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Premature Treatment Termination in Integrated Primary Care: A Mixed Methods Investigation Among African American Adults with Chronic Pain

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PREMATURE TREATMENT TERMINATION IN INTEGRATED PRIMARY CARE:
A MIXED METHODS INVESTIGATION AMONG AFRICAN AMERICAN
ADULTS WITH CHRONIC PAIN

by

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A Dissertation

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Dedication

To God, I appreciate the time spent to craft me and keep me ever aligned in your glory. To my ancestors—I humbly harvest the crop you diligently planted with blood and lovingly cultivate the heirlooms. To my circle of love, those faces of God in the form of family, friends, and strangers—thanks for being my megazord (yes, this is a Power Rangers reference) of excellence to conquer this feat. To my children, do the things that even your wildest imagination dare not to contain. To the younger version of myself, it is my sincerest gratitude that you showed up, endured the pain, and never stopped believing. To people of color born on the soil of America, the rhythm of my heartbeat is FOREVER tuned to the frequency of our collective healing.

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iv

Abstract

Despite the growing number of U.S. patients impacted by chronic pain (Nahin, 2015), many, particularly African Americans go without adequate treatment due inequitable care (Anderson, Green, & Payne, 2009; Resnik, Rehm, & Minard, 2001). Even when the gold-standard treatment is accessible, many African Americans do not remain in care, electing to prematurely terminate treatment (Bonham, 2001; Green, Baker, Sato, Washington, & Smith, 2003). The Behavioral Model for Healthcare Utilization (BMHU) is widely used to understand how individuals engage in health care treatment and was recently expanded to be more inclusive for racial minorities (Bradley et al., 2002). However, little research has applied this model to premature termination, particularly in patients with chronic pain. The current study investigated the three-part BMHU model (i.e. predisposing, enabling, and severity factors) to explore associations with the decision-making process for African Americans patients with chronic pain who prematurely terminated treatment. A concurrent parallel mixed methods study design was used. Participants, recruited from Church Health Center – a midsouth integrated primary care center, were seen by a physical therapist between 2015-2018. Retrospective medical chart review was conducted for the 164 African American patients with chronic pain who had demographic data, depression (PHQ-9) total scores, anxiety (GAD-7) total scores, and pain severity (MPQ item for qualitative pain rating) scores. Results of a point-biserial correlation assessing the relationship between the variables of interest and premature termination did not suggest any significant relationships. Additionally, logistic regression analyses were not statistically significantly. A subset of the quantitative sample was interviewed for the qualitative arm. Specifically, an open-ended interview of 15 African

American patients with chronic pain who ended treatment prematurely was completed. Qualitative interviews identified three domains of patient concerns: *perceived treatment inefficacy, patient-provider disconnection,* and *treatment de-prioritization.* These findings highlight how critical patient's perception of the first treatment session is for continued care and the value of mixed methods research in gaining a complete picture of participant's experiences. Future researchers should examine retention interventions that can be implemented in the first treatment session for African American patients with chronic pain.

Table of Contents

Premature Treatment Termination in Integrated Primary Care: A Mixed Methods Investigation

of African American Adults[1] with Chronic Pain

Introduction

Chronic pain is a pervasive health condition in the United States impacting approximately

25 million people (Nahin, 2015). The economic burden on society, due to lowered productivity

and increased medical costs, is an alarming 630 billion dollars annually (Gaskins & Richard,

2012). The impact of chronic pain is further exacerbated by disparities in pain treatment, which

is particularly inequitable among African Americans relative to Whites resulting in significant

undertreatment (Anderson, Green, & Payne, 2009; Hampton, Cavalier, & Langford, 2015).

Undertreatment has been attributed to a number of factors resulting from a) providers not

administering treatment, b) patients not readily seeking treatment, or c) patients self-electing to

discontinue treatment before they reach the optimal dosage (Resnik, Rehm, & Minard, 2001). In

many ways integrated primary care facilities address and attempt to minimize the many barriers

that contribute to undertreatment, particularly improving accessibility to the "gold standard" pain

treatment, i.e., multimodal approaches (Kaiser, Treede, & Sabatowski, 2017). However, despite

integrated primary care providers serving millions of individuals with chronic pain annually,

rates of attrition and premature termination from treatment remain high, particularly among

African American patients, due to self-elected discontinuance of treatment after the first session

or before the recommended number of sessions (Bonham, 2001; Green, Baker, Sato,

Washington, & Smith, 2003). To improve the quality of care in integrated primary care facilities

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[1] The racial denotations of African American and Black will be used interchangeable throughout the text.

serving chronic pain patients, it is important to understand what contributes to the incidence of premature termination.

Pain Classification

Pain is a complex multidimensional phenomenon. Williams and Craig (2016) define pain as "a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive, and social components." This points to the importance of identifying several key attributes in order to classify the pain condition: 1) underlying cause, 2) duration, 3) frequency, 4) location, and 5) intensity (Cole, 2002). For each attribute of classification, a number of variables need to be considered, in addition to the sensory, emotional, cognitive, and social components.

Despite the obvious presentation of discomfort, the underlying causes of pain can be broadly distinguished into three etiologies (Woolf, 2010). The first and most common etiology of pain is the signaling of damaged tissue and/or the potential of damaged tissue (Thienhaus & Cole, 2002; Woolf, 2010). This signaling process is a result of nociceptors (i.e., sensory receptors for pain) located in the skin, muscle, joints, and viscera, to selectively respond to potentially damaging stimuli (Dubin & Patapoutian, 2010; Gold & Gebhart, 2010). Nociceptors are designed to detect stimuli that may cause mechanical, chemical or thermal threats; thus, serving as the body's defense system to warn when there is harm being done (Dubin & Patapoutian, 2010). When nociceptor cells are activated, they send electrical signals to the central nervous system and brain; it is in the brain that the electrical signal is perceived as pain (Dubin & Patapoutian, 2010). An example of this type of pain is the experience of being cut on the arm. The second etiology of pain is the indication of an inflammatory response associated with the immune system working to repair or heal injured tissue or infection (Marchand, Perretti,

& McMahon, 2005; Woolf, 2010). This type of pain is most associated with post-surgery, whereas the body is healing but may experience significant pain (Beilin et al., 2003). Although the first and second origins of pain are unpleasant yet adaptive, the third underlying role of pain is indicative of pathology. The third underlying role of pain could to be due to a host of reasons. One is neuropathy, referring to continued dysfunction or damage to the nervous system (Woolf, 2010), another reason is maladaptive functioning of the nociceptive receptors, wherein individuals become increasingly sensitive and/or attentive to stimuli (Dubin & Patapoutian, 2010). Damaged tissue may have healed as determined by medical evidence, yet lingering psychological and/or physically unpleasant sensations continue to be perceived by individuals. When this occurs, the warning signals are considered to be out of proportion to the actual threat. This is the type of pain most often associated with "chronic" pain. The heterogeneity of the underlying mechanism of chronic pain requires proper assessment to tailor an effective treatment (Scholz & Woolf, 2002).

Considering the second and third pain classifications, i.e., duration and frequency, pain can be divided into two additional categories: acute and chronic. Acute pain is relatively short in duration, occurring within a 3-month period following an incident (Mifflin & Kerr, 2014). Acute pain is often associated with the underlying causes of signaling tissue damage or an inflammatory response, both term limited phenomena. A distinguishing feature of acute pain is the biological restorative process which eventually ends the pain process (Feizerfan & Sheh, 2015). However, a pathophysiological change can occur, thus transitioning acute to chronic pain as a result of frequent and persistent nociceptor stimulation (Feizerfan & Sheh, 2015; Mifflin & Kerr, 2014). This type chronic pain typically persists for longer than 3 months (Mifflin & Kerr, 2014). This increased sensitivity of the nociceptors cells is also known as hyperalgesia (Gold &

Gebhart, 2010; Mifflin & Kerr, 2014). Functional nociceptors have a high threshold and are selective in their response (Dubin & Patapoutian, 2010). When nociceptors are sensitized, excitability is increased, setting the occasion for previously innocuous stimuli to now illicit pain (Gold & Gebhart, 2010). Chronic pain can also be due to tissue damage that has not healed, wherein an underlying biological mechanism can make it difficult for the immune response to begin the reparative process (Marchand, et al., 2005) This is particularly relevant for autoimmune disorders, where a malfunction within the immune system causes pain (Marchand, et al., 2005).

Neuropathy can also be an underlying cause of chronic pain resulting from a damaged nervous system (Nicholson, 2006). This damaged nervous system can be secondary to medical comorbidities like diabetes (Obrosova, 2009), cardiovascular disease (Burns, et al., 2015), or obesity (Burns, et al., 2015; Miscio, Guastamacchi, Brunani, Priano, Baudo, & Mauro, 2005; Singleton, Volchmann, Graham, & Smith, 2014), to name a few. Neuropathic pain in patients with diabetes is common, experienced by one out of two patients diagnosed (Obrosova, 2009). Although pain can often co-occur with cardiovascular disease and obesity, there is evidence that each condition can be independently associated with neuropathy (Burns, et al., 2015). Singleton, Volchmann, Graham, and Smith, (2014) found that nondiabetic patients averaging a body mass index of 44 had a higher occurrence of asymptomatic neuropathy than individuals considered to be "lean" (the control group). Being overweight places an additional burden on musculoskeletal health, with "high" obesity noted to be most associated with paroxysmal pain. In this case, the neural damage appears to be more a result of obesity-associated inflammation (Hozumi et al., 2016; Miscio, et al., 2005). Moreover, the experience of having obesity is often associated with increased psychological concerns of body dissatisfaction, stigmatization, depression, anxiety,

and decreased perceived quality of life (Wardle & Cooke, 2005; Taylor, Forhan, Vigod, McIntyre, & Morrison, 2013). The increased risk for comorbid psychopathology associated with being obese points to the importance of considering the unique impact this may contribute to the chronic pain experience.

The fourth attribute of pain classification is location. Chronic pain can be widespread (i.e., diffuse musculoskeletal pain experience) or localized (i.e., pain experience in a specific area). Fibromyalgia, a rheumatic syndrome, is the most notable condition typifying widespread chronic pain (McBeth, Macfarlane, Hunt, & Silman, 2001). Fibromyalgia is defined by excessive tenderness in the bilateral, upper and lower body, and spine (Goldenberg, Burckhardt, & Crofford, 2004). Widespread chronic pain is often regarded as occurring in multiple sites of localized pain. The felt experience of localized pain can be characteristically different, with widespread pain often perceived as more disabling (Kamaleri, Natvig, Iklebaek, & Bruusgaard, 2008; Natvig, Bruusgaard, & Eriksen, 2001). Low back pain is typically experienced as a feature of widespread pain, although many experiences it as more localized (Natvig, Bruusgaard, & Eriksen, 2001). As many as 80% of the population is estimated to experience acute localized back problems in their lifetime; however only a small percentage transition to chronic low back pain (Patrick, Emanski, & Knaub, 2014). Most chronic pain low back pain is classified as non-specific, meaning that a precise anatomical etiology is often not identified (Deyo & Weinstein, 2001). Factors that increase the risk of transitioning from acute to chronic back pain include psychiatric comorbidities and avoiding work or activity due to pain (Chou & Shekelle, 2010). Identification of the pain location can be helpful in determining classification, but it is also critical to assess the intensity of the chronic pain.

Depending on the pain intensity (the fifth classification attribute), individual experiences can be described as ranging from discomfort to severely disabling. A number of factors are known to impact chronic pain intensity. For example, baseline pain intensity recorded after an acute injury could be a useful indicator of whether a person may develop chronic pain (Mehta, Macdermid, Richardson, Macintyre,& Grewal, 2015). Garbi, Hortense, Gomez, da Silva, Castanho, and Sousa (2014) found that chronic back pain intensity, depression, and disability were positively correlated. Pain intensity and disability rating have been noted to be significantly higher for Blacks when compared to Whites, with all other aspects being equal (Carey et al., 2010). Back pain is one of the most common reasons for missed work and the second most common reason for visits to the doctor's office (Licciardone, 2008). Thus, pain intensity is an essential classification tool particularly for treatment because it provides an indication of the pain course and treatment efficacy.

Psychosocial Aspects of Chronic Pain

Although biological factors are critical for understanding pain, they highlight only one facet of the experience of living with chronic pain, (Kirkham, Smith, & Havsteen-Franklin, 2015; Smith & Osborn, 2007). Thus, it is equally important to highlight psychosocial components involved in the experience of chronic pain. Pain is an internal perception and is not always obvious to others. Some individuals with recurrent pain may find themselves trying to convince people (often healthcare providers) as well as others who may view their condition with skepticism, invalidation, and/or disbelief of the severity of their condition (Werner & Malterud, 2003). This need to constantly convince others that their highly disabling health condition is "real" can lead to internalized stigma, heightened stress, and negative affect (Slade, Molloy, &

Keating, 2009; Waugh, Byrne, & Nicholas, 2014), thereby giving rise to depression, anxiety, and related concerns (Jackson, 2005).

Depression is highly interrelated with chronic pain for a number of reasons: the constant experience of physical pain, feelings of hopelessness and helplessness, perceived disability, and a host of other conditions (Campbell, Clauw, & Keefe, 2003). Chronic pain can also negatively impact cognitive functioning. Specifically, chronic pain is associated with increased complaints of forgetfulness and difficulties concentrating (McCracken & Iverson, 2001). Socioeconomic status is another psychosocial component relevant to the experience of chronic pain. Residing in a low socioeconomic neighborhood is associated with greater pain disability (Fuentes, Hart-Johnson, & Green, 2007; Green & Hart-Johnson, 2012). Demographic factors, such as age, race, and gender, also impact chronic pain. For example, African Americans in general report higher pain-related disability (Green, Ndao-Brumblay, Nagrant, Baker, & Rothman, 2004). The incidence of chronic pain reporting is greater in women and adults who are older (Tsang et al., 2008). Accordingly, identifying the psychosocial components an individual may be experiencing is crucial to determining the best course of treatment.

Chronic Pain Treatment

After the accurate pain classification has been determined, an appropriate treatment can be provided. Given the considerable variability in pain classification, it should come as no surprise that opinions vary about how chronic pain should be treated. The American Chronic Pain Association guidelines for chronic pain treatment terms the various types of treatment as: passive, active, self-directed, or functional restoration (ACPA, 2018). Passive treatment is when the patient is merely a recipient of care, such as receiving medication (ACPA, 2018). Considering the current opioid epidemic, current guidelines suggest non-invasive non-

pharmacological treatment efforts as preferable, accompanied by passive treatments as ancillary efforts when needed (Volkow, Frieden, Hyde, & Cha, 2014; Wenger, Fillipo, Findlay, Genung, & Heiden, 2018). Active treatment requires that the patient is actively engaged, such as participating in yoga or physical therapy (ACPA, 2018). Self-directed treatment is conducted independently by the patient with minimum health provider supervision, examples are mindful meditation in between appointments (ACPA, 2018). Functional restoration approaches prioritize aligning patients' goals of how best to optimize functioning given their pain condition. This type of treatment is achieved through the formation of an interdisciplinary care team, wherein multiple providers contribute to a holistic care plan (ACPA, 2018).

Of the four types of treatment, functional restoration is recommended as the most effective treatment modality by the American Chronic Pain Association (ACPA, 2018). The literature supports this treatment modality, citing chronic pain as a multidimensional condition whose treatment should follow a multimodal approach, (Kaiser, Treede, & Sabatowski, 2017; Scascighini, Toma, Dober-Spielmann, & Sprott 2008). However, many providers are not following the recommended guidelines, as a national survey indicates that few patients are engaged in multi-provider care, with most receiving at least one medication to treat their chronic pain (Rasu, Sohraby, Cunningham, & Knell, 2013).

Treatment options can vary tremendously for providing relief from chronic back pain, such as psychological therapies (Henschke, et al., 2010; Hoffman, Papas, Chatkoff, & Kerns, 2007; Monrone, Greco, & Weiner, 2008), lifestyle changes like increasing exercise (Searle, Spink, Ho, & Chuter, 2015), and medication therapy (Martell et al., 2007). Moseley (2002) found that the combination of physiotherapy and neurophysiological education sessions are effective for chronic low back pain and produces clinically meaningful reductions in pain and

disability ratings. Similarly, Louw, Zimney, Johnson, Kraemer, Fesler, and Burcham (2017) found that education for older adults, specifically about the relationship between aging and low back pain, produced a reduction in pain. A randomized controlled trial highlighted that racial minorities who had low-income and engaged in yoga as a chronic pain treatment used less opioids and had lower pain ratings than the control group (Saper, Sherman, Cullum-Dugan, Davis, Phillips, & Culpepper, 2009). Ladeira's (2011) review of evidenced-based practice guidelines for physical therapy treatment of chronic low back pain recommends that education and exercise be combined for optimal effects. Evidence regarding the efficacy of physical therapy combined with exercise is compelling. A one-year follow up study of patients with chronic low back pain who received both components remained significantly improved from baseline with respect to disability and pain intensity ratings (Sahin, Karahan, & Albayrak, 2017). Fuentes and colleagues (2014), in an investigation of the mechanisms underlying chronic pain treatment, found that enhanced therapeutic alliance during physical therapy treatment contributed significantly to treatment outcomes. Extending upon the study by Fuentes et al. (2014), Fagundes and colleagues (2017) examined whether therapeutic alliance might be the driving force for treatment efficacy when an intervention for chronic low back pain is minimal. The researchers found that patients receiving minimum treatment, only education about pain, from physical therapists for chronic non-specific back pain reported significant reduction in pain ratings when therapeutic alliance, a specific protocol to emphasis empathetic provider communication, was provided (Fagundes, et al., 2017). Wertli and colleagues (2014) found that fear avoidance beliefs moderated the relation between low back pain and pain ratings; when fear avoidance beliefs were included and addressed within treatment patients had more successful outcomes. While these studies are helpful in identifying factors that can influence treatment outcomes, reports in the

literature indicate that back pain persists for a number of patients despite multiple treatment attempts. Many of these patients go on to be referred for a variety of surgical procedures, chief among these being electrode implants to stimulate the dorsal column (spinal cord stimulation) (Taylor, Buyten, & 2005). Despite the vast variability in treatment options, the important component emphasized in the joint clinical practice guidelines from the American College of Physicians and the American Pain Society is that there is a combination of therapies provided based on detailed assessment (Chou, et al., 2007). Accordingly, to disseminate the gold standard of care for chronic pain, the treatment setting is an important factor in accessibility.

Treatment Setting

Chronic pain treatment can be accessed in various settings; considering the diversity in treatment, the settings vary accordingly. Ironically, a significant amount of chronic pain patients seek care in the emergency department (ED), contributing to approximately 15% of ED visits (Poulin et al., 2016). The patients seeking care in the ED typically describe the pain as emergent, despite its long-standing chronicity and the fact that they are typically concurrently being seen for this issue by a general practitioner (Poulin et al., 2016). Overall, most patients seek care in a private practice setting, pain specialty clinic, or at a primary care facility. In an effort to understand potential differences between patients with chronic pain who seek treatment at a primary care or a specialty pain clinic, Fink-Miller, Long, and Gross (2001) reported similarities among these patients who differed only with respect to pain intensity; patients seeking treatment in primary care reported higher pain intensity ratings. This points to one potentially important difference for why an individual chooses a particular treatment setting. As specialty clinics can provide greater access to tailored treatments, the cost of care is typically higher, thus limiting access to patients who have low-income and/or are uninsured (Turk, 2002), many of whom are

African American and other racial/ethnic minorities (Turk, 2002; Oliver & Shapiro, 2013).

Primary care was established as an inclusive form of treatment, one where a patient typically had

the same physician as their point of access. This allowed the physician an opportunity to get to

know the patient history more fully and it better equipped the provider to help navigate the

patient's care. Initially, the primary care provider was required to treat patients with very

complex medical concerns without needing more specialization in training. However, many

primary care facilities have had to alter their model of care, frequently referring patients out for

more specialized care. This can result in undue burdens for patients, as well as present ethical

dilemmas for well-intentioned providers who struggle with ways to minimize referrals while

continuing to provide treatment in-house when not possessing all needed training.

　　　To better serve the needs of help seekers who require specialty care within a primary care

setting, some practices have evolved into what has been termed a "medical neighborhood"

(Greenberg, Barnett, Spinks. Dudley, & Frolkis, 2014). These medical neighborhood settings

include specialists, such as nutritionists, physical therapists, and mental health providers, who

collaborate toward one shared goal of treatment—integrated care that acknowledges the person

as a multidimensional being in needed of conjunctive treatment for an array of medical and

mental health concerns (Bholat, Ray, Rensilver, Ling, & Shoptaw, 2012). As previously noted,

this type of multidisciplinary approach is viewed as the optimal modality for treating chronic

pain (Kaiser, Treede, & Sabatowski, 2017; Stephenson, 2008). Integrated primary care is

seemingly the optimal environment to provide chronic pain care because it is structured for

multidisciplinary collaboration. Despite the increasing availability of integrated care settings,

utilization rates vary considerably for patients with chronic pain.

Treatment Utilization

Treatment is only as effective as it is readily accessible, provided, and received (Singal, Higgings, & Waljee, 2014); therefore, treatment utilization is an important concept to understand in effort to improve quality of care. The Behavioral Model of Health Service Utilization (BMHU) was created to help understand the phenomena influencing treatment seeking (Andersen, 1968). This model suggests that three groups of factors need joint consideration in order to predict health care utilization or lack thereof: predisposing, enabling, and need-based factors (Andersen, 1995; Andersen, 1968).

Predisposing factors are personal characteristics that influence the likelihood of seeking health care such as demographics (i.e. age or sex), social factors (i.e. level of education, ethnicity, or occupation), and health beliefs (i.e. attitudes, values, knowledge of health condition and treatment) (Andersen, 1995). The first component of the model emphasizes the individual factors that could impact the decision-making process involved in health care utilization. Aside from pathology, patient attitudes and expectations are critical to treatment outcomes. For example, patients with chronic pain who expected acupuncture treatment to work noted better improvement even when receiving placebo treatment (Linde et al., 2007). Differences in expectations can also impact patient-provider communication (Parsons et al., 2007; Matusitz & Spear, 2014). The decision-making process is further complicated by the unique characteristics that are associated with differences in race. Despite comparable rates of chronic low back pain experience across racial groups, a significant difference in treatment experience remains that can impact subsequent treatment seeking (Plesh, Adams, & Gansky, 2011). Certain fundamental differences exist between how African Americans and Caucasian Americans perceive healthcare utilization for chronic pain. Notably African Americans relative to Whites make significantly more ED visits for chronic pain, report that their chronic pain was a major reason for financial

problems, and perceived pain medication as a management tool (Green, Baker, & Ndao-Brumblay, 2004). Other factors that may be predisposing and relevant to chronic pain is mental health (Lerman et al., 2015; Surah, Baranidharan, & Morley, 2014), comorbid health conditions (Burns et al., 2015), and perception of pain management (Booker, 2016).

Enabling factors acknowledge the organizational or contextual level of impact, specifically accounting for finances, means of transportation, and availability of treatment resources (Anderson, 1995; Babitsch, Gohl, Lengerke, 2012). The second level of the model highlights how the societal structure and context are determinants for health care use (Anderson, 1995; Babitsch, Gohl, Lengerke, 2012; Phillips, Morrison, Andersen, 1998). Carey and colleagues (2010) found that having insurance, the degree of disability, and level of education, were predictive of number of visits. Thus, this level extends the narrative of placing the onus solely on individual choice, there are instead adjacent factors that can impact subsequent utilization.

The third component of the BMHU includes the needs-factors, such as health condition severity or perceived need of treatment (Anderson, 1995; Babitsch, Gohl, & Lengerke, 2012). Questionnaires provide an objective measure of pain, particularly for the commonly used McGill Pain questionnaire. The McGill Pain questionnaire is a multidimensional assessment tool designed to provide insights into the pain experience. As objective measures are important to understand in treatment utilization studies, and so is the perceived urgency of the condition. This is evident in the treatment seeking literature previously discussed, where it was noted that patients who sought care in the ED described the pain as more severe and of urgent concern (Poulin et al., 2016) and those that sought treatment in primary care rather than specialty pain clinic endorsed higher pain ratings (Fink-Miller, Long, & Gross, 2001). Although severity of

symptoms can provide some indication about treatment seeking, it is only one component of the complex decision-making process involved in health care utilization (Shaw, Brittain, Tansey, & Williams, 2008). BMHU model conceptualizes health care utilization as a multidimensional decision-making process which includes individual factors, contextual factors, and a needs assessment.

BMHU provides a useful theoretical framework for understanding health care utilization, yet Bradley and colleagues (2002) assert that there are additional factors to consider when addressing the unique experiences of racial/ethnic minorities. Bradley and colleagues (2002) "expanded" the BMHU conceptual model to examine the concerns of African Americans deciding upon long-term care use. In their more inclusive model, psychosocial factors were noted to be of utmost concern, thus the predisposing level of the model is explored in greater depth and found to be most impactful in health care decision making (Bradley, et al., 2002). Bradley and colleagues (2002) suggest that using race or ethnicity as a predisposing factor over-simplifies the complexities of these particular groups. The authors found significant thematic differences between the African American and White study participants including: accessibility of information, social norms, self-determination, and privacy (Bradley, et al. 2002). These African American participants noted feeling less informed about treatment, internalized social norms that were inconsistent with formalized long-term care such as noting that family members were obligated to provide long-term care rather than strangers; their ideas of self-determination suggested taking care of themselves rather than seeking care; and they noted concerns with personal privacy and unwillingness to trust the providers, an additional factor inconsistent with seeking care. A theme that interestingly did not emerge in the Bradley and colleagues (2002)

examination of the BMHU model among African American patients were psychosocial concerns that could impact the enabling factors. such as perceived discrimination.

Extensive research argues that providers may discriminate against patients with chronic pain who are Black by not providing treatment or equitable quality of care (Anderson, Green, & Payne, 2009; Bach, Pham, Schrag, Tate, & Hargraves, 2004; Upshur, Bacigalupe, & Luckman, 2010). There is some evidence that many White medical students hold the false belief that Black patients have "thicker skin" and must experience pain less intensely as White people (Hoffman, Travalter, Axt, Oliver, 2016). Microaggressions, based on race and chronic pain condition, is more subtle, yet it is as impactful as blatant acts of discrimination (Bleich, 2015). These concerns have led some researchers to question the accuracy of pain assessment with patients who are African American due to tendencies of some providers to disproportionately invalidate and dismiss complaints of pain among this racial group (Anderson, Green, & Payne, 2009). Bradley and colleagues' (2002) expansion of the BMHU model to identify unique psychosocial factors relevant for racial minorities lends support to examining this model for African Americans with chronic pain treatment.

Current Study

Understanding treatment utilization is as much an exploration of how and why patients initiate therapy as it is an investigation of how and why they make the decision to discontinue treatment; yet, most studies focus on access to care rather than exploring reasons for termination of treatment (Babitsch, Gohl, Lengerke, 2012). A number of African American patients with chronic pain remain untreated or, when treatment has begun, terminate prior to achieving an "effective" dosage or trial (Hoffman, Trawalter, Axt, and Oliver, 2016); this could be attributed to a number of factors. Considering that so many factors may impact treatment termination, it is

important to understand the interrelationships among the factors. Thus, the current study was designed to provide an in-depth investigation of the experiences of African American patients with chronic pain who have chosen to terminate treatment prematurely despite initiation of multidisciplinary treatment in an integrated primary care clinic. The expanded BMHU model guides the conceptual framework in this exploration, as the role of predisposing (sex, age, depression, anxiety), enabling (income), and needs-based (pain severity) factors were examined as predictors of premature termination. Consistent with the expanded BMHU there was further investigation of psychosocial factors that also contributed to premature termination.

To investigate the factors African American attribute to the discontinuance of treatment, the study design consisted of a mixed methods approach, specifically a convergent parallel design. The convergent parallel design was used to concurrently and quantitatively assess the tripartite model of BMHU (predisposing, enabling, and needs-based factors) and qualitatively assess the psychosocial factors explicated with premature termination. Quantitative and qualitative findings were aggregated to provide a more complete narrative for understanding premature termination of treatment among African American patients with chronic pain. Statistical analysis for the quantitative arm will include a three-step model (predisposing, enabling, and needs-based) sequential logistic analysis. Based on prior research (Bradley et al., 2002), it is hypothesized that the predisposing factors would be most predictive of premature termination. The qualitative arm involved conducting semi-structured interviews, which were coded and explored for consistent themes across participants.

Methods

Participants

Participants were eligible to be in the study if they sought care at the Church Health Center for diagnosis and treatment of a chronic pain condition. The Church Health Center, a medical clinic in the mid-south region of the US, is unique in that it is a Christian-based organization serving patients having low income, patients who are underinsured, and those who are employed but unable to afford insurance. It is a medical home that offers integrated, specialty care services, including physical therapy and behavioral health services. Notably of the patients who were referred to physical therapy from various departments only about a third actually engage in treatment. Although the Church Health Center staff at large has some diversity, the physical therapy providers were all White during the study period. Participants were adults aged 18 and older fluent in English. Patients were included in the study if they: 1) had their medical chart denote their race/ethnicity as African American, 2) were referred to the physical therapy department by a primary care physician, 3) were receiving care from at least two providers, 4) had been diagnosed with chronic pain as denoted on the physical therapy initial appointment documentation, and 5) had attended at least one appointment between January 2015 and December 2018. A total of 190 participants met this criterion, however only 164 participants had valid data across all study variables. Therefore, the final quantitative sample comprised of 164 African American patients with chronic pain. Participants were eligible for the qualitative arm if they had prematurely terminated, defined as attending only one appointment. There were 53 individuals who met this criterion. Due to purposeful sampling a total of 15 participants were selected to be interviewed for the qualitative arm. These participants were selected based on variability in age, gender, income, depression, anxiety, and pain score and agreeing to participate in the study.

Design

This study employed a mixed-methods approach, specifically a convergent parallel design (Creswell & Plano Clark, 2012). Data collection included quantitative and qualitative components that occurred simultaneously. The quantitative arm consisted of a secondary data analysis of information accessible via electronic medical records, including demographic information, assessment measures administered to patients during their initial physician visit in the physical therapy department, and appointment records. For the qualitative arm, select patients were interviewed about psychosocial factors and experiences that led them to prematurely terminate treatment. Data from the quantitative and qualitative arms are presented in parallel.

Procedures

After receiving Institutional Review Board approval, the investigator began extracting demographic data and assessment measures from the electronic medical records for all patients who were identified as African American (as designated in their medical chart) and who had been seen for chronic back pain over the identified four year block. The necessary data points: demographics, treatment attendance, depression, anxiety, and pain severity scores (see materials section) were aggregated into a de-identified data set and saved on a password protected flash drive. Data was used in compliance with the data usage agreement (see Appendix A). While conducting the secondary-data analysis, a subset of participants was purposefully sampled based on their history of prematurely terminating treatment (i.e., discontinued treatment after the first session). All participants who prematurely terminated were contacted and those who agreed to be interviewed participated in the qualitative arm of the study. These participants represented various age groups, income, sex, depression, anxiety, and pain severity ratings. This strategy of purposeful sampling was used to ensure maximal variation sampling, a strategy of purposely selecting differing perspectives of a phenomenon of interest to adequately represent the

complexities (Creswell & Clark, 2017). See Table 3 for demographic details about the qualitative sample. Study participants were contacted via phone by the investigator. Phone numbers listed in the medical records and were dialed by a representative at Church Health Center, as patient contact details were protected information that the researcher did not have access to. The Church Health Center representative introduced the participants to the qualitative study and invited to them to participate before handing the phone over to the investigator to provide additional details. If the potential study participants agreed to participate, informed consent was verbally obtained prior to engaging in the semi-structured open-ended survey (see Appendix B). Participants were compensated for their time with a $10 gift card, which was mailed to each participant by the Church Health Center representative with a copy of the informed consent.

Materials

Quantitative materials (see Appendix A).

Demographics. Demographic data was extracted from the medical history forms that were in the patients' medical charts. Details about participants' age, sex, income, race, and ethnicity were reported to their provider during their initial appointment and these details were extracted from the chart for the present study.

Generalized Anxiety Disorder (GAD-7). The GAD-7 is a brief 7-item self-report screener often used in medical settings to assess for generalized anxiety disorder (Spitzer, Kroenke, Williams, & Lowe, 2006). This measure assesses the frequency of experiencing symptoms of generalized anxiety disorder within the timeframe of the last two weeks asking respondents: "Over the last 2 weeks, how often have you been bothered by any of the following problems?" A sample item is "…. Not being able to stop or control worry?" The GAD-7 includes a Likert Scale

with items scores ranging from 0 to 3 (Not at all - Nearly every day). The total score ranges from 0-21, with cut-off scores of 5 representing mild anxiety, 10 representing moderate anxiety and 15 representing severe anxiety. At the moderate anxiety threshold score of 10, the GAD-7 has a sensitivity of 89% and specificity of 82%. The significant correlation between two widely used anxiety scales (Beck Anxiety Inventory and the anxiety subscale of the Symptom Checklist-90) suggest good convergent validity (Spitzer, Kroenke, Williams, & Lowe, 2006). Additionally, this measure has excellent internal consistency (Cronbach α=0.92) in a primary care patient population (Spitzer, et al., 2006). Total scores were extracted from medical records. Due to using only the total score, an alpha coefficient was not computed for this sample.

Patient Health Questionnaire (PHQ-9). The PHQ-9 is a brief 9-item self-report screener (Kroenke, Spitzer, & Williams, 2001). This measure assesses for frequency of experiencing depressive symptoms within a two-week period. Respondents are asked "Over the last 2 weeks, how often have you been bothered by any of the following problems?" A sample item is "… little interest or pleasure in doing things" followed by the four-point Likert scale ranging 0 to 3 (Not at all - Nearly every day). The total score ranges from 0-27, with cut-off scores at 5, 10, 15, and 20 representing mild, moderate, moderately severe, and severe depression respectfully. PHQ-9 scores at the threshold of 10 had a sensitivity of 88% and specificity of 88%. The internal consistency of the PHQ-9 is Cronbach's α = 0.86 in a primary care patient population (Kroenke, Spitzer, & Williams, 2001). Total scores were extracted from medical records. Due to using only the total score, an alpha coefficient was not computed for this sample.

Short-Form McGill Pain Questionnaire (MPQ). MPQ is a 15-item self-report measure assessing patients' pain experience (Melzack, 1975). Respondents are prompted to describe the quality or characteristics of their pain. Example items are "throbbing," "shooting," and

"punishing-cruel" followed by a 4-point Likert ranging from 0-3 (None - Severe). The pain descriptors are categorized into two subscales of pain experience: sensory and affective. This scale has a reported internal reliability Cronbach's α ranging from 0.75 to 0.90 across populations experiencing pain (Wilkie, Savedra, Holzemer, Tesler, & Paul, 1990). The scale also included a Present Pain Intensity (PPI) rating item, assessing pain on a scale 0-5 (No pain-Excruciating). Participants in this sample consistently answered the PPI item, therefore it was extracted from medical records and used to assess pain severity. Due to using the one item score, an alpha coefficient was not computed for this sample.

Premature termination status. From the medical records, a history of appointment attendance was extracted for all patients. Thus, appointment engagement was coded as a count variable specifying the number of appointments each patient attended. For the purpose of this study, premature termination was defined as treatment disengagement after the first session. Patients that prematurely terminated received a value of 0, patients that attended two or more session were coded as 1. All patients who were seen in the clinic were recommended by the provider (as noted within the intake report) for follow-up treatment with a physical therapist, therefore one session was not indicated for any patient in the sample.

Qualitative Materials

Participants were invited to respond to a semi-structured interview (see Appendix B). The open-ended questions focused on identifying reasons for the premature termination and describe the factors that were most impactful in their choice to make the decision to end care. The interview was constructed to highlight psychosocial concerns (i.e. identity, race, and societal factors) consistent with the expanded BMHU (Bradley et al., 2002), in addition to the predisposing, enabling, and needs based factors.

Data Analysis

This mixed-methods study consisted of two stages of analysis: quantitative and qualitative. The findings of both stages were synthesized to provide joint interpretation.

Stage 1. Quantitative. Prior to analysis, data were screened following guidelines established by Tabachnick and Fidell (2013) to assess for missingness and normality. The study N meets the criteria for sufficient power in predicting a medium effect size. G*Power 3 analysis were conducted to evaluate the minimum sample size necessary to detect a medium effect size (Faul, Erdfelder, Lang, & Buchner). For the analysis used in this study, a minimum number of 111 participants were necessary to detect an effect. All analyses were conducted in SPSS 24.0. To assess for the relationship between the study variables and premature termination, point-biserial correlations were employed. After significant relationships were established, the initial analysis plan was to conduct a sequential logistic regression across three steps (predisposing, enabling, and needs factors). However, given the non-significant point-biserial correlations, an alternate plan was devised. Specifically, t tests were conducted to examine determine if there were significant mean differences between the participants who prematurely terminated or continued treatment, across each continuous variable of interest (age, income, depression, anxiety, pain). Additionally, to examine the relationship between the categorical variables gender and premature termination, a chi square test was conducted.

Stage 2. Qualitative. To further understand the psychosocial factors most relevant to African American patients with chronic pain decision making process around premature termination, qualitative interviews were conducted via phone by the primary investigator. The 15 participants answered a semi-structured interview consisting of open-ended questions about their clinic experience (see Appendix B). The interviews lasted from 10-20 minutes, depending on

how gregarious the participant was in answering the questions. The audio recorded interviews were transcribed using an online transcription company. To analyze the interviews this study employed thematic content analysis (Braun & Clarke, 2006) with computer assisted qualitative data analysis software (CAQDAS) (Fielding & Lee, 2002). The CAQDAS used in this study was Dedoose statistical software, a web application for managing, analyzing, and presenting qualitative and mixed method research data (Taylor & Treacy, 2013). The transcribed text was coded using Dedoose and the coded text was discussed between two independent researchers to compare and edit codes. The independent researchers were Clinical Psychology doctoral graduate students trained in conducting qualitative research. Codes were consistent among researchers without discrepant views, however there were some text in which the content was interpreted similarly but the code label differed coders. In those cases, the investigator identified the code label that seemed most representative of the content. The two independent researchers were consulted again for interpretation of the themes. The themes were identified by the lead investigator, then the researchers provided feedback on whether the themes appeared to adequately capture the data.

Results

Quantitative Analysis

The study sample consisted of 164 African American patients; 33.5% (N= 55) men and 66.5% (N=109) women ages 21 to 64 (M_{age}= 50; SD=9.5), diagnosed with chronic pain. The data met standards for normality with a skewness= 1 and kurtosis=2. The income of the patients ranged from $0 - $37,500 per year with an average income of $8,379 (SD=$7,821). Of the sample of 164 patients, 32% (N=53) did not return after the first session, meeting our criteria for premature termination. Regarding the psycho-emotional functioning of the study patient

population, the mean score on the GAD-7 was 7.7 (SD=6.6; range=0-21) suggesting that on average the sample had mild levels of anxiety severity. The overall mean score for PHQ-9 was 9.6 (SD=7.2; range=0-27), similarly suggesting mild depression concerns. The self-reported pain ratings on the MPQ were an average rating of 2.6 (SD=1.33; range=0-5) which suggests a level of "discomforting" pain.

Point-biserial correlations between the variables of interest (gender, age, income, GAD-7, PHQ-9, and MPQ), and premature termination revealed no significant associations (see Table 1). There were significant relationships among the other study variables. There was a positive correlation between gender and age with older participants being mostly female participants. There was a positive correlation between income and gender, with higher income associated with being a female participant. Anxiety was positively correlated with depression and pain severity; and inversely related to income. Depression and pain severity were positively correlated. There was an inverse relationship between depression and gender, with an increase in depression severity associated with being a male participant. Depression was also inversely correlated with income, as income increased depression severity decreased. Similarly, pain severity and income were inversely correlated, as income increased pain severity decreased.

To further understand what may be contributing to the insignificant results, ad hoc tests were run. Independent samples t-tests were conducted between the continuous variables (age, income, depression, anxiety, and pain severity) and premature termination to assess for any significant differences between each group (i.e., patients who prematurely terminated and patients who attended more than one treatment appointment) and the continuous variables. Equal variances were assumed for all variables based on the t test. There were no significant differences between patients who prematurely terminated and patients who stayed in care for 2 or

more sessions across age, income, depression, anxiety, and pain severity scores (see Table 2). Additionally, to examine the relationship between premature treatment termination and the categorical variable gender, a chi square test was performed. Chi square test results suggest that no association was found between gender and premature termination ($X^2(2) > = .006$, $p = 0.936$).

Qualitative Analysis

Of the 53 patients who prematurely terminated during the study period of 2015-2018, only fifteen participants agreed to be interviewed to further understand what contributed to their decision to prematurely terminate treatment. Three themes emerged from the eighteen coded concepts to understand why patients prematurely terminated treatment (see Table 4). The three themes were: perceived treatment inefficacy, patient-provider disconnection, and treatment de-prioritization.

Perceived treatment inefficacy. Several categories of concerns were identified: perceived treatment inefficacy, familiarity with the treatment strategy, inconsistency with expectations, time wasted, and pain symptoms persisting. A number of participants noted treatment not being "helpful" or "waste of my time." This theme highlighted patients concerns with the first session of treatment not being effective in lessening their pain experience, thus contributing to their decision to not return. One 60-year-old woman participant stated, "I don't remember feeling anything when I left other than it was a waste of my time, to be honest with you." When one participant, a 45-year-old male participant, was asked whether the session was consistent with their expectations for chronic pain treatment, he responded "…it was basically inconsistent because they couldn't help me." Another participant responded with a rhetorical question that was consistent with the theme of perceived treatment inefficacy noting: "If they couldn't resolve the problem why would I keep coming back?"

Patient-provider disconnection. This theme included several categories that suggested ruptured rapport or disconnected communication between the patient and provider. The most commonly noted point of disconnection was the perception of no-follow up. Several participants indicated lack of awareness that providers required follow up for treatment continuation. One 52-year-old female participant said "she [the provider] didn't tell me about anything else that we're doing, or that we were going to do next time that was different or anything…." Poor experience with the provider was another concept of this theme. A 57-year-old female participant described a poor experience with support staff who was not directly providing her pain treatment, highlighting the importance of all staff being aware of the quality of patient care. Having an unfavorable experience with any provider within the facility impacted the patient's decision to prematurely terminate treatment. Lack of compassion, lack of trust, and doctor-avoidance were integral components to this theme of patient-provider disconnection. When asked what would have made you more likely to stay in treatment? A 57-year-old female participant stated "It could have been more information, more compassion for my pain…" Additionally, another commonly stated concern that perpetuated the patient-provider disconnection was misdiagnosis, whereby the patient perceived a different etiology for their chronic pain than what the provider communicated within the first session. One 46-year-old female participant described the provider being concerned with her weight "… well it was about getting on a healthy diet type plan, and trying to get my weight down, and I don't think that was the problem."

Treatment de-prioritization. This theme emphasized the negotiation process patients engage in when considering attending their medical appointments. Patients described several factors including emotional distress, insufficient finances, and mobility challenges, which were barriers to treatment for the first session that took precedent over attending subsequent

26

appointments. A few patients described their experience with mental health leading to treatment de-prioritization. One 58-year-old male patient described: "I went into depression mode. I've been unable to get out," and another 52-year-old female patient said: "I was too depressed to do anything, even talk to anybody. I secluded myself from everybody." A number of patients noted financial barriers, "I didn't have money to afford the gas to make it to the appointment." Conversely, a few patients noted that their first session was successful, so much so they noticed improved symptomology and did not need to return. As described by an 39-year-old male patient, "They showed me some exercises that I can do. When I started doing those things, I felt my knees getting better and better. Now I rarely have problems with my knees." Other patients noted taking the strategies they learned within the first session to self-treat at home, explicated by a 57 year old female participant "… after they showed me things that I could do at home, I just didn't see any reason to come back. I said, 'Well I can do this at home. Why come out?'" Another concept illustrated by several patients revolved around pushing-through the pain and continuing to function despite the pain. One 61-year-old male participant stated, "The pain was pretty bad, but I tried to work through it." This concept of pushing-through contributed to treatment seeking not being a high priority.

Triangulation

Quantitative analysis, although not statistically significant, suggests that gender, age, income, GAD-7, PHQ-9, and MPQ scores are not good predictors for premature termination in the current sample. Qualitative interviews were complimentary to the quantitative findings, such that participants did not solely attribute any one particular factor (i.e. emotional distress, income, or mobility concerns) to why they prematurely terminated. The findings from each stage of analyses emphasizes the complexity of the decision for African American patients with chronic

27

pain who choose to not return to treatment after the first appointment. There were varied

perspectives that highlighted concerns about perceived treatment efficacy and quality of the

relationship with the provider. The psycho-emotional factors of depression were noted as a

concern; however it was not a salient reason for not returning to treatment. Income also did not

emerge as a significant predictor of the treatment negotiation process, as the participants were

able to make a way to the initial appointment despite their income, some chose not to return to

the clinic. Regarding pain, the majority of patients stated that their pain severity was not

considered in their decision not to return to treatment. The quantitative results suggests

predicting premature termination is not attributed to any particular index that likely contributed

to the patients initial treatment seeking, the qualitative results suggests there is a secondary

process that occurs after engaging in the first session that is critical in the decision making to not

continue treatment. .

Discussion

This study was an investigation of premature treatment termination among African

American patients with chronic pain. The expanded BMHU model (Bradley et al., 2002) was

employed as the guiding framework to examine this phenomenon and explore the predictive

factors using both quantitative and qualitative research methods. The quantitative and qualitative

results provide an enriched story to highlight the complexities in the decision to prematurely

terminate treatment. The quantitative analysis did not reveal any significant predictors of

premature termination. Gender, income, depression, anxiety, and pain severity did not have a

significant relationship with premature treatment termination, as assessed in this study. Potential

explanations for nonsignificant findings are that the variables examined were not the best

predictors of premature termination and perhaps instead variables related to the patient-provider

relationship, treatment experience, and relative importance of treatment to other life concerns may be better predictors of who does and does not remain in treatment (as alluded to by the qualitative results). This is an interesting finding considering that the literature consistently suggests an association between these variables and chronic pain (Campbell, Clauw, & Keefe, 2003; Green & Hart-Johnson, 2012; Tsang et al., 2008). However, it is important to note that although the association between the variables of interest and chronic pain are evident in the literature, there are few studies that address these variables within the context of premature termination in treatment utilization. It is possible that these demographic variables are better suited to predict treatment seeking (Kleinke & Spangler, 1989) rather than treatment termination. The mild severity levels of psychopathology (with respect to depression and anxiety symptoms) in the sample it may limit the generalizability with similar samples whom often endorse higher distress. An older study that similarly examined possible predictors for completion of chronic pain treatment found that completers of treatment had less psychopathology (King & Snow, 1989). Regarding gender, female patients with chronic pain have been shown to be less likely to seek pain specialist treatment than men (Meghani & Cho, 2009). The opposite was found by Goode and colleagues (2013), where rural women had higher odds of seeking a physical therapist for pain treatment than rural men. There are mixed findings regarding the impact of income on treatment seeking, Meghani and Cho (2009) found that individuals with the lowest income had higher odds of seeking treatment from a pain specialist than their counterparts with higher income. However, Goode and colleagues (2013), showed that Black patients with chronic pain had a lower odd of utilizing treatment if they had low income. The varied findings in the literature provides some insight into the nonsignificant relationships in the current study.

Despite the various plausible reasons to explain why the variables of interest did not statistically predict premature treatment termination in the quantitative analysis, it is important to note while evaluating both the quantitative and qualitative results concurrently it is very likely that the quantitative variables represent an accurate representation of the sample within the context of the qualitative results and the proposed variables were not salient factors in the decision making process to not return to treatment for the patients. As the same variables were examined in the quantitative analyses and discussed within the qualitative interview, patients often discussed the variables within the context of various other concerns. Given that the concerns were multifaceted, that could explain why each of the variables did not have a strong enough relationship with treatment termination. Considering the complexity of the decision to not return to treatment, it is possible that the BMHU does not adequately function as a quantitative model for this particular cohort. The expanded BMHU was examined qualitatively in the 2002 study (Bradley, et al., 2002), therefore examining the domains of predisposing factors, enabling factors, needs factors, and psychosocial factors may be better suited for the flexibility of open-ended interviews.

In examining the nonsignificant quantitative findings, a reconsideration of the theoretical perspective is useful. This study utilized a variable centered approach for quantitative analyses, suggesting that patients' demographics influenced the outcome of premature termination. The qualitative findings may suggest person-centered results. It may also suggest that a culturally responsive method for assessing the perspectives of African American patients may require allowing room for discussion rather than using solitary metrics.

The qualitative findings were more consistent with previous literature, although there were some novel revelations. The first theme of *perceived treatment inefficacy* highlights a major

30

concern contributing to patient satisfaction. Many of the patients described the first session to be a "waste of time" while others noted familiarity with the treatment strategy. This is consistent with the perspective of Anderson, Green, and Payne (2009), who suggest that African American patients with chronic pain are not adequately assessed; whereas an adequate assessment could have addressed past treatment interventions for future treatment planning. Another concern explicated within this theme is inconsistency with treatment expectations. Richmond and Carmody (1999) found that alignment of expectations and goals of treatment is of utmost importance for treatment adherence. When the patient's goals are not met, there is notable dissatisfaction. Barbosa and colleagues' (2012) review of the literature makes evident the direct relationships between treatment adherence, compliance, and persistence in treatment with patient satisfaction. It is likely that shared decision-making between the patient and provider could facilitate solidifying unified treatment goals, which would likely result in improved patient satisfaction (Joosten, et al., 2008). However, given the complexity of chronic pain, particularly the variability in pain etiology, there could be misalignment in treatment expectations because the patient may anticipate symptom reduction and the provider may suggest symptom management given the etiology of the patient's pain. Thus, there may be a critical distinction between the goals of treatment as perceived by the patient and the provider, which may be fundamentally different despite open communication.

Communication is a major component in the decision-making process for patients considering termination from treatment, as communication was an underlying concept of the major theme of *patient-provider disconnection*. It has been well-documented that the patient-provider relationship is essential to treatment outcomes (Fuertes, et al., 2007; Matthias, et al., 2010; Vowles & Thompson, 2012). Few patients reported concerns about providers requiring

follow-up for treatment continuation, suggesting a lack of connectedness or communication that would make it evident that patients' presence is necessary for continued treatment. In addition to treatment expectations and goals, the concept of shared decision-making between the patient and provider should also be considered in the conceptualization of diagnosis (Joosten, et al., 2008). The incongruency of diagnoses can rupture relationships, as evidenced by the patients suggesting misdiagnosis as a factor for not returning. Communication between the patient and provider highlights a meta-process of the healthcare exchange that can impact treatment outcomes.

The *treatment de-prioritization* theme highlights the negotiation process patients engage in as a function of considering various psychosocial concerns juxtaposed to their healthcare utilization needs. Patients could reasonably identify barriers to care as potential roadblocks to attending the first session; however, the quality of the experience from the first session provided the basis for barriers to outweigh the need for continued treatment seeking. This was a surprising finding as it was expected that barriers to treatment would have a direct impact on whether the patient attended appointments. The findings in this theme suggest resilience amongst the patients, as they are engaging in care despite noted barriers. It also points to the importance of addressing the barriers to treatment engagement and assessing motivation as it can erode attendance over time (Miller, 2005). There is concern that because a physical therapist requires treatment appointments more often, it may be more costly of an investment, thus more burdensome financially (Goode, et al., 2013). Yet, it is notable that a statistically significant relationship did not exist for income in the current study. Despite the sample earning relatively low income, less than $34,000 per year, majority were able to attend physical therapy. Church Health Center is a community faith-based organization for the uninsured or underinsured, therefore much of the financial burden may be addressed in this model of care. However, for

those that did prematurely terminate therapy income was a factor that was negotiated within the context of other competing barriers to care.

Another coded content of this theme was the concept of "pushing through." The patients were describing what could be interpreted as psychological resilience. The concept of resilience has been examined within the context of chronic pain patients, notably attributed to increased self-efficacy and active engagement in medical treatment (Rolbiecki, et al., 2017). However, considering that the chronic pain patients examined in Rolbiecki and colleagues' (2017) study were all Caucasian, resilience in African American patients with chronic pain may function differently. This concept of "pushing though" was similar to the "just getting on with it" concept, whereas participants in a study examining resilience in chronic pain described the importance of getting on with life and not succumbing to pain (West, Steward, Foster & Usher, 2012). This self-efficacy may function more like self-reliance in African American patients, and what would have been a facilitator of treatment now promotes the opposite effect. Jennings and colleagues (2015) explored the relationship between self-reliance and treatment seeking within the context of perceived stigma and self-stigma, notably concluding that the three-path model was associated with more negative treatment seeking attitudes. In this study perceived stigma was associated with treatment seeking through self-stigma and self-reliance, whereas higher score contributed to decrease probability of treatment seeking for mental health concern (Jennings, et al., 2015) However, it is important to note that some of the patients expressed improved symptomology. Although, there isn't any empirical evidence to support single session chronic pain treatment, these patients could have very well gained benefit from the appointment to effectively manage their pain independently, thereby increasing their perception of self-efficacy highlighted in previous studies on resilience in chronic pain. However, given the high rates of use of

complementary or alternative medicine (such as, meditation, herbal medicine, massage, or raw food diet) among ethnic minorities, there may have been improvement in symptomology that occurred concurrent to the first treatment appointment that could not be solely attributed to medical treatment (Ho, Jones, & Gan, 2008).

Additionally, it is important to note that although all of the physical therapy providers were Caucasian, treating African American patients, concerns with racial discrimination were not reported. While there likely could have been racial discrimination that the patients simply did not perceive, or feel comfortable enough to report, it is notable that it was not a highlighted concern, as literature would suggest (Anderson, Green, & Payne, 2009; Hampton, Cavalier, & Langford, 2015). This could be due to the economic structure in the city of Memphis that reflects the broader United States, whereby majority of African Americans do not hold high level executive, managerial, supervisory positions and thus may be accustomed to inequity and disregard microaggressions from those positions of power (Delavega & Blumenthal, 2019). The lack of attributing race to the patient experience could also be due to the racial identity of the participants, considering the different stages of Black Identity the perception of race relations could vary drastically (Cross & Fhagen-Smith, 1996). Additionally, there could be hesitancy to discuss racial microaggressions, as negative interactions may be perceived by others as unfounded or without sufficient evidence. There is literature that supports the invalidation of microaggressions as leaving many ethnic minorities voiceless (Lilienfeld, 2017; Wheeler, 2016).

Strengths and Limitations

There were a number of strengths in this study. The mixed methods approach allowed for a richer exploration of the research question. Given that the quantitative stage of analyses was inconclusive regarding identifying predictors, the qualitative interviews provided an important

component to adequately capture the perspectives of the patients. Additionally, there are few studies that examine African American patient perspectives of treatment termination, despite the evident disparity in termination relative to white patients. The current study provided insight into the pain treatment decision-making process for African American patients with chronic pain who did not returning to treatment. Another strength of this study is the examination of the expanded BMHU for treatment termination in African Americans with chronic pain. This study lends support to examining this model within a qualitative framework; however, it could also be foundational in developing a more complex model to adequately capture the nuances of deciding to terminate treatment prematurely. The manner in which the qualitative interviews were conducted, i.e., utilizing phone interviews, may have made the study more accessible to participants who may otherwise have not participated due to financial, transportation, and or mobility barriers. Participants also may have felt more comfortable discussing their thoughts given the phone context, rather than a more formal in-person meeting at Church Health Center, the location they could have had disparaging feelings about.

Despite the many strengths, there were some limitations. One limitation was the time period that the qualitative participants were sampled. Each of the patients were interviewed in 2019 about seeking services several years ago, for some up to 4 years ago. Although each of the participants were able to provide a recollection of their treatment experience, relying on memory is susceptible to recall bias. Future studies would benefit from interviewing patients shortly after premature termination to get the most updated perspective. Specifically, there was minimal variance across socioeconomic status, thus the homogeny could have contributed to the inability to statistically predict premature termination or generalize to a wider array of African American patients with chronic pain. Another limitation is that there was minimal information about

35

additional providers seen by the patients. The patients were included in the study sample on the basis that they were engaged with other providers, as that is typical of the integrated healthcare model; however, available data did not indicate the type of treatment the patient was getting, and if it was indeed coordinated care. Patients could have been receiving multidisciplinary care rather than interdisciplinary care, meaning some patients may be receiving care from several providers who may not collaborate while some patients may be receiving care from a team of providers who coordinate and communicate about a collective care plan. This information may have made a difference in the interpretation of the findings. Additionally, there is limited information the content of the first session for each patient. It is an underlying assumption that the first session was consistent for all patients; however, the difference in providers could lend to difference in experience. Data was not obtained on who the providers were for patients who prematurely terminated treatment, and thus, it is unknown if a particular provider influenced the results. It would also have streamlined the study if the chronic pain diagnosis was centralized to one location (i.e., chronic back pain). Given that there were a number of chronic pain locations the results are likely influenced by the nuances of pain experiences. Additional information on body mass index and medication list would have been beneficial. Many of the important indicators were not recorded or were inconsistently recorded within the medical chart. Clinical documentation in some settings may not be a rigorously recorded as research data documentation. Accordingly, managing the practical application of examining experiences in a clinical setting may have posed some limitations in the quality of the obtained data, which was needed to fully explore this phenomenon. This impacted several data points that could have been used in the sample, particularly pain, limiting the investigation to a single item assessment. Due to the examining a single item, alpha coefficient was not determined, limiting the information

about internal reliability. There was also inconsistent records of the participants body mass index and additional health conditions. Data was also not obtained about whether the patient was taking pain medication and at what point they initiated medications, which could have impacted their decision to continue with physical therapy treatment. Future studies should include these missing data points to gain a more balanced view of factors contributing to premature treatment termination. Considering that this study did not focus on exploring what contributes to patient retention in treatment, future studies should examine this and gain perspectives of patients who did not prematurely terminate.

Clinical Implications

Understanding why African American patients with chronic pain prematurely terminate treatment is clinically relevant for several reasons. Healthcare providers are trained to provide the best treatment to those in need and these findings can support that goal, further informing ways to modify care to improve retention of all patients. If providers are able to better understand possible barriers to treatment and combat those barriers, particularly improving communication effectiveness, it is likely that the occurrence of premature termination may drastically be reduced. Consistent with the literature, the findings of this study highlight the importance of establishing a strong therapeutic alliance within the first session. This alludes to the utility of motivational interviewing, where the patient and provider establish a partnership and because the patient feels heard, barriers and ambivalence are likely to be discussed. The provider expresses compassion and acceptance of the patient's life circumstance and how that can impact the course of treatment, while eliciting ways to create opportunities that support treatment. The use of motivation interviewing can address many of the communication issues that were revealed in the qualitative portion of this study.

These findings also have implications for narrowing the gap in health inequality for African American patients with chronic pain. The value of building trust is noted in this study and reflective of the broader literature, thus highlighting the need for clinicians to prioritize safe spaces for African American patients. It is also important to note that the concept of "pushing through," or psychological resilience was a factor for some patients. Further exploration of this concept of resilience could be fundamental in the development of culturally tailored strengths-based approaches to patient care and promoting self-efficacy while encouraging continued help seeking. The study findings provide essential information for future intervention development for inclusive patient care.

Conclusions

Premature termination of treatment is a critical issue within healthcare. Considering that the number of patients that actually engage in the first session of treatment are only a subset of patients referred, premature termination compounds the number of people who need services and are not getting needed care to improve their condition. This phenomenon is particularly important to study as it is exacerbating the health disparity associated with equitable treatment outcomes for African American patients with chronic pain. The results suggest that the expanded BMHU has limited ability to capture the various factors influencing premature treatment termination for this particular cohort, although the open-ended qualitative interview was better suited for investigation using this guiding framework. The finding of no significant relationships between the variables of interest and premature termination should be regarded with caution. Although the qualitative interviews provide support for the research questions, given the level of complexity of factors, there could be statistical constraints impacting the quantitative analyses. Patients identified several factors that likely contributed to their decision to not return to

treatment, highlighting that the perceived interactions that occurred in the first session were associated with three domains of concerns: *perceived treatment inefficacy, patient provider disconnection, and treatment de-prioritization.* These findings highlight the added value of mixed methods research which allows for examination of a broader range of variables pertinent to the lives of diverse patients that may not be regularly assessed in hospital settings. It behooves providers to consider patient-provider interaction concerns, perceived treatment efficacy, and value of treatment relative to other life factors for future intervention development. This may allow for more tailored initial appointments in order to increase the likelihood that African American patients with chronic pain remain in needed treatment.

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Table 1

Demographic variables, Depression, Anxiety, Pain Severity, and Premature Termination

Relationships: Correlations and Descriptive Statistics (N = 164)

Variables	1	2	3	4	5	6	7
1. Age	–						
2. Gender	.302**	–					
3. Income	.113	.155*	–				
4. GAD-7	-.085	-.030	-.240**	–			
5. PHQ-9	-.084	-.024**	-.227**	.835**	–		
6. Pain Severity	-.146	-.082	-.192*	.303**	.269**	–	
7. Premature Termination	.064	.006	-.009	-.029	.032	-.027	.--
Mean	50.59		8,379	7.73	9.58	2.66	
SD	9.53		7,821	6.57	7.21	1.33	
Range	21-64		0-37,500	0-21	0-27	1-5	

Note: **p<.01; *p<.05

Table 2

Summary of T-tests: Mean differences among predictor variables and premature termination (N = 164)

Variable	Premature Termination		Continued Treatment		
	M	*SD*	*M*	*SD*	*Sig.*
Age	49.72	9.187	51.01	9.710	.819
Income	8484.29	7860.35	8330.19	7837.84	.480
GAD7	8	6.352	7.59	6.706	.523
PHQ-9	9.25	6.762	9.74	7.446	.271
Pain Severity	2.72	1.262	2.64	1.36	.391

Note: 'Continued treatment' refers to participants that engaged in more than 1 treatment appointment; M=Mean, SD= Standard deviation; Sig.= statistical significance.

Table 3

Qualitative Participants demographic data

Patients	Gender	Age	Income	GAD-7	PHQ-9	Pain
Patient 1	Male	61	11064	9	14	2
Patient 2	Male	61	2136	19	20	2
Patient 3	Male	39	20800	11	15	5
Patient 4	Male	42	0	5	8	4
Patient 5	Male	45	0	9	10	3
Patient 6	Female	54	1000	17	20	2
Patient 7	Female	60	0	4	7	2
Patient 8	Female	41	11400	3	3	5
Patient 9	Female	46	0	2	1	1
Patient 10	Male	58	5478	3	3	1
Patient 11	Female	63	9600	14	10	1
Patient 12	Female	49	12228	2	6	1
Patient13	Female	52	20800	8	22	4
Patient 14	Female	52	8400	12	16	5
Patient 15	Female	57	19200	11	11	3

Table 4. Qualitative Themes

Theme	Codes	Number of Occurrences
Perceived Treatment Inefficacy	Perceived treatment inefficacy	7
	Familiar with strategy	2
	Inconsistent with expectations	5
	Persistent Symptoms	3
	Time-wasted	2
Total		*19*
Patient-Provider Disconnection	Perceived No follow-up	4
	Poor provider experience	3
	Doctor Avoidance	1
	Perceived Lack of provider compassion	1
	Lack of Trust	1
	Misdiagnosis	3
Total		*13*
Treatment De-prioritization	Deprioritized	2
	Emotional Distress	6
	Financial improvement/challenges	1
	Improved symptomology	2
	Mobility challenges	3
	Pushing-through	4
	Self- treatment	3
Total		*21*

Note: Number of occurrences refers to amount of times the code was identified in the qualitative interview data

Data Usage Agreement

This Data Use Agreement ("Agreement"), effective as of ___February 1, 2019___ ("Effective

Date"), is entered into by and between _____Courtney Maclin_____ ("Recipient") and
Church Health Center ("Covered Entity"). The purpose of this Agreement is to provide the
Recipient with access to a Limited Data Set ("LDS") (as defined below) for use in the
following titled research project: **Chronic Pain Assessment Considerations in Integrated
Primary Care: Evaluating Premature Treatment**

Termination Among African American Patien, under the direct supervision of __Drs. Frank
Andrasik and Idia Thurston in accord with the HIPAA Regulations.

> A Limited data set is defined as health information that excludes certain direct
> identifiers (listed below) but that may include city; state; zip code; elements of
> date; and other numbers, characteristics, or codes not listed as direct identifiers
> (below). The Privacy Rule's limited data set provisions requiring the removal of
> direct identifiers apply both to information about the individual and to
> information about the individual's relatives, employers, or household members.

The following identifiers **must** be removed to qualify as a limited data set:

1. Names
2. Postal address information (other than town or city, state, and zip code)
3. Telephone numbers
4. Fax numbers
5. Electronic mail addresses
6. Social security numbers
7. Medical record numbers
8. Health plan beneficiary numbers
9. Account numbers
10. Certificate/license numbers
11. Vehicle identifiers and serial numbers (including license plate numbers)
12. Device identifiers and serial numbers
13. Web universal resource locators (URLs)
14. Internet protocol (IP) address numbers
15. Biometric identifiers, including fingerprints and voiceprints
16. Full-face photographic images and any comparable images

The following outlines the agreement requirements for the use of the data and assure compliance with the requirements by all staff and collaborators approved as part of the agreement.

1. I will not use these data except for statistical analysis and reporting as described in the IRB approved proposal.
2. I will not use nor permit approved collaborators and staff to use these data to conduct analyses other than those described in the IRB approved proposal.
3. I will not release the data set or any part of it to any person other than those listed as collaborators in the IRB approved proposal. I will assure that all approved collaborators understand that they may not share the data set or any part of it.
4. I will not attempt or permit others to use the data set or link it with other data sets to attempt to learn the identity of any participant. If the identity of a respondent should be inadvertently discovered, I will make no use of this knowledge, nor will I permit others to use the knowledge.
5. All oral or written presentations of the results of the analyses will include an acknowledgment of Church Health Center.
6. When the proposed analyses are completed, all copies of these data will be destroyed or returned unless an additional project is proposed and granted IRB approval.
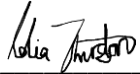
My signature and the signature of all investigators indicate compliance with the aforementioned data usage agreement

Primary Investigator:
Signature: _____
Print name: Courtney Maclin   Date:_____02/05/2019

Faculty mentors: *Frank Andrasik*
Signature: _____
Print name: Frank Andrasik, PhD   Date:_____02/04/2019

Signature: _____
Print name: Idia Thurston, PhD   Date:_____02/04/2019

Collaborators:
Signature: _____
Print name: Prof. Jiwen Chen   Date:_____02/04/2019

Church Health Director of Research:
Signature: _____
Print name: Fedoria Rugless, PhD   Date:_____02/04/2019

58

Generalized Anxiety Disorder- 7 (GAD-7)

Over the last 2 weeks, how often have you been bothered by any of the following problems?
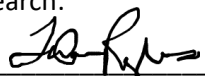(Use " ✔ " to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3
FOR OFFICE CODING	**0** +	**_____** +	**____** +	**_____**
	=Total Score:			

PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?
(Use " ✔ " to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING   **0**   **+**   **_____**   **+**   **____**   **+**   **_____**

=Total Score:

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all … Somewhat difficult … Very difficult … Extremely difficult …

SHORT-FORM McGILL PAIN QUESTIONNAIRE
RONALD MELZACK

PATIENT'S NAME:_____   DATE:_____

	NONE	MILD	MODERATE	SEVERE
1. THROBBING	0) ____	1) ____	2) ____	3) ____
2. SHOOTING	0) ____	1) ____	2) ____	3) ____
3. STABBING	0) ____	1) ____	2) ____	3) ____
4. SHARP	0) ____	1) ____	2) ____	3) ____
5. CRAMPING	0) ____	1) ____	2) ____	3) ____
6. GNAWING	0) ____	1) ____	2) ____	3) ____
7. HOT-BURNING	0) ____	1) ____	2) ____	3) ____
8. ACHING	0) ____	1) ____	2) ____	3) ____
9. HEAVY	0) ____	1) ____	2) ____	3) ____
10. TENDER	0) ____	1) ____	2) ____	3) ____
11. SPLITTING	0) ____	1) ____	2) ____	3) ____
12. TIRING-EXHAUSTING	0) ____	1) ____	2) ____	3) ____
13. SICKENING	0) ____	1) ____	2) ____	3) ____
14. FEARFUL	0) ____	1) ____	2) ____	3) ____
15. PUNISHING-CRUEL	0) ____	1) ____	2) ____	3) ____

```
|-----------------------------------------------------------|
0                                                          10
NO                                                       WORST
PAIN                                                   POSSIBLE
                                                         PAIN
```

PPI

0	NO PAIN	____
1	MILD	____
2	DISCOMFORTING	____
3	DISTRESSING	____
4	HORRIBLE	____
5	EXCRUCIATING	____

Appendix B

Interview Protocol

We are interested in understanding the perceptions of chronic back pain treatment and the factors associated with the decisions to discontinue care.

1. Please tell me about your experience with chronic pain; what are the challenges?
2. When your primary care provider referred you for treatment with the physical therapist what were your expectations for the first session?
3. In what ways were the session consistent or inconsistent with your expectations?
4. What was your understanding of the goal of treatment for your chronic pain?
5. Why did you decide to not return for treatment?
6. What factors were most important when you decided not to return for treatment?
7. Why did terminating treatment seem like the best choice for your situation in that moment?
8. How important was having a trusting relationship to your treatment?
9. What could have made it more likely for you to stay in treatment?
10. What are some characteristics that are unique to your identity that may have impacted your experience with treatment?
11. Could you identify some ways in which your race may have impacted treatment in positive or negative ways?
12. What are some societal factors that may have impacted your decision to discontinue treatment?
13. How might your mental and emotional health impacted treatment?
14. How did you factor in the intensity of your pain in your decision to discontinue treatment?
15. What would you want providers to know about you and your chronic pain?
16. What would you want providers to know about how to best care for your chronic pain?
17. Anything else you would like to share about your experience receiving services for chronic pain at this facility?

IRB #: PRO-FY2018-398

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Status: Closed
Principal Investigator: Courtney Maclin
Review Board: University of Memphis
Sponsor:

Study History

Submission Type Initial	Review Type Expedited	Decision Approved
Submission Type Closure	Review Type Unassigned	Decision

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