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# The Experience Of Chronic Pain As Described By African American Indigent Adults Attending An Urban Primary Care Clinic

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**THE EXPERIENCE OF CHRONIC PAIN AS DESCRIBED BY AFRICAN AMERICAN  
INDIGENT ADULTS ATTENDING AN URBAN PRIMARY CARE CLINIC**

by

**JAMIE CRAWLEY**

**DISSERTATION**

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

**DOCTOR OF PHILOSOPHY**

2010

MAJOR: NURSING

Approved by:

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Advisor

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## DEDICATION

This dissertation is dedicated first to God the Father, for His unconditional love, gift of health and every day miracles.

To my best-friend and husband Tim and my beautiful children Faith and Jordan for their patience, hugs and understanding. I could not have accomplished this journey without your love.

To my parents Jim and Terri Renaud for instilling within me the values of determination and faith to pursue my dreams.

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## TABLE OF CONTENTS

Dedication.....	ii
Acknowledgments .....	iii
List of Tables.....	xi
List of Figures.....	xii
Chapter 1 “Introduction” .....	1
Definition of Pain .....	2
Problem of Pain .....	3
Race, Income, and Pain .....	4
Purpose and Goals of Study .....	8
Significance of the Study .....	10
Overview of the Dissertation .....	12
Chapter 2 “Review of the Literature” .....	13
Introduction .....	13
Enrollment of African Americans .....	14
Influence of income .....	15
Socioeconomic variables not examined .....	17
Pain care centers .....	19
Specific types of pain .....	20
Survey data .....	23
Telephone surveys .....	26
Secondary data analyses .....	28
Other qualitative studies.....	30

Summary .....	32
Conclusion .....	34
Theoretical Framework.....	36
Health as Expanding Consciousness .....	36
HEC and Chronic Pain for African American Indigent Adults .....	37
Terms used in HEC.....	39
Life Patterns of Pain .....	44
Uncontrolled pain .....	44
Application of theory to study .....	44
Chapter 3 “Methods” .....	48
Introduction.....	48
Research Design .....	48
The Clinic and Its Clientele .....	51
Inclusion criteria .....	53
Data Collection .....	54
Data collection instruments .....	60
Protection of Human Subjects .....	65
Compensation.....	68
Ethnographic research cycle.....	69
Challenges with data collection .....	70
Data Analysis.....	74
Trustworthiness.....	77
Race, gender and trust.....	80

Conclusion .....	84
Chapter 4 “Findings” .....	86
Descriptive Findings .....	86
Participants’ Backgrounds .....	87
Demographic data form.....	87
Brief Pain Inventory (Short Form) .....	92
Waiting on Pain – “Ain’t gonna never stop” .....	98
Duration of pain in their lives and effect on waiting .....	98
Chronic pain and waiting to take pain medication .....	99
Activities to ‘pass the time’ while experiencing pain .....	101
Comfortable place – while waiting for pain.....	103
Waiting for time of day that is best for activities .....	107
Time spent waiting on others for help .....	112
Future goals influenced by chronic pain.....	114
Coping with Chronic Pain – “I don’t want to be high, I just want to be pain free” .....	116
Chronic pain and coping – items that help .....	117
Chronic pain and coping – activities that help .....	123
Pain medication and coping .....	130
Coping with pain when run they’ve run out of pain meds .....	132
Coping with chronic pain and concern with addiction and side effects...	135
Health care providers concerns with addiction and pain meds .....	136
Chronic pain and moods – sadness and resilience .....	139



Feelings of control over chronic pain.....	145
Prayer and chronic pain .....	147
People and coping – supportive and not supportive.....	149
Challenges with Chronic Pain – “You don’t look like you’re in pain” .....	154
Challenges with pain care if different race .....	154
Challenges with pain care – insurance.....	157
Challenges with chronic pain and others believing you have pain .....	159
Chronic pain’s effect on walking and climbing stairs .....	164
Challenges with chronic pain and feeling burdensome to others .....	169
Challenges with completing activities of daily living .....	171
Challenges with sleeping and preparing food .....	176
Challenges with concentration and health care instructions.....	178
Negotiating Pain in a Vulnerable Environment – “blessed to still be alive...”....	181
Negotiating chronic pain inside the apartment .....	182
Negotiating pain with reduced incomes.....	183
Resources in their environment.....	189
Vulnerable environments – poverty, violence, loss .....	192
Sharing Wisdom about Chronic Pain – “...try to put their selves in our situation” .....	198
Advice to others about living with chronic pain.....	198
Advice to health care providers about improving chronic pain care .....	201
Chapter 5 “Discussion” .....	204
Summary of Experiences of Chronic Pain .....	204
Comparison of Findings to the Research Questions .....	204

Comparison of Findings to Theory.....	206
Time, consciousness, movement and space.....	206
Expanded consciousness .....	208
Comparison of Findings to the Literature.....	213
Implications for Clinical Practice .....	219
Future Research Directions .....	226
Strengths and Limitations .....	228
Conclusion.....	230
Appendix A .....	234
Appendix B .....	240
Appendix C .....	241
Appendix D .....	242
Appendix E .....	245
Appendix F .....	249
Appendix G .....	250
Appendix H .....	252
Appendix I .....	253
Appendix J .....	256
Appendix K .....	258
Appendix L .....	259
Appendix M .....	260
Appendix N .....	261
Appendix O .....	262

Appendix P .....	267
References .....	268
Abstract .....	291
Autobiographical Statement .....	293

## LIST OF TABLES

Table 1: Demographic Data Form .....	89
Table 2: Brief Pain Inventory (Short Form) .....	94

## LIST OF FIGURES

Figure 1: Waiting on pain – View when looking at ceiling .....	102
Figure 2: Waiting on pain – Her front porch .....	103
Figure 3: Waiting on pain – Comfortable place.....	104
Figure 4: Waiting on pain – ‘Nice Scenery’ .....	105
Figure 5: Waiting on pain – Supportive chairs .....	106
Figure 6: Waiting on pain – Comfort food .....	107
Figure 7: Waiting on pain – Time needed to arrive on time for appointments.....	108
Figure 8: Waiting on pain – Time of day .....	111
Figure 9: Waiting on pain – Working elevators .....	114
Figure 10: Coping with chronic pain – Items that help, bath stool .....	118
Figure 11: Coping with chronic pain – Two comfort tools .....	119
Figure 12: Coping with chronic pain – Running boards on truck .....	120
Figure 13: Coping with chronic pain – Sticker for parking .....	122
Figure 14: Coping with chronic pain – Cane, “my buddy” .....	123
Figure 15: Coping with chronic pain – Soaking in bath water.....	124
Figure 16: Coping with chronic pain – Planting flowers .....	125
Figure 17: Coping with chronic pain – Looking at nature.....	126
Figure 18: Coping with chronic pain – Pets .....	127
Figure 19: Coping with chronic pain – Neighbor’s pets .....	128
Figure 20: Coping with chronic pain – Reading books .....	129
Figure 21: Coping with chronic pain – Face of pain .....	141
Figure 22: Coping with chronic pain – Prayer guide.....	148

Figure 23: Challenges with chronic pain – Climbing stairs .....	165
Figure 24: Challenges with chronic pain – Stairs and unsafe railing .....	166
Figure 25: Challenges with chronic pain – Walking .....	167
Figure 26: Challenges with chronic pain – Slope on sidewalk .....	168
Figure 27: Challenges with chronic pain – Steep overpass .....	169
Figure 28: Challenges with chronic pain – Manual locks in cars .....	174
Figure 29: Challenges with chronic pain and preparing food .....	177
Figure 30: Negotiating pain in a vulnerable environment – View when cannot get out of bed .....	183
Figure 31: Negotiating pain in a vulnerable environment – Income limiting safety .....	188
Figure 32: Negotiating pain in a vulnerable environment – Helpful resources such as benches at bus stops .....	190
Figure 33: Negotiating pain in a vulnerable environment – Potholes in the street .....	193
Figure 34: Negotiating pain in a vulnerable environment – Forgotten street pole .....	194
Figure 35: Negotiating pain in a vulnerable environment – Deteriorated streets .....	195
Figure 36: Negotiating pain in a vulnerable environment – Finding newborn in an abandoned building .....	196
Figure 37: Negotiating pain in a vulnerable environment – Drive-by shooting .....	197

## CHAPTER 1

### INTRODUCTION

Inadequate pain control, especially for chronic pain, has far-reaching implications. The International Association for the Study of Pain (2008a) stated that relief of chronic pain should be a “human right.” People at highest risk for inadequate pain control include the poor, marginalized or minority groups, and those with fewer resources (American Pain Society, 2004). African American indigent adults are one such group (Benkert & Peters, 2005; Green, Baker, Sato, Washington & Smith, 2003; Pieper, Vallerand, Nordstrom & DiNardo, 2009).

Investigators have described how chronic pain affected the lives of African American people (American Pain Society, 2008; Green, Anderson et al., 2003; McNeill, Reynolds & Ney, 2007; Todd, Deaton, D’Amano & Goe, 2000; U.S. Department of Health and Human Services, 2004; U.S. Department of Health and Human Services – Office of Disease Prevention and Health Promotion, 2005). Some studies did not enroll equal numbers of African Americans in the sample for comparison purposes (Green, Baker, Sato et al., 2003; Green, Baker, Smith & Sato, 2003; Green, Ndao-Brumblay, Nagrant, Baker & Rothman, 2004; Riley et al., 2002). These studies failed to explore the possible influence of income on pain care (Bernard & Wright, 2004; Cano, Mayo & Ventimiglia, 2006; Douglas, Windsor & Wollin, 2008; Richardson, Ong & Sim, 2008; Vallerand & Nowak, 2009), or only examined subjects attending a multidisciplinary pain center (Edwards, Moric, Husfeldt, Buvanendran & Ivankovich, 2005; Green, Baker, Sato et al., 2003; Green, Baker, Smith et al., 2003; Green, Ndao-Brumblay, Nagrant et al., 2004; Merry, Edwards, Doleys, & McGuire, 2007; Riley et al., 2002). Several published

research studies obtained data from surveys (Poleshuck, Giles & Tu, 2006; Pieper et al., 2009; Edwards et al., 2005; Green, Ndao-Brumblay, Nagrant et al., 2004; Im et al., 2007; Im, Lim, Clark & Chee, 2008; Nguyen, Ugarte, Fuller, Haas & Portenoy, 2005; Pieper, et al., 2009; Portenoy, Ugarte, Fuller & Haas, 2004; Ruhlman, Karoly & Newton, 2005) and participants were not able to verbally describe how experiences with chronic pain influenced their lives. The present study explored the experience of chronic pain as described by African American indigent adults attending an urban primary care clinic. Participants' experiences and patterns of pain were examined within Newman's (1986; 1994) theory, health as expanding consciousness.

### **Definition of Pain**

Pain is subjective and multidimensional (National Pain Foundation, 2009b). Pain is a disagreeable, emotional, and sensory experience related to potential or actual damage of tissue (International Association for the Study of Pain, 2008b). For almost two decades, pain has been recognized as real for the person, even without an observable pathological cause (Diamond, 1991). Despite this recognition, pain continues to be inadequately treated (Freeman & Payne, 2000; National Pain Foundation, 2009a). Any combination of pain sub-types, neuropathic (nerve pain), nociceptive (signaling tissue injury), somatic (involving the cutaneous or musculoskeletal tissues) or visceral (pain involving the internal organs), can result in chronic pain (Webster, 2008). Pain pathways can become overactive when pain is constant. Pain pathways are formed as the brain and body rewire themselves in response to injury (Loeser & Melzack, 1999).



Chronic pain is defined as “pain or discomfort that persisted continuously or intermittently for longer than 3 months” (Elliott, Smith, Penny, Smith & Chambers, 1999). Chronic pain is a serious health problem that may affect a person’s quality of life, and may include frequent severe flare ups occurring on average 6 out of 7 days per week (American Pain Society, 2008; American Pain Society and Janssen Pharmaceutica, 1999). Many individuals have been living with chronic, unresolved pain for more than 5 years.

### **Problem of Pain**

Pain can be debilitating, with patients often facing significant barriers in the diagnosis, treatment, and management of their pain (National Pain Foundation, 2009a). The loss of productivity and the inability to perform daily activities due to pain is substantial. Pain is a common complaint in 50-70% of all primary care visits (Sullivan & Egel, 2005).

More than 75 million Americans live with chronic and acute pain caused by various diseases, disorders, or accidents (National Pain Foundation, 2009a). It has been estimated that pain might be responsible for as many as 36 million Americans missing work and could affect the ability of 83 million Americans to participate in social activities (Weiner, n.d.). Chronic pain costs almost \$100 billion per year in terms of lost productivity at work, loss of income, and use of health care resources (American Pain Society, 2008; National Pain Foundation, 2009b). Emotional well-being and quality of life can improve substantially for those whose pain is controlled (International Association for the Study of Pain, 2008a). In a community survey examining moderate to severe chronic pain experiences, using a cross section of the United States

population of which more than 2,600 individuals participated, only 39% of people with severe pain indicated that their pain was under control (American Pain Society and Janssen Pharmaceutica, 1999).

Inadequate pain control can lead to depression, reduced coping, diminished capacity to work, reduced quality of life, decreased ability to concentrate, and reduced socialization (American Pain Society and Janssen Pharmaceutica, 1999; Block & Brock, 2008; Green, Baker, Sato et al., 2003; Gureje, Von Korff, Simon & Gater, 1998; National Pain Foundation, 2009b; Pieper, Szcsepaniak & Templin, 2000; Vallerand, Saunders & Anthony, 2007). The influence of chronic pain on the ability of people to seek and maintain employment can be particularly distressing for people in lower socioeconomic brackets (Riley et al., 2002). Other studies have found that inadequate income makes other prerequisites for health (e.g., food, housing, medication, and alternative measures of pain control, etc.) difficult to obtain (Hofrichter, 2003; Isaacs & Schroeder, 2004; National Pain Foundation, 2010; Raphael, 2004; World Health Organization, 2009).

### **Race, Income, and Pain**

Ethnic and racial minorities continue to report the lack of adequate pain management (Green, Anderson et al., 2003; Meghani & Houldin, 2007). Due to historical experiences of mistrust and discrimination, health care disparities could be exacerbated if health care providers fail to demonstrate caring and trusting interpersonal cues that convey partnerships with patients (Benkert & Peters, 2005; Boulware, Cooper, Ratner, LaVeist & Powe, 2003; Cooper et al., 2003; Hunt, Gaba & Lavizzo-Mourey, 2005). A minority group that generally does not receive adequate pain control is African Americans (Green, Baker, Sato et al., 2003; Sullivan & Eigel, 2005). African

Americans reported greater feelings of fear and depression than Caucasians in terms of the influence of chronic pain on their emotional responses and pain behaviors (Riley et al., 2002). On average, African Americans reported greater pain disability and interference with activities in their lives due to pain than Caucasians (Cano et al., 2006; Vallerand, Hasenau, Templin & Collins-Bohler, 2005).

Caucasians described greater pain control and more thorough pain assessments than other ethnic groups (Van Ryn & Burke, 2000; Van Ryn & Fu, 2003). Van Ryn and Fu (2003) suggested that providers might have their decisions for treatment influenced by “moral rationing,” meaning a practitioner judges whether a person is “more or less deserving of treatment” (p. 251). This phenomenon of labeling, racial profiling or victim-blaming has been discussed in previous studies (Chirayath, 2007; Freeman, 2004). Stereotyping by health care providers based on gender, race and diagnosis may influence the care they provide to patients (McDonald, 1994; McDonald et al., 2003). Gender and race of the health care provider can influence the type of pain treatment offered to the patient. Physicians were more likely to prescribe pain medications if the patient was similar to them in regard to gender and ethnicity (Weisse, Foster & Fisher, 2005; Weisse, Sorum & Dominguez, 2003).

Raphael (2004) stated that income levels and race were social determinants of health that could influence the quantity and quality of resources available to individuals. Resources could include money for, or access to, adequate pain control. Caucasians reported a significantly higher use of prescription medication to control their pain, while African Americans used over-the-counter medications for pain control (Ruehlman et al., 2005). Some pharmacies located in minority neighborhoods, did not stock adequate

analgesia to treat patients with severe pain (Green, Ndao-Brumblay, West, & Washington, 2005; Morrison, Wallenstein, Natale, Senzel, & Huang, 2000). Additional disparities existed in terms of providing adequate pain relief for African American indigent adults (Nguyen et al., 2005).

Studies have been published that investigated pain experiences and pain control, with some specific references to African American populations. These reports supported and contrasted with the present study in various ways. Studies by researchers have addressed quantitative analyses of reports of pain (Todd et al., 2000; Green, Anderson et al., 2003; Green, Ndao-Brumblay, Nagrant et al., 2004; Pletcher, Kertesz, Kohn & Gonzales, 2008). Their research found direct correlations between lack of adequate pain control and race. However, they frequently used interviews of patients in hospital emergency rooms, retrospective chart reviews, and secondary data analyses in their studies.

Differences in pain management practices align with socioeconomic status. Individuals living in middle to higher socioeconomic brackets reported using more prescription medication to control their pain and relied less on hope and prayer than those in lower brackets (Cano et al., 2006; Meghani & Houdlin, 2007). Individuals who were poor had increased pain levels and fewer opportunities to control their pain levels than those who were not living in poverty (Freeman, 2004; Mauksch et al., 2003).

Other studies have examined African Americans and pain centers. Pain studies have been completed where one-third or less of participants were African American indigent adults (Ndao-Brumblay & Green, 2005; Nguyen et al., 2005). Other research has been done with persons attending multidisciplinary pain centers (Green, Baker,

Sato et al., 2003; Green, Baker, Smith et al., 2003; Edwards et al., 2005). Some multidisciplinary pain centers have additional resources for patients, including physiotherapy, counseling, and other ways to help patients control their pain (International Association for the Study of Pain, 2008c). The participants in the present study sought general health care at an urban primary care clinic and, they did not attend a multidisciplinary pain center.

When they were included in research studies, African American indigent adults completed telephone surveys to allow researchers to examine the experience of pain of community-dwelling populations. Limitations in these studies were that people were offered fixed responses from which to describe their pain and only individuals with telephones were able to participate (Nguyen et al., 2005; Ruehlman et al., 2005). In a previous study that examined challenges of collecting data by telephone from low-income African Americans, 20% of potential participants had their telephones disconnected and for those with telephones, the number of attempted phone calls to participate within the study was 9.5 attempts (Artinian, Denison & Nordstrom, 2007). There may be additional challenges when describing pain care experiences.

Researchers have highlighted challenges associated with the use of a numeric scale to describe pain (Benkert & Peters, 2005; Vallerand, Pieper, DiNardo, Nordstrom & Templin, 2008). Subjects have indicated the difficulty trying to measure pain using a numerical system as their pain was not a static experience and fluctuated throughout the day (De Souza & Frank, 2000). Other subjects have indicated that the words used within pain assessment tools to describe pain, are not similar to how they would describe their pain experience (De Souza & Frank, 2000; Warms, Marshall, Hoffman &

Tyler, 2005). As few objective tools exist that can measure pain satisfactorily, the person's description should be considered the most reliable indicator (National Pharmaceutical Council, 2006). Another challenge may be convincing health care providers to believe that the patient is experiencing pain (Neville-Jan, 2003).

Underassessment was one of the primary reasons for inadequate pain management; therefore, the American Pain Society and The Joint Commission consider pain to be the "5<sup>th</sup> vital sign" (National Pharmaceutical Council, 2006). The assessment of pain was labeled the 5<sup>th</sup> vital sign to increase the visibility of a patient's level of pain. This labeling of pain was to ensure that health care providers assess a person's pain as frequently and with the same vigilance as they would a patient's blood pressure, pulse, respirations and temperature. The Joint Commission introduced standards that emphasized patients' rights to appropriate pain assessment (National Pharmaceutical Council, 2006). These standards infer that health care providers must be vigilant in their ability to assist with pain management strategies (National Pain Foundation, 2009a; Loeser & Melzack, 1999). Additional research is needed to understand African American indigent adults' experiences of chronic pain.

### **Purpose and Goals of the Study**

The purpose of this study was to examine the experiences of chronic pain as described by African American male and female indigent adults attending an urban, primary care clinic. The goals of this study were to interview participants who were marginalized due to income and race (Boulware et al., 2003; Isaacs & Schroeder, 2004; Raphael, 2004) and provide them with opportunities to share what their experiences with chronic pain meant to them and their perceptions of how improved management of

their chronic pain would enhance their lives. In addition, participants used photovoice (Baker & Wang, 2006; Wang & Burris, 1997) to capture on film the experiences of living with chronic pain. Photovoice does not require high literacy levels and it empowers individuals by allowing them to decide which pictures and life details to share with the researcher. This study delineated the importance of the influence of race and poverty on chronic pain and health (Newman, 1994; Raphael, 2004; Spradley, 1980).

Goals of the HHS Strategic Plan Goals and *Objectives - FY 2007-2012* (U.S. Department of Health and Human Services, 2007) and *Healthy People 2010* (U.S. Department of Health and Human Services – Office of Disease Prevention and Health Promotion, 2005) have indicated the importance of closing treatment gaps through the elimination of racial and ethnic health disparities. Their objectives included identifying difficulties these populations experience with access and quality of health care services and improving health care providers' understanding of preventable disparities. The importance of increasing the quality and number of years that one may live a healthy life, as well as elimination of preventable disparities in health care also are priorities. Disparities of health care include differences experienced by certain racial and socioeconomic groups in regard to receiving adequate pain management, particularly for members of society who are African American and indigent (Green, Baker, Sato et al., 2003). African Americans who experience high levels of discrimination suffer from poorer health, emotional distress and higher levels of chronic pain (Edwards, 2008). Individuals living in poverty also experience increased levels of physical pain and emotional distress (Mauksch et al., 2003). Improving one's quality of life would provide

African American indigent adults with effective pain management. Unresolved chronic pain for African American indigent adults has been identified as a health care disparity.

Research questions posed for this study included:

1. What were the experiences of chronic pain as described by African American indigent adults attending an urban primary care clinic?
2. How did chronic pain as experienced by urban African American indigent adults affect their lives?
3. What did urban African American indigent adults believe were the disparities of chronic pain management?
4. What did urban African American indigent adults believe the solutions were for improving their experiences with chronic pain?

### **Significance of the Study**

This study was important because it filled a gap in the research literature by discussing the experience of chronic pain and identifying resources for pain control for African American indigent adults. African American indigent participants described their chronic pain and the influence of pain on their day-to-day lives in terms of movement, time, space, and consciousness (Newman, 1994). The findings provided suggestions of how to best treat chronic pain from participants' perspectives.

This study examined the relationship between poverty and chronic pain through interviews that explored the experience of pain for African American indigent participants. It examined the influence chronic pain had on their socioeconomic status and the potential influence that their socioeconomic status had on their current chronic pain experience. Participants were asked questions that illuminated challenges they



experienced when accessing appropriate pain management, their perceptions of the influence of race on their current pain experience and the influence of their financial situation on their chronic pain. In addition, African American indigent adults were asked their ideas about managing chronic pain.

Newman's (1986; 1994) theory, health as expanding consciousness (HEC), guided the examination of participants' meaningful experiences and patterns of pain. HEC views pain as a life pattern within health. Enhanced awareness of the patterns of pain for the participant who is indigent and African American may expand the individual's consciousness and health. Interview questions were asked of participants regarding what their chronic pain meant to them and how their suffering influenced their sense of time, space, movement, and consciousness (Newman, 1986; 1994). Discovering how chronic pain influenced the participant's relationship to these parameters would allow nurses and health care providers to have greater awareness of challenges experienced by African American indigent adults seeking adequate pain control. Enhanced awareness holds potential to develop improved pain management for this group.

This study was unique in its qualitative, focused ethnographic design. African American indigent adults were interviewed two to three times and participated in photovoice one to two times (Wang & Burris, 1997) to share their experiences of living with chronic pain. The participants provided examples of how they managed their chronic pain outside of the health care provider's office. They shared their challenges in obtaining adequate pain relief, feelings of discrimination when discussing their chronic

pain, and ways that health care providers' treatment of African American indigent adults who live with chronic pain could be improved.

This study was a significant contribution to nursing because it opened new horizons for discussing pain with African American indigent adults. Participants shared challenges they experienced while living with chronic pain, their ability to interact with others, their mobility and sleep patterns, and the importance of people and belongings in their lives that influenced their chronic pain. As a consequence of sharing their thoughts and concerns regarding chronic pain, African American indigent adults provided nurses and health care providers with an increased understanding of the experiences of living with chronic pain. These experiences may provide an impetus to develop additional ethical and cost effective patient-centered pain management. Patient-centered care can improve health and reduce health care disparities (Harrison & Falco, 2005; Leeman, Harrell & Funk, 2002).

### **Overview of the Dissertation**

Subsequent chapters discussed Newman's theory of health as expanding consciousness (Newman, 1986; 1994). This theory was used to examine life patterns of pain for African American indigent adults living with chronic pain. The review of literature summarized the influence of chronic pain, poverty, and stigma on African American indigent adults' ability to obtain adequate pain treatment. Possible solutions as described in the literature and by the participants in this study toward reducing pain disparities were discussed in subsequent chapters.

## CHAPTER 2

### REVIEW OF THE LITERATURE

#### Introduction

A study examining chronic pain in adults in a Midwestern state (Michigan) found the prevalence of chronic pain to be 22.9% and increased with age (Miller, 2008). Musculoskeletal pain accounted for 15% of that pain (Miller, 2008). Pain is a complaint heard during half to almost three-quarters of all primary care visits (Sullivan & Eagel, 2005). Pain has devastating physical and psychological influences on a person's ability to interact with the world (National Pain Foundation, 2009a; Portenoy et al., 2004). Thirty-three percent of individuals living with chronic pain state that pain influenced their quality of life and feelings of well-being (American Pain Society, 2008).

It is extensively documented that health care disparities exist for African American indigent adults (U.S. Department of Health and Human Services, 2004; U.S. Department of Health and Human Services – Office of Disease Prevention and Health Promotion, 2005) including disparities with pain management (American Pain Society, 2008; Green, Anderson et al., 2003; Todd et al., 2000). Patients seen in predominantly minority-populated clinics were “three times more likely to be under-medicated [for pain] than patients seen in non-minority settings” (Green, Anderson et al., 2003, p. 280). People of ethnic minority and low socio-economic status have reported feeling discriminated against particularly for inadequate pain management (Nguyen et al., 2005). Reducing the gaps in treatment for chronic pain experienced by African American indigent adults will help lessen and potentially eliminate ethnic and racial disparities. Challenges exist in studying chronic pain in African American indigent

adults. This literature review provides examples of studies about some of these issues when studying this population.

**Enrollment of African Americans.** Green, Ndao-Brumblay, Nagrant et al. (2004) examined pain severity, depression and pain interference with functional status with almost 3,000 Caucasian and African American patients attending a multidisciplinary pain center. More than 91% of participants were Caucasian, 68.4% married and almost 60% were women. African Americans had a lower median household income, reported higher pain severity and disability and higher depression scores. African Americans had higher prevalence rates of other comorbidities such as high blood pressure, gastric ulcers and chest pain than did Caucasians. African Americans younger than 60 years of age reported greater disability than patients greater than 60 years old. African Americans reported the worst coping scores, highest pain duration and comorbidities. Social support was not examined. Limitations to the study included that patients attended a tertiary care, multidisciplinary pain center and only a small number of African Americans were available to participate. Data for this study were obtained retrospectively through secondary analyses of a previously completed similar study.

In another study by Green, Baker, Sato et al. (2003), young African American and Caucasian patients attending a multi-disciplinary pain center were examined regarding the influence of race towards presentation for management of their chronic pain. More than 3,600 adults less than 50 years of age of which 90% were Caucasian and 10% were African American were surveyed. The annual income of Caucasian adults (\$33,850) was significantly higher than was African Americans (\$27,158) and only 38% of African Americans were married. African Americans reported more sleep

disturbance, pain, depression, suffering, anxiety, dizziness, high blood pressure and chest pain than did Caucasian adults. African Americans with chronic pain reported more impairment with quality of life and health status than did Caucasians. Limitations in this study were its retrospective analysis of a database, someone other than the patient assigned race, and the low numbers of African Americans available to participate. Participants in this study were those patients referred to a pain center so this may influence the results of the study. Additional studies obtaining prospective data on chronic pain experiences with this vulnerable population are needed.

**Influence of income.** Examining the influence of education and race on pain severity, interference, disability and coping, Cano et al. (2006) interviewed 105 participants. Forty-one percent of participants were African American and the remaining 59% were Caucasian. Participants were usually female (59%) with an average annual income of greater than \$53,000. Income however, was not included in the hierarchical regression. Fifty-five percent of African Americans in this study reported having some college or university degree completion. African Americans as compared to Caucasians reported higher mean pain, disability and interference from pain. African Americans also used more hoping and prayer to cope with pain. Patients with more years of education were found to have less interference and psychosocial disability from pain. Unfortunately, socioeconomic status and income were not examined in this study.

Meghani and Houldin (2007) interviewed 35 African Americans about their meaning and attitudes regarding cancer pain. The median age of participants was 55 years, 54% were male, and 46% of participants were female. Forty-six percent of participants had college degrees or higher, 31% were married, and 91% had health

insurance. Themes such as the physical dimensions or actual feelings of “hurt” from cancer pain and the emotional dimensions of fear and uncertainty regarding the meaning of pain were discussed. They believed that their cancer pain and diagnosis were closely linked and that the experiences of pain allowed them to better describe to their health care providers the progression of the disease and subsequent treatment needs. Stoicism was also identified. Participants believed that talking about their cancer pain increased the pain and pushed away family and friends. An underlying fear was of not having their experiences of pain believed by others, particularly by health care providers. In this study, participants were predominantly middle-class, insured, educated African Americans. In addition, the participants’ medical or social history and use of opioids were not discussed. An understanding of patients’ attitudes and meaning of pain will help health care providers tailor interventions to be more client-specific.

African American’s cancer pain experiences were examined using an on-line forum with 11 participants (Im et al., 2008). Although both men and women were equally encouraged to participate, all participants were female, 64% were college graduates or had graduate degrees, 64% were employed and 100% had a religion. Eighty-two percent of participants were not taking pain medication and the average annual income was slightly more than \$48,000. The on-line discussions were printed and coded line-by-line. Themes found by Im et al. (2008) were (a) cancer was a challenge, but could be controlled with positive thinking and prayer, (b) the diagnosis of cancer was stigmatized in the African American culture and others would avoid them should they discuss the diagnosis of cancer or their pain, (c) culture prevented these women from feeling they could discuss and seek help for their pain, as they put the

needs of their families first and complaining about pain was considered a weakness, and (d) spirituality was a source of support and after being diagnosed with cancer, the participants appreciated current moments in their lives. Im et al. (2008) discussed that future research should examine the cancer pain experience with groups that were more diverse as individuals who participated with on-line forums tended to be of higher socio-economic status. Further examination of the influence of culture and family is needed to improve health care provider's understanding of the cancer pain experience for African Americans, which in turn will help reduce health care disparities.

**Socioeconomic variables not examined.** Richardson et al. (2008) interviewed eight participants, four men and four women, between 40-60 years of age about the influence of chronic widespread pain on their experiences with time. Participants were interviewed and wrote in a diary about their pain and time. Findings were compiled as quotes and as part of a 'life grid' or a diagrammatic chronology of participants' lives. Findings included descriptions of clock time and perceived time. Participants described their daily activities and the influence of chronic widespread pain on their lives. It was challenging for participants to not in control of their time, as every day activities took them longer to complete. Participant's feeling of control over time was important (Richardson et al., 2008). Participants who were able to complete daily activities without relying on others for assistance felt more in control of their time. Health care providers who can assist participants with strategies for time management may enable participants to better control time, especially during days when pain fluctuates, making the completion of their daily activities often unpredictable. Limitations of this study were that variables such as race, income and education levels were not reported.

Participant's experiences with chronic pain and time should be examined in future studies.

Focus groups were completed with 32 participants having chronic pain, secondary to a diagnosis of multiple sclerosis (MS) (Douglas et al., 2008). Thirty-two participants, 24 women and eight men, 26-72 years of age described that pain was pervasive and affected all aspects of their lives and that no one truly understood their pain. Participants also said they would try to not complain to others about their pain and said how they would decide and plan activities that may exacerbate their constant chronic pain. Pain affected the completion of daily activities, was exhausting, prevented social outings and made participants feel hopeless (Douglas et al., 2008). Chronic pain influenced intimate relationships, and participants tried to conceal the pain so they would not be a burden to others. Participants said it was frustrating to not have "physical proof" of pain, therefore, others thought that participants were lazy. Race, income and education levels were not examined in this study. Chronic pain may be exacerbated by socio-economic factors and should be considered in future research.

Two interviews were completed with 16 women and 6 men ( $N=22$ ) regarding their experiences with chronic nonmalignant pain and opioid therapy (Vallerand & Nowak, 2009). Participants ranged in age from 29-84 years and were recruited from two outpatient pain practices. Participants described their lives prior to and after receiving opioids for chronic pain. Prior to receiving opioid therapy, participants felt desperate, suicidal and humiliated, as treatments provided by health care providers were not effective for their pain. Participants described an inability to function and how chronic pain influenced their emotional and physical health. After opioid therapy, participants



described balancing life challenges with pain management and concerns with “trading” guilt for using opioids and concern with addiction. Vallerand and Nowak (2009) found that participants feared losing their pain management and kept their opioid usage a secret from others. Participants were thankful for their improved quality of life and ability to focus on things other than pain. Race, income and education levels of participants were not reported. These demographic variables may influence the experiences and treatment of chronic pain.

**Pain care centers.** In a comparison of the chronic pain experience for 291 patients attending a multidisciplinary pain management center, equal numbers of African American, Caucasian and Hispanic patients were chosen for this study (Edwards et al., 2005). The most frequent primary sites of pain were the leg (31%), lower back (30%) and arm or shoulder (31%). Participants completed scales measuring pain-related disability, pain coping, emotional distress and other dimensions of pain. Pain measures such as pain intensity, pain severity or pain disability did not differ across the three ethnic groups. However, using prayer, as a coping strategy was significantly higher for African Americans and Hispanics than it was for Caucasian participants. Pain catastrophizing reached significance ( $p = .03$ ) for African Americans and Hispanics. For all three groups, the greater the pain severity, the greater the distress and disability. Edwards et al. (2005) closely matched participants for pain duration, education and work status, thus suggesting that measures of pain may be explained by variables other than ethnicity. In this study, participants were chosen from those attending a tertiary pain center and data related to income and perceived discrimination were not examined.

Riley et al. (2002) examined racial differences with chronic pain found at a large university pain management clinic. More than 1,500 participants of which 69.6% were Caucasian and 30.4% were African American completed surveys, which examined pain behavior, pain experience and intensity. Of the African American group, 64.7% were female; and of the Caucasian group, 55.9% were female. African American patients reported significantly higher levels of pain behavior, pain unpleasantness and emotional responses to pain including fear and depression than did Caucasians (Riley et al., 2002). Racial differences were not found in pain intensity. Response to pain treatment, discriminatory treatment practices and the influence of access to care, such as attendance at the multidisciplinary pain center were not examined.

**Specific types of pain.** Meghani and Keane (2007) examined analgesic preference for 35 African Americans with cancer pain. Semi-structured interviews were completed with participants to study the patient-level factors that influenced the under-treatment of cancer pain. Participants were predominantly insured, middle-class, highly educated African Americans with 54.3% of those sampled being male. Most (90%) reported experiencing moderate to severe pain in the week before the interview but only 34% preferred to take their analgesics as prescribed (Meghani & Keane, 2007). Few participants (25%) were concerned about side effects from the pain medications or taking too much pain medication. While 80% were prescribed at least one opioid for their pain, one-third expressed a need for stronger medication than what had been prescribed. Over-the-counter pain medication was taken by 14% of participants and 39% of participants were only receiving 50% relief from their current pain care protocols. Out-of-pocket expenses were not a concern, and 95% stated that their local pharmacy

stocked their pain medication. Some participants believed that by masking the pain, they might not be aware of signals within their bodies should their cancer change or progress. These participants would only take their pain medications if they believed it was absolutely necessary. Individuals who took pain medications as prescribed or similar to prescription rates, had fewer side effects from the analgesics, and verbalized more pain relief. Assuming that all ethnic groups are homogenous with their pain management beliefs promotes disparities with pain care (Meghani & Keane). Feeling understood and believed about their pain, enhanced patient's trust towards their health care providers.

Anderson et al. (2002) interviewed 31 low-income minority patients (14 African Americans and 17 Hispanic patients) with cancer regarding their pain management needs and barriers toward achieving effective pain management. Equal numbers of African American males and females participated, 36% had obtained a high school education, 50% were single, 43% did not have health insurance and 50% stated that they were disabled and not employed due to pain. Patients in both ethnic groups stated that pain significantly interfered with their activities of daily living and 75% reported pain scores that indicated severe pain intensity (Anderson et al., 2002). Fifty-seven percent of African American participants stated that their health care provider did not ask them about their pain until they themselves mentioned it during the visit. Only 25% of health care providers used a pain intensity scale with patients; all patients found the pain scale helpful. Many African Americans (82%) waited until their pain was 10 on a scale of 0 to 10 before calling their health care provider for assistance. Forty-three percent of African Americans did not know the name of their pain medication and 42% reported some

difficulty with obtaining medications including the health care provider's reluctance to write a prescription for pain medication. Twenty-five percent of African Americans reported receiving a script for analgesics, but not filling the script at the pharmacy; and 42% reported filling the script but not taking the pain medications. Reasons for both occurrences included having taken the medication before and knowing it was not effective for pain, fear of side effects from the medication and a concern with tolerance to the medication. Prayer was used by 83% of African Americans to cope with pain. Findings included that patients wished to have more educational information related to their pain, treatment and medications. Anderson et al. (2002) stated that additional research was needed to further examine the effects of socio-economic status on pain-related needs among disadvantaged groups and financially secure groups.

In a study examining toothache pain, eight focus group sessions were completed with 66 low-income Caucasian, African American and Hispanic participants (Cohen et al., 2007). Approximately 67% of participants were female and 48% were African American, with the median income of participants between \$1,001 and \$15,000 per year. The age range of most participants was between 25-54 years, 38% were never married and almost 47% of participants reported having some college or technical school. While 33.3% of African Americans rated their overall health to be excellent/very good, when having toothache pain, 43.3% rated the pain as being very high, and gave a rating of 9 or 10 on a scale of 0 to 10. Participants described the toothache pain as an experience that controlled their lives and made housework, employment, eating, socializing, sleeping and talking difficult (Cohen et al., 2007). Pain caused participants to feel depressed and anxious and to reduce pain, participants would seek out

medications from family members, perform self-dental extraction, rinse with alcohol or toxic chemicals such as gasoline or rubbing alcohol or use other home remedies. African Americans stated that prayer was used to help with pain. All groups stated that negative attitudes by health care providers but most importantly financial barriers such as missing work, transportation, and cost of care prevented the use of dental services unless the pain became unbearable. Limitations in this study included that findings could not be generalized to others outside of these income and cultural groups. Cohen et al. (2007) suggested that additional studies were needed to gain further insight into the self-care practices used by low-income patients when treating dental pain.

**Survey data.** Examining the patient level factors surrounding chronic pain is important. A total of 242 low-income, non-pregnant women attending an urban teaching hospital women's health clinic were surveyed regarding their frequency of pain and depressive symptoms (Poleshuck et al., 2006). Of women sampled, 64% were African American, 62% single, and 65.1% had less than a high-school diploma. A household income of less than \$10,000 annually was reported by 55.8% of low-income women. Almost 20% of patients surveyed reported symptoms of depression and pain; however, reasons for the women's visits to the clinic were not for depression or pain. Both pain and depression influence physical, social and emotional functioning. Limitations in the Poleshuck et al. (2006) study include that onset of pain symptoms, course of pain and duration of pain were not examined. Diagnostic interviews would have provided additional information. Suggestions include that future research should examine interventions specifically targeting low-income female patients.

Mauksch et al. (2003) examined the health concerns that prompted low-income, mostly uninsured adults to seek care primary care in a semi-rural health clinic. Five hundred patients, of which 68% of the sample was female and almost 75% of the sample was Caucasian and 14.2% were Hispanic, completed questionnaires. Health care providers for these patients listed what they believed were the greatest concerns for the patient and subsequent reason for the primary care visit. The most common chronic medical problems reported by patients were headaches (33.7%), chronic back problems (32.6%) and arthritis (29.2%). When patients were asked what they hoped to discuss with their health care provider during that primary care visit, the most common health problem listed by 29.2% of patients was with their mood. Health care providers listed medication refills as the greatest reason for the patient's health care visit (10.6%) followed by problems with mood (9.8%) and hypertension (9.0%). Mauksch et al. found that patients with lower incomes had greater concerns about pain. Patients who expressed experiencing persistent pain also had greater concerns with depression and anxiety. Health care challenges that may be unique to ethnic groups such as low-income African Americans were not examined as the entire patient sample was analyzed as one group and the majority of patients were Caucasian. Results from this study may be different than those obtained from patients attending an urban primary care clinic.

To determine ethnic differences in the experiences with cancer pain, 480 participants were recruited via the Internet and through community settings to complete demographic and several pain-scale surveys (Im et al., 2007). Participants completed pen and paper or Internet surveys including questions related to their cancer pain

experience, symptoms accompanying cancer pain and functional status. In the sample, 79% were women and almost equal numbers of participants were recruited from the ethnic groups of Hispanic, Caucasian, African American and Asian. For African Americans, aching pain was the most frequently reported descriptor of pain and most distressing symptom was lack of energy. African Americans reported lower cancer pain scores than Caucasians and Hispanics, but reported lower functional status than Hispanics. These findings may be because the majority of African American participants were recruited from a cancer support group. Differences in scores from one pain scale to another within ethnic groups may indicate developmental issues with the scales or the appropriateness of using the scales with certain ethnic groups. More women than men participated in this study and cultural values may have influenced the cancer pain experience. There is no way to know if participants completing the surveys via the Internet filled out the surveys themselves or if others did it for them. Future research should include qualitative interviews to examine the influence of cultural values and beliefs on the cancer pain experience (Im et al., 2007).

Bernard and Wright (2004) examined the issue of chronic pain in adults in the emergency department. From the 476 patients asked to complete a short demographic survey and pain questionnaire prospectively in the emergency department, 40.6% of patients indicated that they had chronic pain lasting three months or longer and 13.7% of patients stated that their chronic pain was the reason for the current emergency room visit. Spine and abdominal pain accounted for 58.5% of patients with chronic pain and four or more visits to the emergency room in the last year because of their pain. Of those living with chronic pain, 58% indicated that their chronic pain was severely limiting

and caused high disability in their lives. Higher rates of chronic pain were reported by those who were unemployed, disabled or lived alone. In this study, race and household income were not examined.

Pieper, Vallerand, Nordstrom and DiNardo (2009) examined bodily pain for 301 patients with and without venous ulcers and pain's relationship to functional status, perceptions of control, coping and depression. All patients attended an indigent care clinic, more than half completed high school and 92% were African American. Patients without leg ulcers reported higher average pain scores ( $M=6.6$  vs  $6.0$ ) and less relief from their current analgesia for pain (44% vs 55%). Both groups did not differ in scores for depression or pain interference with functioning; great interference and feelings of depression indicated severe chronic pain. Patients were disabled due to pain and approximately one-third reported using alcohol and illicit drugs to treat their pain (Pieper et al., 2009). Those with leg ulcers used more nonopioid prescription medication for pain. The groups had low perceptions of control over pain, 17% used herbal or alternative therapies and pain levels were disabling. Due to the nature of survey data collection, participants were not able to describe how chronic pain influenced their mood, relationships and ability to complete daily activities. Participants were not able to offer suggestions for improving chronic pain care.

**Telephone surveys.** Portenoy et al. (2004) completed phone surveys of more than 1,300 community residents. Equal numbers of Hispanics, Caucasians and African Americans completed questionnaires about chronic pain management, the effects of pain and other demographic characteristics. Caucasian participants were more likely to have health insurance, higher incomes, greater educational attainment and were



married than were African Americans or Hispanics. African Americans were more likely to report pain in the lower extremities. Many participants (76%) complained of experiencing moderate to severe pain in the past week and 73% stated that the pain was the worst they could imagine during that same time period using a 0 to 10 point pain scale. For participants who were employed, African Americans reported more lost days from work due to pain than did Hispanics and Caucasians (Portenoy et al., 2004). Disabling pain was reported most by females, those with less than a high school diploma and by those with an annual income of less than \$25,000. Disabling pain was strongly associated with feelings that pain had ruined participant's lives, feeling isolated, unable to participate with family and friends in activities and feeling like the pain was preventing them from living life to the fullest. Only participants with telephones could take part in the study.

Ruehlman et al. (2005) compared self-reports of pain adjustment and pain experience from a national community sample for Caucasian and African American participants ( $N = 428$ ) not enrolled in specialized pain clinics. Equal numbers of African American and Caucasian adults were chosen from a telephone survey. Caucasians in the sample, were older (56 versus 51 years), had higher levels of educational attainment and were more often married (58% versus 39%). For both groups, the most frequently reported areas for pain were the neck, hips, muscles, back, bones, joints and head (Ruehlman et al., 2005). Race was significantly related to reduced employment due to pain with almost 71% of African Americans and almost 40% of Caucasians reporting this result. African Americans also reported more interference due to pain with parenting, self-care, routine physical activities, social life, sexuality and household

chores. African Americans reported significantly higher levels of catastrophizing, more pain-induced fear, lower levels of control, higher perceptions of disability and higher use of over-the-counter pain medications versus prescription medications than did Caucasians. Income, chronicity of pain, cultural practices, occupation and access to health care were not examined. Participants could only complete the survey questions if they had access to a telephone.

Nguyen and colleagues (2005) examined racial and ethnic differences with chronic pain care. Equal numbers of Caucasian, Hispanic and African Americans participated in this telephone survey of more than 1,300 adults. Most African Americans (94%) stated that they had consulted their primary care practitioner regarding their pain. Low-income African American males (families earning less than \$25,000 annually) were three times more likely to report that they felt discriminated against in their efforts to obtain adequate treatment for their pain. Nguyen and colleagues (2005) found that having low access to pain care was significantly associated with being male, single, younger (18-34 years of age), having less than a high school education, a family income of less than \$25,000 and financial concerns preventing treatment for pain. Low access to chronic pain care was associated with having low pain interference in life and complaints of mild chronic pain. Limitations in this study include that follow-up questions could not be asked of participants to clarify answers provided, and only adults with telephones could participate.

**Secondary data analyses.** Pletcher et al. (2008) found that regardless of initiatives to reduce pain disparities, opioid prescription remained significantly lower for African Americans than for Caucasians in the emergency department where 42.6% of

all emergency visits were pain-related. Using a National Hospital Ambulatory Medical Care Survey (NHAMCS), researchers examined opioid prescription rates for all pain-related visits including long bone fractures and nephrolithiasis/kidney stones. For all pain-related visits, Caucasians comprised 66% of visits and African Americans only 20% of visits. Caucasians were more likely to have private insurance. When examining opioid prescribing rates for all emergency room visits over the last 13 years (1993-2005), while overall opioid prescribing trends have increased, African Americans had the lowest rates 23%, with Caucasians receiving 31%, Hispanics 24% and Asians 28% (Pletcher et al., 2008). This was a secondary analysis of a national database. The NHAMCS did not have detailed information related to each patient encounter such as knowing whether the patient had requested pain medication, or what quantity of opioids were prescribed for each patient. Another limitation is that race/ethnicity was recorded by hospital staff and not the patient.

Green, Baker, Smith et al. (2003) examined, through secondary analyses, the effect of race with chronic pain management in 2,040 older adults attending a multidisciplinary pain center. In this study, 92% of patients were Caucasian and 8% were African American; 60% were female; and Caucasians earned almost \$9,000 more annually than did African Americans. African Americans reported significantly more depressive symptoms, suffering, pain and less control over their pain than did Caucasians. African Americans were 50% more likely than Caucasians to report more comorbidities such as high blood pressure, gastric ulcer and asthma. This was a retrospective analysis of a database and someone other than the patient assigned race. The patients in this study were those attending a pain center.

Using a retrospective chart review, Todd et al. (2000) examined whether African American patients ( $n = 127$ ) with extremity fractures were less likely to receive appropriate pain medications in the emergency room compared to Caucasian patients ( $n = 90$ ) with similar injuries. Caucasian patients were significantly more likely to receive analgesics than African American patients (74% versus 57%). In addition, African American patients were 66% more likely to not receive analgesia at all when compared to Caucasian patients even when explicit notations of reports of pain were reported equally for both African American and Caucasian patients. When given an analgesic in the emergency room, 87% of Caucasian patients and 77% of African American patients received an opioid (Todd et al., 2000). Although the differences were not statistically significant ( $p = .13$ ), the absence of appropriate analgesia for long bone fracture would be extremely painful. The study was a retrospective chart review design where errors in recording may have occurred. While there were no associations between analgesic prescription for patients and ethnicity of the emergency room physician, future studies should examine if health care provider ethnicity was a factor with analgesic prescription.

**Other qualitative studies.** Photovoice was used to examine 27 participants older than 50 years of age about their lives with chronic pain (Baker & Wang, 2006). Participants were interviewed, completed surveys, took photographs and wrote narratives describing the photographs of their experiences with chronic pain. Participants study attended a multidisciplinary pain clinic ( $n = 7$ ) or did not attend the clinic ( $n = 20$ ). All participants who attended the pain clinic were Caucasian. One third of participants were African American, 67% were female and the average number of

years of education was 15 years. Thirteen participants completed the entire study. During the interview, participants said they appreciated the opportunity to discuss their chronic pain and they wanted to help other chronic pain sufferers (Baker & Wang, 2006). Descriptions of the 13 participants who completed all aspects of the study were not provided, including income levels. Challenges described by participants included writing narratives beneath each photo. To reduce attrition, participants should complete fewer research steps and special accommodations should be considered for chronic pain sufferers, including transportation. Reasons why participants do not complete all aspects of studies may be due to a variety of reasons and require further examination.

Community-dwelling people with spinal cord injury or amputation were mailed survey questionnaires about pain (Warms et al., 2005). Of the 1,473 participants, 797 or 54.1% wrote unsolicited comments in the margins of the survey tools. Those who wrote comments were mostly Caucasian (87.6%) and not employed (67.6%). Comments included: how to improve questions asked on surveys, descriptions about pain, sources that exacerbated pain and treatments for pain. Other comments included: how pain affected mobility, sleep, coping, relationships, the ability to work, health care encounters and how pain influenced feelings of depression. Participants described their prosthesis and wrote that many health care providers only prescribed opioids for a short period of time, so patients either lived with unrelieved pain or were perceived as drug seekers. Opioids were said to only reduce pain and never relieve pain completely (Warms et al., 2005). Comments written on the survey tools were unsolicited so it is difficult to know more about participants' experiences with pain. People with pain are

experts of their experiences and have unique stories that health care providers can learn from when negotiating pain treatment.

### **Summary**

It is important to examine the experiences of chronic pain of African American indigent adults and, though an emerging research literature exists, gaps in what are known remain. For instance, some studies used focus groups instead of individual interviews to collect data, potentially limiting what interviewees felt comfortable disclosing (Cohen et al., 2007; Douglas et al., 2008). Other studies asked patients to complete surveys, which did not allow examining in detail other issues patients felt influenced their chronic pain experience (Edwards et al., 2005; Green, Ndao-Brumblay, Nagrant et al., 2004; Im et al., 2007; Im et al., 2008). Though some patients completed surveys face-to-face (Poleshuck et al., 2006; Vallerand et al., 2008) or on the telephone (Nguyen et al., 2005; Portenoy et al., 2004; Ruehlman et al., 2005), in all cases researchers' interests guided research instrumentation, and failed to allow implicit patient knowledge to emerge. In other research, secondary data analyses predominated (Green, Baker, Smith et al., 2003; Green, Baker, Sato et al., 2003; Pletcher et al., 2008), including retrospective review of charts (Todd et al., 2000), distancing such research from patients' perspectives.

Research has examined the pain experience for patients outside of the urban primary care clinic and within multidisciplinary pain centers. In multidisciplinary pain centers, care is provided by pain specialists and other professions such as physiotherapy, alternative medicine and psychotherapy, which may change the influence of chronic pain (Edwards et al., 2005; Green, Baker, Sato et al., 2003; Green,

Baker, Smith et al., 2003; Green, Ndao-Brumblay, Nagrant et al., 2004; Riley et al., 2002). Other studies have examined the pain experience using only one focal diagnosis, such as cancer (Anderson et al., 2002; Im et al., 2007; Im et al., 2008; Meghani & Keane, 2007) or toothache (Cohen et al., 2007) thus potential limiting hearing from patients who have been diagnosed with various painful diagnoses.

Some studies have enrolled only 10-30% of African Americans (Green, Baker, Sato et al., 2003; Green, Baker, Smith et al., 2003; Green, Ndao-Brumblay, Nagrant et al., 2004; Riley et al., 2002) or none at all (Mauksch et al., 2003). With such small numbers of African Americans sampled, it is possible that results obtained do not reflect the true experience for African Americans. Staff has identified the patient as being African American leading to possible errors when assigning ethnicity (Pletcher et al., 2008). It has been documented that poverty lends itself to poor health (Hofrichter, 2003; Raphael, 2004), yet other studies have examined patients with high socio-economic status and possibly greater access to resources (Cano et al., 2006; Im et al., 2008; Meghani & Houldin, 2007; Meghani & Keane, 2007).

In addition, studies that have not examined social support (Green, Ndao-Brumblay, Nagrant et al., 2004), requests by the patient for pain medication (Pletcher et al., 2008) or questions regarding the onset of pain symptoms and duration and course of pain (Poleshuck et al., 2006), thus potentially missing important topics that influence the experience of living with chronic pain. Questions related to the influence of income (Bernard & Wright, 2004; Cano et al., 2006; Richardson et al., 2008), access to care and discrimination were not examined in prior studies (Edwards et al., 2005; Riley et al., 2002) particularly towards obtaining an analgesic prescription (Todd et al., 2000). The

factors listed above, may have an influence on the experience of chronic pain for African American indigent adults attending an urban primary care clinic. Information related to chronicity of pain, culture and occupation require further discussion (Ruehlman et al., 2005). Missing from the Meghani and Houldin (2007) study was knowledge of participants' social and medical history and use of opioids. Questions related to pain treatment were not asked in the Riley et al. (2002) study. Many patients have a desire to discuss their experiences of chronic pain and poverty to feel better understood (Meghani & Keane, 2007; National Pain Foundation, 2009a; Nickasch & Marnocha, 2009; Smith & Friedemann, 1999; Vallerand et al., 2008; Warms et al., 2005).

## **Conclusion**

Even though approximately 37% of American adults aged 20-44 reported pain that lasted one year or longer as did more than 60% of adults over the age of 65 years (U.S. Department of Health and Human Services – Centers for Disease Control and Prevention – National Center for Health Statistics, 2006), analgesia is not provided equally to Caucasians and African Americans. African Americans are under-treated for their pain (Institute of Medicine of the National Academies, 2003). Exhaustion from chronic pain increases frustration for patients as even simple tasks become monumental to complete. Patients feeling over-tired, depressed or focused on their pain may miss important information regarding follow-up care and treatment protocols (Pieper & Templin, 2003).

Patients have suggested that because the experience of pain was so highly subjective, that it was difficult to quantify the experience and their verbal descriptions



should be used to help describe pain (Vallerand et al., 2008; Warm's et al., 2005). The present study examined the experience of chronic pain as described by African American indigent adults attending an urban primary care clinic. Using interviews and photovoice, those with greater disparities in health were able to discuss the chronic pain care experience. The present study advances the knowledge of health care providers towards providing care that reduces health care disparities.

## THEORETICAL FRAMEWORK

The theory of health as expanding consciousness (HEC) views pain as a life pattern within health (Newman, 1986; 1994). Accordingly, patients describe within the pain experience the people and experiences meaningful to them. During this interaction, patients can become aware of personal patterns and are transformed to expanded consciousness and health. Pattern recognition is expanded consciousness; expanded consciousness is health. Through caring in the human health experience and awareness of pain patterns, nurses develop relationships with patients and both patients and nurses are transformed (Newman, 2002).

Pain among the African American indigent population is a phenomenon that remains largely misunderstood by health care providers (National Pain Foundation, 2009a). Pain has patterns within the concepts of time, space, movement, and consciousness (Newman, 1994). Enhanced awareness of the patterns of pain for African American indigent adults will expand consciousness and health.

### **Health as Expanding Consciousness**

Margaret Newman (1986) developed the theory of health as expanding consciousness (HEC). Newman believed that a person labeled as sick by the medical community could still feel well. Newman realized that a medical diagnosis or label did not lessen one as a person. She understood that patients with chronic illnesses were still people; in fact, they were “whole” people. Newman discovered that people with chronic illness; and for the present study, participants with chronic pain, have altered and deepened thoughts pertaining to space, mobility, and time. Rogers (1970) believed that health and illness were expressions within life processes, with one not more

important than the other. Newman (1986), building on Rogers' science of unitary human beings, identified health and illness as patterns within the whole person. Newman began to think of the terms, life and health and the underlying meaning they provided for people. Developing mutual relationships with patients can be empowering for both patients and nurses, with these types of relationships at the center of the praxis of nursing. Newman (1995) stated, "the essence of nursing is not doing or manipulating but is being open to whatever arises in the interaction with the patient. It is being fully present, with an unconditional acceptance of the patient's experience" (p. 196).

Losses to patients' physical self and the experience of chronic pain can limit the ability to control the environment and has a direct influence on one's freedom of space, mobility, and time. Individuals must then look inward to develop new ways of thinking, as the old ways of being are not working. This inward reflection equates to growth and transformation with the recognition that physical immobility does not equate to the loss of identity as a person. Patients' with physical limitations continue to expand their consciousness as they learn new ways to interact with people and their environment. This expansion of consciousness is the creation of new rules for patients' experiences with mobility, space, and time (Newman, 1986).

### **HEC and Chronic Pain for African American Indigent Adults**

Health is viewed "as the evolving pattern of the whole" (Newman, 1986, p. 82). According to Newman, within HEC, nurses interview patients so patients may discuss people who are meaningful in their lives and important life experiences. The experiences that are labeled as most meaningful to patients indicate their pattern.

Newman believed that people were open systems with normal fluctuations with their environment (Newman, 1986). As energy fields, a person and the environment have wave patterns that are always changing and becoming more diverse. A person as a unitary being is engaged in life processes with their environment (Rogers, 1992). Life processes develop unidirectionally along the space-time continuum.

Newman (1986) felt that during human evolution, the person reached higher levels of development as they interacted with each other and with their environment. When the person experiences something critical in their environment, unpredictability and disorganization occurs. When new properties in the environment emerge, the person must respond to this change. The person's energy levels increase in complexity with their environment (Newman, 1986; 1994). The individual is capable of moving to a higher level of complexity by dispersing high entropy or high levels of energy back into their environment. The person develops new traits or behaviors in self-determination and challenges the norm by adapting to this complex environment. Newman has coined this turning point, a client's "choice point" (Newman, 1994, p. 65), as the person realizes that old solutions do not work anymore. A higher level of thinking and development must occur. This higher level of thinking, equates to growth for the individual and a transcendence of energy and greater complexity of human patterns of behavior. The pattern recognition is expanding consciousness, which is health (Newman, 1986; 1994).

The critical events in a person's environment may include feelings of discrimination as African Americans who are indigent seek treatment for their chronic pain. Transformation may occur regardless of the client's socio-economic status, prior

history or lifestyle choices. Blame and guilt are removed from the person because the unitary paradigm does not hold a causal worldview (Neill, 2002). Patterns can be identified and how the African American indigent adult with chronic pain may transform their lives. The ultimate goal is for participants to deepen their relationships with others, as these relationships will provide support.

From a unitary paradigm, the outcome from the nurse-client relationship is unpredictable (Fawcett, 1993). When a nurse practices from a unitary transformative paradigm (Newman, 1986; 1994), the way they view the world, the client and the client's world dramatically changes. The nurse is transformed during each client interaction, from gaining insight into the lives of African American indigent adults and their experiences with chronic pain.

The human experience is shared through stories that the client depicts as meaningful. The client's point of view is respected, valued and held by the nurse as truth. By sharing their life stories, clients can acknowledge their strengths and personal journeys (Neill, 2002). No matter what the life journey that brought the client to the nurse, HEC can assist with transformation in the client's life. HEC pattern recognition may help to expand consciousness, and may give those living with chronic pain hope for future.

**Terms used in HEC.** *Consciousness* is the informational capacity of people and includes cognition, affect, and the interaction of the individual, family, or community with their environment (Newman, 1994). In relation to the present study, chronic pain influenced thought processes, affect and the individual's interaction with others. Chronic pain influenced the energy patterns of African American indigent participants.

The *environment* is the energy field with which individuals interact to create health. Participants' awareness of their pattern manifestations can assist them with identifying how they interact with their environment. With this insight, ways to move or transform to higher consciousness can be accomplished (Newman, 1986; 1994). In the present study, through interviews and photography, African American indigent adults described how the environment influenced their experiences with chronic pain.

*Expanding consciousness* is pattern recognition; it is determining new rules when old rules do not work anymore. This recognition is transformational and is health (Newman, 1994). Expanding consciousness were the solutions offered by participants to improve their health and experiences with chronic pain. *Health* is the process of expanding consciousness and is the synthesis of disease and non-disease. Through interviews and the use of photovoice (Wang & Burris, 1997), the participants discovered that they have unique resilience as they live with the day-to-day influence of chronic pain.

*Movement* is a way for a person to "control their environment" (Newman, 1994, p. 46). During illness, people need to find ways of inner control when their physical bodies will no longer allow movement. Movement was difficult for individuals experiencing chronic pain. This immobility reduced their ability to remain employed or to participate in social activities. Chronic pain influenced their connection with health care and nursing. *Nursing* is "being fully present with patients in the disorganization and uncertainty of their lives – an unconditional acceptance of the unpredictable" (Newman, 1994, p. 103). The nurse remained open to the thoughts and feelings offered by African American indigent patients as they shared their experiences of chronic pain.

*Pattern* includes characteristics from one's past that unfold in the future. *Pattern* is the language essential to identify the wholeness of the person-environment interaction (Newman, 1994). Throughout the present study, as participants shared their life experiences, they started to become aware of patterns (i.e., personal or environmental influences) that influenced their chronic pain. *Pattern recognition* is the insight for change that allows a participant to evolve to expanded consciousness. Some people may describe pattern recognition as their inner voice or "intuition" (Newman, 1994, p. 42). Through pattern recognition, African American indigent adults with chronic pain began to acknowledge some solutions to barriers impeding their pain control. The *person* is consciousness and is an open system interacting with the environment. The person brings "personal meaning and quality of life at the forefront" (Newman, 1994, p. 126) of the nurse-patient relationship.

HEC is being open and accepting of the patient. The holistic interaction between patients and nurses is empowering and mutually transforming (Newman, 1995). The present study helped expand the *praxis of nursing* research, by providing nurses with greater insight into the experience of chronic pain for African American indigent adults. The findings of the present study does lead to additional research with this population, a deeper respect and understanding of African American indigent adults with chronic pain, and the development of effective interventions designed to meet their individual needs. The *praxis of nursing* would be enhanced through nurses advocating and demanding changes to the current pain practices toward African American indigent adults.

Personal space, shared space, and geographical space are examples of *space*, which is aligned with time. People did not want someone around them interfering with

their space when they were experiencing pain, however, because of economic factors, space for African American indigent adults, was often limited at best. Subjective time, private time, and objective time are examples of *time*, which is united with space (Newman 1986; 1994). A person experiencing chronic pain felt that time was moving too slowly when waiting for pain relief. Both space and time are linked through *movement*, particularly for individuals who were unable to control their movement due to chronic pain.

From a unitary perspective (Newman, 1994), the nurse actively listened during the interview process and asked more focused questions as needed. The nurse was “fully present in the moment” (p. 148) and was sensitive to patients’ experiences. The interviews were transcribed and the nurse arranged key statements from the interviews in order of their significance. Those persons or events that were discussed most or described as most meaningful for the patient were listed first and these statements were grouped with other statements of similar topics. This process is analogous to a domain analysis as completed during ethnography (Spradley, 1980). The events that were discussed most were reviewed with each participant for clarification and additional insight at a follow-up interview.

It was during this person-environment interaction of the nurse and the patient that life patterns were recognized (Newman, 1994). These life patterns were the experiences of chronic pain as described by African American indigent participants. The importance of this process was the emphasis that participants describe, identify and recognize their life patterns. The nurse was part of this process of recognition, but the nurse does not dictate to the patient, nor does the nurse perform further detailed



theme analyses or taxonomic and componential analysis (Spradley, 1980) until the participant has verified the patterns.

The patient was recognized as the expert during the initial interview and follow-up interviews (Harrison & Falco, 2005). African American indigent adults experiencing chronic pain were the experts in this present study. It is the participant's personal knowledge and pattern recognition that guided subsequent nursing research interventions (Fawcett, 1993).

In a unitary transformative paradigm, the nurse's role remains to empower the patients through the patient's recognition of the power within themselves to make a change. Pattern recognition included awareness of behavior changes toward others when experiencing chronic pain. Participants shared that they experienced either bouts of anger or self-seclusion when experiencing chronic pain (National Pain Foundation, 2009b). New awareness of these behaviors may lead individuals in the future to change their current way of interacting with others. This awareness is pattern recognition, which is health. African American indigent adults shared that they have patterns of pushing people out of their lives. This revelation or pattern recognition is the 'ah, ha!' moment in someone's life, the possible turning point from which new patterns may be created. Nursing practice from a unitary transformative paradigm focuses on the pattern of the whole (Newman, 1986; 1994). The pattern of the whole examines people, their family and the community in which they live and recognizes that people cannot be subdivided into parts.

## Life Patterns of Pain

People who experience pain have pain related life patterns. Patients who experience chronic pain and illness often describe how the illness and pain developed and challenged their lives (Candib, 2004). Patients will try to make sense of the chronic pain in their lives by discussing their experiences. In the present study, African American indigent adults experiencing chronic pain were asked questions from the interview guide (see Appendix A) addressing the HEC concepts of time, space, movement and consciousness (Newman, 1986; 1994). A model depicting the life patterns of pain may be found in Appendix B.

**Uncontrolled pain.** According to the American Pain Society (2008), National Pain Care Policy Act 2007, pain that is not controlled may depress a patient's immune system, influence quality of life and lead to emotional distress (National Pain Foundation, 2009b). Decreased perception of control over one's pain leads to lower functional status and increased pain-related distress, particularly with African Americans (Vallerand et al., 2005). Patients, predominantly those from ethnic minorities and low socioeconomic strata, often feel discriminated against in their efforts to obtain adequate treatment for their pain (Nguyen et al., 2005). Most health care providers are not up-to-date with effective pain management in their education and practice; this is a barrier to adequate pain control.

**Application of theory to study.** Participants in the present study were asked to describe the experience of time when living with chronic pain. African American indigent adults were asked questions that encouraged them to describe how time affects them as they wait for the analgesic to provide relief. According to HEC, space is

linked with time (Newman, 1986; 1994). Questions that were asked of participants in the present study related to space included a query of how pain influenced their feelings about space. For example, did they need to change their living accommodations due to chronic pain? Some African American indigent adults wished to reduce the amount of personal space they kept around them by having individuals they cared about nearby. The opposite feeling was true too, when participants expressed a desire for wanting space alone and to themselves, thus pushing people away (Candib, 2004). African American indigent adults may have reduced space if they are accessing an overcrowded shelter or increased space if living on the street (Crowe, 2007). The people they may want around them when they are in chronic pain may have deserted them. Items that provide comfort and meaning to them may have been stolen.

Movement may be restricted because of chronic pain. These restrictions were discussed using the interview process and HEC (Newman, 1986; 1994). Participants were asked to describe what their pain keeps them from doing; if pain affected their ability to sleep, ambulate, care for themselves, manage household responsibilities and attend outside appointments. Movement brings change and is important to consciousness. African American indigent adults need movement to seek shelter, for personal safety and to organize food. Chronic pain affects movement and limits the ability to seek adequate nutrition and safe housing, thus compounding other chronic illnesses.

Restrictions in movement, space and time as it relates to HEC (Newman, 1994) reduce one's freedom. "Movement provides a way of controlling one's environment" (Newman, 1994, p. 46). Chronic pain reduces patients' abilities to move freely and

challenges their ability to remain independent. This lack of independence increases the reliance on others for assistance. African American indigent adults with reduced movement because of chronic pain did not always have the ability to attend follow-up health care appointments and prescribed treatments.

Consciousness or the ability to think, feel and interact with the environment is influenced by the patient's ability to move and perceptions concerning time and space (Newman, 1986; 1994). African American indigent adults were asked if pain affected their interactions with others. Participants were asked if they thought that others believed they had pain and if they felt others treated them differently when they experienced pain. Patients who are labeled as 'drug seeking' and are not believed to be in pain receive inadequate pain treatment (Nguyen et. al. 2005). Sharing experiences about chronic pain in a non-judgmental environment improves feelings of trust (Newman, 1994). Participants identified how patterns of pain within consciousness affected their ability to experience meaningful relationships with others. African American indigent adults discussed how health care providers perceived their expressions of pain. Participants identified their patterns of relating to others and discussed future health care interactions.

In summary, patterns of pain for African American indigent adults may be discussed using the theory health as expanding consciousness. Nurses examine the life patterns of patients when patients describe the important people and meaningful experiences in their lives. Feeling heard and trusted when describing chronic pain, improves the health care provider or nurse-patient relationship. African American indigent adults identify patterns of pain. This pattern recognition leads to

transformation, expanded consciousness and health (Newman, 1986; 1994). The next chapter describes the methods used for the present study and how focused ethnography gathered findings from photovoice and interviews.

## CHAPTER 3

### METHODS

#### Introduction

Using focused ethnography, the purpose of this study was to examine the experience of chronic pain as described by African American male and female indigent adults attending an urban, primary care clinic. The research design, description of participants, data collection strategies and data analysis will be discussed. Protection of human subjects and trustworthiness will be described. Focused ethnography was an appropriate research design for the present study.

#### Research Design

A qualitative, focused ethnographic research design was selected to examine "informant expressed [chronic pain] needs" and to situate these needs in research participants' lives (Spradley, 1980). Ethnography is one of many research designs that use qualitative data (LeCompte & Schensul, 1999). Originally developed by cultural anthropologists and embedded sociologists for their research, ethnography depends on data from participant observation field notes, formal and informal interviews of those in the research sites, and collection of artifacts used and produced by participants (Spradley, 1980). However, for the present study, a focused ethnographic approach was used, with photovoice (described later) used instead of detailed participant-observation field notes. Among the strengths of ethnography is the ability to capture a holistic view of everyday life. Rather than studying people, ethnography allows researchers to learn from people (Spradley, 1980). This focused ethnographic approach was an appropriate design for the present study because it provided health

care providers with an understanding of the experience of chronic pain for African American indigent adults.

Any group of people, who share knowledge about an activity or event, may be said to share a culture. Ethnographic inquiry includes asking specific questions to elicit rich cultural meanings (Parse, Coyne & Smith, 1985). Descriptive questions help participants describe explanations of their world, structural questions help expand on not only what people know but how they organize what they know, and contrast questions show differences in the way participants describe symbols (Spradley, 1979). In the present study, key informants were chosen to discuss the experience of chronic pain as they experience it in their everyday lives (Parse et al., 1985).

Focused ethnography may also be called a microethnography or small-scale ethnography (Speziale & Carpenter, 2003). However, it still uses the principles of ethnography as researchers do learn from participants. A focused ethnography is a brief study of a few days to a few weeks in length that is focused on a specific concern or cultural domain. Large amounts of data are gathered and analyzed in a relatively short time period (LeCompte & Schensul, 1999). Focused ethnographies cannot occur without prior familiarity with the setting and/or knowledge of the field prior to entering it (Knoblauch, 2005). Different from conventional ethnography where the research focus is broader and everything in the environment is studied, with focused ethnography, a specific topic is the focus of inquiry. Questions asked during the research process are known prior to entering the setting (Knoblauch, 2005; Muecke, 1994). Parts of the ethnographic method may be modified such as the use of interviews and other documents instead of participant observation (Morse, 2007). Data collection may be

completed using audio recorders and photographs (Knoblauch, 2005). Focused ethnography is still attentive to the emic (the participant's point of view) but on a smaller scale and related to specific activities, people and behaviors in everyday social interaction.

Using the principles of focused ethnography (LeCompte & Schensul, 1999), the researcher should already be familiar with the field setting or cultural context. In the present study, the researcher did have familiarity with the clinic and the population. The researcher had previously assisted with an earlier quantitative study at this clinic (Vallerand et al., 2008; Pieper et al., 2009), reading questionnaires to the clients to examine pain and its relation to functional status, coping, depression and perception of control. The researcher also worked for several years as a staff nurse and then a case manager at an urban community hospital located not far from the current clinic setting. Patients at the urban hospital experienced similar life challenges. The researcher also has prior homecare experience caring for low income individuals and families, has volunteered at food bank services and is a member on the executive board for a homeless coalition committee.

In focused ethnography, one aspect of culture is studied i.e. questions about health; making it different from traditional ethnography where broad questions about a topic are answered (LeCompte & Schensul, 1999). Knowledge gained from this type of research design has practical application for health care providers (Muecke, 1994). In the present study, it was the experience of chronic pain as described by African American indigent adults attending an urban primary care clinic. Questions to be asked were specific to the participants of this study and their feelings of discrimination and/or



treatment for their chronic pain. Other criteria of focused ethnography are that the researcher should work with experts in the chosen setting (LeCompte & Schensul, 1999). In the present study, nurse practitioners working in the urban primary care clinic assisted with choosing participants who were reliable and who did return for the second interview and in some cases, a third interview (additional information about the participants of this study is described later). In addition, all members on the researcher's committee had expertise with the chosen population, the methods used to obtain data and/or the participants. The urban primary care clinic and the patients at the clinic are described.

### **The Clinic and Its Clientele**

The urban primary care clinic where the present study occurred is embedded within a large, urban teaching center that is adjacent to an emergency department. The clinic is located along a bus route and/or is within walking distance for most patients. The hours of operation for the clinic is from 8:30-5:00pm Monday through Friday excluding national holidays. Approximately 750-800 patients are cared for at this clinic each month and 39 medical residents also rotate within this clinic towards partial completions of their clinical hours each year (M. Wicker, personal communication, January 15, 2009). Staff working at the clinic also includes seven clerical staff, two registered nurses and two nurse practitioners (NP's). Only one of the NP's is full-time. Internal medicine recently received a grant to allow a psychiatrist, psychologist and a social worker to begin assisting patients' with support and services. A nurse manager organizes schedules, budgets and offers additional staff and patient support. The health care providers at the clinic care for single adult patients between 21-64 years of

age and earning less than \$250 per month (Pieper & DiNardo, 2001; Pieper et al., 2000). Patients must make an appointment to be seen by a health care provider at this clinic and are enrolled with Plus Care-Med Basic insurance provided by the State Department of Social Services (M. Wicker, personal communication, January 15, 2009).

Patients register with the front desk clerical staff and then wait for their name to be called while sitting on one of approximately 20 chairs in the waiting area/lobby. Once their name is called, patients are allowed entry through a closed door and into the examination area at the back of the office. The clinic where the present study occurred has approximately six examination offices.

Additional information about the patients, who receive health care at this urban, primary care clinic, was obtained from the following study. A study of 301 participants by Vallerand et al. (2008), at this clinic examined functional status, perceptions of control, coping and depression related to pain. The average participant age was 48 years with 92% being African American. Participants had been diagnosed with a variety of chronic illnesses such as hypertension (61%), arthritis (54%), unspecified breathing problems (33%), mental illness (31%), leg ulcers (23%) and neuropathies (23%). Equal numbers of men and women took part in the study and 53% were single or never married. Approximately 30% of participants had not completed high school and 70% had a high school diploma or some college and/or technical training. Seventy-three percent of participants did not work and 48% indicated that they were disabled due to pain. In other studies it was found that a high percentage of patients at the clinic have a history of illicit drug use (Pieper & DiNardo, 2001; Pieper et al., 2000) and may have

wound ulcers from previous injection drug use. Participants invited to participate in the present study met specific inclusion criteria.

**Inclusion criteria.** There were 15 patients invited to participate, from which 13 African American indigent adults (6 women and 7 men) attending this primary care clinic chose to participate in the present study. Participants were invited if they were registered as patients at the clinic, they did not seek care at a multi-disciplinary pain center, spoke English, did not show obvious signs of cognitive impairment and self-identified as being African American. Participants were enrolled in the present study if they denied currently using illicit drugs when asked by the researcher and if they had been experiencing moderate to severe chronic pain for greater than three months. Patients were excluded from the present study if they did not fit the criteria for inclusion.

Nurse practitioners working at the clinic and familiar with the patients referred the names of patients to potentially enroll into the present study. Patients were referred based on their history of being reliable and returning to the clinic for follow-up appointments. Patients who were able to provide accurate information were referred, as were patients that did not admit to current, illicit drug use.

Criterion-based selection was used to identify those patients who were most eligible to participate based on the characteristics of the patient matching the present study's research questions (Schensul, Schensul & LeCompte, 1999). The nurse practitioners working at the clinic used reputational case selection to identify and recommend to the researcher, patients who because of their characteristics, best represented the community of interest. Patients were chosen for the present study as they allowed the researcher to learn from the patterns of being African American,

indigent, experiencing chronic pain and attending an urban primary care clinic (Schensul, Schensul et al., 1999). Similarities or differences among patients helped enhance the researcher's understanding of the patterns of chronic pain.

### **Data Collection**

Several data-collection strategies occurred within the present study. Copies of a flyer approved by the Human Investigative Committee (HIC) at Wayne State University describing the study were left in the clinic office (see Appendix C). Participants also contacted the researcher using the contact phone number for the research office at Wayne State University. The research office answering machine was checked daily for messages and patients expressing interest in the study were called to discuss the study. The patients who were suggested to be reliable by the nurse practitioners were approached in the lobby as they waited to be seen by their health care provider. African American indigent adults were asked if they were currently experiencing moderate to severe pain and if this pain had continued for greater than three months. In a study by Li, Harris, Hadi and Chow (2007), moderate to severe pain was rated by subjects as being a score between 5 to 10 *on a scale of 0 to 10; where 0 was rated as no pain, and a score of 10 was described by participants as being the worst pain imaginable.* In the present study, when patients acknowledged that they had a pain score between 5 to 10 *on a scale of 0 to 10*, for greater than three months, the researcher asked them if they wanted to participate (see Appendix D).

When African American indigent adults agreed to participate, they were invited to learn more about the study. Research interviews for patients who discussed the study by telephone were scheduled for a time when patients had other appointments with their

health care providers at the clinic. Patients, who wanted to learn more, were allowed entrance into the examination area at the back of the clinic and further discussion about the study continued in one of the examination offices. If patients did not admit to having moderate to severe pain or did not wish to participate, patients were precluded from the study and thanked for their time.

Upon entering the examination office at the back of the clinic, and prior to signing the Informed Consent/Acknowledgement and Release, patients responded to four questions in the shortened version of the Abbreviated Mental Test the AMT4 (Swain & Nightingale, 1997). The AMT4 is a screening tool used to quickly assess cognitive function. All data collection instruments are described in greater detail in the pages that follow. If cognitive function was intact, the Informed Consent/Acknowledgement and Release was obtained (see Appendix E). Participants then completed a short demographic form (see Appendix F), filled out one brief pain inventory survey (see Appendix G), and responded to interview questions about their experiences with chronic pain.

The researcher conducted all interviews with participants in one of the clinic examination rooms. Participants described the important experiences and people in their lives (Newman, 1994) particularly how these experiences and people influenced their chronic pain. The researcher remained nonjudgmental and was an active listener (Newman, 1986; 1994; Spradley, 1980). Two audio recorders were used to record all interviews. The audio recorders were placed in the examination room and the participant's wishes were respected if they wanted the recorders turned off at any time during the interview. No participants requested that the recorders be turned off at any

time during the present study. The use of two recorders was to prevent the loss of valuable data due to any unforeseen damage to the tape or malfunction of one of the audio recorders (Schensul, LeCompte, Nastasi & Borgatti, 1999).

The researcher recorded some non-verbal behaviors that occurred during the interview, such as the participant's movements, speech patterns and emotions (Pharris, 2002). These recordings are called field notes (Spradley, 1980). In the present study, following the completion of each interview, the researcher wrote additional field notes describing participants' nonverbal behaviors, affect and any observable signs of pain that took place during the interview. The recording of field notes was explained to participants and was written in the Informed Consent/Acknowledgement and Release.

African American indigent adults were asked to describe the resources they used to help reduce or relieve pain, whether they felt supported by others while experiencing pain and to describe the experience of chronic pain in their lives. These descriptions related to Newman's (1986; 1994) concepts of pattern, pattern recognition and expanding consciousness. Two to three semi-structured interviews was completed for each participant to allow for the "flexibility of the unstructured, open-ended interview with the directionality and agenda of a survey instrument" (Schensul, Schensul & LeCompte, 1999, p. 149). Within HEC, the relationship that developed between the researcher and participant was integral to allow for transformation and health. The interviewer was fully present so that interviewees felt comfortable sharing their stories (Newman, 1994).

Spradley (1980) wrote that it is best to look at "informant expressed needs" (p. 18); therefore, interview questions were rephrased or abandoned if they hindered the

flow of communication and rich descriptions provided by participants. Areas of interest expressed by the participant as having precedence were pursued during the second and third interviews. Interviews and pictures described the life patterns of pain within HEC (Newman, 1986; 1994).

Once the first interview was finished and prior to the participant leaving the examination room, the participant was reminded to complete the photovoice portion of the present study as was described to them in the Informed Consent/Acknowledgement and Release. A date was discussed and scheduled with participants for the follow-up interview to take place approximately two weeks after the first interview. This date was written on the information provided to participants. During the first interview, the researcher obtained a phone number from participants, so the researcher could contact participants to remind them about the study. Participants were given a 27-exposure disposable camera and instructed, within one weeks' time, to return the camera via mail in a postage-paid, return-addressed envelope. Participants were coached about the use of the camera. Information shared with participants included a reminder of the ethics of photography and photovoice. Participants were reminded that they had to obtain written consent from individuals prior to photographs being taken of other people and were instructed to remain vigilant about their personal safety (Wang & Redwood-Jones, 2001). In addition, participants in the present study were given handouts to distribute to individuals they photographed (Appendix H). Within the handouts, the purpose of the study and use of the photographs was described in detail. As did occur throughout the entire research study, all questions from participants were answered.

Participants in the present study captured, on film, the events, places and activities in their lives related to their experience of living with chronic pain (Spradley, 1980). They were instructed to take pictures of the culture of chronic pain, or the artifacts (what items the participant used when they were experiencing chronic pain) to help them cope with the pain. Some of the participants took pictures of the important people in their lives (individuals who had an influence on their chronic pain). Participants took pictures of the knowledge or behaviors they performed (rituals) which affected the experience of chronic pain; including the activities they performed to reduce the chronic pain or worsened their pain (Spradley, 1980). In addition, photographs taken by participants helped describe Newman's concepts of consciousness, movement, space and time (Newman, 1986; 1994).

After the photographs were taken, participants placed the disposable camera in the postage-paid, return-addressed envelope. The cameras were mailed to an address provided by one of the researcher's committee members, to a mailbox at Wayne State University. The researcher retrieved the mailed cameras and had the pictures developed at a local camera shop. Two copies of all photographs were made so that one copy of the pictures could be given to the participant during each of the second and third interviews. Copies of all pictures were saved on a CD for research purposes.

During the second interview, the researcher verified the phone number of the participant to again ensure that the number the participant had provided was still current. The researcher contacted participants within one week after the first interview to remind them to complete the photovoice part of the research. The second interview was scheduled approximately two weeks after the first interview. The second interview



may or may not have coincided with the participant's scheduled clinic appointment. The second interview was scheduled to take place at the clinic at a time that was most convenient for the participant to reduce the burden of travel on them. Most interviews were scheduled by the participant when the participant knew they were able to obtain transportation to the clinic.

Part of the second interview (Appendix I) was the participant's description of the photos and clarification of any questions that arose from the first interview. "Photovoice allows individuals who ... provide services... at the individual, program and policy levels the means to understand and assess the magnitude of how chronic pain influences the patient's life" (Baker & Wang, 2006, p. 1410). During the second interview, participants again were observed for any nonverbal behavior; their affect or observable indicators of pain. These observations were recorded as field notes (Spradley, 1980).

During the second interview, if there were remaining questions to ask participants; if participants had additional information about their chronic pain that they wished to share; or if the first camera was used for pictures that were not related to the study; participants were asked if they wished to continue to participate in the research study. Five participants were invited to participate with a third interview (Appendix J) and to participate during a second photovoice session. These participants were invited to continue to describe the experiences of chronic pain using photovoice and they were given a second camera. These participants were then invited to return for a third interview to discuss the images captured on film from the second camera. The steps described in detail to participants for using the second camera in photovoice were

identical to the steps described to participants for the first photovoice session. All questions from participants continued to be answered.

The researcher contacted participants within one week after the second interview to remind them to complete the photovoice part of the research. The third interview was scheduled to take place approximately two weeks after the second interview. The third interview was scheduled to take place at the clinic at a time that was most convenient for them to reduce the burden of travel for them.

Participant attrition did not occur in the present study. All 13 participants completed two interviews and one photovoice session and of those participants, five participants completed a third interview and second photovoice session. Discussions regarding possible attrition did take place with the researcher and her committee members, as one participant needed to cancel the second interview several times. After several rescheduled appointments, the participant did return to the clinic to complete the second interview. The data collection instruments are described in greater detail below.

**Data collection instruments.** Some of the data collection instruments used for the present study were the cognitive screening tool, demographic form, brief pain inventory survey, interview questions and photovoice. The AMT4 is a screening tool used to quickly assess cognitive function. The AMT4 includes questions about the participant's age, date of birth, current location/setting and current year (Swain & Nightingale, 1997). The tool is quick to use and easy to score. It was used during this initial screening when enrolling participants and to assess the participant's ability to continue in the research study during the second and third interviews. A score of less

than 4 indicates possible cognitive challenges (Swain, O'Brien & Nightingale, 2000). No participants scored 0 to 3 on the AMT4, so all participants who wished to participate were included in the present study.

At no time during the interviews did any of the participant's behavior change and all participants appeared to be cognitively intact, therefore the AMT4 did not need to be completed a second or third time. At no time during the present study were interviews stopped and participants did not need to be referred to the clinic staff for follow-up care. In fact, more than one of the participants, queried if the researcher was asking 'trick questions' as they found the questions on the AMT4 easy to answer. Questions listed in the AMT4 have been said to provide greater relevance for the African American indigent adults. A participant's educational level may influence scores obtained from questions asked on other tools (Swain & Nightingale, 1997). Examples of questions asked on the 20 question Abbreviated Mental Test (AMT) includes asking participants the name of the Monarch or to cite the year World War 1 began. The AMT4 compared to the AMT showed a predictive efficiency of 83.3% for cognitive state and a strong linear relationship with a Somers' d statistic of 0.83 ( $p < .001$ ). When the AMT4 was compared to the Mini-Mental State Examination (MMSE), the predictive efficiency for cognitive state was 73.2% and a strong linear relationship with a Somers' d statistic of 0.69 ( $p < .001$ ) (Swain, O'Brien et al., 2000).

Participants completed a short demographic form that lists questions about the participant's age, gender, marital status, education levels, employment status and current living arrangements. Additional questions on the demographic form query the number of years the participant has experienced chronic pain and whether participants

know the cause of their pain. The demographic form was read to participants and answers were recorded by the researcher. The demographic form took approximately 10 minutes to complete.

After the demographic form, participants were asked to complete the Brief Pain Inventory (Short Form) by Cleeland (1991). The Brief Pain Inventory (Short Form) was used as an explanatory tool to help describe the experience of chronic pain for African American indigent adults. The Brief Pain Inventory (Short Form) took approximately 10-15 minutes to complete. Participants were provided with the form and a pen and were asked to draw the location of their chronic pain on a body drawing. Questions on the Brief Pain Inventory (Short Form) were read aloud to participants and participant's responses were recorded by the researcher on the form. Questions from the form include rating the average, worst, least and current pain participant's experienced in the previous week. In addition, participants were asked to describe current treatments or medications they took for pain and how much the presence of chronic pain interfered with certain aspects of their lives, such as mood, sleep and enjoyment with life (Cleeland). The Brief Pain Inventory (Short Form) (Cleeland, 1991) has a Cronbach alpha reliability ranges from .77 to .91, and has been validated in more than three dozen languages (The University of Texas M. D. Anderson Cancer Center, 2008).

Once the Brief Pain Inventory (Short Form) was completed, all participants chose to respond to interview questions in the examination room at that time. Participants were asked questions in the interview guide that specifically focused on the concepts of space, time, movement and consciousness to identify patterns of pain within health as expanding consciousness (HEC) (Newman, 1986; 1994). Questions asked of

participants inquired into their perceptions pertaining to the disparities of chronic pain management, and possible pain management solutions. The interview lasted as long as participants wished to discuss their experiences with chronic pain. Most interviews lasted between approximately 30 minutes to almost 1.5 hours in length.

Photovoice is a data-collection strategy that helped give participants control over representation of their world. Photovoice is a participatory action strategy that enables those taking photographs to record through images, their community's strengths and problems. It evokes dialogue about important issues and engages policy makers (Thompson et al., 2008; Wang & Burris, 1997). It is empowering to people and provides marginalized individuals with a medium to showcase their world and provides individuals with the ability to influence how the rest of the world perceives them (Carlson, Engebretson & Chamberlain, 2006; Photovoice, 2006; Wang & Burris, 1997). Photovoice enables those who are traditionally the subject of photos by the researcher or journalist to instead be the creators of these images (Photovoice, 2006; Thompson et al., 2008). Individuals took pictures of their everyday health, in this case their experience with chronic pain, to help enhance the understanding of chronic pain for health care providers and policy makers. Photovoice captured with images, the pain experience that is not easily explained through quantitative measures (Baker & Wang, 2006).

Individuals who have traditionally been stigmatized due to illness or other social conditions, are instructed how to use a camera to provide a unique emic or insider viewpoint about their lives (Schensul, LeCompte et al., 1999; Speziale & Carpenter, 2003). In the present study, the emic viewpoint was the experience of being African

American, indigent and living with chronic pain. Photovoice provides marginalized individuals with cameras so they may record their daily experiences and community life and be catalysts of change instead of passive recipients of other's images and intentions (Wang & Burris, 1997). Photovoice provides health care researchers and providers of care with greater accuracy in terms of a needs assessment, as what is deemed meaningful to the client may be different from what is viewed to be important to researchers (Wang & Burris, 1997). It is a data collection method that is helpful to those with low literacy, as it does not require that the person taking images can read or write. Being the photographer of one's world can evoke feelings of pride when sharing the meaningfully created images with others (Wang & Burris, 1997). The methodology of photovoice enables those taking the pictures to advocate for their own and for others' improved health.

Several studies have used photovoice, such as when examining, family and child health (Wang & Pies, 2004); community pride (Carlson et al., 2006); homeless individuals living at a community shelter (Wang, Cash & Powers, 2000); women's health concerns (Wang, 1999) and chronic mental illness (Thompson et al., 2008). Empathy is said to be a valuable outcome of photovoice as often judgment or condemnation may be felt towards marginalized individuals (Wang, Burris & Ping, 1996). Participants in the present study have shared information that may be used to educate policy makers and health care providers about how to improve care towards individuals living with chronic pain.

In previous studies, people living with chronic pain have doubted that others believe they experience chronic pain (Douglas et al., 2008; Vallerand et al., 2008).

Feeling that no one truly understands their pain can further isolate individuals and add to their emotional pain (Aderibigbe, Bloch & Walker, 2001; Smith & Friedemann, 1999). In the present study, participants had the power to choose what pictures to take, therefore “the traditional power imbalance between photographer or researcher and subject [is] broken down” (Frohmann, 2005, p. 1399). Participants were able to document their experiences with chronic pain, their relationships with others and their environment.

### **Protection of Human Subjects**

Prior to the initiation of any research activities, approval for the present study was granted from the Institutional Review Board (IRB) Human Investigative Committee (HIC) at Wayne State University, Detroit, Michigan (Appendix K) and the Detroit Medical Center (DMC) Research Review (Appendix L). Ethics approval was also granted from the researcher’s home employment institute, the Research Ethics Board (REB) at the University of Windsor, Windsor, Ontario, Canada (Appendix M). Permission to proceed at the clinic site was given by the manager of the urban primary care clinic and the medical director of the clinic (see Appendix N for letter of support). Prior to the initiation of research activities and with each research visit, the researcher introduced herself to the clinic health care providers and staff. Support for the study occurred with the identification of research participants, and was provided by the nurse manager of the clinic and by the nurse practitioners working in the clinic.

Upon entering one of the examination offices, the purpose of the study was explained to participants. All participants were asked to read and sign an informed consent/Acknowledgement and Release, which outlined the purpose, risks, benefits,

etc... of the present study. The informed consent/Acknowledgement and Release also granted permission that photographs taken by participants may be used for publication and a wider dissemination of knowledge (Wang & Redwood-Jones, 2001). Participants were verbally asked again at each interview if there were any words or pictures they did not want shared with others outside of the research study. Pictures the participants did not want shared, have been removed from the present study and will not be used in future dissemination of research findings. Participants stated that all words from the interviews could be used and shared with others. If participants had questions about the present study they were answered at that time and at any time throughout the research study. Participants were informed that findings from the present study would be used for publication to increase health care professionals understanding and the public at large, of the experience of chronic pain as described by African American indigent adults.

Participants were made aware that they were only to respond to the interview questions they wished to discuss and that at any time they could stop the interview. The care they currently received at the clinic would not change should they decide to not continue with the research study. Participants in the present study responded to all interview questions and participated with all interview appointments. If at any time during the interviews participants expressed feeling emotionally overwhelmed from describing the experiences of chronic pain, or if they were experiencing pain that made completion of the interview uncomfortable, the interview would have been stopped. Participants would have been immediately directed to speak with one of the health care providers working in the clinic. No participants expressed feeling emotionally



overwhelmed or experienced overwhelming pain that prevented them from completing each interview, therefore no immediate referrals of participants were made to health care providers at the clinic. Responses given by participants remained confidential and participants were reminded that assigned research numbers would be used instead of names during data collection or dissemination.

Due to the photovoice portion within the present study, two consents were obtained. When participants were first enrolled into the present study, they signed the informed consent/Acknowledgement and Release which was the agreement to participate in research and within that consent, permission was given to have their photographs disseminated. A separate consent was the informed consent/Acknowledgement and Release for individuals photographed in this study, which was to be signed by individuals not currently enrolled in the present study, but prior to any photography being taken of them by study participants (Appendix O). The African American indigent adults in the present study did not remember to obtain signatures on this document. Pictures of other people not currently enrolled in the present study other than the participant were not used in this present study. Copies of all pictures were given to participants at each follow-up interview.

All tape recordings, pictures and transcripts were kept in a locked filing cabinet within a locked office. Only the researcher and dissertation committee had access to these files. A code number identified recorded tapes and photographs; the exception being, when participants had signed the informed consent/Acknowledgement and Release granting permission for personal photos to be used in publications. Assigned research numbers were used to describe the identity of participants. Per guidelines with

the Division of Research at Wayne State University, transcripts, pictures and tapes will be kept for a minimum of 5 years (Wayne State University, 2006).

**Compensation.** Payment for participation in research when recruiting participants who are indigent must be enough compensation to be equitable with society, yet not too enticing that participants believe they are not able to refuse (Levine, 2003; Todd, 2001). Payment must not coerce participants. Applying a 'wage-payment model' recognizes the time and effort provided by participants but acknowledges the minimal technical skill required. Wages are standardized and equal to wages paid in the unskilled-labor market (Dickert & Grady, 1999).

Payment provided for participation in research recognizes that the individual's participation in the research study is valuable to society (Dickert & Grady, 1999). In the present study, participants were financially compensated for their time and description of chronic pain. Compensating participants acknowledged their time and any inconvenience that may have occurred for taking part in the research study. Wayne State University outlines additional policies regarding compensation to research participants. Payment for participation in research should not be contingent upon completion of the entire study. Payment for participation in research should be given at various stages of protocol completion (Wayne State University, Human Investigative Committee, 2008).

In the present study, participants were paid \$15 after the completion of the first interview, \$10 at the beginning of the second interview for having two weeks prior, taken the photographs and mailing them to the researcher and again were paid \$15 at the end of the second interview. Participants were paid \$10 at the beginning of the third

interview if two weeks prior they had taken photographs of their experiences with chronic pain and were paid \$15 at the end of the third interview. Each time participant's received payment for their involvement in the study, participants signed and dated a payment form (see Appendix P) and circled that 'yes' they had been paid for that portion of the completed research. The researcher made two copies of all photographs and gave participants copies of the photographs to keep. Photographs were also saved for research purposes on a compact disc (CD). Information regarding compensation was outlined in the Informed Consent/Acknowledgement and Release.

**Ethnographic research cycle.** Spradley's (1980) Ethnographic Research Cycle was used for the present study. The research process was cyclical, as first participants were interviewed. After each transcription was reviewed and domain analysis completed, questions that arose during that particular observation were asked during the next field experience or interview. Spradley's Ethnographic Research Cycle requires a cyclical process. Analysis of data led to new ethnographic questions, which in turn, lends itself to the collection of more data pertaining to the experience of chronic pain, more analysis of that data, and so forth. Participants took photographs of their chronic pain experiences that occurred outside from the urban primary care clinic. Participants returned for a second interview to clarify findings from the first interview and discussed the photographs. During the second interview, some participants were invited to take additional photographs and returned for a third interview. The third interview included the discussion of any remaining questions and the participant's description of the additional photos. In the present study, the researcher examined

patterns in the transcribed data, using domain, taxonomic and componential analyses within the ethnographic research cycle (Spradley, 1980).

**Challenges with data collection.** Some challenges occurred during data collection, including challenges with photovoice, contacting participants, challenges for participants with transportation and scheduling. Photovoice was a challenge for a few participants. One participant who did not take pictures related to the study said that her daughter had accidentally picked up the camera and took pictures of all of her family members at a birthday party. There were no Informed Consent/Acknowledgement and Release forms signed for the individuals photographed, so the pictures could not be included in the study. The participant was provided with another camera, reminded of the purpose of the present study and invited to participate in a second photovoice session. Another participant had taken photographs of some of the historic buildings within the city and other points of interest. The participant was not able to link the pictures he took to his experience with chronic pain. He shared that the researcher, who is Canadian, may learn from the pictures, about the urban American city. The participant was provided with a second camera, reminded of the purpose of the present study and was invited to participate in a second photovoice session.

Other participants took pictures of important people in their lives, but did not obtain Informed Consent/Acknowledgement and Release forms from the individuals photographed. These pictures were not included in the present study. Participants received copies of the pictures they had taken. The researcher cannot be certain, but wonders if due to few financial resources, if the pictures were taken by participants of meaningful people in their lives as they could not afford to have these pictures

developed. Taking pictures as part of the present study and knowing that the researcher would be developing the pictures, the participants would have copies of the meaningful people in their lives to keep.

One participant contacted the researcher to state that he had misplaced his second camera and the postage-paid, return-addressed envelope. The participant met the researcher at the clinic and was provided with another postage-paid, return-addressed envelope and another camera. When the participant was leaving, he asked the researcher if she had money available to give to him for transportation. The researcher said that she did not and prior to the participant leaving the clinic, discussion occurred regarding the purpose of the present study. There were some challenges with contacting participants.

Other challenges included the initial contacting of participant's by telephone if participants had read about the present study from the research flyer at the clinic and wanted to learn more about the study. If they wanted to learn more, participants would leave a message on the research telephone at Wayne State University. The researcher would retrieve messages from the research telephone and call individuals to discuss the present study. Other telephone contact with participants occurred when the researcher would telephone participants to remind them to complete the photovoice portion of the study and to remind them of the date and time of their follow-up interview. The researcher noted that when contacting participants from a Canadian cell phone, participants would not answer the phone. If someone did pick up the telephone, they immediately disconnected the call with the researcher.

When discussing these occurrences with the nurse manager of the clinic, the nurse manager shared with the researcher that participants were frequently called by repossession agencies, so this may be the reason why participants did not immediately answer the researcher's telephone call. The nurse manager suggested that the researcher call participants, either from the DMC 4A Clinic or from Wayne State and share with participants when they answered the telephone that the researcher was working at the DMC 4A Clinic (M. Wicker, personal communication, July 23, 2009). When the researcher incorporated these suggestions provided from the nurse manager, the researcher found that participants did not immediately disconnect the phone call with the researcher and more participants answered the telephone and spoke with the researcher.

One of the participants did not have a telephone. The participant stated that he did not need to be reminded by telephone about the research study and that he would complete the photovoice session and attend the second interview at the scheduled date and time. This participant did complete the photovoice session, mailed the pictures and did attend the follow-up interview as had been discussed. Another communication challenge occurred when one of the participant's phones became disconnected. Communication needed to occur using the participant's daughter's telephone. Other participants in the present study either did have their own telephone or had access to a telephone where messages could be left for participants. Participants also had some challenges with transportation.

Most participants had challenges with transportation. Participants shared that they either had difficulty being able to afford transportation to come to the clinic or they

needed to rely on others to provide transportation. Some of the participants, who found transportation to be a financial difficulty, had their own vehicle. Participants shared that these vehicles were older, not always reliable or fuel efficient and in constant need of repair. Other participants in the present study relied on the city bus for their personal transportation and could not afford to pay \$1.50 for the one-way bus fair and \$0.25 bus ticket transfer to the clinic (P-3, I-3).

Participants said that waiting and relying on family or friends for their transportation was frustrating. Participants said if the family member or friend was late arriving to take them or early when picking them up, participants said they did not have a choice but either wait and be late or leave prior to receiving the full benefits of an appointment. Participants shared that they could not miss their transportation home as the friend or family member may not be able to return for the participant at a later time. In some cases the family member or friends were not willing to wait for participants to finish with their health care provider appointments. There were challenges scheduling participants for their interview appointments.

There were some challenges scheduling participants for their interview appointments, but thankfully the nurse manager at the urban primary care clinic was flexible and generous with the clinic space. Each week, the researcher sent the nurse manager a schedule with the list of dates and times the researcher had scheduled interview appointments with participants. The manager generously reserved a clinic examination room for the researcher but knew that the interview schedule often changed due to the participant's other competing needs in their lives. There were times when the interview schedule changed within the same day. Rescheduling with

participants had to be done multiple times throughout the duration of the study. The nurse manager and the researcher were flexible to accommodate the participant's changing needs.

### **Data Analysis**

The present study produced rich descriptions of the experience of chronic pain as described by African American indigent adults attending an urban primary care clinic. There were more than 2000 pages of transcripts that were reviewed by the researcher three times and from which more than 500 pages of quotes were gleaned from participants. Quotes were chosen based on participants' recurring, triangulated, corroborating ideas related to the research questions. There were more than 400 photographs taken by participants from which more than 100 pictures were coded for themes. Thirty-seven photographs were chosen for the present study in terms of how they best answered the research questions.

From the domain analysis of 112 domains, a taxonomic analysis was completed to cluster information that was similar and for the discovery of themes (Spradley, 1980). All thirteen participants responded to all questions asked of them during the interviews. Words shared by the participants will be described below including direct quotes given by participants and applicable photovoice pictures.

A professional secretary with experience in transcription transcribed all recorded interview data verbatim. All transcripts were coded for similarities and differences (Spradley, 1980). Descriptions of the photographs were analyzed for any emerging themes. Frequency of recurring activities was examined through an analysis of the transcriptions. The patterns described by participants was prioritized and shared with



the participant to verify their accuracy and for chronic pain pattern recognition (Newman, 1994).

Interviews were spaced two weeks apart to allow for domain analysis to occur prior to the second interview. The domains examined were the experience of chronic pain as described by African American indigent adults attending an urban primary care clinic. Participants were invited to be interviewed more than twice if they wished to participate in a third interview and second photovoice session and when new themes emerged. These additional interviews helped to ensure that saturation of information for the cultural domain was achieved (Schensul, Schensul et al., 1999).

From the transcribed interviews and participant observations, domain analysis was completed by hand (Spradley, 1980) and by using NVIVO8 qualitative software (QSR International, 2008). In domain analysis, semantic meaning, or patterns of meaning were examined. Recorded quotes from the transcription, description of photographs and observations from field notes were grouped according to their patterns of similarity, relationships to each other and to the whole. These patterns of meaning were called included terms. Included terms or quotes from the descriptions of the photographs, interviews and field notes provided by participants were clustered together under specific cover terms during domain analysis. These cover terms were systematically grouped into overarching cover terms, and the relationships of the terms grouped into the larger whole or larger semantic domain (patterns of meaning). Some of the semantic categories that were created from the data included, 'medication is a way to cope with chronic pain' and 'being with nature is a way to cope with chronic pain'.

Following domain analysis, taxonomic analysis occurred to identify categories as outlined in the domain analysis. These categories were further organized on the basis of a “single semantic relationship” (Spradley, 1980, p. 112). With taxonomic analyses, all the included terms within a particular domain were grouped together with the similarities clustered to show their relationships to the larger whole or larger semantic domain (patterns of meaning). In other words, larger domains were further partitioned in meaningful smaller domains, to form single overarching domains. All of the included terms for both domains were grouped together according to their relationships within the new domain. Some of the taxonomic analyses included the domain ‘ways to cope with chronic pain’ becoming the overarching cover term for the two domain analysis terms, ‘medication is a way to cope with chronic pain’ and ‘being with nature is a way to cope with chronic pain’. Included terms were systematically reviewed for their fit within this new domain. Taxonomic analyses thus looked for finer-grained, within domain categories of sameness, as well as relationships between and among categories, while componential analyses examined subtle differences in meaning and patterns of contrast (Spradley).

Componential analysis examined the patterns of contrast that are found within a domain (Spradley, 1980). It is the “systematic search for attributes” (p. 131) that provided dimensions of contrast within a particular domain. These contrasts were later expounded in text as they provided insight into a particular culture or pattern of behavior and the meaning that African American indigent adults ascribed to the pattern of chronic pain. In componential analysis, the included terms within the taxonomic analysis were examined within specific categories as determined by the researcher. These categories

were determined by patterns of behavior and the meaning given to these patterns by participants as they described the experience of chronic pain in their lives. Some of the categories examined from included terms were, 'Poverty is a characteristic of inadequate pain control' and 'Communication may be used to improve chronic pain care'. It is these differences that also provide insight into the cultural meaning that participants assign to their world.

Transcriptions were reviewed three times to ensure that accuracy of the interviews was maintained and any gaps in meaning were avoided. This reviewing of transcripts offered a reliability check (Schensul, LeCompte et al., 1999). Codes elicited from the data were reviewed and discussed with the researcher's committee members. This committee member understood the purpose of the research, had expertise with ethnography, and was knowledgeable about the culture being studied. Reviewing each code helped to ensure intercoder agreement also known as interrater agreement and improved reliability of the findings for the present study (Schensul, LeCompte et al., 1999). Descriptive statistics were used to analyze the means and frequencies of variables from the demographic form and for the Brief Pain Inventory Short Form (Cleeland, 1991).

**Trustworthiness.** Lincoln and Guba (1985) discussed ways to maintain trustworthiness for the "naturalistic paradigm" (p. 294). Here, trustworthiness provides for ascertaining research rigor, or establishing the quality of research findings. The naturalistic paradigm defines realities described by participants to be holistic and "value-bound" (Lincoln & Guba, 1985, p. 288). Four central criteria underpin trustworthiness: credibility, transferability, dependability, and confirmability.

Credibility in naturalistic research indicates truth-value, the extent to which findings provide an adequate interpretation of information included in data sets. Credibility is both designed into research, and a product of analysis. This study depended in great measure for its credibility on triangulation of methods (gathering different types of data) and of sources (including different people in interviews). Having data from observational notes taken during interviews, from interviews, and from photovoice interviews provided different vantage points on the same phenomenon. In addition, 7 men and 6 women participants made it possible to determine to what extent patterns observed for one participant are corroborated by another. To a lesser extent, peer review by the dissertation committee and member checks on interpretation undergirds trustworthiness. Member checking allowed participants the opportunity to check accuracy of the researcher's findings. In the present study, member checking during the second and third interviews, confirmed representation of the participant's thoughts pertaining to chronic pain and it corrected any misunderstandings.

Transferability (Lincoln & Guba, 1985) depicted the extent to which what was found in this study had wider applicability for other contexts. Thus, the study included enough rich description so that "similarity judgments" (p. 298) may be made by other readers when they compare this study's context and circumstances to another site or time. In addition, participants' environments, disparities with pain management, and possible solutions to these chronic pain disparities were discussed. Descriptions of chronic pain added to the transferability and the applicability of findings toward the experience of chronic pain for other African American indigent adults (Lincoln & Guba,

1985). Choosing an urban, primary care clinic, typical of many others throughout the U.S., enhanced the likelihood that this study has wider applicability.

Dependability concerns the ability for another researcher to be able to follow the research analysis strategies detailed in the description provided by the original researcher (Lincoln & Guba, 1985). Dependability occurred in the present study through the detailed report describing the data collection strategies and analysis. Through the use of an audit trail, linking all of the “raw data” (p. 319), including summaries, transcriptions, created interpretations, and analysis of findings via citation codes presented in the findings, and such research work products will be kept for a minimum of five years (Wayne State University, 2006). Keeping all materials related to the study is also important to verify that findings from the present study are confirmable, a check made by the dissertation committee’s methodologist. The researcher kept a reflexive journal (Lincoln & Guba), which documented day-to-day research tasks, emerging findings or conjectures that needed to be checked in subsequent data-collection sessions, and the impact of the project on the researcher. These notes aided in reducing the potential of bias occurring. The journal added to the confirmability of the present study and became part of the audit trail (Lincoln & Guba, 1985).

Health as expanding consciousness (Newman, 1986; 1994) provided the theoretical framework to guide the interpretation of findings of the phenomenon of interest – the experience of African American indigent adults experiencing chronic pain in an urban primary care clinic. A methods expert who is one of the researcher’s committee members, and familiar with the phenomenon and mode of analysis provided peer debriefing by reviewing the data (Lincoln & Guba, 1985). Negative case analysis

as described by Glaser and Strauss (1967) occurred to rule out competing explanations for the findings. Findings were reviewed multiple times in a constant-comparative method.

**Race, gender and trust.** In the present study, the researcher who is Caucasian, interviewed the African American participants. Cross-race interviewing deserves discussion to alleviate potential difficulties arising from racial, social status, or income differences. The researcher attempted to make each bi-cultural encounter with participants culturally safe by keeping in mind that potential power differences may have existed between the participant and the nurse researcher. A reflective journal allowed the researcher to reflect on cultural differences related to gender, age, income, race and social privilege (Lempert, 2007). The journal did not change the reality of the participant's situation, but it did enable the researcher to remain mindful of these power differences. In the present study, the element of trust was present as all participants signed Informed Consents/Acknowledgement and Releases and questions about the study were explained throughout the research study. It was crucial to establish trust so that the depth and richness of interview data occurred (Nichter, Quintero, Nichter, Mock & Shakib, 2004). Participants felt valued because the researcher was an empathetic listener concentrating on the participant's words and photographs of their experience with chronic pain (Maxwell, 2005). Several participants shared that they were happy to take part in the present study as they felt that 'someone cared'. African American indigent adults' words and pictures provided the findings for the present study.

Cultural safety was a concept used by Ramsden (2002) to describe a circumstance where each encounter in health care had multiple layers of culture, not

limited to those obvious differences of ethnicity or color, but also differences in socioeconomic status, power, resources and knowledge. The researcher included cultural safety in the present study by remaining aware of the influence of historical injustices that have occurred to participants and by promoting trust (Leeman et al., 2002; Boulware et al., 2003; Sutton, Erlen, Glad, & Siminoff, 2003). To promote cultural safety, it is the participants, not researchers, who define feeling safe and therefore have the freedom to participate in the research process. Power is transferred to the participant (Ramsden, 2002). In the present study, participants stated that they felt safe to discuss their experiences with chronic pain and that they experienced empowerment through participating in photovoice. Feelings of safety and transferring power are integral components of cultural safety (Ramsden).

In addition, trust was promoted by having a candid discussion related to participants' potential feelings of mistrust and fear. African Americans felt that having someone take adequate time to listen to their experiences of chronic pain and having the ability to self choose which pictures to photograph, did increase feelings of trust in the present study. Street, O'Malley, Cooper and Haidet (2008) examined whether racial concordance influenced patients' ratings towards the quality of care received in outpatient clinics. In multivariate models, feelings of similarity, trust and satisfaction towards one's health care provider were predicted by the patient's education and age and the patient-centered communication provided by the health care provider. In some racial and gender-concordant dyads, some patients rated themselves as very different from their health care provider. Health care providers who were more supportive and informative regarding treatment and care had patients who were more likely to trust the

health care provider and adhere to prescribed treatment protocols. Health outcomes for these patients were more positive. Conversely, patient outcomes were not related to patients who perceived themselves as being similar to their health care provider in terms of community, race and ethnicity. Thus, health care providers who demonstrated respect for patients, were supportive of patients and used patient-centered communication connected with patients in a trusting relationship that transcended gender and racial concordance (Street et al., 2008).

Saha, Arbelaez and Cooper (2003) examined racial concordance. The researchers found with more than 6,000 Caucasian, Hispanic, Asian and African American participants of which more than 1,000 were African American, that African Americans were least likely to state a preference for having a racially concordant physician. When examining physician behaviors that enhanced the quality of the patient-physician relationship, physicians who listened and provided greater patient participation with decision-making were qualities most relevant for African Americans. Feelings of respect improved the quality of the health care relationship (Saha et al., 2003). Bonds, Foley, Dugan, Hall and Extrom (2004) examined patient's trust with physicians in training found similar results. Most participants were from lower socioeconomic groups and almost half were African American. Bonds et al. (2004) found no association of trust with race and no association with racial concordance between the patient and physician in training. Trust in the medical institution and maintaining therapeutic relationships were found to be strong indicators of promoting patient satisfaction with care and patient trust.



Schnittker and Liang (2006) found that miscommunication lends itself to health care disparities; therefore, improving communication should reduce disparities. More than 3,800 individuals of whom more than 1,100 were African American, shared that the race or ethnicity of their health care provider did not matter to them. In addition, only 18% of African Americans believed that having a racially concordant physician would eliminate racism in the health care encounter, suggesting that variations within racial groups may be as important as variations between groups. Therefore, because the researcher in the present study was not racially concordant, this perhaps only minimally influenced the research findings. The researcher in the present study did have prior experience with this population and was an attentive listener. When participants in the present study were asked if they felt that being interviewed by a Caucasian researcher would influence their responses to interview questions regarding their chronic pain, all participants responded 'no' and appeared shocked to have been asked such a question. All responses given by participants to that question were without hesitation. The participant's non-verbal cues included, them sitting upright in the chair, their eyes immediately widening, and their heads shaking 'no' as they responded to the question. Many of the participants indicated that 'I don't even see your color'. Participants who were chosen to take part in the present study are familiar with being cared for by a mixed gender and racially diverse group of health care providers.

Another benefit of having the researcher in the present study conduct the interviews was that the researcher was female. Prior studies have shown that patients felt more comfortable sharing their health concerns with a female health care provider as patients believed that the female was more likely to pay attention to the patient's

concerns and explain things more clearly (Schnittker & Liang, 2006; Sohler, Fitzpatrick, Lindsay, Anastos & Cunningham, 2007; Weisse et al., 2005). Weisse et al. (2005) found that African Americans reported greater feelings of pain intensity and unpleasantness if the experimenter was female. Racial concordance was less important when examining interpersonal relationships with health care providers (Sohler et al., 2007). Sohler et al. found that trusting one's health care provider was significantly more important than having similar ethnicity for more than 450 low-income human immunodeficiency virus (HIV) adults of which more than 220 were African American. Having a female provider was also related to greater feelings of trust (Sohler et al.).

## **Conclusion**

Focused ethnography was an effective research method when used to examine the experience of chronic pain for African American indigent adults attending an urban primary care clinic. Through photovoice and participants' interviews, greater awareness occurred regarding the disparities of pain management experienced by this population. This enhanced awareness may improve pain management strategies used by health care providers. Health care provided to African American indigent adults may become more cost effective and patient-centered.

As will become clearer in what follows, except for one participant who was in her 20s, participants ranged in age from 40-50 years old. These relatively young participants experienced significant life challenges related to their chronic pain. The next chapter provides findings from the present study. Findings from the present study were descriptive, and chronic pain influenced participants and their experiences with

waiting, coping, challenges, their environments and ability to provide wisdom. The discussion chapter reviews the findings as they relate to the experience of chronic pain for African American indigent adults attending an urban primary care clinic.

## CHAPTER 4

### FINDINGS

#### Descriptive Findings

This chapter will provide the descriptive findings as discussed and photographed by the participants. Participants responded to all interview questions asked of them. There were five main themes that were created inductively from the words and pictures taken by participants. Participants described the experiences and effects of chronic pain in their lives in terms of how they were 'Waiting on Pain', as chronic pain made participants need to wait as they relied on others for help and at other times, participants had to find things to do to pass the time while waiting for their chronic pain to decrease in severity. Participants provided many examples both verbally and through pictures of how they were 'Coping with Chronic Pain' through the items they used, activities they performed and the difficulty for participants when they did not have enough pain medications to last them until they obtained another prescription.

'Challenges with Chronic Pain' was another theme discussed, and how it was difficult for participants to walk and climb stairs and upsetting when others did not believe participants when they discussed their pain. 'Negotiating Pain in a Vulnerable Environment' was described, as many participants described how experiences with poverty, loss and violence influenced their lives and their chronic pain. Yet despite all of these unique and sometimes difficult experiences, participants were 'Sharing Wisdom about Chronic Pain' and freely offered their insights with others experiencing chronic pain and with health care providers caring for patients with chronic pain. Participants'

experiences with chronic pain may be discussed within the themes and sub-themes. Sub-themes identified, were those experiences most meaningful to participants.

Prior to discussing the themes and sub-themes, meaningful information that was captured through the Demographic Data Form and Brief Pain Inventory (Short Form) (Cleeland, 1991) may be described within the Participants' Backgrounds. Throughout the findings, the researcher would like the reader to remain cognizant, that individuals who do not speak 'traditional/conventional English' have much wisdom to share with us. For the purpose of an audit trail, longer quotes will be identified as participant (P), interview (I) and photovoice (PV).

### **Participants' Backgrounds**

Information about the participants' backgrounds may be found within their responses to the Demographic data form and Brief Pain Inventory (Short Form) (Cleeland, 1991). Some of the participants' responses to the questions from the forms are described in the text that follows. Tables have been created to provide detailed presentations of all responses given by participants to the questions asked of them from the forms. The Demographic data form will be described first, followed by the Brief Pain Inventory (Short Form) (Cleeland, 1991).

**Demographic data form.** Thirteen participants took part in the present study (7 men and 6 women). Means will be shown with standard deviations in parentheses. Participants responded to all demographic questions. Ages of the participants ranged from 40-57 years, but one female participant was 22 years of age. Two participants were married and seven participants identified themselves as being single (see Table 1 for a chart with the complete listing of demographic characteristics for the participants).

Highest level of schooling obtained ranged from grade 9 to some university or college education. Ten participants were unemployed and three participants were disabled; overwhelmingly, all participants indicated that their current lack of employment was due to their chronic pain.

Seven participants indicated that they currently lived with someone else; either friends or family members and paid rent, while six participants stated that they lived alone and paid rent for their apartments. Only one participant indicated that she lived in her own home, however she explained during the interview that she was often borrowing large amounts of money to maintain her home. She said that her water and electricity had been shut off several times for lack of payment to the respective companies. The number of years that participants lived with chronic pain averaged 10.46 years (7.32) with a range from 3 years to 25 years and most participants felt their pain came from prior injuries or leg ulcers. Participants had been patients at the clinic ranging from 1 week to 25 years, average was 6.01 years (5.55) and all said that they spoke with their health care providers about their chronic pain at each clinic visit. All participants indicated that while they may not currently attend church on a regular basis, they did have religious beliefs.

**Table 1: Demographic Data Form**

Participant #	#1	#2	#3	#4	#5
Age (years)	56	49	52	54	49
Gender	Male	Female	Male	Female	Female
Marital Status	Divorced	Single	Single	Single	Lives with someone (Single but considered married)
Highest level of Schooling	Graduated high school (HS)	Grade 10	1 year college	General Educational Development (GED)	2 years community college
Current Job Status	Unemployed	Disabled	Unemployed	Unemployed	Unemployed
Job Status due to Pain	Yes	Yes	Yes	Yes	Yes
Living Arrangement	Alone	Alone	Alone	Lives with someone else	Someone else
How many in household	0	0	0	5	2
Who in household	0	Sometimes family in and out	0	Friends	Boyfriend
Live in own home	Yes	Apartment	Rent home	Rent room in home	Yes
Own home	No	No	No	No	Rent
Number of years with chronic pain	3 years	5 years	5 years	3 years	13 years
What causing pain	Old age and not sure	Injuries	Injuries from lifting heavy items in younger years	Not sure – blood clots	Over-weight
How long coming to clinic	3 years	5 years	10 years	5-6 years	10 years
How many visits talk about pain	Every visit	Every visit	Every time	Every visit	Every visit
Religious beliefs	Baptist	Baptist	Catholic	Protestant	Baptist

**Table 1: Demographic Data Form Cont'd**

Participant #	#6	#7	#8	#9	#10
Age (years)	55	22	57	49	40
Gender	Male	Female	Male	Female	Female
Marital Status	Divorced	Engaged	Married	Single	Single
Highest level of Schooling	11 <sup>th</sup> grade	1 year college	9 <sup>th</sup> grade	11 <sup>th</sup> grade	Some University
Current Job Status	Unemployed	Unemployed	Disability	Unemployed	Disability
Job Status due to Pain	Yes	Could be	Yes and due to stress	Yes	Yes
Living Arrangement	Someone else	Someone else	Someone else	Someone else	Alone
How many in household	2	6	2	2	0
Who in household	Mother	Sister, boyfriend and friends	Daughter	Friend	0
Live in own home	Mother's home	Uncle's home	Daughter's home	Rent	Yes
Own home	Rent	No	No	Rent	Yes
Number of years with chronic pain	25 years	6 years	5 years	6 years	11 years
What causing pain	Slipped and fell on back	Stress adding to pain	Leg ulcers	Generative arthritis & cervical & spine pain	Fall caused injuries and bilateral carpal tunnel syndrome
How long coming to clinic	3-4 years	1 week	6 months	4-5 years	9 years
How many visits talk about pain	Every time	Every time	Every visit	Every visit	Every visit
Religious beliefs	Protestant	Christian	Baptist	Non-denominational	Christian/non-denominational



**Table 1: Demographic Data Form Cont'd**

Participant #	#11	#12	#13
Age (years)	57	52	56
Gender	Male	Male	Male
Marital Status	Single	Single	Widowed
Highest level of Schooling	Grade 12	Graduated HS	1 year college
Current Job Status	Unemployed	Unemployed	Disability
Job Status due to Pain	Yes	Yes	Because of injury
Living Arrangements	Alone	Lives with someone else	Alone
How many in household	0	2	0
Who in household	0	Cousin	0
Live in own home	Apartment	No	Apartment
Own home	No	Cousin's home	Senior citizen apartment
Number of years with chronic pain	15 years	20 years	19 years
What causing pain	Ulcers on legs and back problems	Leg ulcers	Spine injury due to assault & chronic back pain
How long coming to clinic	4 years	2 years	21 years
How many visits talk about pain	Seldom	Every visit	A few visits
Religious beliefs	Protestant	Christian	Church of Christ

**Brief Pain Inventory (Short Form).** Participants responded to all questions in the Brief Pain Inventory (Short Form) (Cleeland, 1991). Means are shown with standard deviations in parentheses. Participants drew the location of their chronic pain on a body drawing and showed that there were multiple locations on the body where they experienced chronic pain (see Table 2 for a chart with the complete list of findings from the Brief Pain Inventory Short Form). Participants experienced pain in 3-9 different places on the body with the back, sacral, hips and leg areas being the most common locations for their chronic pain. When asked to rate their chronic pain at its worst in the last 24-hours, chronic pain was rated at its worst by participants as being an average of 9.31 (0.75) *on a scale of 0-10, where 0 was no pain and 10 would be the worst pain they could imagine*. The least amount of pain experienced by participants in the last 24 hours ranged from a score of 2 to a score of 8, with an average least pain score of 5.31 (1.93) *(on a scale of 0-10, where 0 was no pain and 10 would be the worst pain they could imagine)*. The average pain score rating given by participants was 7.38 (2.07).

When asked to rate their pain at the time of the interview, pain scores ranged from 2-9, but all participants said they wanted to continue with the research study. Often during the study, participants would stop the interview to take pain medication. While 100% of participants were taking prescription medication for pain, the mean relief was 53.08% (22.87) from their current pain medication. Eight of the 13 participants or 61.53%, in the present study were prescribed opioids for their chronic pain. These opioids included hydrocodone 7.5mg and acetaminophen 750mg ('Vicodin ES') or hydrocodone 7.5mg and acetaminophen 750mg and ibuprofen ('Vicodin ES') and ('Motrin'), with one participant receiving hydrocodone 7.5mg and acetaminophen 750mg

('Vicoden ES') and acetaminophen 300mg and codeine 60mg ('Tylenol #4') for his chronic pain. Four participants (31%) were prescribed nonopioids including, ibuprofen ('Motrin') 800mg and one participant was prescribed celecoxib ('Celebrex').

Pain affected participants' general activity in the last 24-hours an average score of 7.23 out of 10 (2.77) and pain affected their mood an average of 8.17 (1.64) (*on a scale of 0-10, where a score of 0 indicated that pain did not interfere with that particular activity in the past 24-hours and a score of 10 indicated that that pain completely interfered with that particular activity*). Participants verbally stated when responding that the score they were providing was for most days in their lives, not only a score for the previous 24-hours. One male participant was not included in the mood score as he indicated that he tries to block out the pain and when he is unsuccessful, he could not rate the pain on a scale as it is "too much to even try" to describe. (P-12, I-1)

Pain was rated by participants as affecting their ability to walk an average of 8.38 (1.33) and their ability to complete work both inside and outside of the home an average score of 7.62 (2.1). Interference from chronic pain was rated an average of 7.83 (1.27) for its affect on relationships with others and again, the same male participant said that he could not score this category as he tries to block out the pain so that chronic pain did not affect his mood or relationships with others. Again, if he was unsuccessful blocking out the pain, he stated that he could not assign a number to his pain as it would be 'indescribable'. Chronic pain affected participants' abilities to sleep an average score of 8.08 (2.18) and pain affected their enjoyment with life an average of 8.21 (1.62). Once again, the same male participant as described above for the reasons listed above could not rate his pain in the enjoyment with life category.

**Table 2: Brief Pain Inventory (Short Form)**

Participant #	#1	#2	#3
Where on body pain	Both knees & both hands & lower back/sacral area	Entire right arm & right shoulder radiating up to right neck & left middle back & entire backs of both legs & front of right leg from foot to knee	Entire right arm & entire left leg
Pain number at worst ( <i>scale 0-10</i> )	10	9	9
Pain number at least	7	5	5
Pain number on average	7-10	9	5-9
Pain number now	9	9	6
Meds currently taking for pain	"Celebrex & Tylenol plain"	"Vicodin ES"	"Vicodin & Motrin"
How much pain relieved by meds (percentage)	10%	80%	50%
Pain affects general activity – number	10	1	7
Pain affects mood – number	6	9	7
Pain affects walking – number	9	8	7
Pain affects normal work – number	9	8	7
Pain affects relationships with others – number	6	8	7
Pain affects sleep - number	10	9	7
Pain affects enjoyment with life – number	10	9	7

**Table 2: Brief Pain Inventory (Short Form) Cont'd**

Participant #	#4	#5	#6
Where on body pain	Chest & Middle of back & entire both legs & right groin	Both entire legs & lower back/sacral area & entire back & both hips & both entire legs & esp. behind left knee	Left hand & entire left hip area & back of right hip
Pain number at worst ( <i>scale 0-10</i> )	8	10	9
Pain number at least	3	7	6
Pain number on average	8	10	6-9
Pain number now	6	7	7
Meds currently taking for pain	"Vicodin & Heating pad"	"Vicodin 750mg & Motrin 800mg & Lidocaine ointment & Tylenol #4"	"Vicodin 750mg & back brace"
How much pain relieved by meds (percentage)	30%	50%	60%
Pain affects general activity – number	8	10	4
Pain affects mood – number	9	9	0 (pt states he blocks it out)
Pain affects walking – number	9	10	7
Pain affects normal work – number	9	9	4
Pain affects relationships with others – number	9	9	0 (block it out)
Pain affects sleep - number	9	6-8	6
Pain affects enjoyment with life – number	9	9	0 (block it out)

**Table 2: Brief Pain Inventory (Short Form) Cont'd**

Participant #	#7	#8	#9
Where on body pain	Lower back/sacral area & entire pelvic area & entire groin area	Front of left leg from toes of left foot to knee & middle of back/sacral area	Both entire arms, both buttocks & both sides of groin & both hands & both shoulders & both knees
Pain number at worst ( <i>scale 0-10</i> )	10	8	9
Pain number at least	3	2	8
Pain number on average	8	2	8
Pain number now	4	2	9
Meds currently taking for pain	"Tylenol PM & Motrin & Advil"	"Motrin & Unna boot"	"Motrin 800mg & Tylenol ES & Bayer rub/BenGay"
How much pain relieved by meds (percentage)	40%	90%	30%
Pain affects general activity – number	10	4	8
Pain affects mood – number	10	9	6
Pain affects walking – number	10	7	10
Pain affects normal work – number	10	3	8
Pain affects relationships with others – number	8	9	7
Pain affects sleep - number	10	3	10
Pain affects enjoyment with life – number	10	2-9	7

**Table 2: Brief Pain Inventory (Short Form) Cont'd**

Participant #	#10	#11	#12	#13
Where on body pain	Both entire legs & both hands & both wrists & entire lower back/sacral area & spine up to middle of back & entire top of head & back of neck and entire back of shoulder blades	Lower Back/sacral area & entire left leg	Both entire calves of both legs & both feet & right hip	Both elbows & both hands & entire lower back/sacral area and both feet and both lower calves
Pain number at worst ( <i>scale 0-10</i> )	10	9	10	10
Pain number at least	8	6	5	4
Pain number on average	8	6	8-10	5
Pain number now	9-10	6	8	5
Meds currently taking for pain	"Vicodin ES"	"Motrin & Unna boot"	"Vicodin 750mg"	"Vicodin & Tylenol #4 & Motrin"
How much pain relieved by meds (percentage)	80%	50%	70%	50%
Pain affects general activity – number	10	7	7	8
Pain affects mood – number	10	7	6	10
Pain affects walking – number	10	7	7	8
Pain affects normal work – number	10	7	7	8
Pain affects relationships with others – number	10	7	6	8
Pain affects sleep - number	10	6	8	10
Pain affects enjoyment with life – number	10	6	9	7

### **Waiting on Pain – “Ain’t gonna never stop.” (P-6, I-1)**

Participants described their experiences with chronic pain. Their descriptions depicted a sense of needing to wait on their chronic pain. Waiting on their chronic pain included the duration of their pain and waiting for pain medications to take effect. Waiting also included activities they completed to help them pass the time while they waited for their pain to reduce in intensity and the need to wait for others to assist them with their daily needs. Chronic pain influenced participants’ abilities to achieve future goals they had set for themselves. The influence of waiting on chronic pain may be found in the examples provided by participants’ interviews and photovoice pictures.

**Duration of pain in their lives and effect on waiting.** All participants said that their chronic pain had been a part of their lives for “far too long.” Participants discussed the duration of chronic pain in their lives and how they needed to wait for their pain to reduce in intensity before they could take part in daily activities. Participants provided examples of the duration of chronic pain in their lives. Chronic pain was said to continue throughout the day with little variation in terms of the intensity of their pain. The pain was described as lasting “all day, every day.” (P-9, I-1) Other participants found their pain incessant, “‘cause it looked like this pain’s ain’t gonna never stop” (P-6, I-1) and “I’m in pain 24 hours a day”. (P-9, I-1) One participant said, “I was bed ridden for two or three days. Couldn’t get up just pain, pain, pain, constant pain.” (P-7, I-1) Particularly if they were waiting for their pain to ease in intensity, the time seemed to slow down “and you’re still in pain just sittin’ and waitin’...like time stops...it takes forever.” (P-1, I-1) Another female participant discussed her chronic pain and the experience of time in the following way,



It feels like time just completely stops and I'm constantly lookin' at the clock and I'm like I'm still in this pain are you serious? Can it just go away and I do this and I do that and that's when it becomes worse because I'm constantly looking at the clock. I'm thinking about the things that I need to be doing and I can't do it because I'm in this pain and if I look at the clock again and only two, three minutes and it just gets crazy. I hate it. It's like time just stand still sitting there and in just in pain and that's the only thing you can think about is the pain and how long it's going to be here. (P-7, I-1)

One male participant shared,

And it affect every minute of every hour of my day. Sometimes it's worse, better. Sometimes it's worser than it is. Sometimes I actually have a good day once or twice a month and most of the days be bad days but you learn to live with it 'cause if you don't you just give up. (P-12, I-2)

He added, "Like I say two or three days out the month I actually do have good days, very few, but I see 'em." (P-12, I-1) All participants have noticed that the pain has increased as they have aged. Participants said that pain consumed most of their day and influenced many of the activities they needed to complete each day. Considering how long to wait to take their pain medication also influenced their ability to complete activities.

**Chronic pain and waiting to take pain medication.** Participants described when they needed to take their pain medication. Participants said that because of the intensity of their pain, it was difficult for them to wait to take their pain medication as it had been prescribed. One of the participants said that when they were in pain they did not wait to take their pain medication, when they were experiencing pain "I don't wait. When I'm in pain I take the pill." (P-1, I-1) Most of the participants said that they took their pain medication before their pain became too intense, even if it meant taking the medication sooner than the frequency the medication was prescribed. All of the participants shared that their pain returned with intensity, before a subsequent does of

pain medication could be taken. One male participant described how often he took his pain medication “I take every six hours, my pain is back in four, that ain’t doin’ it.” (P-3, I-2) Most participants stated that they took pain medication “around the clock.”

One participant shared that she wanted to take the medication “back to back to back.” (P-7, I-2) Another female participant said that she waits to take her medication for pain “till I can’t stand it [the pain] anymore.” (P-10, I-2) Living with constant chronic pain, the medication only “calms it down a little bit” (P-1, I-1), but the medication did not ever take the pain completely away. When describing how quickly her pain medication worked to reduce her pain, a female participant explained,

It seem like it takes forever. It’s oh God it’s an irritatin’ feeling, you know, it seem like time just dragged, it just like are these pills ever going to work? How long is it going to take? God I just took it two minutes ago. God I just took it four minutes ago, you know. (P-4, I-3)

Participants said that they knew that leaving their apartment to go shopping, playing with grandchildren or visiting with others may exacerbate their chronic pain. To ensure they were able to complete the activity required of them, participants said they would medicate themselves with pain pills prior to completing that activity. A male participant said that he would take a pain pill and then he would be “doin’ too much” as he would be “walkin’, jumpin’, playin’ with the grandkids too much. And the next day I know my leg done swollen up.” (P-8, I-1) Another person said that she was getting “tired of takin’ all that pain medication” (P-5, I-1), but if she did not take her pain medication prior to an activity, she knew she would not be able to complete that activity. When she had to go outside of her apartment she said she had to “dope myself up to be able to get around.” She further stated that if she waited to take her medication she would not be able to “go nowhere. You know, church, anything, family affairs, anything,

grocery store, shoppin' at the mall, anything.” (P-5, I-1)

One of the participants compared herself to a car and indicated that just like you need “gasoline to drive your car to get around” the pain pills were analogous to a car because “You have to have those pills to kinda make you be able to get where you need to go.” (P-9, I-3) She said that she was limited in her ability to move around her apartment until she took her pain medications and waited for them to begin to reduce the intensity of her pain. Participants have said that they do not like others to see them when they are in pain so prior to others visiting with them or performing certain activities, the participants said that they took their pain medication.

All participants stated that it was difficult to wait for their pain medications to begin to take effect and they wanted their pain medication to “kick in quick.” (P-9, I-1) Participants shared that they needed to monitor the number of pills they took for pain each day so they did not run out of pain medication by the end of the month. They also had to think of other activities to complete while waiting for their pain medications to reduce the intensity of their pain.

**Activities to ‘pass the time’ while experiencing pain.** Participants tried to make the time pass more quickly while they waited for their pain medications to take effect. They described some of the activities they performed to help pass the time while they waited in pain for the intensity of their pain to reduce. Waiting for their pain medications to reduce the intensity of their pain was difficult. Participants stated that they tried to do things to take their mind off of the pain. Some participants watched television or a ‘movie’ or worked on a puzzle, others who lived without air conditioning laid on a mattress under their fans. One 22-year old participant said that when she was

experiencing extreme pain, it was difficult for her to wait for her pain to reduce. When she experienced intense pain, she would lie down on the mattress on the floor of her basement apartment. Her pain was so intense she said she was not able to move around. She took a picture of what she viewed when she was in pain and not able to move from her mattress on the floor of her basement apartment. She said that the view while waiting made her feel 'depressed'. (P-7, I-2) (see Figure 1)

Figure 1. **Waiting on pain - View when looking at ceiling**



“Um this is what I see when I lay on my back. Very boring. Very dismal scene. I try not to lay on my back because it depresses me. There’s nothing there but white, and the poles and light.” (P-7, I-2, PV-1)

Participants would pass the time by performing “meditation exercises” and using “the computer...when my fingers are not acting up on me.” (P-9, I-3) A male participant said it took him longer to accomplish things each day as he needed to wait and try to focus on something else or “take something and relax” while he waited for the pain to reduce enough so he could continue to focus on the task at hand.

There were some days that participants did not leave their homes because of chronic pain. Instead, participants would spend the day lying down or sitting “in one

chair at home all day” (P-2, I-2) waiting for their pain to reduce in intensity. During a separate interview, one female participant described that when she was not able to leave her apartment due to pain, that one of the windows looking out of her apartment became her “front porch.” Similar to sitting outside on a front porch and passing the time by watching the people and traffic pass by, the participant said she would look out of the apartment window at the street and scenery below. (P-2, I-3) (see Figure 2)

Figure 2. **Waiting on pain – Her front porch**



“My street I live on goes this way, this is the other street. This is from the living room and this is from the kitchen window. And of course I had just stacked my dish towels and I just throw them up there over there.” (P-2, I-3, PV-2)

Participants described where they liked to be when they were waiting on their chronic pain to reduce in severity.

**Comfortable place – while waiting for pain.** Participants described areas in their apartments where they liked to be when they were waiting for the severity of their chronic pain to reduce. These areas in their apartments helped participants to relax while they experienced chronic pain. Participants said that by utilizing items such as pillows, chairs and a couch, they were able to create a space that allowed them to relax.

One participant took a picture of a bed and pillows he used when experiencing pain to help him relax and reduce his pain. (P-8, I-2) (see Figure 3)

Figure 3. **Waiting on pain – Comfortable place**



“When it’s not hurtin’, I use em for my head. You know but when my leg starts hurtin’ I take one pillow away and use one for my head and leave one down there to prop my leg up on.” (P-8, I-2, PV-1)

Another participant described where he liked to be when he was experiencing chronic pain (see Figure 4). He explained that the picture was of his living room and when his pain was intense he liked to lie on the couch and watch television or watch a movie. At other times, he liked to listen to music to try and help take his mind “off the pain.” (P-3, I-3) He said he kept plants in his living room, a fan and some pictures of family and these items helped provide him with comfort and ‘scenery’ that helped him to relax.

Figure 4. **Waiting on pain - 'Nice scenery'**



“All with the comfortableness that’s the main thing. Yeah I try to keep some, you know some scenery, nice scenery around.” (P-3, I-3, PV-2)

Other participants discussed their favorite place to be when they were experiencing severe chronic pain. Participants said that they liked to “take their medicine and lay down”, or “be quiet, to myself” (P-2, I-1) or “in bed or sittin’ down in a chair.” Another participant said that when he was waiting on his chronic pain “I got a chair, I got a recliner, you know everything right there.” (P-3, I-1)

One participant took a picture of a chair that is heavy and difficult for her to lift due to the pain in her hands. She purchased the chair at a “resale shop” and uses it throughout her home. She described that she does not have a lot of furniture, but by moving the chair around her apartment, she was able to do other things in her home while she was waiting on her pain to reduce in intensity. Once she moved the chair to where it needed to be, the chair was sturdy and it allowed her to sit in different areas of her apartment more comfortably. She was able to move around her apartment and control her wait, depending on wherever she placed her chair. (P-9, I-3) (see Figure 5)

Figure 5. **Waiting on pain – Supportive chairs**



“And this is my chair. Yeah. It’s not a lot of support but it helps right now. You know before I could get a better one. I had it at a resale shop. This is where I sit when I’m eating. When I’m watchin’ t.v.; if I feel like gettin’ on the computer, where I sit and go on the computer. That’s the same chair. [It’s heavy] Yeah so I try to move it less as possible.” (P-9, I-3, PV-2)

One participant described another helpful space she liked to be when experiencing chronic pain and waiting on her pain to reduce in intensity. She shared that eating certain snacks or sitting in a specific chair on the front porch of her building was relaxing for her. When she was experiencing severe pain, she would eat a Snickers chocolate bar and talk to people while she sat in her favorite chair outside on the porch. (P-4, I-2) (see Figure 6)



Figure 6. **Waiting on pain – Comfort food**



“This is my candy bar. This is what I eat for pain. Chocolate, Snickers. It helps, believe it or not that Snickers chocolate helps. This is what I eat that’s why I took a picture. It relaxes me, I don’t know why but it does and this is my chair.” (P-4, I-2, PV-1)

Participants discussed that they were never free from pain, but there were certain times of the day that it was easier for them to complete activities.

**Waiting for time of day that is best for activities.** Participants shared how certain times of the day were best for them to complete activities. They said it was difficult to wait for their pain to subside before they could move about. For most participants, mornings were the most painful times of the day. One participant wished he had an intravenous (‘IV’) in his arm so that he would not need to move about to fix himself something to eat “‘cause I wake up every morning in this pain and I be like I wish I had a bag in my arm with some of that food like somebody in the hospital.” (P-3, I-1)

In the morning, participants stated that they moved slower as they waited for their pain medication to begin to take effect; “it’s a handicap.” (P-9, I-3) One female participant shared, “It’s like I have to take my medication to get started you know like a

car needs gas to get going.” (P-9, I-2) One participant said, “I woke up one morning and I could hardly walk. I couldn’t get out of bed...I stepped down and I couldn’t walk, my whole leg was paining...I hopped to the chair up from the recliner.” (P-3, I-1) He said he did not know what had caused this sudden pain or change in his ability to walk, but he had to wait until the end of the day before he could walk. Another participant said that in order to arrive at appointments on time, he needed to leave approximately two hours earlier. (P-1, I-3) (see Figure 7) He said he had to wait for his medications to begin to reduce the intensity of his pain and it took approximately two hours for him to get organized to attend appointments.

Figure 7. **Waiting on pain - Time needed to arrive on time for appointments**



“Yeah. To get there on time or before time, I have to leave about 2 hours early.” (P-1, I-3, PV-2)

Chronic pain affected participants most in the morning, so many of the participants said that they preferred a mid-morning health care appointment. A mid-

morning appointment would allow them the minimal two hours needed for them to prepare for the appointment in terms of mobilizing themselves while in extreme pain, eating breakfast and waiting for the medications to begin to take the edge off of their pain. Once the intensity of the pain had somewhat eased, the participants shared that they could then begin to dress themselves and leave their homes for the appointment. Many participants had to walk to a bus stop and wait for the bus, so this time needed to be factored into their planning too.

A male participant shared that he “does have to work around my [his] pain” (P-11, I-2) and another said that he prefers morning appointments as “no matter how hard it is”, he felt that if he waited all day “I [he] might not make it.” (P-13, I-2) For participants experiencing chronic pain, each morning was unknown in terms of how they would be feeling with their chronic pain. One participant shared that one morning he had an appointment but he was not able to go to it as he woke up in severe pain. It was frustrating for participants if they woke up late and needed to begin to get ready for their day before they had waited for their pain medication to begin to reduce the intensity of their pain.

Another challenge occurred when planning an outing, as participants would need to factor into their outings, the ‘break time periods’ necessary to rest during walks in order to complete the outing. A “five minute walk” would take one participant “about half an hour or 45 minutes” (P-1, I-3) to complete. The time it took them to climb up or down steps when leaving their home was a factor that participants needed to consider too when planning their day. One participant when describing the details about chronic

pain's influence on his life said, "I'm dealin' with this every day, on a daily basis you know." (P-7, I-1)

Chronic pain affected participants' abilities to move about quickly and without assistance. They found it frustrating that they had to wait for their pain to be less intense. Participants said they would need to slow their pace and only complete a certain number of activities each day to prevent themselves from suffering with excruciating pain. A male participant said that the pain "slows you down...especially when you wake up." (P-3, I-3) One participant shared that her pain "slows you down, so that means it's like you have to adjust your mind to it too. Yeah, that's why I said it affects you mentally too." (P-9, I-1) Another participant said that at times the pain was so intense that "It's to the point where I can't do anything other than lay around and cry." (P-7, I-2)

Participants shared that they were now walking at a pace that was much slower. They said that if they needed to walk quicker, they would try to hold onto and support whichever limb was causing them pain and they would need assistance to move more quickly. One female participant shared that she would need to hold onto the "bottom of her stomach" and she would move,

...at a snail's pace...if I have to speed up for some unforeseen reason I would need assistance, like my sister would grab my arm...try and rush me on...but my steps are kind of short and choppy-like, not like I would usually walk. (P-7, I-1)

Many of the participants used bus transportation. Participants would need to consider the time it would take them to travel by bus when following up with health care appointments. Participants did not want to take the bus when the students were

travelling to or from school as the students were usually “clownin’ at the bus stop” and would not offer their seat to the participants. (P-1, I-3) (see Figure 8)

Figure 8. **Waiting on pain - Time of day**



“Well I try not to go out when the kids are gettin’ out of school ‘cause it be crowd then. So I try to go out like I said in morning, it’s not crowded outside. And when I’m sore, I can sit down.” (P-1, I-3, PV-2)

They not only needed to be aware of how long it may take them to walk to the bus stop, but also the time added to their wait if they had missed the bus. One participant described how he could no longer run to “catch the bus, just better sit down and wait for the next one to come” (P-1, I-2) if he missed the bus. Participants expressed frustration if they had to wait for another bus.

There were times when the side effects of their medications would influence participants’ ability to control time, as the side effects would make participants wait. One female participant shared that the medication made her feel ‘sleepy’ especially for approximately 30 minutes after taking the medication. She would tell her family members to give her “30 minutes I be all right.” (P-5, I-1) So before planning her day, she had to consider the effects of her medications on her activities planned for that day

and how long after taking her medication she would need to wait before she could participate. Participants also needed to consider the time it would take for others to help them. While they were previously independent with activities, they now had to wait for others to help them.

**Time spent waiting on others for help.** Participants shared that they did not like depending on others for help. If participants were completing a task, they would finish the task quickly, but when waiting on another person to help; they often needed to wait lengthy periods of time. As one female participant shared, “there a lot of people don’t want to take time with you.” (P-5, I-1) She said that because of pain she had to wait for people to help her. She would ask a person who lives in her apartment building for assistance and they would say,

I’ll be there in a few minutes. Sometimes a few minutes turns into thirty minutes. That can be aggravating, because I’m waitin’ and I want to get this done and over with. But I have learned to wait and have the patience because I need people to help me. (P-2, I-2)

Participants still tried to be independent and even though they experienced chronic pain, they tried not to rely on others for their needs. One participant shared, “I don’t want to seem like I’m bein’ a pest...I don’t want to get on nobody’s nerves.” (P-2, I-1) She felt that people would help her more quickly if she had the financial resources to pay them for their help.

Another participant said that he often had to wait for family members to drive him to appointments and to the store. He said that often he would wait all day and if the family member was late arriving or if they “don’t show up, you get frustrated.” (P-1, I-2)

If the participant was waiting for a friend or family member to drive them to an appointment or for the person to help them out with other tasks “waiting on them to do something” could become ‘depressing.’ (P-1, I-2)

A female participant said that sometimes she had to “sit in the car” and wait for someone else to complete grocery shopping for her. (P-2, I-1) She shared that this was difficult as she used to enjoy shopping, but now due to pain, the pain made it difficult for her to travel around the store. Another challenge was that the participant needed to be careful with her money and remain mindful of how much she spent on the items she purchased. She said that she missed being able to complete her grocery shopping on her own, as she could evaluate the items she was buying and find the best prices. She said that if she gave a family member “ten dollars ...to buy a pack of chicken wings” the person shopping for her would not look at the best price and would just purchase the item regardless of the cost. She said that she used to take the time and search through grocery items to find a “two dollar” pack of chicken wings because she needed “that other eight dollars.” (P-2, I-1)

Many of the participants lived in apartment buildings and often relied on the elevator to be operating for them to be able to leave their apartment and reach the ground floor. Participants shared that there were times when the main elevator would not be operational and they would need to wait for the manager to operate the freight elevator. One participant said that there were only certain hours each day when the ‘owners’ would operate the freight elevator for tenants in the building “They’ll run it like they want to run it.” (P-2, I-2) (see Figure 9) If she wanted to leave her apartment earlier or if she returned home later than the times designated for the freight elevator to

run she would need to climb the stairs to her apartment.

Figure 9. **Waiting on pain - Working elevators**



“Now this here is the elevator that they just fixed. This is the one that was down for three weeks. They just fixed it. We have to have elevators, I’m on the 8<sup>th</sup> floor.” (P-2, I-3, PV-2)

Participants expressed how frustrating it was to have to plan their activities around the times when the freight elevator would be in use. It was also frustrating that chronic pain influenced all of their current activities and that pain would be part of their futures. They expressed their frustration knowing that chronic pain was preventing the accomplishment of future goals.

**Future goals influenced by chronic pain.** Some participants expressed their thoughts about their futures with chronic pain. Participants expressed frustration that pain influenced not only their ability to complete current activities, but it would influence the accomplishment of future goals. Many expressed feelings of having their lives ‘put



on hold' due to chronic pain. One female participant said that her chronic pain was preventing her from accomplishing her future goals, saying, "I'm young. I want to go, I want to go back to college. I want to open my own daycare center and these are things that I feel like right now I can't accomplish because of the pain." (P-7, I-1) Another participant said she wanted to "get my GED...and then from there I wanted to go off and take some college courses." (P-9, I-2) She was doubtful that this would be possible because of her chronic pain.

Participants knew their futures would always have chronic pain "I'm going to have to deal with this the rest of my life." (P-13, I-1) Chronic pain did influence their ability to plan their day and plan for the future. Another participant said that even though he had been through a drug dependency clinic and had not used illicit drugs for several years, by having a history of illicit drug use and chronic pain "you be old before your time." (P-12, I-1) Chronic pain affected participants' feelings about themselves and their chronological ages. Their chronic pain made them feel "much older than your age." One participant explained, "I'm a young woman...but my body feels like I'm, I'm old." (P-2, I-1) It was frustrating for participants as they stated that they were "supposed to be in my prime" (P-1, I-1) and they were not able to achieve all they had hoped to accomplish.

Except for one participant who was 22 years of age, all participants were currently in their fifth and sixth decades of life. They discussed they felt much older than their stated age. Participants' faces appeared tired and stressed, and with their physical limp, use of a cane or limited range-of-motion for some extremities, participants did appear to look older than their stated age.

Chronic pain influenced participants' daily activities as 'waiting' was a large part of their lives. Pain had been part of participants' lives for quite some time and influenced when participants could complete certain activities each day. Waiting for pain medication to reduce the intensity of their pain and waiting for others to help was said to be frustrating. Participants knew that chronic pain would always be part of their future and they discussed how pain influenced the accomplishment of future goals. Participants described the ways they needed to cope with their chronic pain. The ability to cope with pain was influenced by several factors which shall be described in the pages that follow.

**Coping with Chronic Pain – “I don't want to be high, I just want to be pain free.”  
(P-5, I-1)**

Participants described how they tried to cope with their chronic pain. Participants discussed the items they used or behaviors they completed to try to cope with chronic pain. Pain medication was important to help them cope with pain and coping was especially difficult during times when they did not have enough pain medication to last them until they obtained a new prescription from their health care providers. Participants described how coping was difficult when their health care providers were concerned about their previous histories of illicit drug usage and did not provide them with opioids for their pain. Chronic pain influenced participants' emotions and their feelings of control over their pain. People who were supportive toward participants helped participants cope. Participants shared that because chronic pain was so pervasive; it was sometimes difficult for them to cope with the pain. Participants discussed the items they used to help them cope with their chronic pain.

**Chronic pain and coping – items that help.** Participants described the items they used to help them cope with their chronic pain. Coping with chronic pain was difficult, as chronic pain influenced every aspect of participants' lives. Chronic pain was said to be 'constant', "everyday life", "it affects every area of my life." (P-11, I-1) One participant added that the pain feels "like something's just weighing down on me" and "It gets hard and dealing with it is a very, very, very difficult challenge. I wouldn't wish this on my worst enemy at all. It's the pain where it's unbearable." (P-7, I-1)

Participants discussed items they found useful to help them cope with their chronic pain. Participants used a 'cane', 'walker', 'knee brace', "back brace", "extra pillows" and they tried 'rubbing' the affected area of the body causing pain. Other items that were said to be helpful for individuals living with chronic pain were "pill bottles, the push top" (P-10, I-2), 'electric toothbrush', 'dishwasher', 'grab bars', and 'railings' on staircases to provide support when climbing stairs. Additional items that were helpful with mobility were, having a "house on one floor", 'support stockings', 'sleep', "shoes...with a grip on them" (P-10, I-2) and bath stools.' (see Figure 10)

Figure 10. **Coping with chronic pain – Items that help, bath stool**



“The stool that I use. I use this stool for 2 purposes. When I’m taking a shower. I use it to so I can, I feel safe using it where I don’t be slippin’ and slidin’ in the tub. And the second use that I use this for is to put my legs up on. To elevate my legs. Yes. I have a pillow that I you know I puts on it and that elevates it and that helps alleviate the pain.” (P-11, I-2, PV-1)

One participant said she was going to ask her health care provider for a “seat to sit in the bathtub...then I could do it [bathe] basically by myself without anybody bein’ there with me.” (P-2, I-1) Participants described that by placing shampoo into bottles with a pump, it was easier for participants to obtain shampoo from the bottle. This was particularly helpful, as they did not need to squeeze the bottle to obtain shampoo when their hands were hurting.

One participant described the items she used to help her cope with her pain. She said that when she was experiencing pain, she would lie on her mattress, watching television (t.v.) while her oscillating fan blew cool air towards her. She said that the t.v. and fan were her comfort tools and provided her with some distraction from her chronic pain. (P-7, I-2) (see Figure 11)

Figure 11. Coping with chronic pain – Two comfort tools



“Both the t.v. and the fan, my two comfort tools. ‘Cause if I didn’t have a t.v. or my fan I think I’d go crazy.” (P-7, I-2, PV-1)

Participants discussed the items they used to try to lessen their pain or distract them from their pain. Participants shared that they had tried ‘ice packs’, “hot water bottle” (P-4, I-1) and ointments such as ‘icy hot’ but these items were not effective to reduce their pain. Participants said they did find some relief from pain when they were ‘asleep’. Another participant said she just wanted to “live and be pain free sometimes.” (P-2, I-3)

Participants described how transportation influenced their experiences with chronic pain. If participants were able to obtain transportation from family members or friends to ride in their vehicles, they shared that small vehicles were the most difficult for them and their pain. One participant explained the reason that small cars were the worst for her pain “‘cause you all crushed up and...have to sit in the back seat.” (P-4, I-

3) Another challenge was that it may be difficult for individuals to physically elevate their legs high enough to enter into a vehicle and they might require help from others to “lift them [their legs] up.” (P- 13, I-2)

One participant described the process he needed to consider when climbing in and out of vehicles. He said that he preferred to travel with someone who had a pick-up truck. He said that if a vehicle, such as a pick-up truck had running boards; these were helpful as he would not need to climb up so high to get into someone’s vehicle. (P-13, I-2) (see Figure 12)

Figure 12. **Coping with chronic pain - Running boards on truck**



“The next picture is his truck. Now that’s very helpful this running board when I get into his truck. It’s very helpful ‘cause a lot of trucks don’t have these. So if I got to get up there [without one] and that’s kind of painful.” (P-13, I-2, PV-1)

The participant said that while he was thankful for the transportation offered by others, at times their vehicles were painful to climb in and out of and he felt as though he was twisting and straining his muscles. Climbing in and out of vehicles may exacerbate his chronic pain.

The 'Metro' transportation van (P-9, I-2) provided by the hospital medical center the primary care clinic was affiliated with, was helpful for participants, as it drove them to each medical building. The van picked patients up and dropped them off free-of-charge to other medical buildings. Another person said that because her legs were "constantly throbbin'" she relied on the transportation services provided by the clinic to help her reach her health care appointment. The services allowed her to get to her clinic appointment, as a person from transportation would take her from the front lobby up to the clinic in a wheel chair. When her appointment was finished, the transportation person would take her down to the front lobby again by wheel chair. (P-5, I-1)

Other items that helped with mobility were the 'handicap' parking spots, as participants would not need to walk as far when in pain. Participants said it was frustrating when these spots were already taken by another vehicle. One participant shared how her 'handicap' parking sticker was helpful as was the rosary attached to her rear view mirror as she would rely on faith to sometimes help her find a closer parking spot. (P-10, I-2) (see Figure 13)

Figure 13. Coping with chronic pain – Sticker for parking



“O.k. this may be more religious, spiritual, but also this sticker allows you to choose to park closer, yes. Especially, God forbid, in the winter....” (P-10, I-2, PV-1)

Some participants described how their canes provided them with balance for mobility. The improved mobility helped them cope with their chronic pain. One participant said at first she was embarrassed to be walking with a cane but now she has come to rely on her cane for assistance. She said there are times when she wonders if she could walk without it, as she thinks that perhaps her cane “was a crutch” (P-5, I-1) but she continues to use the cane for walking. A female participant took a picture of her cane and called it her ‘buddy’. (P-9, I-2) (see Figure 14) Another participant shared how when she was staying at the shelter, a ‘lady’ at the shelter “she gave me a cane and I never let go of it.”



Figure 14. Coping with chronic pain – Cane, “my buddy”



“Oh that’s my buddy. Yeah, he support me. That’s my cane, he supports me. ‘Cause first I was embarrassed to have it you know. And then seem like I seen more since I have my cane. I seen so many people, more people with the cane this year than I ever seen in my life.” (P-9, I-2, PV-1)

Some participants did not find their canes to be helpful, particularly if the canes were too heavy for them to carry. One participant described that while his four-prong cane did make him feel more balanced on his feet than did his single-prong cane, he did not use his four-prong cane as it was too heavy for him to carry when he went out of his apartment. (P-13, I-2) Participants discussed the activities they performed that helped them cope with their chronic pain.

**Chronic pain and coping – activities that help.** Participants described activities they performed to help them cope with their pain. These activities helped them to “forget about the pain” for a while. Participants discussed how using hot water

or a heating pad would soothe the pain for a short time, but once they were finished with the hot shower or turned off the heating pad, the pain returned. Participants said that they would “get in that hot water” (P-9, I-2) and soak in the bath tub to help them cope with their pain. (see Figure 15)

Figure 15. **Coping with chronic pain - Soaking in bath water**



“This is my bath water I was runnin’. I haven’t completely ran it yet. But this when I soak too. Sometimes I soak in Epson salt. I meant to mention that. Yeah, I soaks in Epson salt and it helps for a while. Yeah and it helps my bones. That’s where the pain is right in my bone areas.” (P-9, I-2, PV-1)

Another participant said, “A nice warm shower, it soothes the pain for a minute...after I get cold I’m still back in pain...a heat pad do it just the same way.” (P-1, I-1)

One participant said that attending support ‘classes’ provided by “behavioral services” helped her cope with her pain. (P-10, I-2) For participants with leg ulcers, the ‘Unna boot’ helped provide relief from chronic pain as the ‘Unna boot’ helped their leg ulcers to heal which reduced their pain. One participant shared, “I don’t like to complain because everybody got problems so I keep it to myself and try to put on a smile but it still be hard.” (P-12, I-1) The pain support group offered at the primary care clinic was said to be helpful for three participants, as “it lets me know that I’m not the only one in

life that's goin' through this." (P-9, I-1) At the support group, participants could discuss their week with pain and they learned exercises that they could perform to try to help reduce their pain. One participant said that the exercises did not completely relieve her pain, but they did help to 'lighten' her pain until she could follow-up with her health care provider. (P-9, I-3)

Some participants shared that nature helped them to cope and "forget the pain" for a while. One participant said that she was on her porch crying and her neighbor asked her to help plant some flowers. The participant said that planting did "take your mind off of it [the pain]" (P-4, I-3) and when she is 'hurtin'" she will go water the plants or look at the plants as she finds this to be 'relaxin'.'" She said that prior to her neighbor asking her to help plant the flowers, she had "never done nothin' like this before." (P-4, I-3) (see Figure 16)

Figure 16. Coping with chronic pain - Planting flowers



"I did these when I first started hurtin' I planted these down in there. Yes I love to do stuff like this and believe it or not it relieves your pain. It don't take it away but it takes you mind off of it 'cause you so used to doing this to makin' sure this plant it, with that you forget it. It make you forget." (P-4, I-2, PV-1)

One female participant took a picture of nature. She shared that looking at nature helped her cope with her chronic pain. (see Figure 17) Several participants said that rainbows, clouds and nature were soothing for their pain and helped them cope by taking their mind off of their chronic pain. They said they enjoyed sitting inside their apartment and looking through the window at nature or sitting outside on a bench and appreciating nature.

Figure 17. **Coping with chronic pain – Looking at nature**



“You can just sit there and look and just literally calm yourself down from the picture. And it just like freed my mind. I think I stood there for about an hour.” (P-7, I-2, PV-1)

Another participant said that when she was able to focus her attention on other family members, especially during positive events, that this helped reduce her pain. She gave an example of her granddaughter excelling in school. The participant said that because of her granddaughter’s achievements, she was able to focus on her granddaughter and “got my mind off of myself...my pain.” (P-9, I-3)

Participants said that pets were distracting and helped them cope with their pain. It did not matter if they were the owners of the pet or if the pet belonged to someone else, such as their neighbors, the animals provided some relief from pain. One

participant described how she would pet her neighbor's cats and feed them some of her sandwich if she was sitting outside. She also said that she enjoyed watching the birds and squirrels at the park. (P-9, I-3) Pets were said to be helpful for some participants to help them relax and not think about their chronic pain. (see Figure 18)

Figure 18. Coping with chronic pain - Pets



“That’s an aquarium. That’s where I just sit down and look at the fish floatin’ around. I have a angel fish. That’s peaceful, yeah.” (P-1, I-2, PV-1)

One of the participants explained how the neighbor's dog helped her take her mind off of her chronic pain. (see Figure 19) She shared that when she was interacting with the dog, she was not thinking about her pain at that moment. She said that the neighbor's dog helped her to cope with her pain.

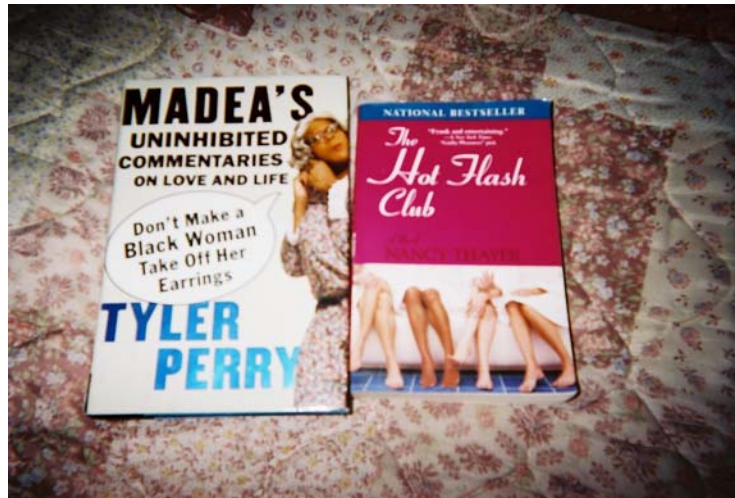
Figure 19. **Coping with chronic pain - Neighbor's pets**



“That’s a little barkin’ dog. He just irritates me and he barks all night. I be cussin’ at him at night. I forget about the pain. I be in the window, he be next door, he just irritates me and you know I cussin’ at him so much until I get sleepy and my pain, I forgets about that you know ‘cause he be barkin’ and I be cussin’ him, he be barkin’ and I be cussin’. And we carry on then, this puppy will carry on a couple of hours a night. I mean every night and he helps me. That little puppy helps me.” (P-4, I-3, PV-2)

Participants had to live with and cope with their pain on a daily basis. Another participant shared, “I try to read a book to get my mind off of it but the pain is still there.” (P-9, I-2) (see Figure 20) She said that when she sat down in her chair to read, she tried to focus on the words in the books and not on her pain. This participant found reading to be relaxing. (P-9, I-2)

Figure 20. Coping with chronic pain - Reading books



“Some of them are reading material. Help me soothe my pain, get my mind off of it. It’s like a therapy. Yeah, it helps get my mind off of the pain. And I’m going and focus on what’s going on in the books.” (P-9-, I-2, PV-1)

Participants said that they sometimes went to the emergency department (ED) when they were not able to cope with their severe pain. For some participants, it was helpful going to the emergency department, as they were given something for “pain relief.” Another participant shared that when he went to the emergency department for his chronic pain he would always rate his pain as being “ten, ten-plus” because he thought he would not receive adequate pain medication unless he scored his pain at the highest rating. He said he would “shoot for the moon hopin’ to get the best.” (P-8, I-2) Other participants were not provided with pain relief and were told to “follow-up with the [primary care] doctor” (P-2, I-1) during their next scheduled appointment. Participants, who did not find that the ED helped them cope with their pain, as they did not obtain adequate pain relief, went to the ED only as “the last resort.” (P-3, I-1) One participant said that prior to enrolling as a patient at the primary care clinic where he now receives scheduled care, he went to the ED “twice a week...and tell ‘em I got the same pain, the

same pain.” (P-6, I-1) He shared that even though he did not obtain relief for his pain when he frequented the ED, he felt he had no other options when trying to cope with his pain and this is why he utilized the services at the ED so often.

When participants were asked how they coped with their chronic pain, some participants said that they tried to “endure it”, as there was “no cure to it so just going to be in pain for the rest of your life.” (P-1, I-1) Participants also said they needed to “deal with it on my own” because they did not want to “be on pills all my life” (P-4, I-1) or ‘dependent’ on medication for pain. Participants discussed how their coping abilities may be influenced by the effectiveness of their pain medications.

**Pain medication and coping.** Participants described how their pain medication helped them cope with their chronic pain. Pain medication was said to ease the pain a little and “make it a little bearable.” (P-12, I-2) Another participant described the effect of pain medication on his chronic pain. “But it doesn’t completely stops the pain. There’s always like a gnawing, you know; constant reminder, you know, that I [my pain] haven’t went anywhere.” (P-11, I-1) Another participant shared that she wished she could have a “pain pump” so that she could give herself some pain medication prior to any outing and she could still be in control of her life. She said, “That way I could be pain free without bein’ sluggish. Just get me out of my pain. I don’t want to be high. I just want to be pain free.” (P-5, I-1) Another participant said that once he took his pain medication he tried to ‘relax’ and ‘block out’ the pain. Another participant said that she did not want to become ‘immune’ to her pain medications. One female participant said that she was “tired of taking that medicine” (P-5, I-2) and needing pills to continue to



function every day, but if she did not take the medication, her pain would be 'unbearable'.

Another participant described how pain medication helped him cope to "be normal, but that's not going to happen." (P-13, I-1) Another participant described how it would be helpful for him to obtain "a stronger medication and then that'll stop me from hurtin' and then you know and then you can see like a brighter day." (P-12, I-1) A female participant said,

I wished they could give me somethin' recommend me a pill that I could take in the morning when I got up, and then just one pill a day is fine, or one every other day...that I can get around, move about, that'll hold me and I be able to walk free of pain. (P-5, I-2)

One female participant with chronic pain in her legs said that to make her situation better she would like to "cut my legs off, honestly. I would amputate my own legs if I could." (P-4, I-1) She said, "you know I'd rather not have legs than go through this." One participant said when discussing her chronic pain "I just wished they had a cure for it." (P-5, I-2) Participants said that they wished they could be pain free and in doing so, this would improve their current situation. They felt that chronic pain prevented their lives from improving.

The effectiveness of their pain medication helped participants cope with their chronic pain. Often, the medication did not completely "take the pain away", but by helping reduce the intensity of the pain, they had improved coping. This improved coping positively influenced other areas of their lives by allowing them to accomplish more throughout their day when their pain was reduced. Another participant said that the pain medication was enough to reduce the severity of the pain "enough to make you function." (P-12, I-1) A male participant said that his pain "it's always there. It's like a

constant companion.” (P-11, I-1)

A female participant said that she chooses to take her pain medication “to survive,” because “I don’t want to be messed up all the time.” (P-2, I-2) One of the participants explained that when he took ‘Motrins’ for his pain, his pain was “maybe 8” (*on a scale of 0-10, where 0 was no pain and 10 would be the worst pain he could imagine*); when he took “Vicodin the pain is about 5 or 6.” (P-6, I-1) He said he was prescribed ‘Vicodin’ only once before and since that time he has been prescribed ‘Motrin’ for pain. He said he had informed his physician that ‘Vicodin’ had been more effective to reduce his pain, but he has not been prescribed ‘Vicodin’ since his initial health care appointment. Participants described the actions they needed to take to cope with their chronic pain when they did not have enough pain meds to last them until the end of the month.

**Coping with pain when they’ve run out of pain meds.** Participants were asked what activities they performed if or when they did not have enough pain medications to last them until the end of the month. They shared that because their pain was severe, it did require them to sometimes take more pain medication than what had been prescribed for them by their physician. Participants said they did try to avoid running out of medication, but it did happen “quite a few times.” Participants said when they did not have enough medication to last them until the end of the month, there were friends or relatives they could borrow medications from or they could “buy some” pain medication. They shared that it was a frustrating situation to be in, because they needed their medication to help them cope with pain, and said, “‘cause you’re the one sayin’ I’m in pain now.” (P-3, I-3)

Another participant described how he coped without pain medication, “You have to suffer with it, you just deal with the pain or try to find someone who’s got the same kind of script or somethin’ to try and soothe the pain. Find someone with some pain pills.” (P-1, I-3) He added, “I know people comin’ round askin’ ‘you got any pills? You got any pills?’ And sometimes I do, and I have a few I can give them and sometimes I don’t, I need them for myself.” Participants said that they did not borrow or ‘buy’ medication from family or friends often, as they did not “want to get [into] a habit” of borrowing other pain medications.

Another participant added,

Like I told her you know and I deal with the pain but I don’t have to. I can go out on the street and buy somethin’ that make me feel better but my legs won’t never heal. And then I tired now. I’m 53 years old. I did that for 30 years. That’s what got me in this shape. If I woulda knew that dope woulda did me like this, don’t you think I wouldn’t touched that. I wouldn’t touched that. (P-12, I-2)

Participants said that they would do what they needed to do to cope with their chronic pain. They said that it was often a daily struggle as they tried to remain sober or illicit drug-free each day especially if they did not have adequate pain medications. One female participant shared that she used to drink to ease her chronic pain as this was easier than it was to try to obtain effective pain medication from her physician; and in doing so, she “became an alcoholic.” She said she would “drink myself to sleep...and then when I’d wake up I’d finish the drink and make another one just to ease my pain.” (P-10, I-2) She said that without pain medication it was difficult for her to cope with her chronic pain and function in life. She enrolled herself twice for rehabilitation treatment for her alcohol addiction. This participant said that she could not “afford to pay” for the pain medications that had been prescribed for her pain so it was cheaper for her to

purchase alcohol and “cheaper to buy a pint or a fifth. Next thing you know I’m drinking it every day.” (P-10, I-1) She said, “You don’t grow up saying, ‘Oh when I grow up I’m going to be an alcoholic or a drug addict’.” She said it was a “vicious, horrible cycle” and she was “working on my problem” every day. (P-10, I-2) She continued by saying that it has been a “life time battle” because the alcohol “keeps me better than a medicine, I hate to say that but it does. But I don’t do that anymore.”

A male participant discussed how he used to use illicit drugs and alcohol to cope with his chronic pain. He had since participated in a drug and alcohol rehabilitation program to recover from his addiction to these substances. He explained his previous coping strategies in the following way. “I was an alcoholic and a drug addiction for 2 years. I went to rehab for two years. So after that the pain just started constantly comin’ on. While I was getting’ high I didn’t feel no pain.” (P-1, I-1)

When challenges occurred throughout the day or their chronic pain became unbearable, it was difficult for participants to not revert back to their previous coping behaviors of consuming alcohol or illicit drugs. When asked how he coped with his pain, a male participant shared that prior to seeking care for his leg ulcers that he was “doin’ it on my own, street drugs, pills, you know what I’m sayin’...and that’s the only way I can sleep or walk or or how, how would I say get through life.” (P-8, I-1) Another participant said that in the past he had difficulty sleeping due to pain so he would “hit some marijuana...I mean not to get high, to go to sleep.” (P-6, I-1) One participant shared that he was “killin’ myself slowly but surely” (P-1, I-3) while he was using illicit street drugs and alcohol “for about 30 years” to control his chronic pain. He shared,

If you on drugs or alcohol you don’t need nothing’ for pain ‘cause the alcohol will kill all the pain and the drugs will too because I was on drugs and alcohol and

there wasn't nothin' botherin' me then, nothin'. When I got off of that, everything started hurtin'. (P-1, I-3)

Participants described the challenges they faced when they did not have adequate medication to help them cope with their chronic pain. Participants said it was challenging to not relapse into previous behaviors to try and cope with pain. One participant said, "I've tried everything from smokin' to drinkin' to try and alleviate the pain um, and it seems like nothin' works, nothin' works." (P-7, I-1) Another concern participants discussed was the side effects and fear of becoming addicted to their pain medications.

#### **Coping with chronic pain and concern with addiction and side effects.**

Some participants expressed concerns with the side effects caused from their pain medication. Some were concerned about becoming 'addicted' to their pain medication because they needed to remain on pain medication to reduce the intensity of their chronic pain. Participants said their physicians had told them the side effects their pain medications could have toward other parts of their bodies. Some of the side effects included potential damage to their 'kidneys', 'stomach' or 'liver'. Some participants said they were concerned about any damage caused to other bodily organs, but they needed to continue to take the pain medication "to survive." (P-2, I-2)

Another participant said that the pain medication he had been taking that was helping reduce his pain was "messing with my [his] kidneys" so the health care provider discontinued that medication. He understood why the medication was stopped, but was frustrated in that "somethin' that works I can't take." (P-12, I-1) He added that he was willing to take a chance with the side effects caused by the pain medication on his body

“cuz I’m in pain.” Participants were willing to endure any possible complications from pain medications if it meant that their chronic pain would be better controlled.

When discussing her pain care another participant said, “See sometimes people use pain medication to get high. But sometime people be really in pain, o.k.?” (P-5, I-1) She added, “but then your body get immune to this pain medication so you can’t even live without it. It come part of your everyday living.” She added during another interview, “nobody should have to live like this.” (P-5, I-2)

Other participants discussed concerns they had from their pain medications and any concerns with addiction. One participant said that addiction “runs in her family.” Another participant said that she was “not addicted to them pain pills ‘cause I would love to stop takin’ em, but I can’t function. I can’t move about without the pain pills.” (P-5, I-1) One of the male participants said, “I was addicted to pills and I refuse to take a pill every time somethin’ hurts now” (P-8, I-1) and another participant shared that in the past when he was “gettin’ high”, he did not experience pain. This participant did not want to repeat his behaviors from the past (P-1, I-1) and possibly continue with the habit of using illicit substances to decrease his pain. Another participant said that he tries to “cope with it [the pain]” because he did not “want to be enslaved in that” (P-11, I-1) and needing to take pain medication all the time. Participants described the difficulty they experienced when obtaining opioids from health care providers if they had a previous history of illicit drug use.

**Health care providers concerns with addiction and pain meds.** Participants said it was difficult when they felt they were treated differently and denied pain care because of having a history of illicit drug use and addiction. Due to a previous history of

illicit drug use, it was sometimes challenging for participants to receive opioids from health care providers. Participants shared suggestions about which pain medications they thought might help them with their pain, as one participant said, “My philosophy is you wouldn’t make it if people didn’t need it.” (P-13, I-1) One participant described how she was cautioned by her health care provider regarding how many pain medications she took each day for her pain. She shared, “They say, ‘oh you can’t take that many pain medications ‘cause you’re gonna OD. It’s called overabusin’, using pain killers’ or somethin’, but I be in pain!.” (P-5, I-1) One participant shared her frustration when she had another ‘substitute’ doctor at the clinic write her pain prescription for her,

And they’re on addiction. I’m not addicted to anything. I just want the pain to go away and when the pain goes away and the 30 minutes I do [get] relief that I do get by where I can fall asleep, take a nap and wake up, the pain is eased up. I don’t have that burnin’ sensation. I mean it works but then you gonna come along substitutin’ and cut the dosage down. He says when I looked at the prescription, I said this is not the prescription. (P-2, I-3)

When asked if they thought patients were treated differently for their pain if they had a history of drug or alcohol use, all participants felt that patients were treated differently. One female participant explained, “Because of the simple reason they look back at your drug history and the first thing they’ll say is maybe you’re back on drugs, maybe it’s the drugs that’s causin’ your pain...they treat people different.” (P-4, I-2) She shared that in her past she had required surgery and the physician would not give her anything for pain with ‘narcotics’ in it because of her history of “drug use.” She said,

Yeah ‘cause it has happened because of my drug use they wouldn’t give me anything with narcotics in it, like I had they gave me, my surgery they gave me like what was that? Motrins. The doctor gave me Motrins. He wouldn’t give me nothin’ stronger because of my drug use...that’s how they do it. (P-4, I-2)

Another participant said she had discussed with her health care provider the reason why she was not being given anything stronger than 'Motrins' for her pain. The participant was told that because she was a "recovering alcoholic" her health care provider did not want to give her 'narcotics' for her pain and "trigger that, wake up that disease." (P-9, I-2) Her health care provider said she did not want this participant to be "dependent on" the pain medication.

Another participant said that he did have a history of using illicit drugs so when he went to his previous health care provider and asked for pain medication the participant said he was told "no, no, no, no." (P-8, I-1) Another participant said, "In my opinion, a lot of people don't want to mess with an ex-dope user or junkie or user 'cause they figure it's a waste of time they think you're goin' to go back out and get high." (P-12, I-1) One participant shared that he had a previous history of using 'heroin' and because of this history he was not able to receive adequate medication for pain relief from his health care provider. He said, "You can tell her your leg is hurtin', she's not goin' to give you anymore. 'Cause that stigma of you're a drug addict, you were a drug addict. So you have to wear that the rest of your life." (P-13, I-1) He said that he had received services for his history of "opiate dependency" but now some of the clinics he used to attend have "closed up." He said, the "insurance people" and "people's attitude towards people tryin' to get help...they're feelin' like people have been in there too long and it's too much money." (P-13, I-2) He felt that services that could help people with their addiction were being reduced, as the community was 'against' people who had a history of illicit drug use. These negative feelings towards people who used to "use drugs" were also present when people requested medication for chronic pain. (P-13, I-2) This



participant said he had experienced these negative ‘attitudes’ and he knew of other people with similar circumstances.

Another participant said that if you have a history of illicit drug use that health care providers would not treat the patient the same for their pain. He said, “They probably holdin’ that against them...‘cause they’ll prefer the one who doesn’t use drugs.” (P-6, I-2) He further elaborated by saying, “for that reason, they send them to the side a little bit maybe and don’t wait on ‘em as quick, I have seen that.” He said, “yeah, stereotype to me, ‘cause if you’re in pain, you’re in pain no matter what you did...a lot of people mess up.” (P-6, I-2) Participants said that because of their histories with illicit drug use that they now had difficulty obtaining adequate and effective pain medication. They discussed how they were not abusing their pain medications; they were trying to live their lives with chronic pain. Participants’ emotions were affected when it was difficult for them to cope with chronic pain.

**Chronic pain and moods – sadness and resilience.** It was difficult coping with chronic pain and this difficulty with coping affected participants’ emotions and moods. Relentless chronic pain led some participants to feel emotions of sadness and anxiety. Other participants said they were not going to let chronic pain destroy their lives and they were determined to not let it “beat them” and cause despair.

Participants said that pain made them feel ‘depressed’, “angry, short tempered, irritated, agitated” (P-10, I-1), ‘overwhelmed’, and “it affects just about every area of my life, my moods.” (P-11, I-1) Another participant said, “I just don’t have no patience when I’m hurtin’, no patience.” (P-12, I-1) He explained that he tried not to leave his home

when he was having a severe pain day as he might say something to another person that would be perceived as being 'disrespectful'. He shared,

So I try not to do anything...like going, anything important I don't try to do it. I'm not going to do it if I'm hurtin' real bad...it's hard to smile and stand up there while you hurtin'. How you gonna smile and pretend, you can't do it, it's impossible. (P-12, I-1)

Another participant said, "Sometimes it just gets to the point where you start beating yourself up because you don't really know what else to do. I mean you've tried everything but your pain is still there." (P-7, I-2) Another said, "It would have to be somebody that's in the situation to really understand or put their self in the situation to really understand what we go through." (P-9, I-2) Chronic pain was also said to cause "depression and anxiety attacks" and when the pain was severe one participant shared, "it was a very dark time in my life and I do not want to go back there." (P-7, I-1)

Another participant said that trying to convince herself and not let the pain affect her life "didn't work" and another said that life with chronic pain; he was just "tryin' to stay alive." (P-1, I-1) Another said that she does not like to complain, so when someone asks her about her well-being she will say, "I'm ok, when I'm really not ok." (P-5, I-2) Another participant shared that when she was in extreme chronic pain, she had a certain look on her face that told those around her, "I don't want to be bothered." (P-4, I-3) Most participants explained that there was a certain look on their faces that revealed to others that there was something wrong; and that the pain they were experiencing was at a high intensity that day.

One participant said that when she was experiencing severe pain she would feel sadness as she was not able to think about anything else but her pain. She shared that she would lie on her mattress and stare at a blank television screen all day. (P-7, I-2)

This participant said that her picture could be used to show others what someone experiencing chronic pain experiences. She titled this picture, the “face of pain.” (see Figure 21)

Figure 21. **Coping with chronic pain – Face of pain**



“So you can see like I literally cannot get up out of bed. This is what I do. I have the light off, hand over my face and just trying to sleep, and I try not to cry.” (P-7, I-2, PV-1)

Participants said it was difficult for them to maintain a positive mood when they were experiencing chronic pain. Participants said that at times when it was difficult for them to cope with their pain they wanted to ‘isolate’ themselves. By isolating themselves, they were able to focus on reducing their pain and they did not need to worry about being in a “bad mood” and possibly offending others.

Other participants said they preferred to have others around them when they were experiencing chronic pain. One female participant explained that when she was

with her family she tried to “keep myself together enough to where they still enjoy my company...because nobody wants to be alone.” (P-2, I-2) She said that she tried to remain in a positive mood so that she did not push her family away. She was concerned that if she was in a negative mood because of her severe pain, that her family may not want to spend time with her.

Participants said that by having family and friends around them, this helped them cope with their chronic pain. Participants said that sometimes people around them tried to assist with reducing their pain, as talking with others helped participants by “takes away most of your concentration on the pain.” (P-13, I-1) A female participant explained, especially if it was “a cheery person, bring a little joy to me, come on in.” (P-2, I-3) She added that they would rather be around other people even when they were experiencing pain “‘cause I don’t like to be by myself you know.” (P-2, I-3)

It was painful for participants to get up and down to open their front door and let people into their apartments. Several of the participants said that they now “leave my door open to come in” so that people could enter their apartment without them needing to go to the door. One participant shared, “you can come in, but if you ain’t cool and you ain’t right don’t even worry about it ‘cause I’m gonna kick you out.” (P-2, I-3) They also left the door open so that if something happened to them due to pain and they were not able to open the door, someone could enter the apartment to help them “without having to kick the door in.” (P-2, I-1)

Another participant shared that his personality was usually friendly and talkative. When he was feeling extreme pain he became quiet and preferred to ‘isolate’ himself from others, as this reduced the frustration of needing to explain to others why he was

in a quiet mood that day. (P-12, I-1) Some participants said they did not want to be thought of as being 'rude' so they tried to stay by themselves when their pain was intense. A female participant shared that when her pain was severe she was not able to "play cards" with her friends so she would "go in my room and elevate my legs and call it a day." (P-4, I-3) She further explained that she wanted "to be by myself...so that way I won't have to snap at nobody...and I can moan and cry by myself." (P-4, I-1) Another said, "it's not fair to them" and "I try to stay pleasant that's why I isolate 'cause I don't want to say the wrong thing or hurt someone's feelin's you know because of what I'm goin' through." (P-9, I-1)

When describing how pain affected their moods, other participants said, "I go down in the basement and watch t.v." (P-6, I-1) and "I don't want to be bothered." (P-4, I-3) Another participant said, "I don't want anything to drink. I don't want anything to eat, I don't want to talk. Just let me lay here", and "leave me alone and just let me be." (P-7, I-2) Another participant said that if she was in severe pain and trying to cope with her pain and another person interrupted her coping she would "shut 'em off...you know I can't deal with that right now, call me back later." (P-9, I-3)

One participant said that chronic pain has made a "big difference" in her life. Another said that it "turned my whole life around"; she further explained that due to the changes she has had to make in her life "My whole life has been made a 180 degree turn." (P-2, I-1) Participants said that in order to cope with their pain, they often "carried...pills with them" wherever they went, just in case they needed to take pain medication when they were out. A female participant shared with tearful eyes, "I can't do nothin'. I still in my mind think that I'm still the perfect mom and the perfect

grandmother but I'm not 'cause I can't do the things I want to do you know." (P-5, I-1) She said that the pain made her sad as she used to be able to help others in her family and now she was trying to cope with the limitations caused by her chronic pain.

One participant said that while pain controlled her life and was depressing at times "I might be in pain but I'm not gone, you know I might get depressed but I'm not going to...I don't want to kill myself. I don't want to die, I want to live." (P-2, I-3) Another participant said, "I don't believe in just givin' up." (P-9, I-3) Around his family, one participant explained that chronic pain "has affected my ability to you know really be the same person around my family and my girl...but I've been, I'm a good actor and I try not to let them know." (P-8, I-2) Participants had learned to "accept the pain" and "deal with it." Another participant discussed that she tried to not complain about her pain with others. She said,

You know so it's like I'm not goin' to burden you with this right, my pain that I'm havin' 'cause you might be goin' through somethin' different or I'll be a burden to you if I'm constantly complainin'. And what good is it is helpin'? You know it's not helpin' me or you, you're constantly complainin'. (P-9, I-1)

Participants shared that they tried to keep "a positive spirit because pain can really knock you out" (P-7, I-2), "it's the will to live" and another said, "I can't afford this just let it take my whole life away from me." (P-12, I-1) Other participants said that "you have to keep going, you have to", and "turn the negatives into positives." (P-7, I-1) Some participants said that they had to 'fight' their chronic pain because they was "sick of bein' like this." One participant said, "I am strong and I need to be strong again." (P-10, I-1) A male participant said that he knew of other people who also experienced chronic pain but they "gave up on life", he shared, "I wasn't ready for that." (P-13, I-1)

One of the male participants shared a story of courage and resilience. He said that in his past, he was addicted to heroin and cocaine. He said that it was his injection drug use that caused reduced blood flow to his legs that led to him having painful venous ulcers on both of his legs. He said he used illicit drugs for 30 years and often lived on the street. He said that he had been “hit in the head with an axe...I got 33 stitches here...I been in a penitentiary twice... I’ve been shot four times. I got a hip replacement. I’ve got stabbed.” (P-12, I-1) The participant explained that in the past 5 years since he stopped using illicit drugs and his legs have begun to heal, he has had moments where he felt proud of himself for his current coping behaviors. He said,

You know, but I try so hard, very hard to try to walk right without limping. You know two years ago younger people start calling me sir, mister and that never. You know it never happened to me like that to get respect like that. And just think a person callin’ me sir and mister. You know I’ve been in the street all of my life. And they care nothin’ about that. And that made me feel so good. (P-12, I-2)

When participants felt resilient, they were able to cope more easily, and felt more in control of their pain. Participants described how their ability to feel in control of their chronic pain affected their ability to cope with their pain.

**Feelings of control over chronic pain.** Most participants said that it was difficult to cope with their chronic pain when they did not feel in control of their pain. They shared that by always feeling pain, they can tell when the pain is at “different levels” or varies with intensity from a ‘7 to a 9’ *out of 10*, but there was often nothing they could do to reduce their pain. They stated that they “need it [the medication] all the time” but they did not take the medication all the time. They often did not know what to do to help feel more control over their chronic pain. All participants stated that they find

their current life with pain ‘frustrating’! Another said that she did not “have control” over her pain and it was difficult for her to cope “it gets out of hand.” (P-2, I-1). She shared,

When I’m thinkin’ I don’t think, because I mean I’m in pain and all I’m thinkin’ about is this here is hurtin’ me and I want this to be over with, you know, I don’t want to die or anything but as I take my meds I want it to be better, you know, make me a little comfortable whilst I’m still here because pain, it’s not easy. I suppose to be doing other things than sittin’ here holding my arms and stuff talkin’ about pain. (P-2, I-1)

One of the male participants said that his pain medication only took away some of the intensity of his pain but the medication never completely relieved him of his chronic pain “if I take somethin’...it don’t matter to me...they still hurt. But it’s the unbearable and the bearable.” (P-12, I-2). Another participant said that she did not know how to control her pain as “it woulda stopped a long time ago.” (P-9, I-1) When describing her pain, one participant said, “this is not normal.” (P-10, I-1)

The one male participant who was not able to score certain answers on the Brief Pain Inventory (Short Form) (Cleeland, 1991) said he tried to control and cope with his pain by blocking the pain out of his mind. He said when he was not successful at blocking out the pain with his mind; he could not score a number to his pain as it was too severe. He further explained how he tried to cope with his chronic pain,

I just try to get my mind and sometime I forget how to do it. And I can’t remember, for nothin’ in this world to get my mind in that state to help myself. You know it’s somethin’ you got to learn how to do and sometimes I forget how to do it. How, how do I handle it you know like I do sometimes. And that’s when I’m really messed up when I forget how to control it in my mind. The days that I can handle it with my mind, yeah. But the days that I can’t, it just, I just have to sit down and lay down and, and, and until the medicine get enough where it takes that heavy pain away and just enough to make me function and then I’m cool. (P-12, I-2)

Only one participant said that sometimes he felt in control of his pain and he could cope with it. He said that he was able to gradually reduce the pain medication



that he had been taking during the past year. He shared, “yeah I think I’ve got a certain amount of control and then you know the medication helps a certain amount of control you know and all of it works together...and you get above it.” (P-3, I-2) Another participant shared that he did not want his chronic pain to take over his life, but there was nothing he could do to prevent this from happening “it’s not that I want it too, it’s, I can’t help it.” (P-6, I-1) Participants shared how chronic pain controlled their lives. Not having control over the pain influenced participants’ ability to cope. Some participants discussed how other activities, helped them cope with their pain. Prayer was said to be an activity that helped participants cope with their pain.

**Prayer and chronic pain.** There were many uncertainties when living with chronic pain and each day challenged participants and their ability to cope with pain. Some participants said they used prayer to help them cope with their chronic pain. They said that they found support each day from their faith and spirituality. One male participant stated,

I just pray for a good day that’s what I do. Every morning I just hope I have a nice day with the pain that I can control and be able to do things. Instead when it’s not I just have to go home and sit down and tough it out. (P-12, I-2)

One participant felt that her pain was “part of the plan” and it was “just something you have to go through.” She shared her “faith in God sometimes it waivers” because of the difficulty with coping and the severe pain she experienced every day. This participant called her pastor and her pastor said that when she focused on God, she was allowing “Him [God] to relieve her pain.” (P-7, I-1) Another participant said, “I got faith” and when “I walk through this hospital and prayer is on my mind, you hear me?”(P-2, I-2) Another

participant said that when she prayed “it relaxes me” and she would go and read her “bible” when she was experiencing intense pain. She further explained, “but I pray a lot and you know it do help.” (P-4, I-2) Another participant took a picture of the prayer guide she says every day to help her with cope with the pain. (see Figure 22)

Figure 22. **Coping with chronic pain - Prayer guide**



“O.k. this is my prayer guide, to accept the things that I cannot change, can you read that? [the courage to change the things I can, and the wisdom to know the difference.] That’s motivation. That’s motivation. Because it lets me know that you know when I’m askin’ Him to grant me the serenity to accept the things that I cannot change, the pain that I’m going through. I can’t change that. But things that I can, give me the courage to do the things that I can which is readin’, readin’ my bible, doin’ the meditation, you know. That helps me to. This is what I can do. About the situation.” (P-9, I-2, PV-1)

One male participant said that he did pray, “pray that you get better. Pray that it don’t get worser and do the best you can.” He added, “I don’t do it [pray] every night. I believe in the Lord and everything but I don’t pray all the time.” (P-6, I-1) Another participant shared that praying helped her “mentally and spiritually” and it “helps her stay stong...instead of givin’ in, I mean there is hope.” (P-9, I-2) Another participant shared that her ‘religion’ and “spirituality helps me out.” A male participant said, “I try and I pray and I know there’s a God and I know if I keep prayin’ He’s gonna make things

better for me. I honestly believe that.” (P-12, I-2) Another explained, “I believe that if God was ready for me to go, I would be gone.” (P-13, I-1)

Chronic pain was always present in participants’ lives making coping difficult, especially if participants “ran out” of pain medications. They shared the concerns they had with pain medication and relapsing back into behaviors such as illicit drug use to try to cope with their chronic pain. They also discussed the importance of having supportive people in their lives who believed they had chronic pain. Supportive people improved their ability to cope and deal more effectively with pain in their lives.

**People and coping – supportive and not supportive.** Participants described the experiences they had with friends, family members and health care providers. Participants discussed the people in their lives they found to be most supportive for them; those individuals who helped them to cope with their chronic pain. There were times when people in their lives were helpful because of participants’ inability to mobilize and complete tasks on their own. There were other individuals in participants’ lives that did not help participants cope with chronic pain and expected participants to complete the tasks themselves.

Participants described the support they received from their current primary care clinic “I feel like this is the best place right here.” (P-2, I-1) One participant shared that the health care providers at the clinic “made me feel nice and comfortable...he listened to me and made sure I was taken care of” (P-2, I-1), other participants said, “she did a marvelous job”, “she cares”, and another said “these people treat me real good.” (P-6, I-1) He added, “they’ve definitely been good to me...I know if I wasn’t around here I would be hurtin’ real bad.” (P-6, I-1)

Participants shared their positive experiences with health care providers who were supportive of them and their chronic pain. One participant said that health care providers who were helpful were “the ones that care, treat you a little more caring” and “they make you more comfortable.” (P-3, I-3) Another participant said that she was happy that she did not need to wait lengthy periods of time to see her health care provider, she said, “I’m very vulnerable right now ‘cause with the pain anythin’ just can trigger me off...if they had me waitin’ out there a long time I was about to lay down on the floor ‘cause I was hurtin’ so bad.” (P-2, I-1) She said she has been attending the primary care clinic for several years and has never had to wait long periods of time to see her health care provider. She shared that this was helpful, as when she was experiencing unremitting pain, it was difficult for her to sit in the waiting room clinic chairs because all she wanted to do was lie down to try to alleviate her pain.

A surprising finding was shared by a female participant who said that when she was living in a different state, she had attended a pain clinic and was told by the nurse at the pain clinic, “You’re not really in pain if you can come in here and you can walk straight.” (P-7, I-1) Another participant said he was told by a surgeon from another hospital that his legs “would never heal” but with the care he was receiving at the clinic, his legs were healing. He shared, “I’d be scared to even try somethin’ else ‘cause what she doin’ is a miracle, what she have already done for me. Wouldn’t dare go no place else.” (P-12, I-1) Overall, the participants spoke positively about the primary care clinic and said the care they received was helpful and supportive.

Participants described other people who were supportive of them and their chronic pain, such as a ‘mother’, ‘sister’, ‘kids’, ‘grandkids’, ‘fiancé’, ‘brother’ and

'neighbor's kids' helped them take their mind off of the pain. These people helped participants cope with pain by making them 'laugh', 'talking' to them and expressing their support of participants. One female participant shared how her granddaughter while "rubbing my [her] legs down" said to her, "Grandma, I hope I don't have to be in pain. She said it hurts me for you be in pain...she said I'm gonna get rid of your pain soon. She said God gonna help you too...." (P-4, I-2) This participant also described how a neighbor helped her cope with pain. Her neighbor was the "Eureka drunk. He comes sits on the porch with me and he makes me laugh all the time. This man is awesome, he has me dyin' laughin'. I mean he makes me laugh till I cry." (P-4, I-2) She explained that the "Eureka drunk" was a man who lived down the road from her and how he would visit every day. He would come and sit with her on her porch if he saw that she was sitting out on the porch too. He would tell her stories and jokes to make her laugh and she said that by laughing she was not thinking about her chronic pain.

Participants shared that there were some people around them who knew about their chronic pain and were more supportive. These supportive individuals either were with them when their legs 'swelled' or occasionally went with participants to the clinic. One male participant who stayed with his mother said, "My mom knows. My mom can look at me. I guess I have it on my face and I'm in pain. She say yeah you're hurtin' a little bit more." (P-6, I-1) Another participant shared, "I guess it shows on my face when I'm in big pain 'cause they say to me, 'Well what's wrong with you. You look like you're dyin'". (P-10, I-1)

Participants described how chronic pain affected their mobility and how it affected their interactions with other people in their lives. Chronic pain caused

limitations with their mobility and these limitations required participants to rely on others for assistance. Participants said there were people in their lives who were supportive and assisted them with their mobility needs and many of their activities of daily living. Participants said they were used to being independent and having the ability to complete tasks themselves, but now due to chronic pain limiting their mobility, they required assistance with many of these tasks. Participants said there were family members or friends who were helpful and assisted them with “cleanin’ around the house”, they “help cook”, “doin’ stuff” and others “goes to the store” (P-4, I-2) for them.

Other assistance that was appreciated by participants included when someone would offer them a seat so they could sit down, while riding on the bus. One participant shared that his daughter would “take me to the market at the first of the month sometime and every now and then she take me down here.” (P-6, I-2) If they were being driven in a vehicle, participants appreciated if the driver would drop them off directly in front of the store entrance to reduce the amount of walking they would need to do from the car to the store.

A female participant explained that she needed to travel to the water company to talk to them about her difficulty paying her water bill and her daughter was with her. The participant said that once they arrived at the building, her pain was so severe that she wanted to leave the building. Her daughter supported her by staying with her that day and told the participant to take her time walking. Her daughter said to her, “Momma...I won’t leave you, I gonna wait on you.” (P-5, I-1) It was because of her daughter’s ‘patience’ and support that she was able to follow up with the company about her water bill payments.

Participants also described when friends and family members were not supportive of them and their reduced ability to mobilize. Participants discussed that they had missed several medical appointments as their family members were not willing to drive them to their appointments. Another male participant shared that his previous wife had said to him, "I'm tired of you walkin' around here like you can't walk." He said he would get up and force himself to walk even though he was in extreme pain. His daughter also said to him, "Ain't nothin' wrong with you, you just don't want to." (P-8, I-1) The participant shared how a few weeks later he went to the emergency department by ambulance on Christmas Eve due to his increasing pain. He said that within two hours of arriving in the emergency department he was having surgery to replace some 'discs' in his back. He said that his family is a slightly more supportive and helps him out a "little bit more" now. Participants said that while they required more assistance with their mobility needs, they did not want to become a burden to others. Participants said that they tried to remain independent with their mobility and activities of daily living and often would force themselves to accomplish all they needed to finish each day.

Participants provided other examples of when some of their family members were not supportive, and would not help them out with important tasks, such as paper work to apply for disability as they told her she could "do it yourself." Regardless if participants told their family members that they were experiencing severe pain, participants shared that their family members would "get a attitude." (P-2, I-3) This participant was frustrated as she had been a caregiver to them and "if the shoe was on the other foot" she said it felt like "they throwin' me away" because now she needed help due to her pain. She shared that her family would "flip the script when they know

you need them” because they told her they wanted to be “paid for my [their] services.” (P-2, I-3) This participant did not have disposable income to pay individuals to help her.

Participants said there were times when their health care providers were not supportive and this made the health care experience frustrating. Participants said it was difficult when their health care providers did not seem to believe them when they spoke about their chronic pain. They also described how it was difficult when they did not receive effective pain medication.

It was important for participants to be able to cope with their chronic pain. Having the ability to cope, reduced the challenges participants experienced with pain. Some of the challenges experienced by participants included difficulty with walking, climbing stairs and not wanting to be a burden to others. Participants described the challenges they experienced with chronic pain.

### **Challenges with Chronic Pain – “You don’t look like you’re in pain.” (P-8, I-2)**

Participants discussed the challenges they experienced with chronic pain. Participants described the challenges they had with obtaining treatment for their chronic pain due to their race or current health insurance. It was frustrating when people around them did not believe participants when they described their chronic pain. It was also difficult for participants to walk, climb steps, sleep and prepare food due to chronic pain. Participants described the challenges of living with chronic pain.

**Challenges with pain care if different race.** Participants described if they thought the care or treatment they received for their chronic pain, if they felt it would be different if they were not African American or if they had a health care provider that was not African American. Most participants said that they felt their pain treatment would be



the same regardless of their race, some said, “pain is pain...pain does not have no picks...it’s all the same” (P-2, I-1), and another said, “no, I think we all created equally, the same, same, same you know.” (P-3, I-1) One participant said that he was “constantly in pain”, and his pain care “it wouldn’t change at all” and “it would still be the same you know ...because we’re all human.” (P-11, I-1) Another male participant said, “well I don’t think I can answer that ‘cause I ain’t ever been those colors.” (P-12, I-1) He further shared,

I think it be pretty much the same. I think it depend on how you conduct yourself to other people. If you be talkin’ to with respect, people will respect you, they should give it back to you and if they don’t then you try to look around at it. So in other words...I would be the treated the same. (P-12, I-1)

One participant disagreed and said that he thought his treatment would be different if he was not African American because of “the stigma you know.” He shared that “blacks have this stigma that everybody’s on drugs. I think America looks at it like that...so it’s on the mind of most people.” (P-13, I-1) He provided an example of how he waited for pain medication when he went to the emergency department and believed that he would have been provided with better pain care if he was not African American.

Participants also were asked if they had experienced different treatment for their pain from health care providers who were of a different race than the participants and were not African American. Participants shared, “no, never make a difference” (P-3, I-1) and one female participant said, “It does not make a difference as long as they’re a good doctor, a good nurse. Their schoolin’ or education has nothing to do with their color. It’s all about being able to help the people.” (P-2, I-1) A male participant said, “as long as the person [has] ...that gift...the talent or whatever you want to call it to talk about anything with anybody.” (P-3, I-1) Another said when discussing the race of

health care providers, “no I don’t judge people by color. I judge them by the inside, not the outside” (P-9, I-1) and another participant said, “I really haven’t paid no attention.” (P-4, I-1) One female participant said that what mattered most to her was how she was treated by the health care provider. She shared that regardless of the race of the health care provider, “don’t shove me around like I’m you know, have a little respect for me...I’m already in pain.” (P-10, I-1)

One male participant said that the race of a health care provider did make a difference when receiving pain care. He said that when he received care from African American physicians that “African Americans are...not that sympathetic towards you.” (P-13, I-1) Another discussed one of his experiences in the emergency department with an African American physician, he said that an “African American guy [physician]” had said to him “that if he had his way of doin’ things he would take me out in the woods somewhere and blow my brains out.” (P-11, I-1) He explained that this African American physician was upset that the participant had a history of “IV drug” or illicit drug use. The participant paused and added these words, “People are just different you know. It doesn’t really matter what race... that they’re part of you know. Some are more caring than others.” (P-11, I-1) The participant felt that his history of ‘IV drug’ use added to the stigma he experienced in the emergency department when he went to the ED for pain care.

One of the female participants shared, “I think after so many years doctors just get tired of bein’ a doctor and they lose sight of their whole purpose of studyin’ medicine was all about.” (P-10, I-1) She felt that regardless if a health care provider was male or female, that often they grew tired of taking care of patients and would become negative

towards all patients. She said that thankfully she did not meet too many physicians who were negative, but when she did, their negative behavior only exacerbated her chronic pain. Participants described any challenges they had with obtaining pain care from their current health insurance.

**Challenges with pain care - insurance.** Participants described the challenges they experienced when receiving chronic pain care with their current health insurance. One participant shared how she was frustrated with her “insurance company” as they would pay for her to have ‘surgery’ on her back, but they would not pay for her to have “physical therapy.” (P-2, I-1) The participant was frustrated as she felt that the least invasive measure of physical therapy would help reduce her pain. She said her insurance company wanted to “cut you and get you over with, you know, throw you to the side, like a slab of meat, you know, just cut this meat up.” (P-2, I-3) Another said that she might be able to “get different medication” (P-7, I-1) for her pain if she had different insurance. A female participant said that there were different pain medications that would help her with her pain but “my insurance don’t cover them.” (P-5, I-1)

Another participant said that he attended a different clinic two or three times, but because at that time he didn’t “have any insurance” he “couldn’t see the doctor.” (P-1, I-1) The participant said he was frustrated as he was “in pain” and he wanted to ask the health care provider to give him something for the chronic pain. Another participant said with different insurance he “would probably get you more attention, more help” (P-3, I-1) for his chronic pain. Another participant said that his “medical doctor” had prescribed for him to see a pain specialists at the pain clinics “and they didn’t take my insurance” so the participant was not able to go to the pain clinic to receive care. (P-12, I-2) Some

participants were frustrated with their current health insurance, as they were not able to afford certain treatments that might help them with their chronic pain and their insurance would not pay for the treatment. A male participant said that his health care provider had ordered for him to receive whirlpool therapy for his leg ulcers but “the insurance wouldn’t over it.” (P-6, I-2) When asked if she felt that having different health insurance would influence the treatment she received for her chronic pain, one female participant paused for a moment to reflect on the question and then said,

I would like [to] go tell the President that you need to do somethin’ about the insurance. Because here he is you got people that can’t afford stuff because they don’t got the insurance, you know what I’m sayin’? First of all I want to know what’s the problem...I mean y’all wanna see us sick and in pain then to give us the care that we need? Regardless if you can afford [it]. I mean shoot you got people out there that worked all these years and they suffer because they don’t got the proper health insurance. Here you is, she done gave you 30 years of her life on your job and now you’re tellin’ me here she is gonna retire and this woman ain’t got no health insurance. She got to suffer or get this ole low price or this generic medicine that half works. And she gave 30 years of her life to somethin’ to a company o.k. That’s what I would tell him...they need to do somethin’. I mean why is it that the rich only get to be livin’ good and feelin’ good? Why can’t the poor and the middle class live and feel good also. You understand? We don’t mean nothin’ ‘cause we ain’t got as much money as they do? They don’t suffer. Only we suffer ‘cause we can’t afford it. That’s stupid. So it means that [if] you aren’t rich and you’re in the world today you can just forget it. And then the rich can don’t do nothin’ but go kill themselves o.k.? ‘Cause they got the money to do and abuses it. The majority I bet you the majority of rich folks die more of overdoses of drugs and medications than just a regular, normal death because they rich, than a poor, or lower, poor, middle class folks. I really believe that. (P-5, I-1)

One of the male participants said that he did not think having different insurance would make a difference with his pain care as he said, “I love it here. I don’t think the insurance got nothin’ to do with it. I think I’m gettin’ top quality with the insurance I got.” (P-6, I-1) Another participant said that he was “just grateful that I got insurance” because he appreciated the care he was receiving at the clinic. He said, “‘cause you

never know what could happen to this insurance thing you know what I mean? They can easily snatch it and what would we be doin'?" (P-12, I-2) Participants discussed the challenges they experienced when family, friends and health care providers did not believe they experienced chronic pain with the degree of intensity they described.

### **Challenges with chronic pain and others believing you have pain.**

Participants said it was frustrating when others did not believe the severity of their pain. One participant said her pain felt like it was burning "like somebody had a cigarette lighter in my leg...it never, never, ever lets up." (P-4, I-1) Other participants described how pain 'handicaps' them, and "I be in more pain than I don't be in pain." (P-5, I-1) Another male participant said that living with chronic pain was "it's just hell. That's the only thing I can share with you about it." (P-12, I-1) A participant said, "I feel crazy sometimes because of the pain" and "the old sayin' 'old grey goat she ain't what she used to be and I'm not old." (P-2, I-1) Another participant shared, "cause this not no joke. You really don't know how it is until it's happening to you. We can sympathize with people but if it's not on our body we can't really say just how bad it hurts." (P-2, I-1)

Participants shared that it was at times difficult, when they felt the health care provider did not believe the participant experienced chronic pain with the intensity or severity they rated their chronic pain. One participant said that she tried to explain to her health care provider about her "different levels of pain." (P-7, I-1) The days she was able to come to the clinic, her pain was not as severe, but there were days when she was not able to come to the clinic and it was because her pain was too severe for her to get out of bed. She shared that she had stopped going to another clinic, as at that clinic

she was always being told that she was “not in pain” and she became tired trying to “convince you that I’m in pain.” (P-7, I-1)

Another participant said that with his health care provider “there are times they doubt you, you know.” (P-3, I-2) A female participant said that because she had been enrolled with the same health care provider “they believe it” but if she were to see a new health care provider “he wouldn’t believe it.” (P-4, I-1) Another participant said,

I don’t think, I mean she knows that I have pain but it’s like she’s never been through it so she can’t really identify with what I’m goin’ through yeah. It’s just like o.k. well I give you somethin’ mild and where I think I need somethin’ a little stronger to help me. (P-9, I-1)

One female participant shared that in less than one year, she had seen three different physicians, four or five different times and “none of the physicians gave me [her] a full exam.” The participant was told that she was constipated and she needed to “go home and have a bowel movement.” (P-7, I-1) She shared that once she was physically examined her diagnosis was polycystic ovarian syndrome. Another participant said it was difficult when health care providers acted like “they didn’t care.” (P-1, I-3) A male participant said he was told by a physician who was replacing his primary care physician for that day, “I just don’t see you in pain. You don’t look like you’re in pain.” (P-8, I-2) He added that he tried to explain to this doctor, “I was tryin’ to tell this other doctor that and I don’t know if he thought I was tryin’ to get some medication out there to sell, but it wasn’t me...they treat patients differently [by] the way they look.” (P-8, I-2) It was difficult for participants when they felt their health care providers did not believe them when they spoke about the intensity of their pain or how their chronic pain affected their lives.

One female participant shared, “like I wish my doctor would try a new medication

for pain. That would help too because I'm doin' my part and I need her to help me do her part." (P-9, I-2) She further explained that when she had asked her health care provider for stronger pain medication, she was told 'no' without an explanation regarding why she was not being prescribed additional pain medication. She was frustrated with her health care provider's lack of explanation and said, "you know and that's just like tellin' a child no. Why? ...'Cause I sayin' so...well that's not good enough for adults...we're grown, we're adults...give them an explanation as to why." (P-9, I-2) The participant discussed during a different interview that when she was told 'no' to the additional pain medication without being given an explanation from her health care provider she said, "and then you start thinkin' well may be they just bein' mean to me. Maybe they don't like me. All kind of stuff start runnin' through your brain because you already in pain, you know?" (P-9, I-3) She shared with her health care provider that she found the pain support classes helpful for her pain, but "what sense is it me havin' the pain classes. I gotta get to 'em." She said, "you know if the shoe was on the other foot it would be a different story." (P-9, I-3) She believed that if her health care provider had the type of pain that the participant was experiencing, that her health care provider would have another physician prescribe additional pain medication.

Another participant said that when he was at the health care provider's and he rated his pain as "9 or 10 that day" *on a scale of 0-10, where 0 was no pain and 10 would be the worst pain he could imagine*, he said his prescription for pain did not change. He said "they still goin' to give you the same prescription." (P-1, I-2) A male participant said that he tried to discuss with his health care provider about the severity of the pain and how often he needed to take pain medication. He said his health care

provider advised him about the correct dosage of his medication. The participant shared, “they tell me I can’t take, you’re not supposed to take two [pills], but I’m tellin’ you I have to take two [pills] at a time...I’m tellin’ you that but you’re not comprehendin’ what I’m sayin’...I’m hurtin’ you know.” (P-13, I-1) A female participant asked her health care provider why she should keep taking the pain medication when she did not feel that the medication was helping her at all.

One of the male participants discussed his frustration with his physician not prescribing him enough pain medication by saying, “I can’t understand why she bein’ a doctor and she know that a person’s sufferin’ she more scared of gettin’ in trouble by the government for writin’ the prescription and not doin’ her job.” (P-12, I-2) Another participant said that “the pain pills don’t do not good, you know?” She was concerned that her health care provider would say to her “well you’re abusin’ that’s why they not workin’.” (P-5, I-1) Participants said it was frustrating and exhausting to try and convince health care providers that they were experiencing chronic pain and that their current chronic pain treatment was not effective.

Participants said there were some family members and friends who did not believe the participants when they discussed their chronic pain. It was difficult when their pain was dismissed as being insignificant as chronic pain influenced every part of their lives. One participant said that she was “really tired” from having constant , chronic pain and when others asked her what was causing her to be so tired, she said, “I don’t even want to explain it, I’m just tired.” (P-2, I-3) Participants shared that there were others who did not believe that they experienced chronic pain. Participants emphasized, “the pains real you know” (P-6, I-1), and “I was hurtin’, real, real bad” (P-8,



I-1) but said that their family and friends did not believe they were having severe pain. Another participant described her pain, "It's like an 11 [on a scale of 0-10]." (P-10, I-1) One participant said, "because they look at me and then they say, 'oh there's nothin' wrong with you.' I say boy oh boy if you only could open me up and look." (P-2, I-1) When family members become frustrated with the participant because she was moving slowly or fell to the ground and they asked her "what's wrong with you?" The participant replied, "I done told you." (P-2, I-1) It was challenging for participants as others around them could not 'see' the pain and often thought that the participants were "making it up", 'playin' or 'faking' the pain to either be excused from an activity or to receive attention.

Often participants would not discuss their pain with others as the response from others was that they either 'forgot' that the person did experience chronic pain which limited their activities or they would say, "I don't want to hear about it right now." (P-7, I-1) Other family members would say, "she's just puttin' on and nobody in the world hurtin' that bad." (P-4, I-1) These responses or actions by others made the participants feel as though those around them "They don't even care" (P-2, I-3) or that they were being 'cruel'. One of the female participants discussed how her daughter reacted to her inability to move about freely by saying, "She thinks sometimes I'm just lazy. She cries. She was like 'I'm so ashamed of you...how can I take you somewhere people gonna be laughin' at you, my momma'." (P-5, I-1) A male participant shared how he and his wife would argue over his need to take pain medication; he described how challenging these arguments were by saying, "She say, 'you take these damn pills to get high.' I say I'm not, I'm hurtin', you just don't know I'm hurtin'." (P-8, I-1) He added, "she's sayin' I'm feignin', you know addicted, and there wasn't a problem. I wasn't addicted, I was

hurting'." (P-8, I-1) He said it was frustrating to be arguing with her over his need to take pain medication to be able to function in life.

Another participant shared, "It's like you have to be bandaged up and bleeding or somethin' to be in chronic pain." (P-10, I-2) There was a feeling of being 'judged' because others were not inside the participants' bodies to experience the pain. Participants said that it was challenging when the people they loved the most did not believe they were experiencing severe pain. Chronic pain also made it challenging to walk or climb stairs.

**Chronic pain's effect on walking and climbing stairs.** Participants said that chronic pain made it challenging to walk or climb stairs. Climbing stairs were particularly difficult for participants as they could only climb "four or five steps and I gotta sit and gotta rest before I start goin' up higher." (P-1, I-2) One female participant explained that if the elevator or freight elevator was not operational, she would have to "climb 119 steps" to reach her apartment. She said that as she climbed these steps she frequently needed "to stop...because my knee, my back, everything is fallin' apart." (P-2, I-2) Once she arrived at her apartment after climbing these steps, she said that her pain was severe and she would need to go to bed and rest.

All participants said it was difficult if an elevator was not functioning and they had to either climb up or down the stairs. They shared that their pain was exacerbated after climbing stairs. One male participant took a picture of the steps he would need to climb to reach his apartment located on the tenth floor. (P-13, I-2) (see Figure 23)

Figure 23. Challenges with chronic pain – Climbing stairs



“Those are the steps when the elevator’s down I have to walk up and down these steps 10 floors. Yeah have to gettin’ out of the building. It’ll stop somebody smokes on it, yeah they go down. Somebody’s movin’ they usin’ the elevator and you can’t get the elevator unless you just got to wait till they move.” (P-13, I-2, PV-1)

One participant said that stairs were so challenging for her that she would often not leave her basement apartment unless it was absolutely necessary, as she did not want to climb the stairs leading from her apartment and exacerbate her pain. If she did climb the steps, she would use the hand rail or railing on the side of the steps to support her while she climbs. She said that often her pain was so intense that she almost had to ‘drag’ herself up and down the stairs. (P-7, I-2) She explained that one time she was having difficulty walking down some steps and she was applying a lot of pressure to the railing for support as she was experiencing severe pain. She said the railing almost broke and she almost fell down the stairs. (see Figure 24)

Figure 24. **Challenges with chronic pain - Stairs and unsafe railing**



“That is the first set of stairs that I have to climb before I can even attempt to go inside the house. And although there’s not many there, but they are horrible. They are horrible. And this little rail over here. O.k. not too sturdy. Not too sturdy at all. And I was in pain and I was trying to hold onto it and it started wobbling. And I almost fell down the stairs.” (P-7, I-2, PV-1)

Photographs of stairs were the most frequent pictures taken by participants. Every participant took pictures of stairs, followed by the second most frequent picture, which were pictures of the inclines or slopes found in the sidewalks and roads. Participants said that chronic pain made it challenging for them to walk and mobilize from both within and outside of their apartments.

Participants shared that chronic pain made it difficult for them to walk. A participant explained, “I can’t walk across the street in 10 seconds.” (P-13, I-2) He shared that when the traffic light changed, he needed to push himself and rush across the street in order for him to cross within the time limit provided by the traffic light. He

said that by the time he arrived on the other side of the street, his pain had exacerbated because he had pushed himself to walk quicker than he was comfortably able to walk in order to cross safely. It was challenging for participants to walk across wide city streets in the allotted time provided by the traffic light. Participants would need to push themselves to cross the street in time and they would be tired and in pain. Often there would not be a bench for them to sit and rest upon after having rushed across the street. (see Figure 25)

Figure 25. **Challenges and chronic pain - Walking**



“This is the bus stop, nowhere to sit. Yeah lean on a pole or stand there and just take it... that’s the same corner. Just showing you how wide it is and the traffic. And they want you to walk across the street in 10 seconds.” (P-13, I-2, PV-1)

Participants shared that they preferred to walk “on flat surfaces” and on ‘cement’ instead of grass, as on cement they had more ‘grip’ because cement was ‘more solid’ for their feet. Another participant said that after walking only “half a block” he would have to “sit down and rest” because he would be “out of breath” and his “knees are achin’ so I gotta sit and wait” (P-1, I-1) for the pain to subside so he could continue. Participants often said their pain would make each day unpredictable in terms of their

ability to walk. There were times when they would be walking and without warning the pain would be so severe that it would cause them to ‘fall’ to the ground.

Participants shared that walking up inclines on the sidewalk was difficult. The slope of a road or sidewalk may exacerbate their pain as it was similar to walking up a hill. If their walks included sidewalks with slopes, it took participants longer to walk to places as they had to pace themselves knowing that they would need to stop and rest along the way. One participant was describing the walk he needed to take to “catch the bus” and shared, “then on the way back I get off at this same spot and it’s like an up-hill.” (P-8, I-1) (see Figure 26)

Figure 26. **Challenges with chronic pain - Slope on sidewalk**



“Remember I told you I had to go up and over. This is what I was talking about, you can see the angle. Yeah and this is not no little bitty bridge either. This is just part of it.” (P-8, I-2, PV-1)

Another participant took a picture of the walk he traveled each day. He explained that the overpass crossing the freeway was steep and challenging to cross. It caused him additional pain to have to cross the overpass. He said he stooped down to take the

picture (see Figure 27) so that the slope of the overpass would be captured in the photograph.

Figure 27. **Challenges with chronic pain - Steep overpass**



“The bridge you have to walk across to catch the bus. Yeah it’s smooth but see goin’ up it’s hard on my legs too. It’s like goin’ up a hill.” (P-1, I-2, PV-1)

Participants said that chronic pain affected every aspect of their lives and it worsened if they mobilized too much during the day. One participant said that he was told by his health care provider that due to deteriorating discs in his spine, he “might be in a wheel chair one day.” (P-13, I-2) He said that he was saddened by this future possibility as this would further limit his ability to mobilize and walk. Participants discussed other challenges they experienced with chronic pain including not wanting to be a burden to others.

#### **Challenges with chronic pain and feeling burdensome to others.**

Participants said that they did not want to become a burden to others. They explained that they tried to remain independent with their mobility needs and activities of daily living. At times they would push themselves to complete activities but by doing so, their pain was exacerbated. Participants did not enjoy relying on others for assistance, as

prior to experiencing daily chronic pain they were used to being independent with their lives. As one female participant shared,

I already have a hard enough time as it is getting somebody to just helpin' me and show me enough that they care so I won't have to be feelin' like I'm being a bother to people, you know. I'm used to doin' things and takin' care of people and helpin' people, not nobody helpin' and takin' care of me but now this is the position I'm in now due to this pain. (P-2, I-1)

One of the participants shared how she needed to ask her daughter "to do my hair for me now because I can't comb it and braid it like I used to because it hurts me, my arm."

(P-9, I-1) This participant did not want to ask her daughter for help as she "felt like I was a burden" because she said that as the mother, she felt that she should be fixing her daughter's hair. She said that she is "still reluctant about askin' her."

Participants explained that they needed someone to accompany them when they went grocery shopping as they could not carry the heavy grocery bags. Participants longed for the days when they were able to continue to be a 'caregiver' for others as this is the role they had performed prior to their chronic pain affecting their lives. Participants were frustrated by the challenges imposed on their lives due to chronic pain.

Some participants shared that while they always have pain, they knew that they had to limit themselves to what they could accomplish each day because if they pushed themselves or "did too much" their pain would be worse. Other participants discussed how they would 'force' themselves to walk around because they thought the exercise would help them. They were used to being active people and shared that they were not comfortable 'sitting around.' Another participant said that even though it was painful and more challenging for her to drive, she "had to do it" because either she or a family



member needed to attend an appointment. (P-4, I-3) One participant said that she forced herself every day to accomplish what she needed to do. She said, “I wish I could do more. I got up...I was in so much pain. I said to myself, just work it, just go. ‘Cause you goin’ to be in pain that’s just it...see brain wash yourself.” (P-5, I-2) She shared that sometimes her chronic pain was so severe that when she could not get out of bed and could not move, it was because of the pain.

Participants said that while they did not like to ask for help from others, that chronic pain affected all parts of their bodies. Participants explained that if their right hand experienced pain and they were dominant with their right hand, then they had to learn to use their left hand to complete tasks. One participant explained her situation by saying, “I gotta try and make this [hand] the strong one.” (P-2, I-1) She said that she often needed to remind herself of her activity limitations due to pain because if she forgot and forced herself to do too much, she would experience greater pain. “And I’m tryin’ to train my brain that you can’t do this or you’re going to hurt.” (P-9, I-2) Participants said there were other challenges brought on by the pain and it was frustrating that chronic pain affected their ability to complete activities of daily living.

**Challenges with completing activities of daily living.** Participants were asked to discuss if, and how, chronic pain affected their ability to complete daily activities. Participants shared that pain impaired their ability “to drive”, “hold a cup of coffee” (P-2, I-1), “use the restroom”, “pickin’ up things”, and “standing a long time.” Chronic pain also affected participants’ abilities with “washin’ up” and when trying “to rest.” Pain influenced their ability “to work” and putting on clothes, as they had difficulty getting dressed and could not pull their pants up over their legs “‘cuz they’re [legs are] too swollen.” (P-4, I-1)

One female participant said that she used to enjoy “dressin’ up”, “puttin’ on her jewelry and goin’ places.” (P-9, I-2) She added that she enjoyed fixing her hair, but she was no longer able to keep her arms elevated for extended periods of time, so “bein’ that I can’t hardly comb it, I put a rag on it.” (P-9, I-2) Participants explained that they had burned themselves while trying to cook and that sometimes leaving their home was exhausting due to pain. One participant shared that she when her pain was severe, she would remain in her apartment and look out of her apartment window and “see the people out there...and when I get tired of sittin’ I go lay down.” (P-2, I-1)

One participant said she used to pride herself on how spotless she kept her home. She shared that her chronic pain now affected everything she did, “You don’t want to do anything. It’s hard to keep the house up. It’s hard to do a load of laundry.” (P-10, I-2) She said that it now takes her several days to clean her home as she can only clean one room at a time and must frequently rest. The participant said that in the past she used to clean her home in one day.

Participants shared that pain made it challenging for them to get out and about. Pain kept them from “goin’ places”, “goin’ to festivals...goin’ on picnics...goin’ to church” (P-9, I-1), and ‘socializing’. One participant who used to enjoy going to recreational and other outdoor events said that due to pain, “I try to stay away from that.” (P-13, I-1) He explained that he would need to hold onto others when leaving his seat during a sporting event, as he may need assistance walking to the restroom and climbing up and down steps. He said, “I’m puttin’ my hands on somebody’s back to balance myself you know...and it took me a while to just accept it.” (P-13, I-1) He said that people were often not understanding of his need to place his hands on their backs for support. The

participant said that instead of possibly 'offending' someone by using their body for balance, he chose to not attend outside recreational events.

A male participant shared how he missed attending recreational events such as watching a sporting event, he added, "I used to play baseball. I don't do that anymore. Pain won't allow me to." (P-6, I-1) He said that due to pain he was not able to enjoy these recreational events as he experienced exacerbated pain, so instead he remained in his apartment. A female participant said that due to the pain limiting her mobility, that unless a store or park had the "electric chairs" that she could drive, she would not be able to enjoy these facilities. She shared that her family had visited the zoo and she wanted to join them but she was not sure if they had the "electric chairs" at the zoo. She was able to go to 'Wal-Mart' and shop "for hours" as she was able to drive an "electric chair." (P-5, I-2) The participant explained that when she went to the mall, she had to wait and "sit on a bench" while her family shopped as they did not have these special chairs for her to drive. If she had her own "electric chair" she would be able to "go places...go sightseeing...go down town...and stuff I like to do." (P-5, I-2) This participant said that her ability to go to different shopping centers was reduced due to her chronic pain.

One female participant explained that when her pain was severe it controlled her life and all of her activities. She was not able to complete her activities of daily living. This participant was a young woman and she felt that her life was limited due to her chronic pain,

It's gotten to the point where I was bed ridden for two or three days. Couldn't get up just pain, pain, pain, constant pain...once I'm in that pain I don't do anything at all. I just, I lay in the bed. I don't eat. I don't drink. I don't watch t.v. I just lay there and cry because it is so unreal...when it's that severe pain, I just lay in the

bed and cry. I don't answer my phone, when people call me... I don't want to talk because I feel like if I talk and then I'll be in pain more like if I get up and try to move around. The only thing that I actually do is get up and go to the bathroom that's it. And I go right back to bed and lay down. (P-7, I-1)

If they did have access to a vehicle, participants said that pain often kept them from driving their family members to events and enjoying other recreational activities. One participant said that while she did own her vehicle, it was older and did not have automatic windows or locks. When her hands were aching, not having automatic locks and windows for her car exacerbated her chronic pain. (see Figure 28)

Figure 28. **Challenges with chronic pain – Manual locks in cars**



“Oh this is just showing that I have manual locks, manual windows and that makes it harder too. Well especially without the AC. I can't reach the other side, I can't take that chance. [The participant is referring to how she does not reach over to open the passenger window while driving.] I come in here on the freeway with my window rolled all the way down. ...the manual roll down window 'cause everybody assumes everything is automatic and it isn't.” (P-10, I-2, PV-1)

Another participant explained that she used to 'crochet' and “play cards and dominos” but she was not able to do this anymore because of her pain. She said that she still enjoys 'watchin' others play, but she is not able to participate. (P-2, I-3) One participant explained, “I thought I was still able...I'd keep myself active, I should be able to do the

same things I do. I'm not one to sit around you know...I was very busy." (P-3, I-1)

A female participant shared that it was frustrating for her that because of the pain in her hands and back, she could not hold her grand kids, "I say grandma can't hold you it hurts, they be lookin' at me like, 'well what are you talkin' about, you know, grandma supposed be able to hold us'." (P-2, I-1) She added that her grand kids wanted to spend time with her but it was difficult for her to care for them as she had difficulty caring for herself. She said, "My little granddaughter she wants to be with me but I tell her, I say 'Grandma can't handle you. I say I can barely get myself together'." (P-2, I-1) Another male participant said that his grandsons wanted him to play football with them, but he was not able to play with them. He explains, "My grandkids, they see me sometimes and [say] 'you must be hurtin' granddad'...so I can't hold that against them either. They always say 'I hope you get better granddad'." (P-6, I-1)

One of the participants described additional challenges brought on because of chronic pain. Chronic pain made it difficult for her to open "jars, bottles" and sometimes she had difficulty "opening my own car door and closing it." (P-10, I-2) She was afraid to ask for help as she did not want to lose her driver's license. She explained that she had to change the type of clothing she wears so that it would be easier for her to put on her pants independently. Her pants now had "elastic waist bands." She also shared that sometimes the pain was so severe in her arms, that it was difficult for her to reach behind and properly clean herself after she went to the washroom. (P-10, I-1)

A female participant described how her family would ask her to return home with a "gallon of milk", but that she needed to remind her family that she could not carry such a heavy load now due to the pain in her hands. She shared that her family members

were used to her “bein’ the way I used to be” as she was always the person in the family “that’s carin’ for others.” (P-9, I-3) She said she was no longer the caregiver in the family and required help for herself.

Another participant shared that “tears go to rollin’ because I get overwhelmed because I’m used to doin.” (P-2, I-1) Another participant said that she would like to attend the pain support group that was offered at the clinic, but sometimes she was in such severe pain that it was too difficult for her to go to the class. She said, “Cause sometimes I done miss some of the pain classes because I be in too much pain to walk to the bus stop. And I can’t stand up there and wait for the bus to come to the classes.” (P-9, I-1) Participants described the challenges they experienced with sleeping and their ability to prepare food due to chronic pain.

**Challenges with sleeping and preparing food.** Participants shared that pain affected their ability to sleep and their ability to prepare food. Participants said they could only rest for a few hours each night and not really “go to sleep”, and as a result they were often “noddin’ through during the day.” (P-1, I-1) One participant said that falling asleep was “the hardest part” (P-7, I-1) and once she was asleep she would wake up in the middle of the night in pain. There were times when she would wake up at 2:00 in the morning and she would not be able to “go back to sleep.” Another participant said that if he did not force himself to go to bed and try to rest, he would be awake all night.

Participants discussed that if they did not sleep well during the night that they knew their pain would have greater intensity the next day. They shared that due to their chronic pain “everybody asleep but me” (P-8, I-2) and another, when discussing the

challenges of chronic pain affecting her sleep said, “It’s a really miserable night, I’m just totally exhausted.” (P-10, I-1) Another female participant said that she slept “sitting in the chair” so that she could “prop my [her] foot up.” She was concerned that by sleeping in this manner, that she was not receiving adequate sleep at night.

Participants described how chronic pain affected their appetite and ability to prepare food. Participants said they needed to have ready-made snacks or foods that were easy to prepare in their homes. Participants explained that many of their medications had to be taken with food; especially their pain medications. They explained that they needed to eat something quickly in order for them to take their pain medication. (see Figure 29)

Figure 29. **Challenges with chronic pain and preparing food**



“O.k. this is my microwave that I use to prepare my frozen meals. I put them in the microwave to prepare my frozen meals. And the cereal. It’s something fast that I don’t have to be standin’, cookin’. This is my fast meals. So this is how I prepare my frozen meals in the microwave.” (P-9, I-2, PV-1)

Some of the participants said that they had “learned the hard way” by taking their pain medications on an empty stomach and then experiencing stomach pain. They now made sure that even if it was the middle of the night that they ate something prior to

taking their pain medication. It was difficult and challenging for participants to stand for lengthy periods of time to prepare food, so they ate foods that could be toasted quickly such as 'Eggs'; eaten cold, such as 'cereal'; or heated up in the microwave such as "boxed potatoes." One participant said he was concerned about his diet and that he was not "getting' my right vitamins." He further explained, "I know my diet is not up to par and I wish it could be but I know I'm not able, I'm not able to do it on my own." (P-3, I-1)

One participant said that chronic pain made it challenging for her to open cans of food. She said her diet consisted of canned foods, but that she would require help opening the can "if I don't have a pop top." (P-2, I-2) Another said that when she was experiencing pain she did not want to move to prepare food, so often she would not eat "when I'm in pain." Another said, "I don't have an appetite" but she knew she had to eat in order to take her pain medications. (P-2, I-3) A male participant said that he purchases "stuff that's already made that you can just, just pull it out and put some hot water, boil some hot water." (P-3, I-3) One participant said "you know I'd be hurtin' so bad I just don't eat. I'll wait till the pain eases up." (P-4, I-1) Another said, "What I do, I buy frozen foods and I stick it in the microwave." (P-9, I-1) Participants said that chronic pain influenced their memory and ability to concentrate. They shared that their pain was so omnipresent that it was difficult to focus on anything but the pain in their lives.

**Challenges with concentration and health care instructions.** Participants shared that chronic pain caused other challenges in their lives. Chronic pain affected participants' abilities to think and concentrate. Some shared that pain made them forget to follow up with certain daily routines in their lives and they had to write information down to help them remember. One participant said that she had difficulty remembering



to take her blood pressure medication and she would either not take the pill or take the pill twice “I forget in a minute...it’s a big difference. Real big difference and that pain is makin’ me forget.” (P-2, I-1) Another participant lost her medications and she had to go to the pharmacy to see if she could obtain additional medications “like my brain’s everywhere. It’s just scattered. I can’t think straight.” (P-7, I-1) Another participant said, “You be in so much pain you can’t think” (P-1, I-1) and “I concentrate on the pain all the time, I don’t remember what I ate yesterday.” (P-13, I-2) A female participant said, “When the sharp pain hits you...you know you put your mind back on your pain and lose concentration on what’s you was doin’.” (P-4, I-1)

Chronic pain made it challenging for participants to concentrate on other areas of their lives. It was often “a big effort” to remain focused on the current task they were trying to finish. Sometimes waiting during health care appointments was difficult if they were experiencing extreme pain. Participants said that all they could think about during the health care appointment was the pain and “let me get out of here.” One participant said that the pain made it difficult for her to follow-up with the instructions given to her from her health care provider. She shared that she would try to listen, but her mind was on her pain. She said,

It do defocus you. Yes it does. It really does ‘cause it be hurtin’ so bad all you can, your mind is right there on it, you know you’re seein’ ‘em talk but you’re not hearin’ ‘em. Now because of this you’re hurtin’ so bad. Yeah I done that route yeah, oh yeah. I done been that route plenty of times. (P-4, I-1)

Another participant said that if he did not write everything down, he would not be able to remember any health care instructions given to him during his appointment. He said,

‘Cause when the pain comes I’m really not concerned about nothin’ else but that pain... I’m not concerned about what I got to do...The only thing my mind is on is pain. I can hear you talkin’ to me but it’s in one ear, out the other...You know I’ll

say 'what did you say?' Yes, I just answer anythin' you know. (P-6, I-1)

Participants discussed the difficulty they experienced when trying to hear or understand the instructions given to them by their health care providers when they were focused on their chronic pain. As one participant explained when he was asked questions by his health care provider and he was experiencing chronic pain, he said, "I just answer anythin' you know." (P-6, I-1)

Added to the difficulty of concentrating when experiencing chronic pain, was the challenges of following up with the instructions given to them from their health care providers. One participant shared that she had been given exercises to do at home when she was in pain but "I don't fulfill it because I don't have no support doin' it." (P-2, I-1) Others were told that they just needed to 'exercise' or 'walk' and maybe the pain would go away. Participants said that it was walking and climbing steps that exacerbated their chronic pain so it was difficult for them to follow these instructions.

Another male participant said that he was instructed to elevate his legs during the day, but as he shared, "if I put my legs up in the air which I supposed to, it make it hurt worser." (P-12, I-2) Another participant said that he had been instructed to elevate his legs, rest during the day and no heavy lifting, but he explained that realistically in his life, this was difficult to do. (P-1, I-2) The participant said he did not have "outside support" from other people, so he had to do things himself. Another said his "doctor don't want me to be on my feet no more than three hours a day. Don't want me to pick up nothin' over ten pounds." (P-12, I-2) He said he tried to follow his health care provider's instructions, but he could not follow the instructions exactly as they had been given to him.

Participants described the challenges they faced due to their chronic pain. They shared that chronic pain affected their ability to walk, sleep, prepare nutritious meals and complete their activities of daily living. Participants discussed how they would push themselves to do more, even if it exacerbated their pain, as they did not want to be a burden to others. Participants described how they needed to negotiate their pain while living in a vulnerable environment. While living in these environments, participants were exposed to poverty, loss and violence. There were times when participants did not feel safe and this added stress exacerbated their chronic pain.

### **Negotiating Pain in a Vulnerable Environment – “blessed to still be alive...” (P-2, I-2)**

Participants in the present study were indigent and they described the environments they lived in, the violence they witnessed and how poverty influenced their chronic pain. Participants described also feeling that the environment around them was potentially threatening, as by others knowing their ‘handicap’ they may be potential victims of crime. These feelings of reduced safety influenced participants’ by making them more fearful about leaving their apartments. Participants also described how their surrounding environments and neighborhoods were not maintained by the ‘city’ therefore adding to participants’ stress and causing increased chronic pain. Participants lived in vulnerable environments that were difficult to negotiate; and added to these stressors was the participant’s chronic pain.

Words used by participants to describe their chronic pain suggested prior episodes of stress and loss. One male participant shared, “My pain evolved from an assault...I was hit in the head with a bottle of beer and a pipe.” (P-13, I-1) Another

participant described her chronic pain “like somebody beat me up and I’m recovering you know from the blows that they hit me.” (P-9, I-1) One of the female participants who was 49 years old, was discussing her youngest daughter’s upcoming birthday and this participant shared that she felt “blessed to still be alive to see these birthdays.” (P-2, I-2) This was such a powerful statement as the participant is not much older than the researcher but the participant shared that because of her chronic health concerns including chronic pain and her current living environment, she felt blessed to still be alive to see her daughter’s birthday. Other individuals outside of the study may state that they hope to experience greater longevity in terms of number of years to live, but this individual had a different mindset towards longevity in life due to her chronic pain and the compounding factors in her life. Participants described how they negotiate their chronic pain from within their apartment.

**Negotiating chronic pain inside the apartment.** Participants said that chronic pain made it difficult for them to leave their apartments or for them to move around to different areas of their apartment. This reduced ability to negotiate their surrounding environments was stressful for participants and increased the intensity of their chronic pain. A female participant took a picture of her surrounding environment in her apartment. This participant took a picture of what she views when experiencing severe chronic pain and she is not able to negotiate the environment around her. This limited ability made her feel ‘sad’ and added to her pain. She discussed her reality with chronic pain. (P-7, I-2) (see Figure 30)

Figure 30. **Negotiating pain in a vulnerable environment - View when cannot get out of bed**



“This is a personal picture. This is one of those days where pain was there and I didn’t clean up that day. My momma always taught me to clean up before you go to bed because you never know what might happen in the morning. And this where her words were ringing true in my head. It’s like if I woulda cleaned up last night I wouldn’t have to look at this. I can’t go anywhere. My stomach is still sore, I can’t get out of bed and this is what I have to look at. It’s kinda depressing it’s almost like yeah this is adding to the situation.” (P-7, I-2, PV-1)

Chronic pain limited participants’ abilities to participate more actively outside of their homes. Participants provided other examples where reduced finances and chronic pain limited their ability to negotiate their environments.

**Negotiating pain with reduced incomes.** Chronic pain combined with living with reduced incomes influenced participants’ ability to seek employment and therefore limited their ability to purchase needed items to help them with their chronic pain. Participants discussed some of the challenges they had with pain care when living with

reduced incomes. Participants said they often did not have enough money to be able to pay for medications or to be able to afford the transportation to attend health care appointments.

One participant said that her chronic pain made her depressed as it prevented her from working and earning an income, she said,

It's all depressing, I don't even really need a rag just give me a bucket put it over my head and just let the tears just drop down in the bucket because look I'm 49, I still have retirin' years to come but I'm not able to do what I set out to do. (P-2, I-1)

She added, "I've missed so many appointments because I don't have the transportation. No bus fare 'cause I don't have income." (P-2, I-1) Participants said that they either could not afford the bus fare or if they did have their own vehicle, they did not have enough money to put gasoline in their cars.

Participants said that they thought 'therapy' would help reduce their chronic pain, but they could not afford to pay for it. Participants also said that they often did not have the money to get a "prescription filled" so they "just got to do without" (P-1, I-1) the prescribed medication. Another participant said that she did not have "the dollar to pay the co-pay for my medicines." (P-2, I-3) She shared that she had "lost my job so I couldn't afford the medicine anymore and that's when it just became constant, just like every day, every other day tight pain." (P-7, I-1) Another individual was concerned as her "heart medication" was not covered by her insurance; a 'generic' form of the medication was covered, but not the medication that was ordered by her health care provider. She said,

It's not covered with that insurance so if this medicine is life and death to me where am I suppose to get the money to pay for this prescription? It's life and death to me but [what] I got to do is come through emergency. (P-2, I-3)

Participants shared that some of the over-the-counter pain medication helped reduce their pain, but they often could not afford to take the over-the-counter medication so they often did without.

One female participant said, "By me not havin' finances...I wasn't even able to make enough quarters." She further stressed, "I'm not crazy, I'm just depressed at times because I need to work. I need money." (P-2, I-3) She further discussed that because she could not afford many of her medications, this added to her stress which increased her chronic pain. She said she wanted to work, but if she were to pick up an application for a job and she was carrying her cane, walking with a limp and holding onto her painful back, she said she was a liability to the company and no one would hire her. It was particularly frustrating for participants to not be employed "if I could work I'd be at work." (P-2, I-1) Living with reduced incomes exacerbated the chronic pain experienced by participants. Participants said it was stressful to not have enough income for pain medications or other treatments that may have helped reduce their chronic pain.

Participants described other challenges with income that limited their abilities to negotiate their environments. Participants shared that within their apartment buildings, it was difficult for them to control the environment around them. Lacking control over their environment increased participants' stress which exacerbated their chronic pain. Some of this lack of control was due to their limited income and the need to live in environments that offered low-income housing.

A participant shared how her mother was staying with her but “luckily she [her mother] did not need to take a shower...[as] the gas was shut off” (P-10, I-2) due to unpaid bills. She said that her pain made her take longer to get washed up and as a result her “water bill had gotten so high because I [she] was taking longer in the shower.” She was concerned about “how am I going to make this payment... and pay the mortgage.” She shared that when she was employed she used to enjoy having her family over for dinner, but now she was on a ‘tight’ budget. She was applying for ‘disability’ but she had “been denied three times.” She said she was still “grateful for what I [she] has” but she wanted to become “independent like I used to be” (P-10, I-2) when she was employed full-time. The participant described that she was tired of borrowing money from the “credit cards” and from “the credit union.” Her lack of income made her environment more challenging and exacerbated her chronic pain.

Living with reduced incomes added stress to participants’ lives, as they were concerned about housing. One participant shared that if it were not for his mother, he did not know where he would be living. Another participant said that she had “been financially embarrassed for, forever” and it was difficult for her, as she did not “have what you need.” (P-2, I-3) This lack of control over her needs exacerbated her chronic pain. Another female participant described how in her past, “I had some downfalls and I went into a shelter.” (P-5, I-1) Participants discussed the condition of the buildings they lived in; some buildings had elevators that were not operating, other buildings were damp and had mold and mildew on the walls or were infested with bedbugs. One participant shared that her building had so many infestations with bed bugs that she had to throw out her box spring and mattress and purchase an inflatable mattress. She said



she could not afford to throw out her mattress and her mattress was more comfortable for her chronic pain, but due to the bug infestations, she had no other choice. (P-2, I-2)

One female participant shared that she lived in an apartment building where the elevator was not functional and the “owners only run” the freight elevator during certain times of the day. (P-2, I-1) As described previously, not only was it difficult for participants to climb stairs due to chronic pain, but the stairwells in the apartment building did not have air conditioning and during the summer the temperature in the stairwells was hot and muggy. The participant shared that a friend of hers had died after climbing the steps in the heat. She said that it took “30 minutes” for the ambulance attendants to help her friend as they needed to find someone to operate the freight elevator. The participant said that she wanted to complain about the ‘owners’ of the building and how they did not run the elevator as often as they should, particularly during emergency situations. She said that she tried to ask other tenants to join her with her complaint, but other tenants in her building were afraid to complain about the inadequate elevator services. (P-2, I-3) She explained that other tenants were afraid that the landlord would “put them out” or evict them. She described that the next time she was experiencing severe pain and the freight elevator was not functioning she was going to “call 911” and ask the ambulance attendants to take her up to her apartment. The participant shared that she was concerned about exacerbating her chronic pain and because of her pain’s influence on her health; she was concerned about climbing the steps in the heated stairwells to her apartment. She said she would “call 911” and tell the operator “there’s no elevator and I want to go home.” (P-2, I-3)

Another participant explained that due to her limited income, she lived in a

downstairs basement apartment. The basement had previous flooded and her apartment was cold and damp. The participant said the stairs she needed to descend to get to her room were steep and did not have lighting. Not only was climbing these stairs painful for her but she was concerned about her safety and falling down the stairs. (P-7, I-2) (see Figure 31)

Figure 31. **Negotiating pain in a vulnerable environment - Income limiting safety**



“But this is actually the first flight and I don’t know if you can tell but these are steeper. Yes, those are, I have but, there’s not a light on the stairs. So if I don’t leave my room door open. With the light on. I have to feel my way down the stairs and they’re so steep that when you step out and try to feel for the next one you gotta almost commit to going down without even seeing the stair. I hate those stairs. Absolutely hate em.” (P-7, I-2, PV-1)

A female participant shared that she used to be homeless but now she has her own apartment. Her pain is exacerbated though with her new living conditions, because

her daughter and baby grandson have moved in to live with her. She explained that her daughter is always 'out' and wants her to take care of the baby. The participant experiences stress as her daughter is not seeking employment. The participant also shared that she does not have any privacy as the "baby's daddy is runnin' in and out of my [her] house." (P-2, I-3) She said that the added stress of not having her own privacy and personal space increased her chronic pain. Participants discussed how the resources in their surrounding environments influenced their chronic pain.

**Resources in their environment.** Participants described the resources in their surrounding environments that influenced their experiences with chronic pain. The resources either made it easier or more difficult for them to negotiate the world around them while they experienced chronic pain. Participants said the resources provided by the Salvation Army van were helpful, as the Salvation Army delivered sandwiches or soup once a day throughout the neighborhood to those in need. Some participants relied on the Salvation Army for their meals. Participants might also attend a soup kitchen located within a local church to obtain their meals. One participant said that he appreciated the food services provided by the Salvation Army as he was able to obtain a nourishing meal that he was not able to prepare for himself. (P-3, I-3) If it was not for these food services, this participant said he did not know what he would be eating.

Participants discussed that the urban city where this study took place has a new bus terminal that was built just a few months ago. The new bus terminal was described by several participants as being helpful, as participants did not need to stand out in the rain or snow while waiting for the bus. Participants said they could now sit on one of the covered benches, as an overhang had been built so that participants would be

protected from the rain or snow. Another help to participants was when the ‘city’ fixed some of the bus shelter benches at bus stops. Participants said that the ‘city’ constructed partitions along the bus stop benches. These partitions were helpful as they could now find a place to sit and rest when they went out for a walk in their environment. Prior to having the partitions, ‘homeless’ individuals would be sleeping on the bus stop benches and participants could not find a place to sit and rest. (see Figure 32)

**Figure 32. Negotiating pain in a vulnerable environment – Helpful resources such as benches at bus stops**



“This is the bus stop where we can sit down. And wait on the bus. They used to have longer benches but people were sleepin’. The homeless people were sleepin’ on the inside. So what they did they sectioned ‘em off. Where a person just can sit.” (P-9, I-3, PV-2)

Some places outside of their apartment buildings lacked resources and were not helpful, and this increased participants’ chronic pain and stress. Participants shared

that at some bus stops, if there was a bus shelter available to them as they waited for the bus, most often the windows in the shelter would be “busted out.” If it rained or snowed, there was little protection from the elements of the weather. As one participant said, “if it’s rainin’ you just out there.” (P-1, I-2) Another participant shared, “I want to show you a picture of this bus stop. There’s no shade, no trees, nothin’ and they [busses] run one time, one every hour you know.” (P-8, I-1) (The picture could not be included as there were other individuals in the picture and an informed consent had not been obtained from the individuals granting permission for us to use the photograph.) Without a bench or shelter at the bus stop, participants would need to stand with their chronic pain for at least “30 minutes” in the hot sun. Participants said there used to be benches and bus shelters at all of the bus stops but the city removed them as people would “tear them up.” Participants said that many of the bus shelters and benches were removed by the city as “they tired of losin’ money.” (P-13, I-2) The city removed some of the benches and bus shelters so they would no longer have to replace them when they became damaged.

Participants lived in vulnerable neighborhoods with reduced resources. Chronic pain added to the challenges faced by participants. Participants said they did not leave their apartments as often, due to their concerns of not feeling safe in their surrounding environments. Participants shared that their chronic pain made them feel more vulnerable in terms of their personal safety. They would not go out walking at night and since some participants needed to carry a cane, they felt that they were seen as easy victims, as they were only able to walk slowly. One female participant shared an experience she had while walking across a busy intersection “‘cause these two guys

comin' cause I'm thinkin' oh wow they might try to...see me with the cane, they might try to rob me, snatch my purse or anything." (P-5, I-2) Another participant discussed that while she appreciated having a 'handicap' license plate so she could park closer to the door and would not need to walk long distances to the front entrance, she felt that the license plate only "advertised my handicap." The participant said the license plate made her more vulnerable to being 'attacked'. (P-10, I-1) She shared that feeling vulnerable toward being attacked was 'stressful' and made her less likely to travel outside of her home. These increased feelings of stress exacerbated her chronic pain. (P-10, I-1)

One of the participants who always travelled by city bus, discussed that the city was contemplating reducing the number of busses each day and possibly stopping bus services on Sundays. If this did take place, the participant would need to remain at home in his apartment on that day of the week. (P-3, I-2) His ability to travel outside of his apartment would be reduced on the days the busses were not running. Participants described how the environments in which they lived exposed them to poverty, loss and violence. Participants provided examples through words and pictures of these vulnerable environments.

**Vulnerable environments – poverty, violence, loss.** Participants discussed how the vulnerable environments they lived in exacerbated their chronic pain. They said that due to having decreased income, the places they were able to reside needed to be within their financial 'limit'. At times there were occurrences that took place in their environments that increased their stress and therefore increased their chronic pain. It was difficult to negotiate pain in these stressful environments.

Participants described the condition of the streets and sidewalks they traversed when attending events outside of their apartments. Participants described that many of their city streets were in need of repair but were never resurfaced by the city. The streets had many potholes, cracks and missing cement. Participants explained that potholes in the street were painful, as they may trip over potholes as they attempted to walk down the street. If a person was traveling by car and the car drove over a pothole, participants said that this was painful for them. The car would bounce in the pothole causing their bodies to jar from the sudden movement. (see Figure 33)

Figure 33. **Negotiating pain in a vulnerable environment – Potholes in the street**



“And this is the pothole that I hit every time I get in the car. I have to again go around as you can see and that really and it bounces my whole car. And they won’t fix this stuff up for nothin’. I got to bounce up that side street to get to 7 mile and it’s all these. You steady, constantly bouncin’ and that hurts.” (P-4, I-3, PV-2)

Participants described events that took place in their neighborhoods and surrounding environments which increased their stress and exacerbated their chronic pain. One participant shared how each day he went for a walk and for the past few weeks, there was a street pole lying on the sidewalk. (P-8, I-2) The participant has had

to walk around the street pole. (see Figure 34) It was frustrating to him as he said the 'city' had not fixed the street pole and instead left it lying on the sidewalk. He said that people have had to walk around the fallen pole for weeks.

Figure 34. **Negotiating pain in a vulnerable environment – Forgotten street pole**



“See the street pole done fell down and they ain’t even took time to pick it up.” (P-8, I-2, PV-1)

Participants shared that living in environments surrounded by disarray or decay was upsetting to them. One participant took a picture of a road that had deteriorated and had not been fixed in months. (P-4, I-3) (see Figure 35) Participants said that when their surrounding space and environments were not maintained “by the city” it added to their feelings of stress and exacerbated their chronic pain. Abandoned homes were vandalized and not demolished, streets were not repaired or repaved and this added to the pain disparities experienced by participants.



Figure 35. **Negotiating pain in a vulnerable environment – Deteriorated streets**



“And it hurts me really bad to have to live around this. You have to live around this. Yeah I fell right in that hole.” (P-4, I-3, PV-2)

One participant shared a story of loss during a time when she was homeless. She said when she “was homeless” and she did not have anywhere to store any of her belongings. Due to the inability for her to store her belongings, she gave them to her son for him to keep until she could find a more permanent place to stay. Her son did not keep track of her belongings and as a result, she lost them all as she believes they were “set out for the rubbish day.” (P-2, I-3)

This female participant added that during the time that she was homeless and needed to sleep “in my [her] car.” She said one morning when she woke up after spending the night sleeping in her car; she noticed that her legs were swollen. When she went to the hospital, she was told that she had experienced a “heart attack” while she was asleep. (P-2, I-3) She explained that she now has her own apartment and a friend who occasionally stops by her apartment to help. Her friend was recently assaulted when a stranger “took an iron pipe and hit her across her face.” The friend is

recovering from her assault and is not able to assist the participant at this time. This ongoing potential for violence in her neighborhood exacerbated the participant's chronic pain. Another participant described an experience of when she was walking in her neighborhood and she found a newborn baby in an abandoned building. (P-4, I-3) (see Figure 36)

Figure 36. **Negotiating pain in a vulnerable environment – Finding newborn in an abandoned building**



"This pictures right here makes me hurt worser because you know this is the house they found that little baby in and I tripped. That's why my friend boarded that up, I fell goin' up there when I heard this little baby in there cryin' and all the windows were broken and I said 'look it's a baby in there' and I fell that's how I messed up my right leg. I never want to get this house and boarded it up and they spray painted that junk on there and the baby survived. They had dumped a new born baby with the cord still on it. You know a year or so ago and I've been callin' the city they need to do somethin' about these houses and I fell goin' up there and pow, my knees just crumbled so I'm never goin' to forget that. Well, we heard it me and my friend were walkin' and we heard 'whay, whay' so we said that's a baby and I ran 'cause you know I want to see and pow and there was a little baby wrapped up in newspaper, bloody newspaper. Whoever had it just had that baby. It was 'whay' in bloody newspaper. So I called the police. And they came and took the baby and I ain't heard no more from it." (P-4, I-3, PV-2)

One of the male participants shared how he had been invited to a friend's home for a visit and his friend's neighbor had a pit bull dog that was not on a leash. The pit bull came over to his friend's home and the participant felt nervous about the dog being

around them. He said his friend “pulled out his knife, he pulled out his knife...’cause he know the dog’s going to attack him.” (P-3, I-3) He said that the neighbor who owned the dog was upset that his friend “pulled out his knife.” The participant said when referring to the neighbor, “I’m like what’s wrong with you, you know what I mean, I mean you ain’t wrapped too tight, I mean damn man that’s how incidents happen with people.” (P-3, I-3) This participant described his environment and the potential for violence occurring in his neighborhood.

One participant took a picture of an event that took place two doors from her home. She described the event somewhat matter of fact, calmly and with a flat affect, as if this was a common occurrence that took place in her neighborhood. She described how she and her neighbors cleaned up the blood on the sidewalk after a child had been the victim of a drive-by shooting. (P-4, I-2) (see Figure 37)

Figure 37. **Negotiating pain in a vulnerable environment – Drive-by shooting**



“Oh no this what that is. This is where the girl got killed and she didn’t die. A week or so ago, the 13 year old girl that got shot...between the eyes. That was right here. That was right here and my house is the 1<sup>st</sup>, 2<sup>nd</sup> house and this is where we clean the blood up. You know what there was so much down there, we clean it up.” (P-4, I-3, PV-2)

Participants' lives had many examples of loss, poverty and violence. The descriptions and pictures shared by participants were only some examples of a lifetime of stress. Participants described how chronic pain influenced their ability to negotiate the environment around them. Participants said it was stressful to live in environments that were outside of their control. Vulnerable environments increased feelings of stress which increased participants' experiences with chronic pain. Even though participants lived within these vulnerable environments, with multiple challenges and stressors, participants wanted to share additional thoughts about chronic pain. Participants wanted to add to the present study by sharing their advice and wisdom with others about chronic pain. Participants wanted to provide advice to others living with chronic pain and to health care providers who care for patients with chronic pain.

**Sharing Wisdom about Chronic Pain – “...try to put their selves in our situation.”**

**(P-9, I-2)**

Regardless of the challenges they faced, participants wanted to share with others advice about chronic pain. Participants wanted to discuss their thoughts and insights since chronic pain influenced all aspects of their lives. They were experts of their chronic pain experience. Participants provided advice to others living with chronic pain and to health care providers when providing care to patients with chronic pain. In providing this advice, the words further help to enhance our understanding of the experience of chronic pain for African American indigent adults.

**Advice to others about living with chronic pain.** Participants had much experience with chronic pain and offered to share their wisdom with others who were living with chronic pain. Some participants said they were struggling daily with pain and

could not offer advice, except to let others know that they were not alone in their experiences with chronic pain. One participant said, "I can't tell them nothin' to help them out...because pain, people experience pain in different ways." (P-5, I-2) She added, "some days you take that medicine it don't even work." (P-5, I-2) One participant said, "I don't know how to make it better, I'm just tryin' to survive goin' through pain that's all. They should find a way. I can't find a way, I don't know." (P-1, I-1) Another participant provided a similar response "I don't know because I don't even have the answer for myself" (P-12, I-2) and another added "I wish everybody never have the pain." (P-6, I-2) While some participants were not able to offer advice to others with chronic pain others did offer their thoughts and insights.

Other participants did want to share their wisdom with other people living with chronic pain and said, "you just have to deal with it", "just take it easy" (P-4, I-3) and "exercise...read...do hobbies" to take your mind off of the pain and try to attend pain "support groups." (P-9, I-3) One of the participants said that he did know "more about it [chronic pain]" as he was living with it "I think that helps a great deal for somebody that hasn't been through it." (P-3, I-1) He said he did think that those who currently live with chronic pain have greater understanding of what others with chronic pain experience. Another participant said that people might have greater mobility if they exercised while taking a hot shower, "Your range of motion might be a lot better when it's up under that hot water." (P-2, I-2) Other participants said, "stick with your medication and pray", "don't let it take over your life...because it will and it will affect everything if you allow it too" (P-7, I-2) and "try and do the best you can with what you got." (P-3, I-3) Another

participant discussed how she shares lessons she has learned from her previous use of illicit drugs with others. She said,

The younger crowd, I tell 'em, 'don't use drugs and you know this is the outcome of my drug use...you want to end up like me go on and use but if you don't want to end in pain like me, don't use. (P-4, I-2)

Another participant said that a person with chronic pain had to do “what’s best for them”, she added, “the one’s that’s in chronic pain are different from the other people.” (P-9, I-3) This participant believed that unless a person was experiencing chronic pain, it was difficult for that person to empathize with another person living with pain. A female participant said that a person just has to “deal with it...I talk to my pain, please stop, just stop for a moment. You know that’s what I do. I pray and I talk to the pain.” (P-4, I-2) Another participant said, “Pray that it don’t get worser and do the best you can...if it get worser you know people may want to die so you know what I mean.” (P-6, I-1) One participant shared, “just find that one thing that can take your mind off of it and allow it [too].” (P-7, I-2) A male participant added, “get up and try to do something yourself...I found out I was makin’ myself feel sorry for myself and not only that, makin’ my family miserable too.” (P-8, I-2)

A participant shared his thoughts by saying, “try to get something for it so you won’t be painin’...try not to let it get you down.” (P-6, I-2) One female participant added, “And get a doctor or a nurse that understands. Or try to understand what we’re goin’ through.” (P-9, I-2) This participant believed that a supportive health care provider made the difference in terms of receiving adequate pain care. She said it helped to have someone with whom she could discuss her challenges with chronic pain; and possibly

offer other treatments which might help reduce the intensity of her pain. (P-9, I-2) Participants offered advice to health care providers when providing care to patients living with chronic pain.

**Advice to health care providers about improving chronic pain care.**

Participants had several suggestions to give to health care providers about how to better help patients living with chronic pain. Some participants said, “they need to listen to patients”, “they need to find more treatments” (P-1, I-1), health care providers need to do “more of this research” and “you got to listen to your people.” (P-2, I-2) One participant added, “I find most people that when they are in chronic pain most of the time they pretty much honest about their pain you know.” (P-11, I-2) One female participant shared, “just do the best you can for that person. I mean there’s only so much you can do for a person in pain even though they have medicines or whatever, it wears off and the pain comes back.” (P-2, I-1) Another said, “When there’s someone coming in constantly, constantly comin’ in and you’re talking about the same pain over and over again... look into it more.” (P-7, I-1) This participant had been to several physicians for the same physical complaints and it was only after many office visits that additional tests were ordered and she was provided with her current diagnosis.

Another participant shared how it was ‘frustrating’ as health care providers would give him a prescription and tell the participant that the pain medication they prescribed should be effective for his pain. The pain medication was not effective at reducing his pain he said, “I’m the one takin’ the pill, I’m the one in the pain...they goin’ by what the book says. Well what about what my, what my body’s tellin’ me.” (P-1, I-2) He said he wished that health care providers would work with patients especially if their current

pain medication was not effective in reducing their pain. Another said, “you have tons of people but you gotta as you have your patients, you gotta take time with each one.” (P-2, I-2) One participant said, “try to find a cure to stop the pain...without takin’ medication.” (P-4, I-1) Another participant shared,

I would recommend that they try to put their selves in our situation. To try to say o.k. if that was me goin’ through the pain that she’s going through what would I do to help her you know and maybe that would help us more, make us feel more like that we have someone there that truly understands what we’re going through, and is willing to help us. (P-9, I-2)

Another participant suggested that health care providers should follow-up with a phone call when prescribing new medications to patients to check to see if the new medication is effective. One male participant said,

I think they should be a little more compassionate and realize that people need this medication instead of formin’ these opinions that everybody sellin’ them or just tryin’ to get high or somethin’. You know, it’s not like that. I’m not sayin’ that’s not being done. I’m just sayin’ not everybody do that. (P-13, I-2)

Another participant shared how he found it frustrating when physicians continued to write prescriptions for the same pain medication when the patient was sharing with the physician that the pain medication was not effective for his chronic pain. (P-12, I-2) He said he realized that there were patients who abused their pain medications but not all patients abused their medications. “You got people that need it...that’s the worse thing in the world to be walkin’ around hurtin’ every day, sufferin’.” (P-12, I-2) During a separate interview he said,

Try to understand that we, we’re human too just because we messed up our legs by usin’ dope it’s no better than a woman or a man that got a sugar and they got leg ulcers. Our legs hurt just like their legs hurt but we brung it on ourselves and maybe they look at it different like that. Matter of fact I know they look at it different like that but at least try to understand that, we tryin’ to do better for ourselves. If we wouldn’t, we wouldn’t be up here, we’d be down on the street.



There are people goin' down the street...they don't care, they not tryin' to get healed. Here we comin' up here and we tryin', real hard, real hard. (P-12, I-1)

Participants said that while they knew there were people who abused the medications they received for pain, not everyone abused their pain medications. Participants said that because of their previous 'mistakes' of using illicit drugs, they now had difficulty obtaining medication from health care providers that would help relieve their chronic pain. They shared that these were frustrating experiences, but hoped that the present study would help health care providers have greater understanding regarding the challenges of living with chronic pain.

Participants described during their interviews and with the use of pictures through photovoice, the experiences of chronic pain for African American indigent adults attending an urban primary care clinic. Findings from the present study were provided by participants in their hopes that their words and pictures would help advance health care providers' understanding of chronic pain care. They wanted to take part in research that may potentially improve the treatment of chronic pain. The final chapter will compare the findings of the present study to the current literature, and to the theory, health as expanding consciousness (Newman, 1986; 1994). The limitations and strengths of this study will be described as will the importance of the present study toward improving chronic pain care and reducing chronic pain disparities.

## CHAPTER 5

### DISCUSSION

#### Summary of Experiences of Chronic Pain

Participants in the present study live challenging and complex lives. It is increasingly evident that chronic pain is enmeshed within all thoughts and activities experienced by participants. Themes for the present study were inductively created, using participants' words and pictures. The five themes identified were, 'Waiting on Pain', 'Coping with Chronic Pain', 'Challenges with Chronic Pain', 'Negotiating Pain in a Vulnerable Environment' and 'Sharing Wisdom about Chronic Pain'. While the themes are listed as five separate categories, it is apparent from the previous chapter that the subthemes may be combined in several ways due to their entwinement and the overbearing influence of chronic pain. Findings from the present study will be compared, to the theory health as expanding consciousness (Newman, 1986; 1994), to the literature and to the research questions posed at the beginning of this study. Implications of the findings to clinical practice and future research directions will be identified as will the strengths and weaknesses for the present study.

#### Comparison of Findings to the Research Questions

Findings from the present study supported the initial research questions. The experiences of chronic pain were described by participants through the use of words during the interviews and pictures during the photovoice sessions. Pictures taken by participants were telling examples of some of the items they used and activities they performed to help them cope with pain. The chronic pain experience was said to make time feel as though it was passing too slowly as they waited for their pain medications to

begin to reduce the severity of their pain. Participants shared that while they did not want to be a burden to others, they were no longer independent with certain activities and they had to wait on others for their help. Participants felt their experiences with pain were influenced by the type of insurance they had and lack of financial resources to obtain pain care. Participants described that some people in their lives were more supportive to them than others.

Discussions of how chronic pain affected participants' lives were identified with examples provided throughout the themes and subthemes. Participants described some of the helpful resources they utilized in their communities such as soup kitchens and food banks. These resources were particularly helpful as participants often lacked the financial resources to purchase food. Participants shared how chronic pain caused challenges in their lives, some of the examples described were how pain affected their ability to sleep, concentrate and follow up with health care provider instructions. Participants described some of the disparities they faced in terms of chronic pain management such as the difficulty with coping when they ran out of pain medications before a new prescription for medication could be obtained. They discussed how they were concerned about the potential side effects brought on by their pain medications and their concerns about potentially becoming addicted to their pain medications. Yet with all of these challenges, participants provided some advice about improving the experiences with chronic pain through offering advice to others with pain and to health care providers about providing care to patients with chronic pain. Findings from the present study will now be compared to the theory, health as expanding consciousness (Newman, 1986; 1994).

## Comparison of Findings to Theory

Findings from the present study both supported and advanced the theory health as expanding consciousness (Newman, 1986; 1994). Health as expanding consciousness describes the dimensions of time, consciousness, space and movement. According to the theory, when patients are able to describe those experiences and people that are most meaningful to them, this is their life pattern. Health care providers assist patients to recognize these life patterns and improve their relationships with others. With the recognition of these patterns, the patient is transformed to a higher level of understanding. Newman calls this growth to a higher level of understanding, expanded consciousness, which is health. Through health care providers' interactions and caring for participants, health care providers may also experience expanded consciousness as they come to have greater awareness and appreciation for the life patterns of these patients. The findings from the present study will be compared to Newman's concepts of time, consciousness, movement, space and expanded consciousness.

**Time, consciousness, movement and space.** While the present study was not wedded in the theory health as expanding consciousness, a few of the present study's themes may be found within Newman's concepts of time, consciousness, movement and space (Newman, 1986; 1994). Newman's concepts did help guide the findings from the present study. The theme 'Waiting on Pain', was closely linked to Newman's thoughts about time (Newman, 1986; 1994). The concept of time includes subjective, objective and private time. Participants in the present study described the different ways they had to wait on chronic pain. This waiting included clock time, for even though

participants might take their medication prior to what was prescribed due to extreme pain, participants had to space their pain medications according to the actual clock time, so they did not run out of medication. Another aspect of time experienced by participants was subjective time, as time seemed to 'slow down' as they waited for their chronic pain. This subjective slowing of time included the time it took for their pain medications to take effect and the time spent waiting on others to help them.

Participants' descriptions of chronic pain may be associated to Newman's concept of consciousness. Consciousness may be described as the thought processes, energy levels, affect and cognitive abilities as participants interacted with their environments while experiencing chronic pain (Newman, 1986; 1994). Chronic pain was described by participants within the theme 'Challenges with Chronic Pain' as pain influenced participants' abilities to concentrate and follow up with instructions provided by their health care provider. When their pain levels were intense, it was difficult for participants to concentrate and focus on other areas of their lives. The theme 'Coping with Chronic Pain' identified how difficulty coping with chronic pain would affect participants' moods or affect as described by Newman.

Movement may include participants' mobility patterns (Newman, 1986; 1994) while experiencing chronic pain. Movement is linked with space. Participants who have increased mobility may have greater control over their environments as they are able to make decisions about their involvement with their environment. A lack of movement or mobility was described by participants experiencing chronic pain within the theme 'Challenges with Chronic Pain.' Participants described how their ability to walk, climb

stairs, prepare food and sleep were decreased due to chronic pain. This reduced ability to mobilize influenced participants' control over their surrounding environments.

Participants described their experiences with chronic pain and their surrounding environments or space. Space may include geographical space, personal space and shared space (Newman, 1986; 1994). Space is linked with movement. Participants described how chronic pain limited their control over the space they kept around them from within and outside of their apartments. At times participants wanted to increase the space they kept around themselves and they wanted to be able to leave their apartments to attend recreational activities. This ability to control space was decreased for participants if their pain was severe or if other factors, such as an elevator not working or reduced bus services made it difficult for participants to be able to travel about in their environments. While there were multiple challenges imposed on participants' lives due to chronic pain, these challenges did not prevent them from experiencing expanded consciousness.

**Expanded consciousness.** Newman wrote within the theory health as expanding consciousness, that even though a person might be labeled as 'sick' by the medical community, the person was not less than, but still considered a 'whole' person (Newman, 1986; 1994). Expanded consciousness or health could be part of a person's life pattern even if the person has been labeled as 'sick' (Newman, 2010). People living with chronic pain, extreme poverty, possible histories of illicit drug use and other life challenges may be judged or labeled negatively by health care providers. These negative judgments may include thoughts that people with chronic pain and other life challenges are less than and have nothing new to add toward our understanding of

chronic pain. Even with all of participants' current life challenges of relentless chronic pain, extreme poverty, environments that are often in decay and disarray and exposure to violence, the participants in the present study are still resilient, 'whole' people. Their chronic pain is their life pattern and they have learned to live with pain as they live out their day-to-day activities.

Through their participation with the present study, participants were transformed to greater awareness about their lives, as was the researcher. The researcher has had many opportunities to reflect on and to discuss with others, the amazing resilience of these participants. Many of the life experiences described by participants were almost surreal for the researcher, as participants discussed life and loss so matter-of-fact and without emotion. It seemed almost as though, participants have accepted these traumatic challenges in their lives, and they accept that there may be other difficult challenges in their futures. While this acceptance by participants may seem to others outside of the study to have elements of apathy, it is known that participants are determined and resilient and have continued to persevere. Based on the findings of this study, it is known that these participants set goals and even offer advice to others with chronic pain and to health care providers caring for others with pain. The findings of the present study and resilience of participants was the 'ah ha' moment of greater awareness and expanded consciousness for the researcher. These important findings will be shared with other health care providers and with the larger research community through the creation of this document, future publications and research presentations.

Newman (1986; 1994) also described that an essential part toward enhancing the nurse-patient or it could be argued, the health care provider-patient relationship, is

an acceptance of the patient's experiences. An important link to theory is the recognition that health care providers need to 'accept' patients and their life histories while reserving judgment towards patients. This 'acceptance', should include the acceptance of the patient's description of their chronic pain experience and believing patients when they describe the intensity and debilitation in their lives because of chronic pain.

Another connection of the findings to theory was the identification of the importance of participants' environments toward their chronic pain. The environment is the energy field participants interact with to create health (Newman, 1986; 1994). Participants' environments greatly influenced their health. Participants shared how 'Negotiating Pain in a Vulnerable Environment' was overwhelming at times. Not only did participants need to struggle each day with chronic pain, but they had to live within environments that were often consumed with loss, poverty and violence. There were times when participants did not feel safe within their surrounding environments. These added stressors influenced their chronic pain.

Participants did experience expanded consciousness, through the interviews and use of pictures with photovoice. Participants spoke positively about the study and shared that they had not been part of a study previously where they were asked to discuss their chronic pain and take pictures of their world with chronic pain. The photovoice portion of the research was described by participants as being a positive experience, as participants said there were different aspects of their lives that they did not take notice of prior to the present study. This new awareness for the participant is growth, which is expanded consciousness (Newman, 1986; 1994). One participant's



comments summarizes his thoughts about photovoice “It was interestin’ cause I seein’ things that I really didn’t notice before.” (P-3, I-3)

Participants provided feedback about the study and said they appreciated the opportunity to be able to discuss their experiences about chronic pain. Participants said that at times, others did not want to hear them describe their chronic pain and how pain influenced all facets of their lives. Participants said that because others did not want to hear about their pain, they felt somewhat isolated and left to struggle alone with their pain. When discussing the present study, one participant said, “I got a lot out of this.” (P-9, I-2) A female participant explained, “I had to get that off of me, thank you. You have, you just feel good to talk to somebody that listens to you and that’s really concerned and that’s really listenin’ to me.” (P-5, I-1) The greatest compliment provided to the researcher was given by a male participant when he said,

So this right here makes me think there’s hope by you’re doin’ this. I’m not doin’ it because of the money. I’m doin’ because it’s hope. Because I’m steady thinkin’ in my mind they’re talkin’ about cuttin’ this off, cuttin’ that off and if people don’t care they’ll cut it off. So what you doin’ I think is a hell of a thing. (P-12, I-2)

All participants wanted the study to continue beyond the two or three interviews and participants said they wanted to participate in future studies related to chronic pain. Participants said they hoped their participation in the present study would help improve health care providers’ understanding toward patients experiencing chronic pain. One participant summarized her thoughts by saying she hoped her participation in the study, “will help a lot of people...it’ll help doctors understand better their patients and questions they may need to ask or steps they need to take to better help their patient.” (P-7, I-2) Because of the present study, participants became aware that they had expertise to share with health care providers and with others outside of the present study. They

knew that their words and pictures regarding chronic pain would become integral parts of improving chronic pain care. Participants were empowered by the present study, as they were able to describe their experiences with chronic pain. Through the discussion and clarification of their words and pictures, participants had expanded consciousness and greater awareness of how to improve their health.

A drawback of the theory health as expanding consciousness (Newman, 1986; 1994) is that it would be difficult to use this theory in its entirety within today's clinical practice. Health care providers are expected to work in a fast-paced environment with fewer resources. Newman's theory requires that the health care provider spend considerable amounts of time with each patient to examine the people and experiences that are meaningful to the patient. While this process worked well within a qualitative research designed study, health care providers do not have the luxury of spending one to two hours with patients during each health care appointment. The researcher was able to ask participants to discuss the experiences and people most meaningful to them during each interview. Health care providers may need to ask these questions over the duration of several health care appointments. Due to the many challenges faced by this population, the patient may not regularly return for follow up care, thus further limiting the usability of Newman's theory in clinical practice. While it may be difficult to integrate the entire theory within clinical practice, health care providers could still ask questions of their patients related to the influence of chronic pain. Next, the findings of this study will be compared to the current literature to discuss similarities and advancements in chronic pain knowledge.

## Comparison of Findings to the Literature

Findings from the present study may add knowledge to the current, growing body of information regarding chronic pain care. Some of the findings from the present study will be compared with the current literature. New knowledge that has emerged will be discussed.

Participants in the present study described a feeling of 'Waiting on Pain'. Within this theme, participants said it was difficult to need to rely on others for assistance as participants felt less in control of their time. Another challenge was that daily activities took longer for them to complete such as preparing for appointments and walking. This frustration with the length of time needed to complete activities and the lack of control over time due to chronic pain was a finding similar to the Richardson et al. (2008) study.

Participants described that when they ran out of their pain medications and did not have enough to last them until they obtained another prescription from their health care provider, they coped by obtaining pain medications from friends and family members. There were times, when they were able to reciprocate the favor and share their medications with others. Due to the lack of finances to purchase necessary items, Cohen et al. (2007) and Payne, DeVol and Dreussi Smith (2001) found that individuals living in poverty share, trade and barter with actual things or resources which includes the sharing of medications.

The reasons participants described for not being able to attend health care appointments included challenges with transportation. Transportation was difficult for participants as they had to rely on family and friends to drive them to their health care appointments. These family members and friends might offer to take the participant, but

then cancel on them without prior notification. For other participants who utilized bus services, during certain times of the month, they said they might not have the financial resources to pay for bus fare. Patients who do not attend scheduled appointments might be labeled by health care providers as being unreliable with follow up care. When examining the reasons why patients do not attend health care appointments, Pieper and DiNardo (1998a; 1998b) also found that challenges with transportation were the primary reason that indigent patients missed health care appointments.

Within the theme 'Coping with Chronic Pain,' participants in the present study described various items and activities they performed to help them cope with pain. One of those activities or subthemes in the study was the use of prayer, which helped participants by giving them hope, when living with continual pain. Some participants said they read their bible, meditated or prayed for themselves and for others. While other participants explained that they did not pray every day, all said that prayer and spirituality helped them cope with chronic pain. The use of prayer for coping with pain was a finding similar in several studies (Cano et al., 2006; Edwards et al., 2005; Im et al., 2008; Lopez, Eng, Randall-David & Robinson, 2005; Polzer & Shandor Miles, 2005).

Participants in the present study shared if they believed their chronic pain care would be different if they were a different race or if their health care provider was from a different race. One participant did believe that being a different race other than African American did make a difference in terms of the care he had received for pain. This male participant said that he had not received adequate pain care because of his racial identity, a finding similar to (Green, Baker, Smith et al., 2003; Pletcher et al., 2008; Rhodes, Hergenrather, Wilkin & Jolly, 2008; Todd et al., 2000). However, most of the

participants said that racial concordance between the patient and health care provider did not matter, as long as they had a, “good doctor, a good nurse” (P-2, I-1). Participants said that if they had a health care provider who listened to their concerns, then it did not matter the race of the health care provider as participants felt that their pain care would not change. Participants in the present study valued having a health care provider who would treat them well and with whom they could trust. Other research also found that trusting relationships between the patient and health care provider is what mattered most to patients (Meghani & Keane, 2007; National Pain Foundation, 2009a; Nickasch & Marnocha, 2009; Saha et al., 2003; Street et al., 2008).

Similar to the study findings of patients receiving opioids for chronic pain by Vallerand and Nowak (2009), it was challenging for participants when others did not believe participants as they described their chronic pain or if health care providers did not change the pain prescription even if the participant described an increase in pain. Participants said that when their loved ones and health care providers did not acknowledge the severity of their pain, they felt that others were being ‘mean to’ them. The importance of improving the health care provider-patient relationship cannot be overstated. Improving this relationship includes the ability of others to trust and believe the patient when they describe the intensity of their chronic pain. Trust may be enhanced when African American patients and health care providers share similar perceptions (Benkert, Hollie, Nordstrom, Wickson & Bins-Emerick, 2009), especially as they relate to pain. Disagreement between the health care provider and African American patient regarding the intensity of a patient’s pain rating or description of pain may reduce feelings of trust (Staton et al., 2007).

Other findings from the present study that were similar to other studies include that chronic pain made participants feel depressed (Green, Ndao-Brumblay, Nagrant et al. 2004; Green, Baker, Sato et al., 2003; Mauksch et al., 2003; Poleshuck et al., 2006; Riley et al., 2002) and most participants said they were not in control of their chronic pain (Ruehlman et al., 2005; Vallerand et al., 2005). The ability to perform self-care was a priority for many of the participants with chronic pain (Ruehlman et al., 2005; Vallerand & Nowak, 2009) as participants were used to helping others (Im et al., 2008) and not needing to rely on others for help. Chronic pain affected their ability to sleep (Cohen et al., 2007; Warms et al., 2005), and it reduced their energy levels (Im et al., 2007) but participants tried not to complain about the pain (Im et al., 2008; Meghani & Houldin, 2007). Pain affects all areas of participants' lives, findings similar in the Cohen et al. (2007) and Portenoy et al. (2004) studies. Participants in the present study said that providing them with effective analgesia would improve their quality of life (Katz, 2002).

Participants felt that patients with a history of illicit drug use should still have their pain needs met. They stated they could be out on the streets using illicit drugs, but instead, they were following up with their health care providers. As one participant added, he was trying "real hard, real hard" (P-12, I-1) to be well. Participants shared that it was difficult to maintain sobriety when they were experiencing extreme pain, a finding similar to Rhodes et al. (2008). When pain was unrelenting, participants would use other substances such as alcohol to try to "lighten" the pain, a finding similar in another study by (Pieper et al., 2009). Chronic pain remains a challenge for health care providers to assess and provide treatment.

There may be a concern by some health care providers that patients are obtaining pain medications for misuse; particularly if patients have a history of illicit drug use (Baldacchino, Gilchrist, Fleming & Bannister, 2010; Burgess et al., 2008; Fornili & Weaver, 2008). A review of the literature by Fishbain, Cole, Lewis, Rosomoff and Rosomoff (2008), of 67 studies or 2,507 chronic pain patients, found abuse of opioids or addiction rates for patients who had been prescribed opioid analgesics for chronic pain to be 3.27%. Webster and Webster (2005) wrote that approximately 20% and Weaver and Scholl (2002) wrote that 16% of American outpatients treated in general practice have challenges with drug or alcohol addiction. While specific rates are difficult to measure, it is obvious that the numbers of patients with a history of addiction who are prescribed opioids for chronic pain who later abuse their pain medications is well below the national average for overall drug abuse.

Participants said that when their chronic pain was unbearable, they would go to the emergency department (ED) in the hopes of having their pain needs met. One participant shared how he would go to the ED two to three times per week complaining about his unrelenting pain. Attending to the ED for pain care is a frequent occurrence across America. A news report suggested that in the state of Texas, nine patients made almost 2,700 visits to the emergency department over the time span of six years, which cost taxpayers more than \$3 million dollars (The Associated Press, 2009). Lower income men used the emergency department 2.5 times more than men with higher-incomes primarily for exacerbations of existing co-morbidities (Schanzer & Morgan, 2004). This finding will be described in detail as an implication for practice, but it is notable that unresolved chronic pain is costly to health care services.

Participants described the influence of their living arrangements and surrounding environments toward their chronic pain. These participants live in neighborhoods that have unmet structural needs such as the need to repave roads, the removal of abandoned buildings and the maintenance of street lights. They also discussed how the deteriorating, chaotic and often violent environments they lived in increased their stress which increased their chronic pain. Individuals living in these chaotic environments may have experienced numerous stressors and losses. Due to these numerous losses and stressors, other physical and psychological concerns may develop, a finding in other studies (Hill, Ross & Angel, 2005; Nowell, Berkowitz, Deacon & Foster-Fishman, 2006). Nowell, et al. (2006) found that neighborhoods can influence one's feelings of self-identity, which may in turn influence feelings of positive mental health. Participants shared that living in poor, disordered neighborhoods exacerbated their stress and their chronic pain.

All participants said they appreciated the opportunity to discuss their experiences with chronic pain and participate with photovoice. Overall feedback about the study was positive and participants said they wanted to participate with other studies related to chronic pain. They hoped that their words and pictures would help advance health care providers' understanding about patients with chronic pain and when providing chronic pain care. The positive influence of photovoice and allowing participants to discuss their pain experiences, were findings similar to other studies (Baker & Wang, 2006; Rhodes et al., 2008).

Some of the findings which are believed to be new to the literature include that participants expressed difficulty when trying to understand the instructions given to them



by their health care providers when they were experiencing severe pain. As one participant explained when he was asked questions by his health care provider and he was experiencing severe chronic pain, he said, "I just answer anythin' you know." (P-6, I-1) This finding has implications for future practice regarding the ability for patients to understand and follow up with prescribed health instructions, and will be discussed in greater detail within the next section.

Other findings that are new include the possible labeling that occurs toward individuals who are disabled due to pain. At times, society and possibly health care providers label individuals with chronic pain as 'lazy' and these pain patients only want to rely on other people and the social safety net programs for their financial resources. Participants in the present study said they would prefer to be 'at work.' It was difficult for them to live in poverty and not have adequate resources for living and for chronic pain. Participants said that chronic pain made it challenging to find and maintain employment. They explained that when they would ask for a job application and they were holding onto their canes and walking with a limp, an organization would not hire them. Findings from the present study help to debunk the possible myth that all chronic pain patients do not want to be employed. Other findings will be described in detail when examining the importance of the participants' words and pictures toward clinical practice. Findings from the present study do have essential implications for clinical practice.

### **Implications for Clinical Practice**

Findings from the present study have numerous implications for clinical practice. Participants in the present study described the many daily challenges they experienced, particularly as these challenges related to their chronic pain and poverty. Participants

had to rely on others for assistance. If friends and family members around them were not supportive by providing reliable transportation, participants said they might not be able to attend health care appointments. Participants discussed that because of the need to wait on others, they might be late for appointments or they might need to leave the appointment before their appointment was finished. During the initial health care visit, health care providers could discuss with patients any transportation concerns. While it may not always be possible to schedule visits around patients' transportation needs, there could be greater empathy expressed by health care providers toward patients who arrive late for appointments due to transportation difficulties.

Another challenge expressed by participants was their need to wait on their chronic pain. Participants shared that there were certain times of the day that were better for them to complete activities. Unrelenting chronic pain influenced the time participants needed to wake up and prepare for an appointment. Participants had to wake up early enough to allow their pain medications to begin to reduce the intensity of their pain before they could mobilize and leave their apartments. They had to painfully walk to the bus stop and wait for the bus in all elements of the weather as often the bus stops did not have benches for them to sit and rest or bus shelters to protect them from the weather. If they missed the bus or if there was not a seat on the bus, participants said that once they arrived at the health care appointment, their chronic pain was exacerbated and they felt exhausted and frustrated. It is important for health care providers to ask participants if there are certain times of the day that might be best for them to travel with chronic pain. While health care providers have many other patients requiring care, if at all possible, health care appointments might be scheduled when the

participant says it is easier for them to attend the appointment. This may reduce the frustration experienced by health care providers and participants when they do not follow up with scheduled appointments.

Participants said it was challenging for them to follow up with prescribed treatment recommendations. Treatment recommendations suggested by health care providers, including exercise, dietary restrictions and pain care, might be difficult or not possible for participants due to a variety of reasons. Participants said it might be difficult for them to follow up with prescribed teachings not only because of chronic pain, but due to their reduced incomes and vulnerable surrounding environments. Assessing the feasibility of patients complying with the health care provider's recommendations will help the health care provider make necessary modifications and increase adherence.

Participants said when they were experiencing severe pain, it was challenging for them to concentrate or focus on the instructions given by their health care provider. Their focus was solely on the pain. Participants said they might nod their head in agreement with the health care provider, but they often have not been able to comprehend what the health care provider has discussed. Making sure the instructions are understood by having the patient repeat them back and providing written instructions will improve adherence. Along with the importance of teaching, is to ensure that patients' pain levels are reduced.

Another challenge was participants' reduced mobility which influenced their ability to walk or climb stairs. If participants were advised by their health care provider that walking would reduce their pain, they said they were less likely to follow up with that suggestion as walking exacerbated their pain. They also discussed that due to having

reduced incomes, participants utilized food banks and often could not purchase food items that met all necessary health and dietary requirements (Valera, Gallin, Schuk & Davis, 2009). Participants also described challenges with preparing food due to pain, so often they ate foods that required minimal preparation. Many times, these foods that were easy to prepare were high in salt, sugar and fat content. Health care providers need to consider participants' income, selection of food choices and ability to mobilize when providing teaching to improve participants' follow up with suggested care.

Finally, due to living in vulnerable environments, participants said they might not feel safe walking alone outside of their apartments. Again, if health care providers have instructed patients to exercise, patients may not feel safe and secure to follow up with these instructions. Health care providers need to include creative and realistic teaching strategies that are developed with the patient. Due to the vulnerable environments where these patients reside, health care instructions need to be uniquely tailored to meet the needs of these patients. Health care providers might ask patients to provide feedback to them during health teaching to ensure that patients understand the instructions given to them, particularly instructions related to chronic pain care. Health teaching will be more effective when the patient is included in the decision-making, thus recognizing the patient's complex needs and valuing the patient's expertise with the management of their lives and chronic pain.

Considering the hardships these participants described as they attempted to seek health care, it is evident that improving the health care provider-patient relationship through trust is essential. If patients do not regularly seek primary care, illnesses, including chronic pain that might have been managed with minimal resources begin to

exacerbate and become costly health care concerns. Positive health care provider-patient relationships will improve the patients' quality of life, as these patients may continue to return to their health care providers for follow up care. This follow up care will allow for better management of existing chronic conditions and the prevention of other co-morbidities from developing. Follow up care will lead to improvements in overall health and pain care for patients and will be more cost-effective for the health care system.

Participants in the present study said it was frustrating to think that because of their past behaviors of alcohol misuse or illicit drug use, that they were now 'labeled for life' (Henderson, Stacey & Dohan, 2008) as being an 'addict.' Participants said they believed this labeling has denied them access to pain care that might reduce their chronic pain. Several of the participants said that they did not want the pain medications so they could 'get high'; they wanted to have their chronic pain reduced. Reducing the intensity of chronic pain would enable participants to seek employment so they would not always have to be financially worried about trying to meet their basic needs. While it is challenging for health care providers to maintain a balance between providing pain care and fueling addictive behaviors, potential solutions are available.

There are many prescreening and pain assessment tools that may be used by health care providers with patients prior to beginning and throughout a patient's treatment with opioid therapy. Health care providers concerned with the potential for misuse or diversion of opioids by patients, particularly patients with a history of illicit substance abuse could consider using opioid contracts with patients. Opioid contracts have been found helpful with some patients, as they outline expected behaviors of

patients to receive opioid therapy and the consequences for patients of not following the contract behaviors (Arnold, Han & Seltzer, 2006). Continuing to develop trusting relationships with patients may help reduce concerns about misuse; as health care providers will know how to best treat their patients' pain care needs.

Participants shared that their health care providers have declined from prescribing certain pain medications due to the potential damage to their kidneys or liver. After completing a comprehensive assessment with patients, the use of combinations of medications, including adjuvant drugs may be helpful in treating patients with chronic pain. The use of nonpharmacological options for treating pain such as patient education, relaxation training, and range-of motion exercises along with prescribing a combination of non-steroidal anti-inflammatory medications, antiepileptics or antidepressants, with opioids may be more effective (Passik, 2009; Weaver & Schnoll, 2002). It is important that health care providers continue to adapt their prescribed treatments for chronic pain with each patient. The patient-health care provider relationship will be enhanced when the health care provider is able to discuss with the patient, the patient's chronic pain concerns and their goals for chronic pain management.

Participants said they often were not able to pay the \$1.00 co-payment for medication prescriptions as they did not have the financial resources. There were times when patients needed to go without medications until they were able to afford to pay for them. This inability to take medications as prescribed will exacerbate their chronic pain and other health conditions. Participants shared that they have utilized other means to treat their chronic pain, such as 'borrowing' medications from family or friends or in the

past, using alcohol or illicit drugs to help relieve their pain. Participants said it was difficult for them to maintain sobriety when experiencing unrelieved chronic pain. Therefore, it is even more important to manage chronic pain. Taking medication that is not prescribed specifically for the patient or using illicit substances to control pain has the potential to create other costly chronic medical conditions. Part of the health care assessment for this population, should be an assessment of patients' financial resources and other financial hardships they experience when accessing care. Even patients with extremely limited incomes, like the study population, need to be assessed for ability to pay co-payments and other necessities.

For patients with inadequate pain treatment, their options are few. This population has no other choice than to go to the ED for care. Several participants discussed how they utilized the services at the ED for their chronic pain, in the hopes that they would receive medication to reduce the intensity of their pain. One participant said he went to the ED for his pain, two to three times per week prior to attending the primary care clinic. Visits to the ED for pain care are costly. Utilizing the emergency room for illnesses that might be managed at a primary care clinic increases overcrowding in the emergency department and escalates health care costs.

The present study has shown that these participants, who live with unremitting chronic pain, also live in environments that are consumed with poverty, loss and violence. While participants have said that living in these environments increased their levels of stress which exacerbated their chronic pain, these participants possess other positive assets. Through the sharing of their experiences with words and pictures, it is apparent that these participants are amazingly resilient individuals with positive

strengths. Health care providers should work to help identify the strengths within each patient and help patients to recognize their own strengths and successes. Building on the strengths of patients creates additional success, which may positively influence patients' health outcomes. The researcher will describe implications for future research and her plans for future research directions with chronic pain care populations.

### **Future Research Directions**

Future research will undoubtedly continue to increase health care providers' understanding of chronic pain care. The researcher hopes to continue her work, advocating for low-income populations experiencing chronic pain. Future studies will include the use of photovoice displays with other populations. The researcher hopes in future studies to move beyond the photovoice portion that was somewhat limited in the present study. Through other public venues such as research forums or with other meetings and events, the researcher would like participants themselves to display and discuss their work. These empowering opportunities will continue to remind these individuals that they are the experts of their world.

Future studies might examine with greater detail, the influence of the surrounding physical environments on chronic pain. Participants in the present study took pictures of their environments from both within and outside of their apartments. It was important for participants to show others how the conditions of where they lived, their homes and neighborhoods, influenced their experiences with chronic pain. The researcher would like to further examine how one's living conditions and neighborhoods influence chronic pain and psychological well-being.



Other research directions include examining the experience of chronic pain after obtaining a Certificate of Confidentiality (U.S. Department of Health and Human Services - Office of Extramural Research, 2009) from Federal government. A Certificate of Confidentiality would enable participants to discuss all experiences in their lives freely without the consequences of being reported. Some of these experiences described by participants might include any possible involvement with illegal activities as they try to cope with chronic pain. Increasing our knowledge of all aspects of participants' lives will advance our understanding of some of their daily challenges and will improve our ability to create patient-centered pain care.

The researcher is Canadian, and she would like to continue to examine and compare chronic pain experiences from within her home country. Future research would include completing a cross-border examination of chronic pain care. It would be interesting to note if there are differences in the type of chronic pain treatment, based on the type of health care system; publically-funded health care or private sector.

This study examined the experience of chronic pain for African American indigent adults attending an urban primary care clinic using the theoretical framework, health as expanding consciousness. Future studies might examine the experience of chronic pain using a different theoretical framework and with other ethnic or low-income groups. Larger scale studies might also be completed to allow for greater applicability of findings. The present study had several strengths and limitations which shall be described in the pages that follow.

## Strengths and Limitations

Strengths and limitations for the present study will be described below. Strengths of the present study include, that at the present time, this seems to be the only study of its kind to examine the experience of chronic pain with African American indigent adults attending an urban primary care clinic. It is unusual for indigent adults to attend a primary care clinic. This population often receives health care through the ED. The opportunity to study indigent African Americans who have a primary care provider allows unique perspectives of this population. The findings from this study will help advance our understanding of this population and their unique needs. Participants described the important experiences and people in their lives particularly related to their chronic pain. Cultural patterns and the artifacts, people, and rituals that were meaningful to the participants as related to their chronic pain were identified. Participants responded to interview questions and participated in photovoice. Photovoice was an effective data collection strategy and enabled participants to visually show their chronic pain experiences. Knowledge was generated regarding the meaning of chronic pain and how chronic pain affects participants' lives.

Other strengths include that because of the triangulation of methods, participants were able to support and clarify the findings from the present study in subsequent interviews and through photovoice. Findings from this study support and advance the theory health as expanding consciousness (Newman, 1986; 1994) and increase our understanding of the meaningful patterns of chronic pain for participants who live with unrelenting chronic pain. Findings also support and advance the current body of literature which adds to the applicability of the findings to other settings.

An integral element of photovoice is its link to participatory action research and the ability for participants to share their world with a larger audience (Baker & Wang, 2006). A major strength of the present study was the invitation for participants to share their expertise through a larger medium. While several participants in the present study were invited to participate, two of the participants agreed to have their photographs taken while sharing some photovoice pictures for a nursing research catalogue produced by the College of Nursing at Wayne State University. The catalogue highlights research focused on reducing health disparities. Through the sharing of themselves and their photographs, this experience was empowering for participants as it once again reminded them that they have much expertise to share with the larger community.

Both participants arrived to the photo shoot site wearing clothing that seemed fancier than the clothing they had worn when they were meeting with the researcher during the interviews. Both participants explained that they wanted to 'dress up' for the photo shoot. Just before the pictures were taken, both participants were smiling and said that they had "never done anythin' like this before." (P-9, P-7) The researcher had offered to send these participants copies of the catalogue once it was printed. Both participants told the researcher to use the phone numbers they had previously given to the researcher while they were taking part in the study. When the researcher tried to contact these participants a few months later, to learn how to connect with them and provide them with the completed catalogue, the phone numbers they had provided during the study were now disconnected. The researcher was disappointed that she was not able to follow up with participants regarding their participation with the

catalogue. This sudden change of contact information for participants thus highlights again, some of the challenges faced by these individuals.

Limitations with the present study include that prior to signing the informed consent; participants were informed that if they discussed their participation with any illegal activities, these activities would need to be reported to the appropriate authorities. The researcher believes that several areas of participants' lives were not discussed during the interviews, as participants were limited in what they might openly discuss with the researcher due to this reporting obligation. Another potential limitation is that one of the inclusion criteria for participants with the present study was their reliability with appointments. Participants identified by the clinic staff were chosen to participate in the present study because of their previous reliability with attending follow up clinic appointments. Patients who are not as reliable with clinic appointment attendance also experience chronic pain and there may be something about their stories that differs from the experiences of participants in the present study.

Finally, because the small sample was limited to those patients attending an urban, primary care clinic, this may prevent findings from being representative of the experience of chronic pain for other African American indigent adults or for other chronic pain people. Future studies may examine this experience using large-scale studies designed to have greater transferability. The conclusion section will identify final thoughts pertaining to the present study.

## **Conclusion**

Chronic pain is all encompassing and causes many difficulties in patient's lives. Chronic pain is often undertreated which adds to the difficulties faced by patients.

African American indigent adults may experience undertreated chronic pain. Participants from the present study described their experiences with chronic pain through the five identified themes of, 'Waiting on Pain', 'Coping with Chronic Pain', 'Challenges with Chronic Pain', 'Negotiating Pain in a Vulnerable Environment' and 'Sharing Wisdom about Chronic Pain' and how undertreated pain may compound additional challenges to their lives.

Some of the challenges experienced by African American indigent adults experiencing chronic pain may include a new dependency on others whereas before they were independent with activities and a lack of transportation to attend health care appointments. It is difficult to focus on anything other than the pain and follow up with health care provider instructions and it is often impossible to find and maintain employment. These individuals with chronic pain have difficulty walking on streets with inclines and climbing stairs and once they do arrive at the bus stop, there are often no benches at the bus stop for them to sit and rest. Other challenges include convincing people in their lives and health care providers that they do experience pain with the intensity they describe and trying to cope with chronic pain. It is difficult to cope and obtain a prescription of opioids for pain especially if patients have a history of alcohol or illicit drug use. Not having adequate pain medications make it difficult for patients to maintain their sobriety and carry out their activities of daily living. If patients did have medication for pain, it was difficult waiting for the medications to begin to reduce the intensity of their pain. Patients are often not able to enjoy previous social activities due to pain.

In addition to the many daily challenges experienced by patients, including loss, poverty and violence, because of their lack of income, patients often live in poor, disordered neighborhoods which may add to the participant's stress and exacerbate their chronic pain. Patients living in poverty do share resources, including pain medications and other pain relief items. It is important for health care providers to remember that even with all of these negative stressors overwhelming patients' lives, patients living with chronic pain and poverty are amazingly resilient and have inner strengths.

Some of the strengths patients have when negotiating these challenging environments include their ability to cope with pain when resources are not available such as taking a hot shower, praying, looking at nature and sleeping. Determining and acknowledging the challenges experienced by patients and their methods of coping will assist health care providers to understand these patients more completely. Health care providers however, after completing a thorough and careful assessment, should not assume that the coping methods used by patients may substitute for adequate and available pain care.

Care for African American indigent adults will be improved with continued advocacy for clients and for health care policies that reduce inequities in care and chronic pain disparities. The costs of untreated chronic pain include decreased quality of life for patients, increased visits to emergency department for pain care and the potential exacerbation of other existing co-morbidities due to untreated stress and chronic pain. These costs described above are not only unethical if left untreated, but they add to the financial burden of the entire health care system.

Findings from the present study describe how to best treat chronic pain from participants' perspectives. It is important to note that building trusting relationships with patients improves chronic pain care. Patient-centered pain care will improve the health of African American indigent adults and will reduce health care disparities. The words expressed by one of the participants, summarizes the importance of health care providers increasing their understanding of the experience of chronic pain for African American indigent adults attending an urban primary care clinic.

I would recommend that they try to put their selves in our situation. To try to say o.k. if that was me goin' through the pain that she's going through what would I do to help her you know and maybe that would help us more, make us feel more like that we have someone there that truly understands what we're going through, and is willing to help us. (P-9, I-2)

## APPENDIX A

### INTERVIEW GUIDE

Before we begin the interview, I am going to ask you a few quick questions about yourself. (See Appendix J for the Demographic Data Form and Appendix K for Brief Pain Inventory – Short Form).

1. Now I'd like to switch gears and talk about what you think about your chronic pain. Please tell me about your pain.

Prompts:

1<sup>st</sup> memory of pain, when the pain started

- How long have they had pain?
- How does it vary on a day-to-day basis?

2. What do you believe are all of the challenges of living with chronic pain?

Prompts:

- Getting people to believe you have pain as 'strong' as you say you do?
- Having pain affect your ability to work?
- Having pain affect your sleep?
- Having pain affect your mood/emotions?
- Having to rely on other people for help?
- Having pain affect your relationships with others?
- Having to rely on the food bank?
- Living with pain at your age?
- Pain affecting your other illnesses?
- Feeling in control of your pain?



- Are there more?
3. Think back to a day when your pain level was relatively high. Describe for me that pain-filled day in your life, from beginning to end.

Prompt:

- What are all of the ways you cope with chronic pain?

Now I'd like to shift gears a little bit and ask you about how other things might play a part in your situation having to deal with chronic pain.

4. What are all of the challenges of receiving chronic pain management?

Prompts:

- Getting people to believe you have pain as 'strong' as you say you do?
- The way you are treated when you go to the hospital/ER?
- Getting referred to a pain specialist?
- Having Plus Care-Med Basic insurance?
- Getting a prescription from your health care provider?
- Does it make a difference if your health care provider is the same gender as you? Same race as you?
- Getting pain medications that you think will work for you?
- Getting the medications filled at the pharmacy?
- Paying for the medications?
- Taking the medication as it is prescribed?
- Understanding the instructions you are given to care for your chronic pain?

- Using other things to help with the pain? Ice/heat, vitamins, herbs, massage, meditation or prayer...
- Having a history of substance misuse?
- Are there more?

(The next questions refer to HEC Concept of Pain and Time)

5. What's it like to wait until the clock says it's time to take your pain meds?

Prompts:

- How do you know when to take your pain medication?
- Does taking medication reduce your chronic pain?
- What's it like to wait until the pain meds take effect?
- Give me an example of what it is like to wait and how fast time is passing?

(The next questions refer to HEC Concept of Pain and Consciousness)

6. Please describe for me what are all of the ways pain influences your ability to interact with others?

Prompts:

- Do you think people believe you have pain? How can you tell?
- Do you think people act differently around you or treat you differently when you are in pain? Could you explain to me how they act differently?
- What are the ways that pain affects your ability to think or concentrate? Such as when?

- Does pain affect other parts of your body? Please, could you explain how pain affects other parts of your body?

(The next questions refer to HEC Concept of Pain and Movement)

7. Tell me how pain affects the things you do. Are there more?

Prompts:

- What about affecting your sleep?
- Doing things away from home?

Rank all of the ways movement affects pain from the most affected to least affected. So put them into three piles most affected – middle affected – least affected.

(The next questions refer to HEC Concept of Pain and Space)

8. Suppose you have relatively high pain, describe your ideal setting.

Prompts:

- Who do you want around? Where do you want to be?
- What happens when someone comes in?
- How does pain affect your ability to keep track of your important personal belongings?
- Has pain affected where you live? What changes have you made?

Now I'd like to switch gears and talk about what you think about your health.

9. OK, we've been talking about your chronic pain and I wonder how you would rate yourself to being healthy?

Prompts:

- What would it mean to you that someone is healthy?

- If there were one thing that you could do to make your situation better, what would it be?
10. Since you know so much about living with chronic pain, what one piece of advice would you give to medical care providers so that they could give you better care?

We're almost done and in this last section I want to ask you how your situation would be different if you were in a different community or group.

11. Would your experience of chronic pain be different if you were white? How so?
12. What about if you were male/female (the other)? In what ways?
13. What about if you had access to a different clinic? Why?
14. What would your chronic pain situation be if you suddenly became wealthy?
15. Is there anything else that you would like to add to help me understand what it is like to live with chronic pain?

I'd like to thank you for sharing your experiences with chronic pain. You have helped me to better understand what these experiences mean to you. I will review our conversation today and will share at our next meeting, some of the thoughts we discussed. At our next meeting you can let me know if these thoughts are correct or how you would like them changed. I look forward to our next meeting in 3-4 weeks. Can we choose a date now that is most convenient for you to meet again here at the clinic? I would like to discuss with you now about the picture-taking part of the research.

The pictures that you take and will share with me and others outside of this study help us to understand what chronic pain means to you. Some things I would like you to think about as you take these pictures include:

What are the objects or things that you use when you are experiencing pain?

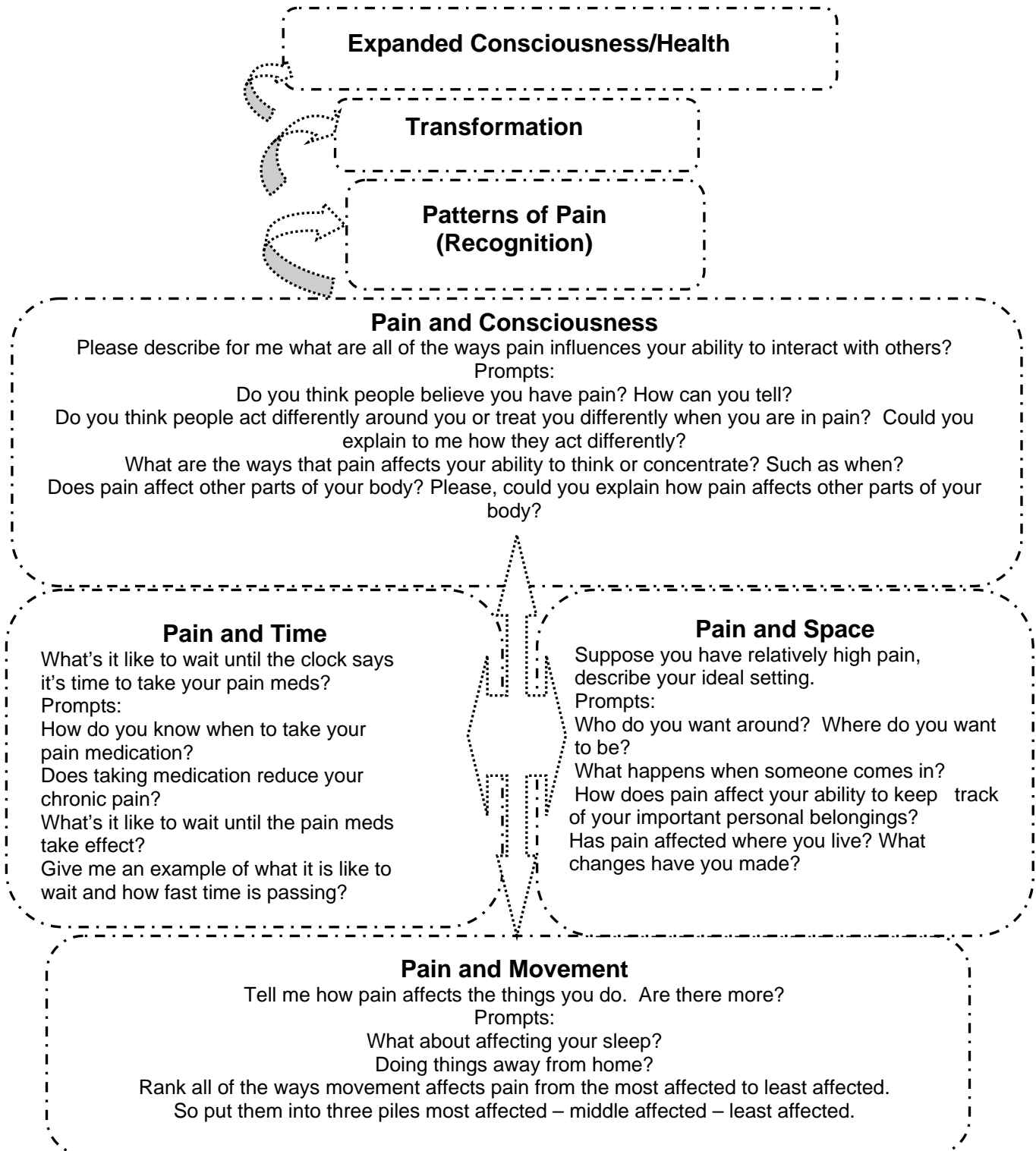
What are some of the actions you do when you have pain?

Who are some of the people in your life when you have pain?

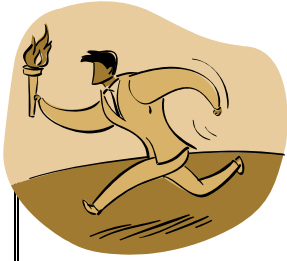
Remember, before you take the picture that you will need to get a signature from the person saying it's OK that you take the picture. This form called the informed consent/Acknowledgement and Release is similar to the form you signed when you first agreed to participate with this study. Also let the person know that the picture will be shared with me and with others outside of this study. I have a handout you can give to the person. My contact information is on that sheet if the person has any questions about the study. Also remember that your safety is most important. Do not take any pictures of anyone or anything that may put you at risk for hurting yourself or that risks the safety of others.

## APPENDIX B

**HEALTH AS EXPANDING CONSCIOUSNESS – LIFE PATTERNS OF PAIN  
(NEWMAN, 1986; 1994)**



APPENDIX C  
RESEARCH FLYER



**Help Improve Chronic Pain Care!**

**Take Part in A Research Study About Chronic Pain!**

My name is Jamie Crawley and I am a student in nursing at Wayne State University. I need **YOU** to help me learn more about your life with chronic pain. If you want to take part in this research study, please call me at - (313) 577-4107 and leave a message with your name and a phone number I may use to call you.

**Who:** I need **YOU!** If you are an African American patient registered at this clinic and you have had chronic pain for more than three months.

**What:** This is a research study that looks at the experiences of chronic pain as described by African American adults who attend this clinic. After you agree to take part in this research study and sign an informed consent, you will answer questions that ask you to talk about your experiences of living with chronic pain. You will be given a disposable camera and will take pictures of your life with chronic pain. You will mail the camera back in a postage-paid envelope and you will return for a second interview. At the second interview we will talk about the pictures you took and I will ask you any questions I have from the first interview.

**Where:** All interviews will take place here at the clinic. The pictures you take will be whatever you decide to share with me about your life with chronic pain.

**When:** If you agree to take part in this research study, we may begin as soon as possible!

**How:** You will receive compensation/money for completing each part of the research study.

**Why:** Health care providers need to learn more about the experiences of living with chronic pain from **YOU!** We need to help improve chronic pain care for all!

## APPENDIX D

### INVITATION TO PARTICIPATE IN PRESENT RESEARCH

The researcher will approach patients waiting in the lobby who have been referred by the nurse practitioners working in the clinic. Patients will be referred based on their self-identification of being African American, their reliability to return to the clinic for follow-up appointments, their expertise with the phenomenon of interest and if they deny current, illicit drug use. Patients who have been referred will be asked the following:

#### Screening Tool

I am completing a research study examining chronic pain and if you are interested in participating, I need to ask you a few questions first to see if you fit the criteria for the study. (The patient will indicate if they are interested with participating in the study.)

1. Have you experienced moderate to severe pain for more than 3 months? For example, have you experienced a score of 5 or more on a scale of 0 – 10, where 0 was no pain and 10 would be the worst pain you could imagine, for greater than 3 months? Patient will respond with a 'Yes' answer or a 'No' answer
2. Would you be willing to discuss your chronic pain experiences with me?  
Patient will respond with a 'Yes' answer or a 'No' answer
3. Are you currently using cocaine?  
Patient will respond with a 'Yes' answer or a 'No' answer
4. Are you currently using heroin?  
Patient will respond with a 'Yes' answer or a 'No' answer
5. Do you identify yourself as being African American or Black?  
Patient will respond with a 'Yes' answer or a 'No' answer



6. Do you attend a specialized pain care center for your pain?

Patient will respond with a 'Yes' answer or a 'No' answer

If when asked the screening tool, patients indicate 'yes' that they have been experiencing chronic pain for > 3 months, 'yes' they would be willing to discuss their chronic pain experiences with me, 'no' they are not currently using cocaine, 'no' they are not currently using heroin, 'yes' they do identify themselves as being African American or Black, and 'no' they do not attend a pain center for their pain, patients will be asked the following:

Would you be interested in learning more about a research study that will allow you to talk about your chronic pain?

(If the patient does not meet the inclusion criteria identified by the responses in the screening tool, or if the patient is not interested in participating in the study, patients will be excluded from the study and thanked for their time).

(For patients who state that they would like to learn more about the research study) If you would like to learn more, would you like to follow me into an examination office here at the clinic to learn more about the study and I can answer any questions you may have prior to having you sign an informed consent/Acknowledgement and Release? Participation in this study is voluntary and you will be asked to complete two brief surveys, participate with interviews and take pictures of your chronic pain once you leave the clinic. The total time for participation today is approximately 1.3-2.3 hours.

Upon entering the examination office to learn more about the research study, patients will be asked the four questions from the AMT4 (Swain & Nightingale, 1997). Patients will be asked these four questions again, prior to completing the second and third interview and at any time during the interviews if the researcher has concerns with the participant's cognitive status. These questions include:

1. What is your age?
2. What is your date of birth?
3. Can you please tell me at what location you are at right now?
4. What is the current year?

If when initially enrolling patients into the present study individuals score less than 4 out of a possible score of 4 on the AMT4, the patient will be thanked for their time and excluded from the present study. If during the interview process the participant scores less than 4 out of possible score of 4 on the AMT4, the participant will immediately be referred to one of the health care providers at the clinic.

## APPENDIX E

## PARTICIPANT'S INFORMED CONSENT/ACKNOWLEDGEMENT AND RELEASE

The Experience of Chronic Pain as Described by African American Indigent Adults Attending an Urban Primary Care Clinic

**[Behavioral] Research Informed Consent  
Acknowledgement and Release of Photographs for Individuals Photographed in this Study**

Title of Study: The Experience of Chronic Pain as Described by African American Indigent Adults Attending an Urban Primary Care Clinic

Principal Investigator (PI): Jamie Crawley  
Nursing  
1-313-577-4107

**Purpose/Why is this study taking place?**

You are being asked to have your picture taken as part of a study looking at the day-to-day world of those who live with chronic pain. You have been an important part of this person's life when he/she has had chronic pain. This study is being done at Wayne State University and at the 4A Clinic – University Health Center, Detroit Medical Center. **Please read this form and ask any questions you may have before agreeing to have your picture taken as part of this study.**

**Study Procedures/What will I need to do?**

If you agree to be part of this study, you will:

- Sign this paper, which is called an informed consent. This lets the person know that it is OK to take your picture. The person knows that they may not take your picture or use your picture as part of this study unless they have you sign the form first.
- By signing this consent you are also saying that it is OK that your picture is shared with other people outside of this study.
- There is a handout that you may keep and the PI's phone number is on the handout if you have any questions about the study.
- Before you have your picture taken remember that your safety is most important. Do not take let your picture be taken if it may put you in danger of hurting yourself or others.

**Benefits/How will this help me or other people?**

By allowing your picture to be taken as part of this study, you may help other people now or in the future who live with chronic pain.

**Risks/Will this study hurt me in any way?**

There may be risks from taking part in this study that are not known to researchers at this time.

**Alternatives/What choices do I have?**

You may choose to **not** take part in the study and to **not** have your picture taken.

Submission/Revision Date: [June 1, 2009]  
Protocol Version #: [1]

Page 1 of 4

\_\_\_\_\_  
Participant's Initials

HIC Date: 01.09

The Experience of Chronic Pain as Described by African American Indigent Adults Attending an  
Urban Primary Care Clinic  
**Study Costs/Will this study cost me anything?**

Taking part in this study will not cost you anything.

**Compensation/How will I be thanked for my time?**

You will not be paid for taking part in this study.

**Research Related Injuries/Can I get hurt in this study?**

If you do get hurt while taking part in this study, treatment will be made available including first aid, emergency treatment, and follow-up care as needed. Follow-up care will be billed in the ordinary manner to you or your insurance company. No reimbursement, compensation, or free medical care is offered by Wayne State University, the 4A Clinic - University Health Center, Detroit Medical Center. If you think that you have been hurt while taking part in this study, call the PI right away at 1-313-577-4107.

**Confidentiality/How will my name and information be kept safe?**

All information collected about you during the study will be kept private to what is allowed by law. You will be identified in the study records by a code name or number. Information that identifies you will not be given to anyone without your written permission. However, the study sponsor, the Human Investigation Committee (HIC) at Wayne State University, or federal agencies with regulatory oversight [e.g., Food and Drug Administration (FDA), Office for Human Research Protections (OHRP), Office of Civil Rights (OCR), etc.] may review your records.

Because you are agreeing to have your picture taken, your identity will be protected or disguised. All pictures will be kept in a locked filing cabinet within a locked office at Wayne State University. The PI will have access to these items and so will the PI's dissertation committee/teachers at Wayne State. By signing this consent you are giving permission to share your pictures with others outside of this study. Pseudonyms or a made up name will be used to describe your identity. All study materials, including your pictures will be kept for 3 years and then will be destroyed as listed in the policy at Wayne State University and the Human Investigative Committee.

**Voluntary Participation/Withdrawal/Can I leave this study at any time?**

Taking part in this study is voluntary or up to you. You have the right to not take part in this study and not have your picture taken. If you decide to take part in the study you can later change your mind and leave the study. Your decisions will not change any present or future relationship with Wayne State University or its affiliates, or other services you are allowed to receive.

The PI may stop you from taking part in this study without your permission. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study.

The Experience of Chronic Pain as Described by African American Indigent Adults Attending an  
Urban Primary Care Clinic

**Questions/What if I have questions?**

If you have any questions about this study now or in the future, you may contact Jamie Crawley at 1-313-577-4107. If you have questions or concerns about your rights as a research participant, the Chair of the Human Investigation Committee can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

Submission/Revision Date: [June 1, 2009]  
Protocol Version #: [1]

Page 3 of 4

\_\_\_\_\_  
Participant's Initials

HIC Date: 01.09

The Experience of Chronic Pain as Described by African American Indigent Adults Attending an Urban Primary Care Clinic

**Consent to Participate in a Research Study**

To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study you may leave the study at any time. You are not giving up any of your legal rights by signing this form. By signing below you are agreeing that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed name of participant

\_\_\_\_\_  
Time

\_\_\_\_\_  
Signature of witness\*\*

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed of witness\*\*

\_\_\_\_\_  
Time

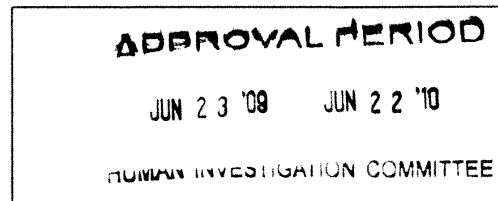
\_\_\_\_\_  
Signature of person obtaining consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed name of person obtaining consent

\_\_\_\_\_  
Time

\*\*Use when participant has had this consent form read to them (i.e., illiterate, legally blind, translated into foreign language).



\_\_\_\_\_  
Signature of translator

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed name of translator

\_\_\_\_\_  
Time

Submission/Revision Date: [June 1, 2009]  
Protocol Version #: [1]

Page 4 of 4

\_\_\_\_\_  
Participant's Initials

HIC Date: 01/09

**APPENDIX F**  
**DEMOGRAPHIC DATA FORM**

1. What is your age? \_\_\_\_\_
2. Are you male or female? \_\_\_\_\_
3. What is your marital status? \_\_\_\_\_
4. What is the highest level of schooling you obtained? \_\_\_\_\_
5. What is your current job status? \_\_\_\_\_
6. Is your current job status because of your pain? \_\_\_\_\_
7. Do you live alone or with someone else? \_\_\_\_\_
8. Who do you live with and how many are in your household? \_\_\_\_\_
9. Do you live in your own home? \_\_\_\_\_
10. Do you own your own home? \_\_\_\_\_
11. How many years have you had chronic pain? \_\_\_\_\_
12. What do you think is causing your pain? \_\_\_\_\_
13. How long have you come to this clinic? \_\_\_\_\_
14. In how many of your clinic visits do you talk about your pain? \_\_\_\_\_
15. What are your religious beliefs? \_\_\_\_\_
16. Does the fact that I am White affect your desire to talk about your chronic pain with me? \_\_\_\_\_

## APPENDIX G

## BRIEF PAIN INVENTORY (SHORT FORM)

STUDY ID# \_\_\_\_\_

HOSPITAL # \_\_\_\_\_

DO NOT WRITE ABOVE THIS LINE

## Brief Pain Inventory (Short Form)

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Time: \_\_\_\_\_

Name: \_\_\_\_\_

Last

First

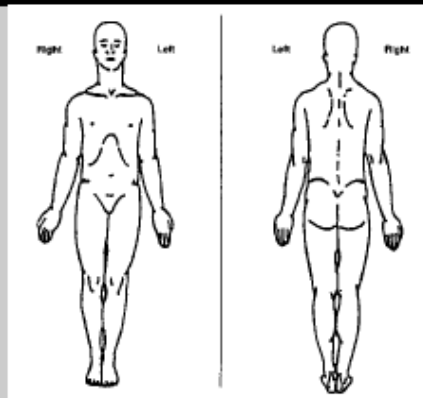
Middle Initial

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

1. Yes

2. No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



3. Please rate your pain by circling the one number that best describes your pain at its worst in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10  
No Pain Pain as bad as you can imagine

4. Please rate your pain by circling the one number that best describes your pain at its least in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10  
No Pain Pain as bad as you can imagine

5. Please rate your pain by circling the one number that best describes your pain on the average.

0 1 2 3 4 5 6 7 8 9 10  
No Pain Pain as bad as you can imagine

6. Please rate your pain by circling the one number that tells how much pain you have right now.

0 1 2 3 4 5 6 7 8 9 10  
No Pain Pain as bad as you can imagine



7. What treatments or medications are you receiving for your pain?

8. In the last 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%  
 No Complete  
 Relief Relief

9. Circle the one number that describes how, during the past 24 hours, pain has interfered with your:

**A. General Activity**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Completely  
 Interfere Interferes

**B. Mood**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Completely  
 Interfere Interferes

**C. Walking Ability**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Completely  
 Interfere Interferes

**D. Normal Work (includes both work outside the home and housework)**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Completely  
 Interfere Interferes

**E. Relations with other people**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Completely  
 Interfere Interferes

**F. Sleep**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Completely  
 Interfere Interferes

**G. Enjoyment of life**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Completely  
 Interfere Interferes

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 Pain Research Group  
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**APPENDIX H****THE EXPERIENCE OF CHRONIC PAIN AS DESCRIBED BY AFRICAN AMERICAN INDIGENT ADULTS ATTENDING AN URBAN PRIMARY CARE CLINIC – HANDOUT**

Thank you for participating in the current research study. This study is helping researchers learn more about what it is like to experience chronic pain. Your friend \_\_\_\_\_ has been asked to take pictures of his/her experiences of living with chronic pain. Some of these pictures may include the people in \_\_\_\_\_'s life that have made a difference when he/she is experiencing chronic pain. If you have been asked permission to have your picture taken, it means that you are one of those people. If you are giving permission to have your picture taken, you will be asked to sign an informed consent/Acknowledgement and Release for individuals photographed in this study. This informed consent/ Acknowledgement and Release for individuals photographed in this study grants permission for your picture to be taken and possibly shared with other researchers as we try to learn more about the world of people living with chronic pain. If you do agree to have your picture taken, it is important that you sign the informed consent/Acknowledgement and Release for individuals photographed in this study. If you do not wish to have your picture taken, then this is OK too. Your friend \_\_\_\_\_ knows that it is only with your signed informed consent/Acknowledgement and Release for individuals photographed in this study, that we may learn from your picture. You may keep a copy of the informed consent. If you have any questions regarding the research study, my contact information is listed at the end of the consent.

Thank you for your time!

Sincerely, Jamie Crawley

## APPENDIX I

### SECOND INTERVIEW GUIDE

During the first time we met, we had discussed several topics about your chronic pain. You had shared your thoughts regarding the experience of chronic pain and how chronic pain has influenced your life. I just have a few questions I would like to ask you based on the answers you gave during the first interview. These questions are to help me to better understand your thoughts. I want to be sure that I understand the meaning of your words to be sure I record these correctly, as these are your words.

1. When you talked about how chronic pain affected (your sleep) you had described it as being \_\_\_\_\_. Can you please help me to understand what you meant when you said \_\_\_\_\_?
2. I have a question about how you described \_\_\_\_\_ as helping you cope with chronic pain. Can you please tell me more about \_\_\_\_\_ so I may better understand your thoughts?
3. In the first interview I had asked you what you thought are all of the challenges of living with chronic pain? You had said that having pain affect (your ability to work, affecting your sleep, affecting your mood/emotions, needing to rely on others for help and having it affect your other illnesses) was most challenging.

Now I'd like you to sort these into three piles for most challenging, sort of challenging, and not as challenging.

What makes these more challenging? Why are these least challenging?

4. We had also discussed what you thought are all of the challenges of receiving chronic pain management? You had said that (the way you are treated at the hospital/ER, getting a prescription from a health care provider, getting referred to a pain specialist, paying for your pain medication and getting the medications filled at the pharmacy) as being the most challenging.

Now I'd like you to sort these into three piles for most challenging, sort of challenging, and not as challenging.

What makes these more challenging? Why are these least challenging?

I have copies of the photographs you took. Here is a copy of the photographs for you to keep. Thank you for taking these pictures. I appreciate you allowing me to see into your world as you live with chronic pain. I would like you to take a look at these pictures and tell me about each picture you took.

5. Can you please share with me why you took this picture? How does this picture tell me more about your experiences with chronic pain?
6. What about this picture? Can you please tell me about this person in the picture and how he/she is part of your world?
7. Tell me about this item in the picture. Is this something you use to help you with your chronic pain?
8. Is anything else you would like to share about these photographs?

I'd like to thank you for again sharing your experiences of chronic pain with me for a second time. You have helped me to better understand what these experiences mean to you. I will review our conversation today and the pictures you took. Would you like to

participate in another Photovoice experience and interview session? If so, I will share at our next meeting, some of the thoughts we discussed. At our 3rd meeting you can let me know if these thoughts are correct or how you would like them changed. I look forward to our next meeting in 3-4 weeks. Can we choose a date now that is most convenient for you to meet again here at the clinic? I would like to discuss with you again now, the picture-taking part of the research. Please remember to again obtain the individual's permission prior to taking the photograph. The individual needs to sign the informed consent/Acknowledgement and Release for individuals photographed in this study prior to the picture taking. Once again, your safety is the number one priority. Do not take pictures of anything or anyone if it would put you at risk for harming yourself or others. Thank you!

## APPENDIX J

### THIRD INTERVIEW GUIDE

Thank you for returning for the third interview. I just have a few final questions I would like to ask you about your chronic pain.

1. In the previous two interviews you describe the difficulty of (keeping track of important belongings) because of your chronic pain. Can you tell me a bit more about this?
2. In the second interview you mentioned that \_\_\_\_\_ might make a difference with your chronic pain. Tell me what are all the ways that \_\_\_\_\_ affects your chronic pain?
3. More than the first and second interview, is there something that stands out in your mind now about why you sorted \_\_\_\_\_ together and these other \_\_\_\_\_ together?

I have copies of the photographs you took. Here is a copy of the photographs for you to keep. Thank you for taking these pictures. I appreciate you allowing me to see into your world as you live with chronic pain. I would like you to take a look at these pictures and tell me about each picture you took.

4. Can you please share with me why you took this picture? How does this picture tell me more about your experiences with chronic pain?
5. What about this picture? Can you please tell me about this person in the picture and how he/she is part of your world?
6. In this picture I see a \_\_\_\_\_. Is this something you use to help you with your chronic pain?

7. Tell me if there is anything else you would like to share about these photographs?
8. Can you please share with me any final thoughts about your experiences with chronic pain?

Thank you for participating with this study. You are the expert of your chronic pain experience. I appreciate you sharing with me so we may better understand your world of living with chronic pain.

## APPENDIX K

## IRB Approval

WAYNE STATE  
UNIVERSITY

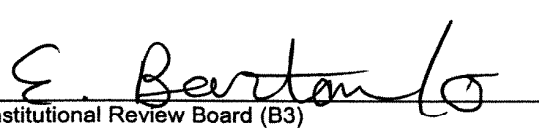
HUMAN INVESTIGATION COMMITTEE  
101 East Alexandrine Building  
Detroit, Michigan 48201  
Phone: (313) 577-1628  
FAX: (313) 993-7122  
<http://hic.wayne.edu>




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**NOTICE OF EXPEDITED APPROVAL**

**To:** Jamie Crawley  
College of Nursing  
5557 Cass Avenue

**From:** Ellen Barton, Ph.D.   
Chairperson, Behavioral Institutional Review Board (B3)

**Date:** June 23, 2009

**RE:** HIC #: 065609B3E  
Protocol Title: The Experience of Chronic Pain as Described by African American Indigent Adults Attending an Urban Primary Care Clinic

Sponsor:  
Protocol #: 0906007218

**Expiration Date:** June 22, 2010

**Risk Level / Category:** Research not involving greater than minimal risk

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The above-referenced protocol and items listed below (if applicable) were **APPROVED** following *Expedited Review* (Category 7\*) by the Chairperson/designee for the Wayne State University Behavioral Institutional Review Board (B3) for the period of 06/23/2009 through 06/22/2010. This approval does not replace any departmental or other approvals that may be required.

- Consent Form for Acknowledgement and Release of Photographs (dated 6/1/09)
  - Consent Form for Acknowledgement and Release of Photographs for Individuals Photographed in the Study (dated 6/1/09)
  - Note to PI – Please file copy of letter of support with signature via amendment before beginning research.
- 

- Federal regulations require that all research be reviewed at least annually. You may receive a "Continuation Renewal Reminder" approximately two months prior to the expiration date; however, it is the Principal Investigator's responsibility to obtain review and continued approval **before** the expiration date. Data collected during a period of lapsed approval is unapproved research and can **never** be reported or published as research data.
- All changes or amendments to the above-referenced protocol require review and approval by the HIC **BEFORE** implementation.
- Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the HIC Policy (<http://www.hic.wayne.edu/hicpol.html>).

**NOTE:**

1. Upon notification of an impending regulatory site visit, hold notification, and/or external audit the HIC office must be contacted immediately.
2. Forms should be downloaded from the HIC website at **each** use.

\*Based on the Expedited Review List, revised November 1998



## APPENDIX L

## DMC APPROVAL



Detroit Medical Center  
Corporate Offices  
3990 John R  
Detroit, MI 48201-2097

### Research Review Authorization

Date: June 10, 2009

Re: Application RR#10596

Protocol Title: The Experience of Chronic Pain as Described by African American Indigent Adults Attending an Urban Primary Care Clinic

Principal Investigator: Jamie Crawley

Dear Investigator:

The Detroit Medical Center (DMC) has reviewed the above-referenced Research Review Application, relevant documents and request to perform a research project (study) at the DMC site(s) specified therein. Through the Research Review process, the DMC has authorized this study, to take place at the proposed DMC site(s), pending approval of the study protocol by the Wayne State University Human Investigation Committee (WSU-HIC), and successful negotiation and execution of a Clinical Trial or other appropriate agreement governing the conduct of the study, between the DMC and the Sponsor.

Upon final approval of the study protocol by the WSU-HIC the study may commence. For your convenience, this Authorization letter will be posted on your Research Review Account where you may print a copy for your records; a copy will also be sent to the WSU-HIC.

This letter shall also serve as notice to the WSU-HIC that you have consented to the DMC being given access to the full content of your WSU-HIC file, including notification from the WSU-HIC in the event of a modification to the study protocol at any time during the course of the study.

If you have further questions regarding the Research Review process, please contact Cassandra Davis, Esq., Director of Compliance at (313) 993-0317.

Sincerely,

A handwritten signature in black ink, appearing to read "M. Safwan Badr".

M. Safwan Badr, MD  
DMC Executive Vice President  
Chief Medical Officer

A handwritten signature in black ink, appearing to read "Stanton M. Beatty".

Stanton M. Beatty, Esq.  
Corporate Vice President, Corporate Audit & Compliance  
Chief Compliance & Governance Officer

Cc: C. Seasock  
Dorothy Nelson

\*The request for waiver of the Research Review Application fee is: GRANTED

## APPENDIX M

### REB APPROVAL

Office of the Research Ethics Board



Today's Date: August 10, 2009  
 Principal Investigator: Prof. Jamie Crawley  
 Department/School: Nursing  
 REB Number: 09-149  
 Research Project Title: The Experience of Chronic Pain as Described by African American  
 Indigent Adults Attending an Urban Primary Care Clinic  
 Clearance Date: August 10, 2009  
 Project End Date: July 22, 2010  
  
 Progress Report Due:  
 Final Report Due: July 22, 2010

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This is to inform you that the University of Windsor Research Ethics Board (REB), which is organized and operated according to the *Tri-Council Policy Statement* and the University of Windsor *Guidelines for Research Involving Human Subjects*, has granted approval to your research project on the date noted above. This approval is valid only until the Project End Date.

A Progress Report or Final Report is due by the date noted above. The REB may ask for monitoring information at some time during the project's approval period.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the REB. Minor change(s) in ongoing studies will be considered when submitted on the Request to Revise form.

Investigators must also report promptly to the REB:

- a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) all adverse and unexpected experiences or events that are both serious and unexpected;
- c) new information that may adversely affect the safety of the subjects or the conduct of the study.

Forms for submissions, notifications, or changes are available on the REB website: [www.uwindsor.ca/reb](http://www.uwindsor.ca/reb). If your data is going to be used for another project, it is necessary to submit another application to the REB.

We wish you every success in your research.

Jacqueline Lewis, Ph.D.  
Delegated (Expedited) Reviewer, Research Ethics Board

cc:

Mark Curran, Research Ethics Coordinator

This is an official document. Please retain the original in your files.



**APPENDIX N**  
**LETTER OF SUPPORT**

Wayne State University  
Human Investigation Committee Office (HIC)  
101 Alexandrine  
Detroit , Mi 48202

To Whom It May Concern:

Jamie Crawley is a doctoral student with the College of Nursing at Wayne State University. She has recently successfully defended her dissertation proposal titled "The Experience of Chronic Pain as Described by African American Indigent Adults Attending an Urban Primary Care Clinic."

I am the manager of the 4A University Health Center Clinic which is part of the Detroit Medical Center. Ms. Crawley has expressed to me a desire to interview patients at the clinic. I do not foresee a conflict of interest should she interview participants at the clinic once she has obtained Institutional Review Board (IRB) approval. I have spoken with the medical director of the clinic, Dr. Lynne Carter and she too supports Ms. Crawley's proposed research study.

Ms. Crawley was one of the research assistants working with her advisor at the 4A Clinic during a previous research project. Ms. Crawley has knowledge of the clinic and the population it serves. I would support Ms. Crawley interviewing patients from our clinic. Learning more about the experience of chronic pain from this population will increase our knowledge as health care providers of how to provide better care for this population. Her dissertation proposal coincides with the goals of the United States Department of Health and Human Services to promote the social well-being of individuals, families and communities, including examining the needs, strengths, and abilities of vulnerable populations (HHS Strategic Plan Goals and Objectives - FY 2007-2012).

If you have any questions, please do not hesitate to contact me from the information listed below.

Ms. Wickers RN, MSN  
Manager – 4A Clinic  
University Health Center  
Detroit Medical Center

**APPENDIX O**

**INFORMED CONSENT/ACKNOWLEDGEMENT AND RELEASE**

**FOR INDIVIDUALS PHOTOGRAPHED IN THIS STUDY**

The Experience of Chronic Pain as Described by African American Indigent Adults Attending an  
Urban Primary Care Clinic

**[Behavioral] Research Informed Consent  
Acknowledgement and Release of Photographs for this Study**

Title of Study: The Experience of Chronic Pain as Described by African American Indigent Adults  
Attending an Urban Primary Care Clinic

Principal Investigator (PI):           Jamie Crawley  
  Nursing  
  1-313-577-4107

**Purpose/Why is this study taking place?**

You are being asked to be in a study looking at the experience of chronic pain for African Americans who are patients at this clinic because you have said that you do have chronic pain and you have agreed to discuss your day-to-day world of living with chronic pain. This study is being done at Wayne State University and here at the 4A Clinic – University Health Center, Detroit Medical Center. There will be about 10-20 people who will be part of this study. **Please read this form and ask any questions you may have before agreeing to be in the study.**

In this study, having chronic pain means that you have said that you have had ongoing or off-and-on again pain for more than 3 months. Indigent means that you live on less than \$250 dollars per month, which is why you are able to come to this clinic. The goals of this study are to interview people, such as yourself and ask you to talk about what your day-to-day world with chronic pain means to you and how you would improve your chronic pain management. Pain management is how you would care for or treat your pain. You will also take part in photovoice, which means that you will be given a disposable camera and will be asked to take pictures of your day-to-day world when living with chronic pain. This study will look at the importance of being African American and indigent on chronic pain and health.

**Study Procedures/What will I need to do?**

If you agree to be part of this study, you will:

- Fill out a demographic form that has questions about your age, your schooling, where you live, etc... This form will take about 5 minutes to fill out.
- Fill out the Brief Pain Inventory, which is a survey that asks about your pain by having you draw on a body drawing where you have pain, and to tell about the pain you have felt in the last week. This form will take about 10-15 minutes to fill out.
- Take part in an interview and will answer questions at this time or at another time here in the clinic that is best for you. You will tell me about your day-to-day world of living with chronic pain and will answer other questions about your pain. The interview may take 1-2 hours to do.
- Be given a disposable camera and you will take pictures of things, the people and what you do when you have chronic pain. You will mail the camera in a postage-paid, return-addressed envelope that I will give you now. In one week I will call you to remind you to do the picture-taking part of the study.

Submission/Revision Date: [June 1, 2009]  
Protocol Version #: [1]

Page 1 of 5

Participant's Initials

HIC Date: 01/09

The Experience of Chronic Pain as Described by African American Indigent Adults Attending an Urban Primary Care Clinic

- In 3-4 weeks you will come back to the clinic and will tell me about the pictures you took and how they help me to know more about your chronic pain. You will then answer any questions that I may have from the first interview. The second interview may take 1-2 hours to do.
- If you wish, you may take part in a second picture-taking activity and come back for a third interview. If you wish to do both, you will be given another disposable camera and will be asked to take pictures of the things, the people and what you do when you have chronic pain. You will again mail the camera in a postage-paid, return-addressed envelope that I will give to you at the second interview. In one week I will call you to remind you to do the picture-taking part of the study.
- In 3-4 weeks after the second interview, you will come back to the clinic and will again tell me about the pictures you took and how they help me to know more about your chronic pain. You will then answer any final questions that I may have about your chronic pain. The third interview may take 1-2 hours to do.
- Two tape recorders will be used in all interviews and I will turn the tape recorders off if you want me to at any time. During the interviews, I will be writing on paper about some of the actions or emotions you show and these notes will be part of the study.
- You only need to answer the questions you want to talk about and at any time you may stop the interview. The health care you now get at the clinic will not change if you decide to not be in the study. If during the interviews you feel sad or nervous from telling me about your chronic pain, or if you are feeling pain that makes answering the questions uncomfortable, the interview will be stopped. I will take you to see one of the healthcare providers in the clinic.
- Your answers will remain private and no names will be used when the study is written up in research reports.
- By signing this consent, you are also giving me permission to share the pictures you take with other people outside of this study. The pictures will help me and will help others to learn more about what it is like to live with chronic pain.
- Before you take pictures of other people for this study, you will need to have them sign a paper like this one called an informed consent. I will give you some informed consents before you leave from the first interview. The consent the person signs says it is OK to take his/her picture and to share the picture with other people outside of this study. I have a handout you can give to this person. My phone number is on the handout if the person has any questions about the study.
- Before you take any pictures remember that your safety is most important. Do not take any pictures of anyone or anything that may put you in danger of hurting yourself or others.

**Benefits/How will this help me or other people?**

By taking part in this study, you will have a better understanding of your day-to-day world of living with chronic pain. Information from this study may help other people now or in the future who live with chronic pain.

**Risks/Will this study hurt me in any way?**

By taking part in this study, you may feel sad or nervous when you talk about your chronic pain.

The following information may be reported to the correct powers that be if during the study there is concern that:

- child abuse or elder abuse has possibly happened,

Submission/Revision Date: [June 1, 2009]  
Protocol Version #: [1]

Page 2 of 5

Participant's Initials

HIC Date: 01.09

The Experience of Chronic Pain as Described by African American Indigent Adults Attending an Urban Primary Care Clinic

- you have a reportable communicable disease (i.e., certain sexually transmitted diseases or HIV)
- you tell me about illegal criminal activities, illegal substance abuse or violence

There may also be risks from taking part in this study that are not known to researchers at this time.

**Alternatives/What choices do I have?**

You may choose to **not** take part in the study.

**Study Costs/Will this study cost me anything?**

Taking part in this study will not cost you anything.

**Compensation/How will I be thanked for my time?**

For taking part in this study, you will be paid money and will receive copies of all the pictures you take.

- After finishing the first interview you will get \$15.
- When you come back for the second interview, you will get \$10 at the beginning of the second interview, for taking the pictures and mailing them to me.
- At the end of the second interview, you will get \$15.
- If you wish, to take part in a second picture-taking activity and a third interview you will get \$10 at the beginning of the third interview, for taking the pictures and mailing them to me.
- At the end of the third interview, you will get \$15.
- You may get a total of \$40 if you take part in two interviews and one picture-taking session or you will get a total of \$65 if you take part in three interviews and two picture-taking sessions.
- Each time you receive money, there is a form we will sign together to keep track of the money you receive.

**Research Related Injuries/Can I get hurt in this study?**

If you do get hurt while taking part in this study, treatment will be made available including first aid, emergency treatment, and follow-up care as needed. Follow-up care will be billed in the ordinary manner to you or your insurance company. No reimbursement, compensation, or free medical care is offered by Wayne State University, the 4A Clinic - University Health Center, Detroit Medical Center. If you think that you have been hurt while taking part in this study, call me right away at 1-313-577-4107.

**Confidentiality/How will my name and information be kept safe?**

All information collected about you during the study will be kept private to what is allowed by law. You will be identified in the study records by a code name or number. Information that identifies you will not be given to anyone without your written permission. However, the study sponsor, the Human Investigation Committee (HIC) at Wayne State University, or federal agencies with regulatory oversight [e.g., Food and Drug Administration (FDA), Office for Human Research Protections (OHRP), Office of Civil Rights (OCR), etc.] may review your records.

Submission/Revision Date: [June 1, 2009]  
Protocol Version #: [1]

Page 3 of 5

\_\_\_\_\_  
Participant's Initials

HIC Date: 01/09

The Experience of Chronic Pain as Described by African American Indigent Adults Attending an  
Urban Primary Care Clinic

When the findings of this study are published or shared with others outside of this study, no information will be included that will tell your identity.

Because you are taking pictures and I am taping your voice, your identity will be protected or disguised. All tape recordings, pictures and study items will be kept in a locked filing cabinet within a locked office at Wayne State University. I will have access to these items and so will my dissertation committee/teachers at Wayne State. By signing this consent you are giving me permission to share your pictures with others outside of this study. Pseudonyms or a made up name will be used to describe your identity. Transcripts, pictures and tapes will be kept for 3 years and then will be destroyed as listed in the policy at Wayne State University and the Human Investigative Committee. You have the right to decide if there are pictures you do not want shared with others outside of this study.

**Voluntary Participation/Withdrawal/Can I leave this study at any time?**

Taking part in this study is voluntary or up to you. You have the right to not take part in this study. If you decide to take part in the study you can later change your mind and leave the study. You only may answer the questions you want to answer. You can leave this study at any time. Your decisions will not change any present or future relationship with Wayne State University or its affiliates, or other services you are allowed to receive.

I may stop you from taking part in this study without your permission. I will let you know if it is not possible for you to continue. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study.

**Questions/What if I have questions?**

If you have any questions about this study now or in the future, you may contact Jamie Crawley at 1-313-577-4107. If you have questions or concerns about your rights as a research participant, the Chair of the Human Investigation Committee can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

Submission/Revision Date: [June 1, 2009]  
Protocol Version #: [1]

Page 4 of 5

Participant's Initials

HIC Date: 01/09

The Experience of Chronic Pain as Described by African American Indigent Adults Attending an Urban Primary Care Clinic

Consent to Participate in a Research Study

To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study you may leave the study at any time. You are not giving up any of your legal rights by signing this form. By signing below you are agreeing that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

Signature of participant

Date

Printed name of participant

Time

Signature of witness\*\*

Date

Printed of witness\*\*

Time

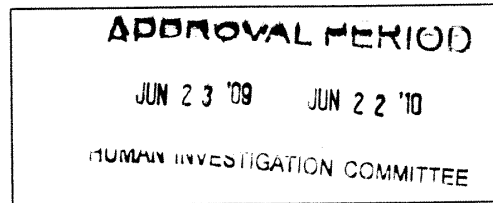
Signature of person obtaining consent

Date

Printed name of person obtaining consent

Time

\*\*Use when participant has had this consent form read to them (i.e., illiterate, legally blind, translated into foreign language).



Signature of translator

Date

Printed name of translator

Time

Submission/Revision Date: [June 1, 2009] Protocol Version #: [1]

Page 5 of 5

Participant's Initials

HIC Date: 01/09



## APPENDIX P

**THE EXPERIENCE OF CHRONIC PAIN AS DESCRIBED BY AFRICAN AMERICAN  
INDIGENT ADULTS ATTENDING AN URBAN PRIMARY CARE CLINIC –  
PAYMENT FORM**

I \_\_\_\_\_ have completed the first interview in the above research project and have received \$15 for participating.

Circle: Yes or No

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

I \_\_\_\_\_ have completed the photography portion in the above research project and have received \$10 for participating using the first camera.

Circle: Yes or No

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

I \_\_\_\_\_ have completed the second interview in the above research project and have received \$15 for participating.

Circle: Yes or No

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

I \_\_\_\_\_ have completed the photography portion in the above research project and have received \$10 for participating using the second camera.

Circle: Yes or No

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

I \_\_\_\_\_ have completed the third interview in the above research project and have received \$15 for participating.

Circle: Yes or No

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

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**ABSTRACT****THE EXPERIENCE OF CHRONIC PAIN AS DESCRIBED BY AFRICAN AMERICAN INDIGENT ADULTS ATTENDING AN URBAN PRIMARY CARE CLINIC**

by

**JAMIE CRAWLEY**

May 2010

**Advisor:** Dr. April Vallerand**Major:** Nursing**Degree:** Doctor of Philosophy

**Background:** Inadequate chronic pain control has far-reaching implications including costs for missed time at work; utilization of health care resources and reduced quality of life. People at highest risk for inadequate pain control include indigent adults and minorities. Newman's theory health as expanding consciousness views the chronic pain experience as a life pattern within health. Qualitatively examining chronic pain from participants' perspectives may improve chronic pain care.

**Purpose:** The purpose of this study was to examine the experiences of chronic pain as described by African American indigent adults attending an urban, primary care clinic.

**Methods:** 13- participants (7 men and 6 women). Inclusion criteria: registered patients at the clinic, spoke English, no sign of cognitive impairment, self-identified as African American, denied current illicit drug use and experiencing moderate to severe chronic pain for more than three months. Focused ethnography, two to three face-to-face interviews and two to three photovoice sessions. Photovoice provides marginalized individuals with a medium to showcase their experiences with chronic pain, and

captures with images, the pain experience that is not easily explained through quantitative measures.

**Findings:** Five themes and numerous subthemes inductively emerged from participants' words and pictures. Participants described how time seemed to slow down as they were 'Waiting on Pain'; they discussed the items they used and activities they performed as they were 'Coping with Chronic Pain' and they described the 'Challenges with Chronic Pain' such as convincing others of the intensity of pain. Participants also discussed how they were 'Negotiating Pain in a Vulnerable Environment' and described their experiences with living in chaotic environments, yet with all of these difficulties, they were 'Sharing Wisdom about Chronic Pain' with others outside of the present study.

**Conclusion:** This study is significant because it opens new horizons for discussing chronic pain with African American indigent adults and from participants' perspectives discusses how to provide patient-centered pain care.

## AUTOBIOGRAPHICAL STATEMENT

JAMIE CRAWLEY

### Educational Background

Wayne State University, Detroit, Michigan	PhD	2010
University of Phoenix, Southfield, Michigan	MBA/HCM	2002
University of Windsor, Windsor, Ontario	BA/Sociology	1996
University of Windsor, Windsor, Ontario	BA/Psychology	1994
University of Windsor, Windsor, Ontario	BScN	1992

Throughout this journey, Jamie was a full-time doctoral student with the College of Nursing at Wayne State University, Detroit, Michigan, a full-time mom and a full-time nursing lecturer with the Faculty of Nursing, at the University of Windsor, Windsor, Ontario, Canada. One of the events for which she feels honored, took place when her study was featured in a nursing research catalogue produced in 2009 by the College of Nursing at Wayne State University. The catalogue highlights research focused on reducing health disparities. While several participants in the present study were invited to participate, two of the participants agreed to have their photograph taken while sharing some of their photovoice pictures. One participant arrived after the pictures had been taken and her picture was taken separately using a disposable camera. Jamie is proud to have been featured in the College of Nursing's research catalogue and looks forward to future opportunities working with others to reduce chronic pain disparities.