HCP to adequately help them. The participants in this study have found HCPs who are listening to them, and they seem confident that their current course of treatment is on track. A big issue now is the interference of the insurance companies and pharmacy benefit managers who believe that they are more knowledgeable about the patient and their treatment than their HCP. Treatments that have been previously approved are now being denied in an effort to save money for these unwanted intermediaries. No regard for relationship between the HCP and patient has been taken for the effort to design a treatment plan that works. The appeals process seems to be a check box as the appeals are denied immediately. Lengthy appeal documents are not reviewed, and the original denial stands. The added cost savings efforts undermine the trust and efficacy of the system of providers. Even as HCPs work to provide care and patients successfully get the understanding and plan, they seek, the treatment can still be denied.

It is even a worse scenario for those who do not have competent healthcare or a means to get healthcare. Our society needs to do better. Programs such as medical humanities are having a positive impact on the rapport between HCP and patient, but now the healthcare systems are failing the patient. As healthcare costs continue to climb and access to healthcare remain unstable in our society, many people will fall through the cracks. The population that is not served by adequate medical coverage has the added burden of the earlier discussed biases that are exhibited within the patient populations and leads to situations where many will not get appropriate treatment from our healthcare system. One step forward and two steps back sometimes seems to be the motto for the underserved and prejudged populations who suffer from chronic pain.

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APPENDIX

APPENDIX 1: WELCOME LETTER

WELCOME

Dear Participant,

I thank you for taking the time to evaluate the Pain Narrative Research Program!

Please read the enclosed informed consent document. If you have no objections to participating in the program, please initial each page and completely sign and date the last page of the consent document.

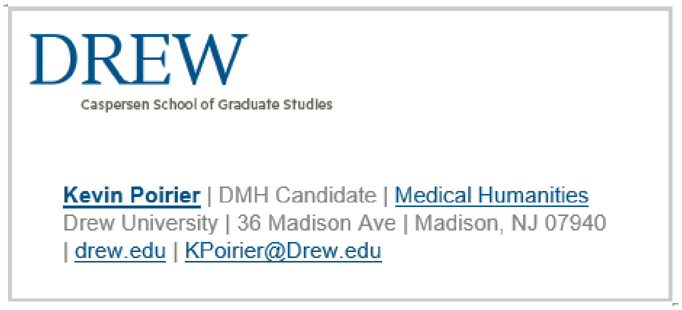
If there are any questions you can feel free to contact me, and I will be happy to clarify and review the document with you or a family member if you so desire.

After you have read and signed the informed consent document, please complete the WHO QoL survey. It will take some time. You should try to complete as much of the survey as possible. If there is a question that you cannot answer or do not feel comfortable answering, please skip to the next question, and mark a line through the question so that I know you have not accidentally skipped the question.

When you have completed both tasks, please mail the documents back to me in the stamped self-addressed envelope provided. The next step will be to set up an appointment for a video conference or a phone conference to capture your pain story. *Please keep one copy of the consent form for your own records.*

I again thank you for participating in this project which could provide insight into the lives of those who suffer from chronic pain.

Sincerely



DREW
Caspersen School of Graduate Studies

Kevin Poirier | DMH Candidate | Medical Humanities
Drew University | 36 Madison Ave | Madison, NJ 07940
| drew.edu | KPoirier@Drew.edu

APPENDIX 2: INFORMED CONSENT

What Can We Learn from Pain Narratives?

An Investigation of the Ethical Gaps in the Treatment of Patients Who Suffer from Chronic Non-Cancer Pain through the Perspective of Patient Narratives.

CONSENT FORM

1. SUMMARY and KEY INFORMATION

You are invited to participate in a research study about subjects who suffer from non- cancer chronic pain. Your participation is voluntary. You were selected as a possible participant because you have responded to a request to participate in a study to help better understand the issues that surround subjects who suffer from non-cancer chronic pain. The purpose of this study is to better understand the subject's view of chronic pain through the telling of their story. The research session could last up to 180 minutes. As part of the study, you will answer questions about the quality of your life using a survey and then telling your story to a researcher by speaking aloud your story about your life experiences with how non-cancer chronic pain has affected you. As part of the study, you will not experience any physical interventions. You will only be asked to answer in writing questions on a survey form and to be a part of a session telling your story to be recorded and then written in story format. Your story will be reviewed along with other subjects to look for parts of your story that are like other subjects' stories and how your story relates to the survey that you took. You may not directly benefit from participating in this study; however, we may learn new things that could help others with non-cancer chronic pain. The study is being conducted through Drew University, Casperson School of Graduate Studies Medical Humanities Program. The study is being conducted by a doctoral program candidate.

We ask that you read this document and ask any questions you may have before agreeing to be in the study.

2. BACKGROUND

There currently exists research along the lines of demographic differences in pain treatment. This study will include a review of demographic surveys to better facilitate the collection of personal non cancer chronic pain narratives. Analysis into the current climate of the opioid crisis coupled with the COVID 19 pandemic may have affected the pain treatment of chronic pain subjects and may have an effect on the quality of life of the subjects that are interviewed. A review of the revised treatment options that are a result of the current crisis conditions will help to see if pain treatments are conducted in an ethical way. The purpose of this study is to analyze a collection of patient narratives that tell the historical and current status of their treatment and the perception of their treatment goals. Subjects will be asked if their treatment goals are fully achieved and to describe the possible rationale of their perception that current pain relief measures may have remained acceptable or unacceptable. Questions as to the types of pain relief will be investigated which would include all treatments including those involving alternative measures that may not be medical in nature. Research will review the perceptions along demographics areas of culture, socio-economic status, race, age, religion, education, and gender. Recruitment of participants may be the result of advertisements placed: in a hospital, at clinical pain management practice, within pain support groups, at local pharmacies or from referrals.

3. DURATION

The length of time you will be involved with this study is approximately 180 minutes.

4. PROCEDURES

If you agree to be in this study, we will ask you to do the following things: You will be asked to read and acknowledge your understanding of this informed consent by signing the consent document , complete a questionnaire supplied to you by mail called the WHO-QOL 100, not all questions have to be answered but you should try complete as many as you can. After returning the completed the WHO-100 questionnaire and signed consent in the provided postage paid return mailer, you will be contacted to choose at time for you to relate your pain history to a researcher, who will collect your spoken history by an electronic device utilizing an industry standard secure internet or phone connection. You will be guided through your history by some questions from the researcher to help provide a more complete history. You may end your participation in the study at any time without consequence or penalty for any reason.

5. RISKS/BENEFITS

There will be no medical interventions administered as part of this study. Participation in this study may cause you to have feelings depression or catharsis related to the intensity of the discussion of your chronic pain history. You may not directly benefit from participating in this study; however, we may learn new things that could help others with non-cancer chronic pain.

6. CONFIDENTIALITY

All records collected from this study will be kept confidential. The researcher has taken all reasonable measures to protect your identity and responses. All data is stored on a password protected database, and IP addresses are not collected. However, e-mail and the internet are not 100% secure, so it is also suggested that you clear the computer’s cache and browser history to protect your privacy after completing any interview conducted over the internet.

You will not be identified in any reports or publications resulting from this study. Only summary data of all participants will be presented as a result of this study. You will be allowed to access this information once the study is finished. You have the right to cancel this consent at any time by giving written notice to Kevin J Poirier (kpoirier@drew.edu). If you cancel this consent, then Drew University and Kevin Poirier will no longer use or disclose your study information.

7. VOLUNTARY NATURE OF THE STUDY

Your decision whether to participate in this research will not affect your current or future relations with Drew University. If you decide to participate in this study, you are free to withdraw from the study at any time without affecting those relationships and without penalty.

8. CONTACTS AND QUESTIONS

Results are to be published in the form of a thesis in the partial satisfaction of the requirements of a doctoral degree in Medical Humanities. The researcher conducting this study is Kevin J Poirier. You may ask any questions you have right now. If you have questions later, you may contact the researchers at email: kpoirier@drew.edu or phone: 732-309-1460. You may also request a final copy of the research by contacting the investigator at: kpoirier@drew.edu,

If you have a need to further discuss mental health issues that arise as an outcome of your meeting to gather research information you can seek out counseling support through the American Association of Counseling website that will help you to search for a mental health counselor in your local area. https://www.counseling.org/aca-community/learn-about-counseling/what-is-counseling/find-a-counselor

If you have questions or concerns regarding this study and would like to speak with someone other than the researcher, you may contact Dr. Alex de Voogt IRB Chair : adevoogt@drew.edu

9. STATEMENT OF CONSENT

Please verify the following: The procedures of this study have been explained to me and my questions have been addressed. I understand that my participation is voluntary and that I may withdraw at any time without penalty. If I have any concerns about my experience in this study (e.g., that I was treated unfairly or felt unnecessarily threatened), I may contact the Chair of the Drew Institutional Review Board regarding my concerns.

Participant signature______________________________________ **Date**____________

APPENDIX 3: NARRATIVE SCRIPT

I am conducting research about your story of chronic pain and how chronic pain affects your life. I will try to guide you through your narrative with some questions that may provide key information that could help me to analyze the commonalities and the trends that describe those who suffer from chronic pain.

At this point you have read and signed the informed consent. If I have received your documents, I will not be reviewing the WHO QoL survey until I am ready to do the overall analysis.

Demographics

1. Age
2. Gender
3. Race
4. Ethnicity
5. Marital status
6. Education
7. Socio- economic group
    a. Currently working? Total family income range?
        i. < 25K
        ii. 25-50K
        iii. 50-75K
        iv. 75-100K
        v. 100-150k
        vi. >150K
        vii. Not comfortable in declaring.
    b. Other Financial Support?
    c. Do you have health Insurance?
8. Religion/ Spirituality- do you feel comfortable elaborating on the aspects of Religion/ Spirituality affect your daily life.
    a. Has Religion shaped your overall ethics and belief system?
    b. Current Practicing
    c. Affiliated with

I am trying to get information that has been previously quantified and verified to affect the type of treatment received in association with the variables listed in the 1st part of this line of

9. Where were you born and where did you grow up?
10. Where you currently live:
    a. House
    b. Apartment
    c. Other
    d. City
    e. Rural
    f. Suburbs
11. Current living arrangement
    a. Alone
    b. Spouse/Partner/Children
    c. Roommates/Housemates
    d. Extended Family
12. Do you have a Support System? Who is your primary Support?
    a. Family
    b. Friends
    c. Neighbors
    d. Institutional,
13. Are you comfortable using the available support? Are they reliable?

Pain Information

14. Current pain today? Wong scale 1-10
    a. Is your pain predictable? (weather)
    b. Cause of pain today?
15. Would is the cause of your chronic pain?
    a. Accident
    b. Trauma
    c. Congenital disease
    d. Idiopathic pain
16. How long have you had chronic pain?
17. When did you start to realize your symptoms of chronic pain?
18. Are you currently being treated for chronic pain?
    a. Types of treatment
        i. Medical
            1. Medicine
            2. Physical therapy
            3. Surgery
        ii. Alternative
            1. Yoga
            2. Meditation
            3. Herbalist
            4. acupuncture
19. What types of treatment have you tried in the past?

- a. Types of treatment
    - i. Medical
        1. Medicine
        2. Physical therapy
        3. Surgery
    - ii. Alternative
        1. Yoga
        2. Meditation
        3. Herbalist
        4. Acupuncture

20. If you are currently being treated what does the treatment regimen consist of:
21. Do you think that your care practitioner listens and understands you?
22. Do you think there are more treatments that could be provided to alleviate your pain that are not being offered to you?
23. If you are using a Rx to help alleviate pain, do you think the opioid crisis has affected your treatment regimen.
24. Has COVID 19 affected your ability to get treatment for pain or affected your access to professionals for help.

Psychological Assessment

25. How does chronic pain effect your everyday life?
    - a. Able to all you want to do.
    - b. Limited to sometimes unable to do what you want.
    - c. Good days and bad days
    - d. Every day is a struggle to do anything.
26. Does pain affect your thoughts on your future?
27. Does pain interfere with your interpersonal relationships, family friends, or co - workers?
28. Does the topic of pain come up in everyday discussions?

From J. Maynadier

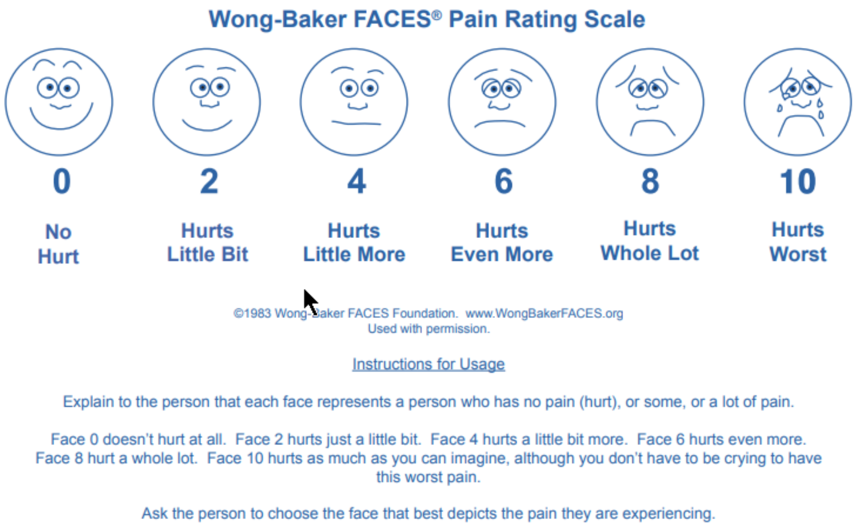
0= no complaint even on questioning

1= complaint only on questioning

2= spontaneous complaint, infrequent, only addressed to specific people among the patient’s contacts

3=partial invasion of speech by the complaint, the patient complains to everyone, but however is able to talk about something else

4= complete invasion of speech by the complaint.



Wong-Baker FACES® Pain Rating Scale

©1983 Wong-Baker FACES Foundation. www.WongBakerFACES.org
Used with permission.

Instructions for Usage

Explain to the person that each face represents a person who has no pain (hurt), or some, or a lot of pain.

Face 0 doesn't hurt at all. Face 2 hurts just a little bit. Face 4 hurts a little bit more. Face 6 hurts even more. Face 8 hurt a whole lot. Face 10 hurts as much as you can imagine, although you don't have to be crying to have this worst pain.

Ask the person to choose the face that best depicts the pain they are experiencing.

- Is there anything else that you think I should know about your chronic pain history? Is there anything that could you some more clarity or that you would like to emphasize.

APPENDIX 4: IRB APPROVED ADVERTISEMENT

Do You Suffer From Chronic Pain?
Would you be willing to tell *your* story so that others may have a better understanding of Chronic Pain?

Join a research project to help better understand the lives of those who suffer from non cancer chronic pain.

We are looking for participants who:

- **Are at least 18 years of age**
- **Have suffered non cancer chronic pain for the past 6 months or longer**
- **Are willing to spend 1 hour completing a survey and consent form and one a 1 - hour session to discuss your history and feelings about your chronic pain**

All study interactions will be through video or phone

Please Contact:
Kevin Poirier
Medical Humanities Program
Drew University
Madison NJ
kpoirier@drew.edu

DREW UNIVERISTY INSTITUTIONAL REVIEW BOARD APPROVED: MARCH 4, 2021. A. de Voogt, IRB CHAIR

APPENDIX 5: IRB APPROVAL

DREW

Institutional Review Board
Drew University
36 Madison Avenue
Madison, New Jersey 07940

Alex de Voogt
Chair, IRB
Associate Professor
adevoogt@drew.edu

March 4, 2021

Dear Kevin Poirier,

The Institutional Review Board has conducted an expedited review of your research for the project entitled “What can we learn from pain narratives? An investigation of the ethical gaps in the treatment of patients who suffer from chronic non-cancer pain through the perspective of patient narratives.” The IRB has approved your research project. Please note, if you make any modifications to your research, you will need to obtain IRB approval for those changes.

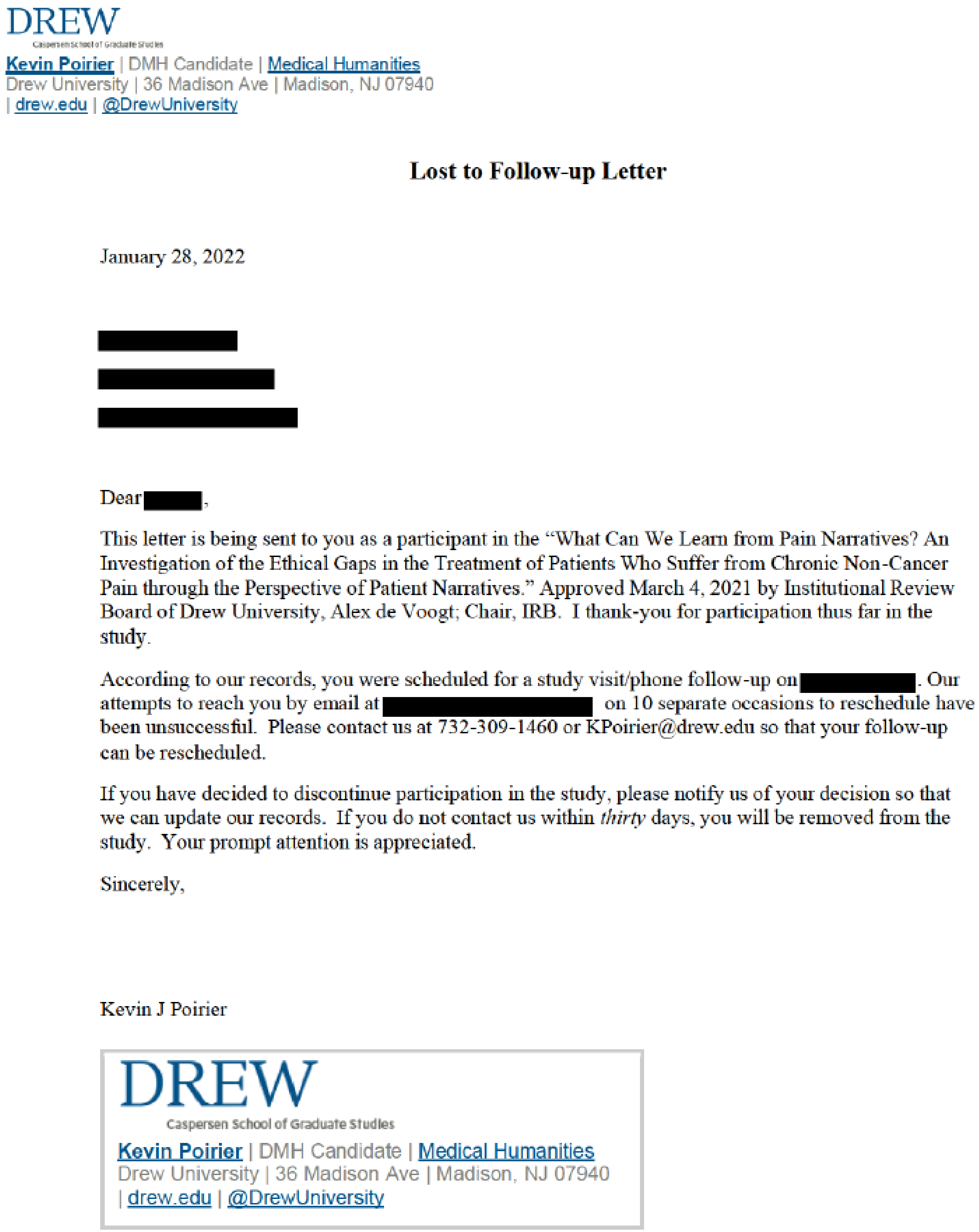
Best of luck with your research!

Sincerely,

Alex de Voogt

IRB Chair

APPENDIX 6: LOST TO FOLLOW UP LETTER



DREW
Caspersen School of Graduate Studies
Kevin Poirier | DMH Candidate | Medical Humanities
Drew University | 36 Madison Ave | Madison, NJ 07940
| drew.edu | @DrewUniversity

Lost to Follow-up Letter

January 28, 2022

[redacted]

Dear [redacted],

This letter is being sent to you as a participant in the "What Can We Learn from Pain Narratives? An Investigation of the Ethical Gaps in the Treatment of Patients Who Suffer from Chronic Non-Cancer Pain through the Perspective of Patient Narratives." Approved March 4, 2021 by Institutional Review Board of Drew University, Alex de Voogt; Chair, IRB. I thank-you for participation thus far in the study.

According to our records, you were scheduled for a study visit/phone follow-up on [redacted]. Our attempts to reach you by email at [redacted] on 10 separate occasions to reschedule have been unsuccessful. Please contact us at 732-309-1460 or KPoirier@drew.edu so that your follow-up can be rescheduled.

If you have decided to discontinue participation in the study, please notify us of your decision so that we can update our records. If you do not contact us within *thirty* days, you will be removed from the study. Your prompt attention is appreciated.

Sincerely,

Kevin J Poirier

DREW
Caspersen School of Graduate Studies
Kevin Poirier | DMH Candidate | Medical Humanities
Drew University | 36 Madison Ave | Madison, NJ 07940
| drew.edu | @DrewUniversity

APPENDIX 7: PAIN MANAGEMENT CONTRACT

I, ____, agree to undergo pain management by Dr. ____________________________. My diagnosis is ____. I agree to the following statements:

I will not accept any narcotic prescriptions from another doctor.

I will be responsible for making sure that I do not run out of my medications on weekends and holidays, because abrupt discontinuation of these medications can cause severe withdrawal syndrome.

I understand that I must keep my medications in a safe place.

I understand that Dr. ______________________________ will not supply additional refills for the prescriptions of medications that I may lose.

If my medications are stolen, Dr. ______________________________ will refill the prescription one time only if a copy of the police report of the theft is submitted to the physician's office.

I will not give my prescriptions to anyone else.

I will only use one pharmacy.

I will keep my scheduled appointments with Dr. _______________________ unless I give notice of cancellation 24 hours in advance.

I agree to refrain from all mind/mood altering/illicit/addicting drugs including alcohol unless authorized by Dr. _____________________.

My treatment plan may change based on outcome of therapy, especially if pain medications are ineffective. Such medications will be discontinued.

My treatment plan includes:

Medications ____

Physical therapy/exercise ____

Relaxation techniques____

Psychological counseling _______________________

I understand that Dr. ___________________________ believes in the following "Pain Patients’ Bill of Rights."

You have the right to:

- Have your pain prevented or controlled adequately.
- Have your pain and medication history taken.
- Have your pain questions answered.
- Know what medication, treatment or anesthesia will be given.

- Know the risks, benefits, and side effects of treatment.
- Know what alternative pain treatments may be available.
- Ask for changes in treatments if your pain persists.
- Receive compassionate and sympathetic care.
- Receive pain medication on a timely basis.
- Refuse treatment without prejudice from your physician.
- Include your family in decision-making.

A. The doctor may terminate this agreement at any time if he/she has cause to believe that I am not complying with the terms of this agreement, or to believe that I have made a misrepresentation or false statement concerning my pain or my compliance with the terms of this agreement.

B. I understand that I may terminate this agreement at any time.

If the agreement is terminated, I will not be a patient of Dr. _____________________ and would strongly consider treatment for chemical dependency if clinically indicated.

_______________________________ ______________

Patient Signature Date

_______________________________ ______________

Physician Signature Date

_______________________________ ______________

Witness Signature Date

APPENDIX 8: MENTAL HEALTH FIRST AID CERTIFICATE

NATIONAL COUNCIL
FOR BEHAVIORAL HEALTH

National Council for Behavioral Health operates Mental Health First Aid in the USA. The National Council for Behavioral Health and the Missouri Department of Mental Health founded Mental Health First Aid USA.

Kevin Poirier

has completed the course and is now certified in

Adult
Mental Health First Aid
USA

and has been trained to provide initial help to someone experiencing a mental health or substance use challenge.

Charles Ingoglia

Chuck Ingoglia
President & CEO
National Council for Behavioral Health

This course is eligible for 7.5 contact hours of continuing education credit.

USA
MENTAL
HEALTH
FIRST AID

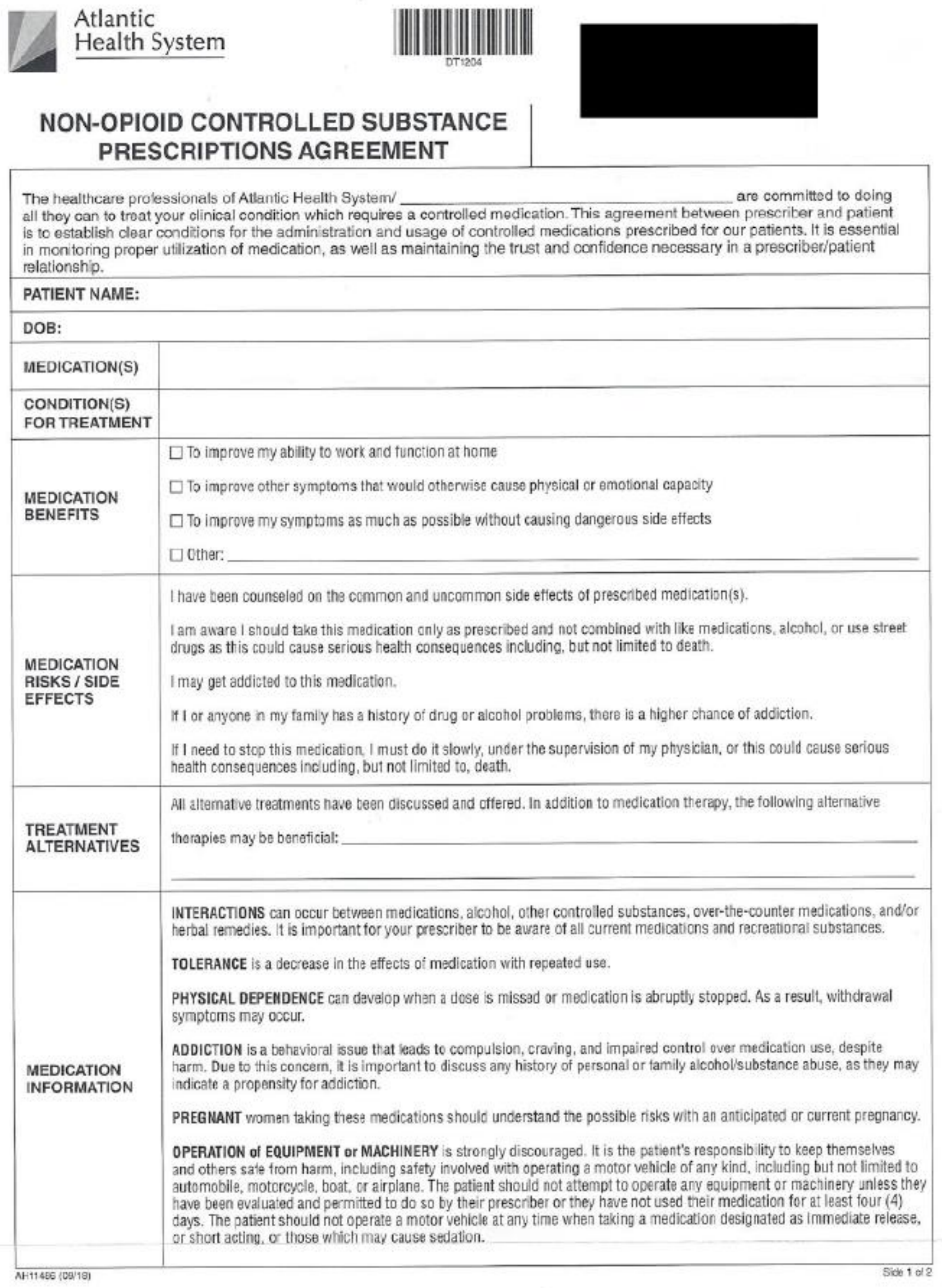
This certificate became **effective** on:

4/21/2021
Date

This certificate **expires**:

3 yr from effective date
Date

APPENDIX 9 NON-OPIOID CONTROLLED SUBSTANCE AGREEMENT



Atlantic Health System

DT1204

[redacted]

NON-OPIOID CONTROLLED SUBSTANCE PRESCRIPTIONS AGREEMENT

The healthcare professionals of Atlantic Health System/ ________________________ are committed to doing all they can to treat your clinical condition which requires a controlled medication. This agreement between prescriber and patient is to establish clear conditions for the administration and usage of controlled medications prescribed for our patients. It is essential in monitoring proper utilization of medication, as well as maintaining the trust and confidence necessary in a prescriber/patient relationship.

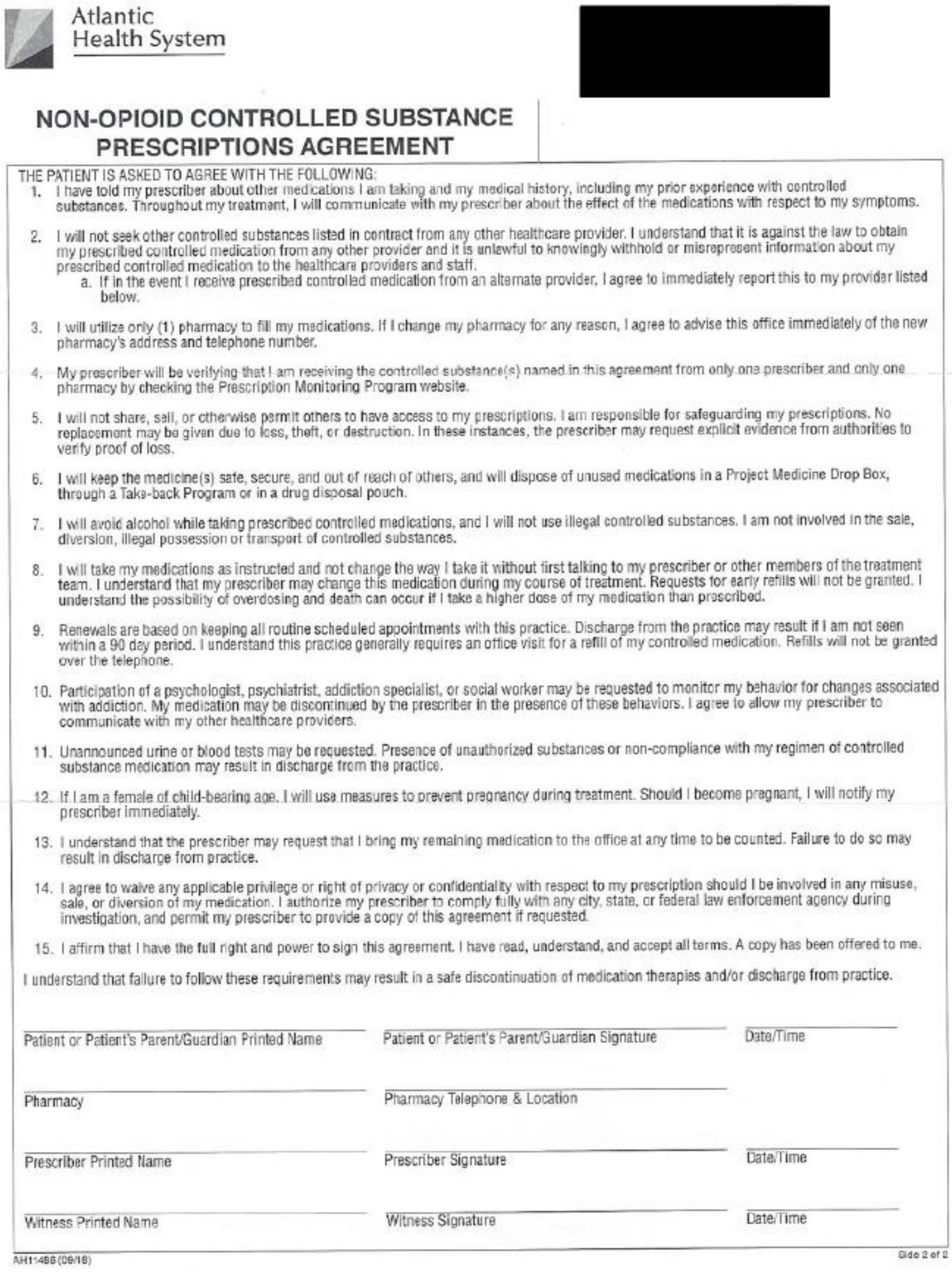
PATIENT NAME:

DOB:

MEDICATION(S)	
CONDITION(S) FOR TREATMENT	
MEDICATION BENEFITS	☐ To improve my ability to work and function at home ☐ To improve other symptoms that would otherwise cause physical or emotional capacity ☐ To improve my symptoms as much as possible without causing dangerous side effects ☐ Other: ________________
MEDICATION RISKS / SIDE EFFECTS	I have been counseled on the common and uncommon side effects of prescribed medication(s). I am aware I should take this medication only as prescribed and not combined with like medications, alcohol, or use street drugs as this could cause serious health consequences including, but not limited to death. I may get addicted to this medication. If I or anyone in my family has a history of drug or alcohol problems, there is a higher chance of addiction. If I need to stop this medication, I must do it slowly, under the supervision of my physician, or this could cause serious health consequences including, but not limited to, death.
TREATMENT ALTERNATIVES	All alternative treatments have been discussed and offered. In addition to medication therapy, the following alternative therapies may be beneficial: ________________
MEDICATION INFORMATION	**INTERACTIONS** can occur between medications, alcohol, other controlled substances, over-the-counter medications, and/or herbal remedies. It is important for your prescriber to be aware of all current medications and recreational substances. **TOLERANCE** is a decrease in the effects of medication with repeated use. **PHYSICAL DEPENDENCE** can develop when a dose is missed or medication is abruptly stopped. As a result, withdrawal symptoms may occur. **ADDICTION** is a behavioral issue that leads to compulsion, craving, and impaired control over medication use, despite harm. Due to this concern, it is important to discuss any history of personal or family alcohol/substance abuse, as they may indicate a propensity for addiction. **PREGNANT** women taking these medications should understand the possible risks with an anticipated or current pregnancy. **OPERATION of EQUIPMENT or MACHINERY** is strongly discouraged. It is the patient's responsibility to keep themselves and others safe from harm, including safety involved with operating a motor vehicle of any kind, including but not limited to automobile, motorcycle, boat, or airplane. The patient should not attempt to operate any equipment or machinery unless they have been evaluated and permitted to do so by their prescriber or they have not used their medication for at least four (4) days. The patient should not operate a motor vehicle at any time when taking a medication designated as immediate release, or short acting, or those which may cause sedation.

AH11486 (08/18)

Side 1 of 2



Atlantic
Health System

[redacted]

NON-OPIOID CONTROLLED SUBSTANCE PRESCRIPTIONS AGREEMENT

THE PATIENT IS ASKED TO AGREE WITH THE FOLLOWING:

1. I have told my prescriber about other medications I am taking and my medical history, including my prior experience with controlled substances. Throughout my treatment, I will communicate with my prescriber about the effect of the medications with respect to my symptoms.
2. I will not seek other controlled substances listed in contract from any other healthcare provider. I understand that it is against the law to obtain my prescribed controlled medication from any other provider and it is unlawful to knowingly withhold or misrepresent information about my prescribed controlled medication to the healthcare providers and staff.
    a. If in the event I receive prescribed controlled medication from an alternate provider, I agree to immediately report this to my provider listed below.
3. I will utilize only (1) pharmacy to fill my medications. If I change my pharmacy for any reason, I agree to advise this office immediately of the new pharmacy's address and telephone number.
4. My prescriber will be verifying that I am receiving the controlled substance(s) named in this agreement from only one prescriber and only one pharmacy by checking the Prescription Monitoring Program website.
5. I will not share, sell, or otherwise permit others to have access to my prescriptions. I am responsible for safeguarding my prescriptions. No replacement may be given due to loss, theft, or destruction. In these instances, the prescriber may request explicit evidence from authorities to verify proof of loss.
6. I will keep the medicine(s) safe, secure, and out of reach of others, and will dispose of unused medications in a Project Medicine Drop Box, through a Take-back Program or in a drug disposal pouch.
7. I will avoid alcohol while taking prescribed controlled medications, and I will not use illegal controlled substances. I am not involved in the sale, diversion, illegal possession or transport of controlled substances.
8. I will take my medications as instructed and not change the way I take it without first talking to my prescriber or other members of the treatment team. I understand that my prescriber may change this medication during my course of treatment. Requests for early refills will not be granted. I understand the possibility of overdosing and death can occur if I take a higher dose of my medication than prescribed.
9. Renewals are based on keeping all routine scheduled appointments with this practice. Discharge from the practice may result if I am not seen within a 90 day period. I understand this practice generally requires an office visit for a refill of my controlled medication. Refills will not be granted over the telephone.
10. Participation of a psychologist, psychiatrist, addiction specialist, or social worker may be requested to monitor my behavior for changes associated with addiction. My medication may be discontinued by the prescriber in the presence of these behaviors. I agree to allow my prescriber to communicate with my other healthcare providers.
11. Unannounced urine or blood tests may be requested. Presence of unauthorized substances or non-compliance with my regimen of controlled substance medication may result in discharge from the practice.
12. If I am a female of child-bearing age, I will use measures to prevent pregnancy during treatment. Should I become pregnant, I will notify my prescriber immediately.
13. I understand that the prescriber may request that I bring my remaining medication to the office at any time to be counted. Failure to do so may result in discharge from practice.
14. I agree to waive any applicable privilege or right of privacy or confidentiality with respect to my prescription should I be involved in any misuse, sale, or diversion of my medication. I authorize my prescriber to comply fully with any city, state, or federal law enforcement agency during investigation, and permit my prescriber to provide a copy of this agreement if requested.
15. I affirm that I have the full right and power to sign this agreement. I have read, understand, and accept all terms. A copy has been offered to me.

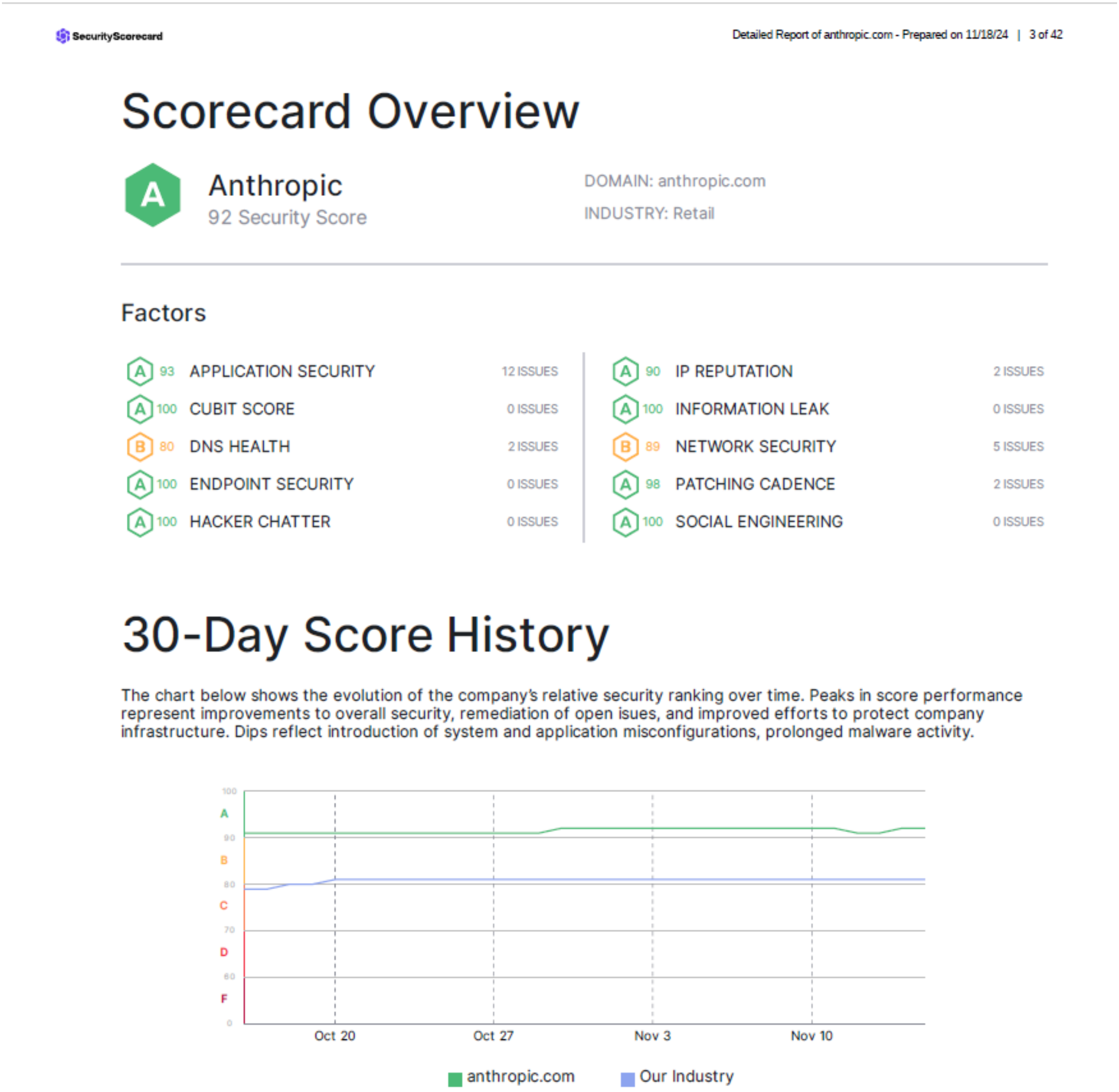
I understand that failure to follow these requirements may result in a safe discontinuation of medication therapies and/or discharge from practice.

Patient or Patient's Parent/Guardian Printed Name	Patient or Patient's Parent/Guardian Signature	Date/Time
Pharmacy	Pharmacy Telephone & Location	
Prescriber Printed Name	Prescriber Signature	Date/Time
Witness Printed Name	Witness Signature	Date/Time

AH11486 (09/18)

Side 2 of 2

APPENDIX 10: SECURITY REPORT FOR CLAUDE AI



SecurityScorecard

Detailed Report of anthropic.com - Prepared on 11/18/24 | 3 of 42

Scorecard Overview

A **Anthropic**
92 Security Score

DOMAIN: anthropic.com
INDUSTRY: Retail

Factors

Grade	Score	Factor	Issues	Grade	Score	Factor	Issues
A	93	APPLICATION SECURITY	12 ISSUES	A	90	IP REPUTATION	2 ISSUES
A	100	CUBIT SCORE	0 ISSUES	A	100	INFORMATION LEAK	0 ISSUES
B	80	DNS HEALTH	2 ISSUES	B	89	NETWORK SECURITY	5 ISSUES
A	100	ENDPOINT SECURITY	0 ISSUES	A	98	PATCHING CADENCE	2 ISSUES
A	100	HACKER CHATTER	0 ISSUES	A	100	SOCIAL ENGINEERING	0 ISSUES

30-Day Score History

The chart below shows the evolution of the company's relative security ranking over time. Peaks in score performance represent improvements to overall security, remediation of open isues, and improved efforts to protect company infrastructure. Dips reflect introduction of system and application misconfigurations, prolonged malware activity.

VITA

Full name: Kevin Joseph Poirier

Place and date of birth: Burlington VT, February 1, 1961

Parents' Names: Mary Stout and Bruce Stout

Educational Institutions:

School	Place	Degree	Date
Secondary: St Anthony HS	Hamilton, NJ 08610	HS	1979
Collegiate:Rutgers University	New Brunswick, NJ 08901	BA	1987
Graduate: Drexel University College of Medicine	Philadelphia, PA 19129	MS	2008
Graduate: Drew University	Madison, NJ 07940	DMH	2024